

# ALZHEIMER'S POLICY TOOLKIT FOR MEMBERS OF THE EUROPEAN PARLIAMENT (MEP)



## FOREWORD BY SIRPA PIETIKÄINEN MEP A PERSON IS MUCH MORE THAN A DIAGNOSIS



Unfortunately, there remain many misconceptions and a lot of stigma related to memory disabling diseases. This is associated with a sense that little is known and little can be done about them. In reality, a lot can be done to help people with memory disabling diseases today and tomorrow.

The approach has to be holistic, as with all health issues. Prevention is the first step. We know of many environmental issues that impact health; we know that physical and mental exercise for example can delay and curve the onset of memory disabling diseases. In this context, knowledge of genes and other factors is also important.

Addressing the often silent biases against people with memory disabling diseases, that we may not even be aware of, is also essential. This is key to increasing the willingness of people with memory disabling diseases to be diagnosed early, and to building accessible and inclusive societies, that do not stigmatise and discriminate against those with memory disabling diseases. The burden of memory disabling diseases as neurological disorders should not be further enhanced by attitudes and restrictions to work and life unfairly imposed by others.

Recognising the rights of those with memory disabling diseases and creating accessible societies can greatly improve quality of life. It means finding innovative solutions and thinking about things from the perspective of people with neurological conditions – investing in human environments which are 'neurological disorder friendly'. Could public transportation be designed so that it reminds an individual when they need to get off and where they are going, for example?

I fully support the efforts to find ways to move forward on these recommendations and I commit to continue to engage on these issues.



## ABOUT THIS POLICY TOOLKIT

Alzheimer's disease (AD) – the most common cause of dementia – is one of the most significant medical and societal challenges of our time.<sup>1</sup> It does not discriminate and affects everyone, across all generations – from the people who develop the condition, to the families that care for them and the taxpayers who fund health services.

By providing facts and figures, polling findings and by highlighting what you can do on EU and national level to aid people with AD today across the EU, this toolkit is designed to help you promote change by driving the policy debate to benefit people with AD, their families, caregivers and society as a whole. In particular, you will find suggested steps that you can take to refresh the debate on EU level and, crucially, shape policy on national level – where change has so far been less forthcoming – to improve AD/dementia services and empower people with AD/dementia to live better lives.



Find out what you can do  
on EU and national level to  
help people with AD today  
across the EU



Dementia imposes a major burden on patients, carers and society. Timely diagnosis and early intervention can help change the patient experience, potentially improving outcomes for patients and carers while reducing costs. We hope this toolkit can inspire action and lead the way to lessening the burdens placed on those living with Alzheimer's and all neurology patients across Europe. ”

Prof Monica Di Luca  
President  
European Brain Council  
(EBC)



With more than 1 in 3 people facing the prospect of living with a neurological disorder in their lifetime, and spiralling costs for healthcare systems globally, it is very clear that we must work together to tackle the impact and burden of these disorders on our societies. This toolkit sets out a series of clear and simple actions that MEPs can undertake to help lessen the burden of Alzheimer's Disease in Europe. Success here could create a path for other brain disorders to follow in the future – leading to a better quality of life for all neurology patients, their families and wider society. We would very much value your interest and support! ”

Joke Jaarsma  
President  
European Federation of Neurological Associations  
(EFNA)



## WHAT IS ALZHEIMER'S DISEASE?

AD, which accounts for between 60 to 80 percent of cases of dementia, is a progressive and neurodegenerative condition that damages the brain.<sup>1</sup>

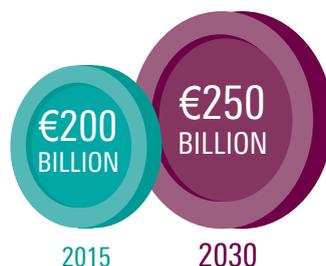
Affected patients experience a gradual loss of memory, language skills and the ability to manage everyday activity. In the later stages, these symptoms become more severe and the person will need day-to-day support with everyday tasks.<sup>2</sup>

AD represents a huge social and economic cost, putting significant pressure on carers, most of whom are female.<sup>3</sup> The broader impact of dementia on health systems in Europe is expected to rise to some €250bn by 2030.<sup>4</sup>

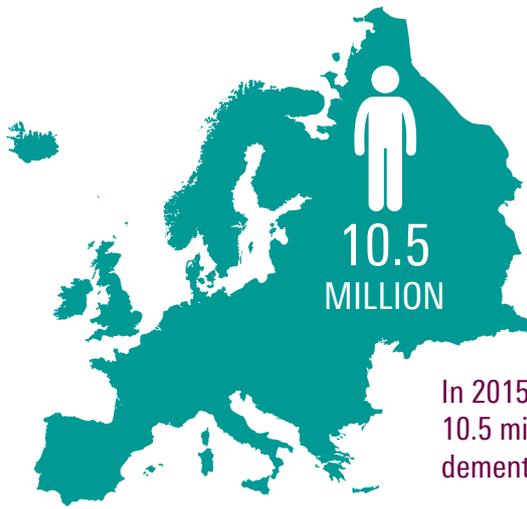


Patients experience a gradual loss of memory and language skills

In Europe, the estimated cost of dementia in 2015 was €200bn<sup>4</sup>



# THE SCALE OF THE CHALLENGE



In 2015, there were approximately 10.5 million people living with dementia in Europe (EU-28)<sup>5</sup>



Most people currently living with dementia have not received a formal diagnosis of their condition<sup>6</sup>

Informal care (provided by non-professional caregivers) and direct social care costs account for the greatest proportion of cost<sup>6</sup>



With the number of people with dementia is expected to increase<sup>6</sup>

The *Lancet Neurology Commission* has called the development of a therapy for AD “perhaps the greatest unmet need facing modern medicine”<sup>8</sup>

However, national strategies in the EU are sub-optimal with over 90% containing no measures to address the ethical and human rights issues linked to the treatment of AD, for example.<sup>9</sup>

EU and national level policymakers must take steps so that national dementia strategies offer people with AD a clearer, more comprehensive and adapted care pathway. Current systems are often too complex and there is a big variation between countries, resulting in health inequalities across Europe.<sup>10</sup>



Today, there is no cure nor treatment that slows or stops the progression of AD<sup>7</sup>

## THE IMPORTANCE OF EARLY DETECTION AND DIAGNOSIS

One reason the cost of informal care is so high is because of the delay in diagnosing AD, defined as the length of time between the onset of symptoms of cognitive decline and the clinical diagnosis. Work is underway to find innovative technological solutions to support the early detection and diagnosis of AD barriers to early detection and diagnosis are also linked to the prevailing stigmatisation of AD and gaps in national policy frameworks, both of which can only be addressed through concerted cooperation with stakeholders and the public.

Despite these pressing issues, a Censuswide poll, commissioned by MSD on public attitudes towards early detection and diagnosis of AD in 12 European countries, shows broad support for technologies which support early detection.<sup>11</sup>

In addition, the revised European Medicines Agency and Food and Drug Administration clinical guidelines for the investigation of treatments for AD recognise the need to develop new approaches for measuring the outcomes of treatments which target the pathology of AD, not simply its symptoms. Such developments are promising and suggest the regulatory agenda has now caught up with the research community’s focus on early detection.<sup>12,13</sup>

Over **70%** of respondents would want to know if they or a member of their family are at increased risk of developing AD<sup>11\*</sup>

\* ensuring that the “right to know” and the “right not to know” are safeguarded is key in protecting people and ensuring the integrity of the early detection research agenda. We must also seek solutions regarding patient privacy and confidentiality to prevent undue stigmatisation.

Only **18%** of respondents agreed that a diagnosis doesn’t matter because there is nothing we can do to help people with AD (with 70% disagreeing)<sup>11</sup>

# THE ALZHEIMER'S PATIENT JOURNEY



Am I at risk of developing Alzheimer's disease?

Some people have a genetic disposition that affects their risk of developing AD. A person with a relative affected by the condition has a higher risk of developing it. Genetic tests can help identify whether the relevant genetic mutation is present. Other risk factors such as age, high blood pressure or diabetes have also been linked to increasing a person's chances of developing the condition.<sup>7,14</sup>

## DIAGNOSIS



- Today, physicians can diagnose AD often too late, with a thorough medical evaluation and the detection of certain molecules present in the brain (in particular Amyloid Beta and Tau protein)<sup>8</sup>
- Scientific evidence suggests that the build up of amyloid plaques may begin as much as 20 years before symptoms emerge<sup>8</sup>



How do I get diagnosed for Alzheimer's?

Can I get support to help me and my family manage my condition?



## POST-DIAGNOSIS

- A diagnosis of AD has a major impact on affected patients and their families
- But access to post-diagnostic support – such as counselling and digital solutions – means that people can live well with AD; accessing care, support and treatment after diagnosis

## CARE & TREATMENT

- Today, there is no cure available for people with AD. Available treatments can provide symptomatic relief for affected people but do not slow the progression of the disease<sup>1</sup>
- The care provided varies according to country and the specific needs of the affected patient and their family. In the later stages of the illness, support can include home care assistance helping the patient with everyday tasks such as bathing, getting dressed or housework<sup>15</sup>



What can I do to stay independent as long as possible with Alzheimer's disease?



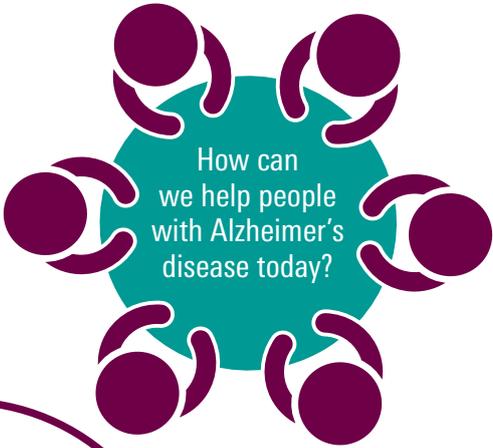
What can  
MEPs do today  
and in the  
2019-2024  
mandate?



To provide answers to the above question, MSD has engaged with the EU AD community to highlight the policy actions that MEPs can take today to help people with AD lead better lives. These actions were agreed at a series of *What if* policy roundtables focused on refreshing the European policy debate on the future of AD treatment in the EU.



The policy roundtables brought together a wide range of stakeholders interested and involved in the AD space, including decision-makers at EU and national level, patient associations, industry and civil society groups.



How can  
we help people  
with Alzheimer's  
disease today?

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# WHAT IF... POLICY ROUNDTABLES

*What if*



PUT THE  
EXPERIENCE  
OF PEOPLE WITH AD  
AT THE HEART OF  
THE DEBATE



1

## THE RIGHT TO DIGNITY

### SUMMARY

The first *What if* policy roundtable on *The right to dignity: Overcoming the stigma, discrimination and inequalities faced by people with Alzheimer's* was held in the European Parliament on 28 September 2017.

The event was hosted by [Deirdre Clune MEP](#) and also attended by [Heinz Becker MEP](#), both of whom are members of the [European Alzheimer's Alliance](#), a group of 126 MEPs which supports Alzheimer Europe in making dementia a public health priority at EU and national level.

PATHWAY  
TO IMPROVED  
CARE FOR  
PEOPLE  
WITH AD

As a result of the first *What if* roundtable, Deirdre Clune MEP and Heinz Becker MEP have already committed to the below steps on the pathway towards better treatment and care for people living with AD. To build on this progress, you may wish to endorse these actions as stakeholders in the AD space, build momentum and move forward in the journey towards improved care for people with AD today.

## CALLS TO ACTION

## 1

## THE RIGHT TO DIGNITY

## EU LEVEL

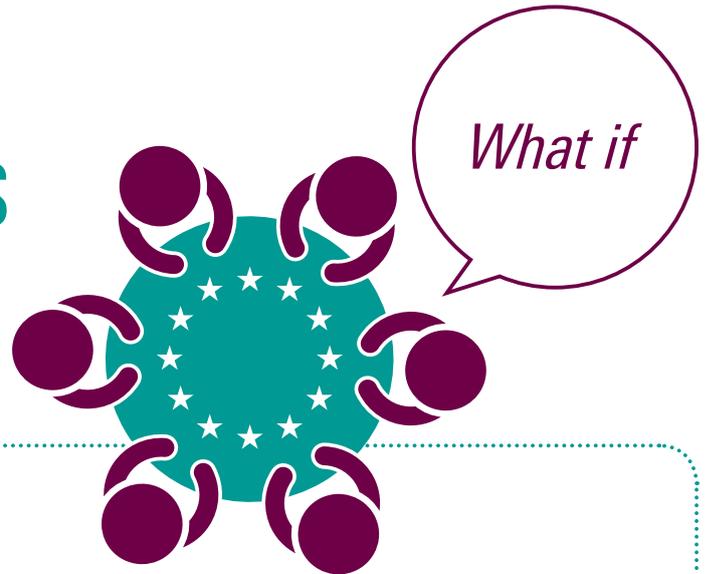
- Table a parliamentary question** for response by the European Commission on what initiatives are in place to protect the rights of people with AD and what more can be done to advance this cause
- Use political campaigns** ahead of the 2019 European Parliament Elections as an opportunity to raise awareness of the rights of people with chronic neurological conditions such as AD
- Initiate engagement** with the European Commission Group of Governmental Experts on Dementias
- Coordinate national MEPs** to write a joint letter to the national Health Minister calling for policy action or guidance in support of the right to dignity
- Advocate for for a high level European Commission coordinator** for dementia to ensure better coordination over numerous Directorate Generals (DG) and units
- Table a parliamentary question** for response by the European Commission on a draft recommendation on the future of treatment and care for people with AD
- Table a parliamentary question** for response by the European Commission on how the next Multi-annual financial framework and Horizon Europe will support research into AD and other neurological disorders

## MEMBER STATE LEVEL

- Write to your party's health spokesperson** about improving the human rights protection of people living with AD
- Write to your party's health spokesperson** about the need to improve coordination at national level between the various ministerial departments which inform national policy on AD, eg the national ministries for health, social care, finance, employment and inclusion
- Meet with national campaigning organisations and professional groups** to ask about their experiences of living with dementia and their recommendations for improving dementia services
- Seek meetings with people living with dementia**, health leaders and policymakers to collaborate in improving dementia services
- Promote the national implementation of the European Commission's health initiatives**, focusing on the collection of quality and robust real-world evidence, to enable research and decision making that reflect real needs in society, especially in the AD and neurological disorder patient community



# WHAT IF... POLICY ROUNDTABLES



## 2

### OVERCOMING THE ETHICAL CHALLENGES OF EARLY DETECTION AND DIAGNOSIS

#### SUMMARY

The second MSD *What if* policy roundtable on *Overcoming the ethical challenges of the early detection and diagnosis of Alzheimer's disease* was held in the European Parliament on 30 January 2018.

The event was co-hosted by [Sirpa Pietikäinen MEP](#) and [Nessa Childers MEP](#), both Vice-Chairs of the EAA. [Deirdre Clune MEP](#) and [Heinz Becker MEP](#), both members of the EAA, were also in attendance.

Discussions were informed by an essay from neurology expert [Prof. Adrian Ivanoiu](#), Professor of Neurology, UCLouvain.

Do people want to know if they are at a higher risk of developing AD?

ethical challenges

diagnosis

early detection

How can we support individuals diagnosed with AD after the diagnosis?

How do we ensure people's privacy and confidentiality following the early detection of AD?

## 2

## OVERCOMING THE ETHICAL CHALLENGES OF EARLY DETECTION AND DIAGNOSIS

## EU LEVEL

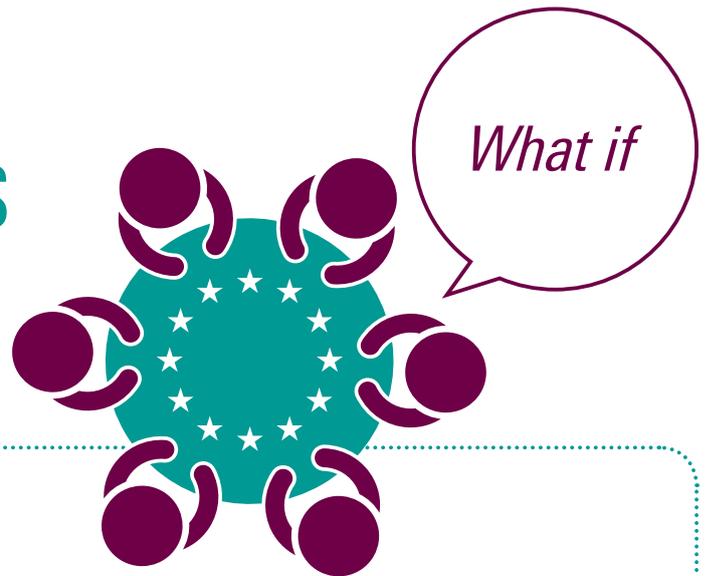
- Endorse the 'Alzheimer's Roadshow', a pan European project bringing together the EU institutions and national AD stakeholders committed to pursuing the *What if* calls to action to reform and improve national level policy and strategies
- Sign a joint letter to the European Commission calling for funding to support the development of technologies for the early detection and diagnosis of AD
- Table a parliamentary question for response by the European Commission on:
  - What steps are being taken to officially recognise AD as a disability?
  - what measures can be taken to promote and support the early detection or diagnosis of AD?
  - What mechanisms are in place to protect people's privacy following the early detection and diagnosis of AD?
- Coordinate national MEPs and write a joint letter to the national Health minister to begin the dialogue on practices such as the cognitive roadmap to track people's cognitive health throughout their lives
- Advocate for a Patients' Rights Directive focused on enshrining the 'right to know' and the 'right to not know'

## MEMBER STATE LEVEL

- Put into practice the 'Alzheimer's Roadshow', a pan European project bringing together the EU institutions and national AD stakeholders (national patient groups, national and regional governments) committed to pursuing the *What if* calls to reform and improve national level policy and strategies
- Engage with national AD stakeholders and campaign nationally on further investment in schemes to combat the stigma associated with the early detection and diagnosis of Alzheimer's disease as well as the stigma associated with care more generally
- Where applicable, engage with your party's health spokesperson on:
  - The revision of national dementia strategies to take into account the ethical dimensions of early detection and diagnosis
  - What steps are being taken to officially recognise AD as a disability?
  - What mechanisms are in place to promote and support the early detection or diagnosis of AD?
  - What mechanisms are in place to protect people's privacy following the early detection or diagnosis of AD?



# WHAT IF... POLICY ROUNDTABLES



Informal care is estimated to represent more than 40% of the total costs of dementia worldwide and can be considerably more in regions where formal care services are less well established.<sup>1</sup>



The direct cost per person with dementia in the EU has been estimated at around €22,000 per year, although with significant variations between countries since the social care costs differ greatly from Northern to Eastern Europe.<sup>2</sup>

## 3

### THE SOCIOECONOMIC IMPACT OF AD IN EUROPE

#### SUMMARY

25 September 2018 marked the conclusion of the *What if* series of policy roundtables, with a collaborative event between MSD and the European Brain Council (EBC) on *The Socioeconomic impact of Alzheimer's in Europe*.

In keeping with the spirit of the *What if* series, the roundtable brought together key stakeholders in the AD and neurology communities, including leading academic and policy experts on the socioeconomic burden of AD.

The roundtable was co-hosted by [Heinz Becker MEP](#) and [Marian Harkin MEP](#) both members of the EEA. The European Commission, Organisation for Economic Co-operation and Development, European Federation of Neurological Associations and European Patient Forum also contributed.

There was consensus amongst stakeholders for the need to prepare health systems for the arrival of an innovative treatment for AD to ensure that the right people can benefit from clinical breakthroughs in a timely manner. Discussants recalled the importance of the need for action today to lower the direct and indirect costs of AD and also called for policy solutions to break silos between countries, within institutions and across therapy areas.

REFERENCES: 1 Organisation for Economic Co-operation and Development, *Care Needed – Improving the lives of people with dementia*, OECD Publishing, Paris, 2018, <https://doi.org/10.1787/9789264085107-en>, accessed on: 20/12/2018 2 Wimo et al. The economic impact of dementia in Europe in 2008-cost estimates from the Eurocode project. *Int J Geriatr Psychiatry* 2011;26(8):825-832

## CALLS TO ACTION

# 3

## THE SOCIOECONOMIC IMPACT OF AD IN EUROPE

### EU LEVEL

- Collective stakeholder engagement** with MEPs, national parliamentarians and organisations representing people with AD on the need for policy action and further social care funding across the EU to alleviate the informal care burden of AD
- Table a parliamentary question** for response by the European Commission on:
  - What initiatives are in place to reduce silos between countries, within institutions and across therapy areas when it comes to addressing the economic burden of AD and other neurological disorders?
  - What initiatives are in place to generate further EU-wide data on the economic burden of AD?



### MEMBER STATE LEVEL

- Engage with national and regional AD stakeholders and campaign nationally** on:
  - The need for action today to ensure that national health technology assessment and pricing and reimbursement systems are prepared for the arrival of disease modifying treatments for AD
  - The need to improve community based services in lieu of hospitalisation, potentially shifting costs from acute hospital to community health and social care
  - The long-term value of investment in training and support programmes for families and carers who deliver informal care for people with AD
- Write to your party's health spokesperson** on:
  - The importance of early training and support for families and carers to reduce their strain and psychological burden, which could increase the efficiency of care and delay, or even avoid, transition into care homes of people with AD
  - The importance of breaking silos between national regions, institutions and therapy areas when it comes to taking action on the economic burden of AD
- Meet with national organisations representing carers** to ask about their experiences of caring for people with dementia and explore ways to mitigate the burden of informal care