

Models Of Patient Engagement for Alzheimer’s Disease

Moving towards earlier diagnosis of Alzheimer’s disease

PUBLIC EDUCATION/AWARENESS RAISING STRATEGIES



Alzheimer’s disease (AD) is a societal challenge that will be exacerbated in the future: it is the most common form of dementia (60%-70% of the cases¹). It is a major cause of disability and dependency. In 2018, it was estimated that 7% of the population over 60 were affected by dementia in the European Union (EU). Age being a risk factor, this number is expected to rise to 8% by 2040 due to the ageing of the population. The disease generates significant costs that are a challenge to the sustainability of the healthcare services². **It is therefore imperative to find some intervention to halt the AD burden.**

There are still too many undiagnosed cases of AD in Europe despite the fact that its early diagnosis is cost-effective^{3,4}.

AD has a preclinical stage when it is probably the best moment to intervene⁵: people with early AD (mild cognitive impairment (MCI) due to AD and mild AD dementia) remain outside of clinical settings and the diagnosis rates are low. **The subjective cognitive decline paradigm can identify individuals at risk of developing cognitive impairment.**

Dementia researchers are increasingly focusing their efforts on finding ways to prevent the onset of dementia symptoms in the first place. For this, they need to reach people who are still in the very earliest stages of the disease through **raising awareness of general population, health care professionals and decision makers to design and implement the best preventive strategies.**

Several modifiable risk factors have been identified, that can be used for **preventive multi-domain strategies or to identify high risk populations.**

The cultural and socio-economic diversity between countries (including the healthcare systems that are basically different) imply that the best patient engagement strategy could be distinct for each country.

Reaching out to the relevant stakeholders

The urgency to tackle AD shows us the need to raise awareness about AD and dementia among a large spectrum of stakeholders (citizens who may be developing the disease without being aware of the symptoms, the health professionals who are not equipped with sufficient knowledge to be able to detect the disease or feel confident about talking about the disease, the work-place, businesses, policy makers...). Specific attention must be paid to women as a population disproportionately affected by the disease (as patients, carers and professionals) and presenting higher risks of developing the disease⁶.

There is value in raising awareness and educating the public about dementia, its symptoms, risk factors and prevention. This should be an on-going strategy, with clear messages and definitions, in lay language.

The value of a timely diagnosis must be clearly promoted (increased quality of life for patients and carers, cost benefits to society) while taking into account the ethical issues linked to the disclosure of such a diagnosis and the specificities of each EU Member State (differences in the availability and access to support and treatment, reimbursement schemes).

Awareness and public education campaigns such as World Alzheimer’s Day/Month, National Carers Day, International Women’s Day are key dates to increase attention towards the topic and therefore chances of being heard.

The material produced by leading AD associations (Alzheimer’s Disease International) or the World Health Organisation (WHO), EU projects like MOPEAD serve as a solid basis for raising awareness and educating the public. Patients’ testimonies are also an essential pillar to awareness and education strategies.



This is what MOPEAD has helped address by studying two strategies whereby citizens actively performed a cognitive test: **Citizen Science** (online pre-screening tool), **Open House** (pre-screening tests performed in a memory clinic without a physician’s referral) and two strategies for patients at risk, in which their cognition was tested in two settings: **Primary Care setting** (patients were identified and tested by their General Practitioner [GP]); **Tertiary Care setting** (the identification and tests were performed by endocrinologists specialised in treating Type 2 diabetes, a risk factor for AD). The persons considered of being at risk were then offered a full diagnostic assessment in a memory clinic that they were free to accept or refuse.

Overall, the Citizen Science and Open House strategies were attractive to recruit subjects to participate in pre-screening. In the Tertiary Care setting, it appeared more difficult to engage healthcare professionals in recruiting participants. Also, in Primary Care, it was somewhat problematic to recruit participants. Once identified as possibly presenting cognitive impairment, many subjects were often reluctant to get a formal diagnosis.

The most cost-effective patient engagement strategy identifying people with cognitive impairment was in the Tertiary Care setting, followed by Primary Care. However, these care settings have capacity problems for dementia diagnostics. The Citizen Science and Open House can be more cost effective after modifications and adjustment.

The results of the survey among GPs, conducted during the project to evaluate their engagement in the diagnosis of dementia, revealed that more than two thirds held the view that an early diagnosis was of value and the benefits of an early diagnosis outweighed the risk. The barriers to timely diagnosis of the disease included the perception that currently available pharmacological treatment options presented no benefit or low benefit, lack of time, lack of confidence regarding diagnostic procedures. The perception of reimbursement of diagnostic procedures differed between sites. Non-pharmacological treatment options were widely accepted by GPs (85% considering them as beneficial) despite a high proportion of the respondents indicating that they were not sufficiently available.



The **MOPEAD** (Models Of Patient Engagement for Alzheimer’s Disease) project is based on the fact that in clinical practice, the diagnosis of AD is still occurring late in the disease process. This creates a barrier to access available treatments and support services, as well as the opportunity to enrol in clinical trials at early stages of the disease.

The project responds to the cultural shift towards early diagnosis of AD, at the initial symptomatic stages of the illness, as detection of early AD is the first step toward providing patients with optimal opportunity for intervention and involvement in clinical trials.

MOPEAD will also positively influence public education about AD, memory complaints and cognitive decline.

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Understanding the basics of AD - dementia	
Definitions - Messages	Target population
<ul style="list-style-type: none"> • What is dementia? What is AD? • What are the symptoms? • How is it diagnosed? • What are the treatments available? • What kind of support is available? • What are the risk factors? • What is the value of an early diagnosis? • Are there ethical issues? • Is there a gender bias? • Is there a genetic influence? 	<ul style="list-style-type: none"> • General public • Health professionals • Businesses • Policy makers

Lifting the obstacles to an early diagnosis: Breaking the stigma

There are still a number of obstacles to lift to move towards an early diagnosis of AD or dementia. The starting point of all public education and awareness-raising campaigns is to break the misconceptions and stigma around the disease.

- Misconception that AD is a normal part of ageing
- Stigma associated to ageing and AD
- Ignorance that AD has a long pre-symptomatic stage
- Ignorance that preventive interventions may be feasible
- General Practitioners feeling they have little to offer to patients even if an early diagnosis is made

After receiving my diagnosis, I could understand the problems I had been experiencing and could take actions (like taking part in research projects) that I firmly believe are slowing the progression of the disease'
Hilary Doxford, England

Early diagnosis gave me time to understand the disease, discuss it and draw my care plans with my doctor and my family for now and for the future. It enabled me to choose how to live the rest of my life and engage in peer support.
Agnes Houston, Scotland

Making the point : Benefits of an early diagnosis of AD

Often, a diagnosis of AD is made late, when the symptoms are severe and difficult to deal with. The benefits of an early diagnosis for patients and families avoids delays in treatment, enables life changes that may help slow down disease progression, provides timely information to reduce the anxiety about the disease.

Why is timely diagnosis of Alzheimer's disease so important?
 A timely diagnosis offers benefits to patients and families, healthcare providers, and society as a whole.

1 The benefits of a timely diagnosis for patients and families	2 The role of healthcare providers in timely diagnosis	3 The value of timely diagnosis for society
<ul style="list-style-type: none"> Avoids missed or misdiagnosis and delays in treatments. Enables lifestyle changes that may help slow down disease progression. Provides timely information to reduce anxiety about the disease. Helps patients and families prepare and make decisions for the future. 	<ul style="list-style-type: none"> Gives patients access to non-medical support and evidence-based treatment as the disease progresses. Triggers a coordinated multi-disciplinary support to patients and families. Enables the inclusion of patients in clinical trials investigating new medications. Provides support to patients and families to adapt to the new condition. 	<ul style="list-style-type: none"> Increases awareness and empowers people to recognize early symptoms. Preserves patients and carers inclusion and active participation in society. Offers patients and carers the opportunity to shape a dementia-friendly environment. Helps reduce the social stigma associated with Alzheimer's disease.
<p><i>When I was given the diagnosis, confirming the beginning of dementia, my life changed a lot. For the better! I became more alert, accurate, well prepared and disciplined... And my quality of life is better. I am really more committed, because I know what is ahead of me. But my present is quite OK. Let it last.</i> Temes, Slovenia</p>	<p>MOPEAD works to achieve a timely diagnosis. This means having a chance to stop with the disease, delay your life and enjoy every moment. Timely diagnosis will give people the chance to make crucial decisions. This can range from enrolling in a clinical trial to spending more time with their loved ones. Marek Bonda, Neurologist and Medical Director, Fundacja ACE</p>	<p>Alzheimer's disease impacts patients, their families, caregivers and society as a whole. Timely diagnosis and early diagnosis is vital to reduce the toll of the disease and empower those affected by it. Peggy Maguire, Director General, European Institute of Women's Health</p>

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Implementing a supportive environment

In addressing the objectives of reducing stigma, increasing understanding of dementia and empowering people with dementia, many stakeholders must rally to create an environment so people with dementia and their carers feel confident once a diagnosis is made, they are not left in the dark and excluded from society.

By being partners in the development of Dementia Friendly Communities (DFC) patients and their families create a place or culture in which people with dementia and their carers are empowered, supported and included in a society that understands their rights and recognise their full potential. They rally a broad and inclusive network of stakeholders (organisations, businesses, individuals, including people living with dementia) who together provide leadership and vision to implement a DFC. The impact of dementia friendly communities initiatives must be evaluated so any change to make the initiative sustainable can be made.

Core messages



It is possible to live with AD as long as a diagnosis is made at an early stage. It enables people with the disease, their relatives and friends to understand the problems encountered, take actions that can help slow disease progression, make decisions for the future, take control over their life, engage in meaningful and rewarding activities such as participation in research, awareness-raising and advocacy.

As directly impacted by the disease, patients and carers are experts who can play a key role in helping lift the taboo and stigma. When given the opportunity, they have demonstrated high skills to talk about their experience of living with the disease. Most importantly, they are very vocal about acknowledging that an early diagnosis of dementia has radically changed their lives: they could decide what was best for them, engage in public education and policy advocacy, participate in research.

Core messages



It is acknowledged that receiving a diagnosis of AD gives patients the opportunity to preserve the person's autonomy, safety and quality of life for as long as possible and can slow disease progression.

A timely diagnosis also empowers patients to take decisions affecting them. It also allows them to have access to available support, organise their life, plan the future and be part of society.

People with dementia can decide to take part in clinical trials.

Core message



Creating Dementia Friendly Communities raise awareness about the challenges faced by people with dementia in society. They also empower them to feel confident and have a sense of belonging. Their expertise with the disease make them indispensable in providing leadership and vision to implement a dementia friendly and inclusive environment.

Increasing healthcare professionals confidence in initiating discussions about AD with their patients

Primary care practitioners are on the front line in the detection of AD, its diagnosis and follow-up. Often, they do not feel confident about making and disclosing a diagnosis and managing the care follow-up.

MOPEAD's findings on the engagement of primary and tertiary care professionals confirm that it is more difficult to engage them in the diagnosis of AD: lack of time, feeling they cannot offer support in the absence of a cure. Nevertheless, they agree that an early diagnosis of dementia may be valuable.

A number of initiatives where people with dementia educate the health professionals have delivered promising results in increasing confidence among general practitioners. The under-detection and under-diagnosis in primary care could also be improved by collaboration with other primary healthcare professionals such as nurses. Studies involving specialised nurses or nurses having been trained on assessing cognitive functions have shown that these nurses interventions could enhance the primary care practitioner ability to manage people, provide faster and timely access to care.



Core messages

Primary care professionals have a key role to play in shifting the diagnosis of dementia: they are the entry point for people concerned with memory problems and are well-placed to detect cognitive problems with their regular patients.

The primary care professionals stereotypes on the diagnosis and disclosure of AD must be reversed. This can be overcome by adapting and updating medical education. Anti-stigma training will help reduce stereotypes and increase primary care professionals confidence.

Learning directly from persons with dementia is an innovative approach for medical students to understand the disease.

Health literacy - Risk factors and prevention

Existing national and European health campaigns on nutrition, prevention of cardiovascular diseases, smoking, the benefits of sport... rarely mention that developing AD and other forms of dementia can also be reduced by adopting the recommendations conveyed by these prevention campaigns. As many of the risk factors for dementia are shared with those of noncommunicable diseases, key recommendations for preventing AD must be integrated into these health and prevention campaigns.



Core messages

With no disease-modifying therapy currently available for AD, the importance of primary prevention to prevent or delay the onset of the disease needs to be seriously addressed at all levels.

Citizens need to be made aware of the evidence that has accumulated around the following vascular risk factors: diabetes mellitus, hypertension, smoking and obesity.

Physical activity, healthy diet, cognitive training and social participation also enhance cognitive ability and reduce the risk of cognitive decline.

New technologies also offer interactive and friendly health literacy/education opportunities.

Mottos like MOPEAD's 'Mind your memory, mind yourself' should be used in awareness and education strategies.

Risk factors for Alzheimer's disease

non-modifiable

- Age**: The average Alzheimer's patient is 77 year old.
- Sex**: Most of people affected by Alzheimer's disease are women¹.
- Genetic background**: The most important genetic risk factor identified to date is the APOE 4 gene^{4,5}.

potentially modifiable

- Diabetes (type 2)**: Diabetes is associated with an increased risk of dementia with evidence suggesting up to 2.5-fold increased risk^{1,2}.
- Unhealthy lifestyle**: Smoking, alcohol consumption, etc. can increase AD risk by 30%.
- Others**: Other risk factors can be physical inactivity, midlife hypertension, midlife obesity, depression etc.

Mind your memory, mind yourself.

[1] World Alzheimer Report 2014 - Dementia and Risk Reduction an analysis of protective and modifiable factors. [2] Sakihara Niizumiya - Curr Diab Rep (2014) 14:487. [3] Ridge et al. https://www.ncbi.nlm.nih.gov/pubmed/27036079. [4] Wingo et al. https://www.ncbi.nlm.nih.gov/pubmed/21911656

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Core messages

There are differences between normal ageing memory complaints and dementia memory issues. This must be clearly promoted to unlock the misconceptions about the disease and avoid unnecessary worrying.

MOPEAD's 'Memory matters' infographic introduces a specific recommendation that can be used in other awareness-raising and public education material: 'If you are worried, ask your doctor or visit a memory clinic'.

Memory matters

Normal Ageing

- Unable to remember the name of an acquaintance.
- Occasionally having difficulty finding words.
- Able to use common objects (i.e. remote control, microwave oven).
- Maintains prior level of interpersonal social skills.

Dementia*

- Not recognizing or knowing the names of family members.
- Frequent pauses and substitutions when finding words.
- No longer able or unable to operate common devices...
- Exhibits a loss of interest in social activities and inappropriate behaviors.

If you are worried, ask your doctor or visit the nearest memory clinic

*These are general statements. This is not an exhaustive list. For further information visit www.mopead.eu.

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Participating in clinical trials

The importance of developing therapies that prevent, slow or stop the progression of dementia calls for concrete steps to help ensure people with dementia are encouraged to enrol in clinical trials.

The dissociation between when patients are identified by their healthcare providers as having AD and the patient populations needed to develop disease modifying therapies at earlier stages of disease is a significant impediment to successfully accomplishing clinical research with a goal of discovering impactful therapies.

Market Place

Breaking the stigma—Lifting the obstacles

- ◆ **Engaging patients to speak out about their condition:** Alzheimer Europe [European Working Group of People with Dementia](#) and National Alzheimer associations give a voice to patients with dementia and their carers.
- ◆ **International dates:** [World Alzheimer Month](#) (September) and World Alzheimer Day (21 September) are regular opportunities to speak about dementia.
- ◆ **Build messages on existing material** such as [Alzheimer's International World Reports](#), [WHO infographic](#), [MOPEAD infographics](#), [MOPEAD Educational Leaflet](#) or [MOPEAD videos](#)
- ◆ **Patient testimonies:** [MOPEAD Educational Leaflet](#) and [MOPEAD Value of timely diagnosis infographic](#), Alzheimer Europe [Dementia in Europe Magazine](#) runs a regular feature about peoples' experiences from different countries around Europe.

Increasing healthcare practitioners confidence

- ◆ **Dementia Champions** is a multi-professional educational initiative (UK). A Dementia Champion is a health and social care professional who has completed an intensive programme which teaches participants to see, hear and feel the experiences of people living with dementia through working closely with them, their carers and their families.
- ◆ **Time for Dementia** is an educational programme (UK) designed to create a new generation of healthcare professionals who are more aware and understanding of dementia. It was developed to improve the knowledge, attitudes and skills in dementia among healthcare students by pairing them with a person with dementia and their carer in their homes over a period of two years.
- ◆ **EU Joint Action Act On Dementia 'Anti-stigma project':** the project targeted GPs and medical residents (France, Poland and Bulgaria). The anti-stigma programme focussed on specific areas such as the right to know, diagnosis disclosure techniques, personalised care management and care pathways, tailored support for carers. The pilot project showed that it was possible to improve the competence and confidence of the participants and reduce their entrenched stereotypes.

Risk factors - Prevention

- ◆ **WHO Guidelines on Risk Reduction:** these guidelines on risk reduction of cognitive decline and dementia provide evidence-based recommendations on lifestyle behaviours and interventions to delay or prevent cognitive decline and dementia. They are a tool for all stakeholders (healthcare providers, governments, policy-makers...) to strengthen their response to the dementia challenge.

Using new technologies

- ◆ **The My Brain Coach project** (NL) aims to increase public awareness on the relationship lifestyle and brain health and motivate people to make brain-healthy lifestyle choices using and online platform.
- ◆ **Muistipuisto (Memory Park)** is an online brain training application and programmes in Finland that focus on specific areas of brain health. The service applies game-design elements and game principles to improve the user's motivation, engagement, learning and life-changes.
- ◆ **DeepSpA project:** this EU EIT Health project is looking at speech analysis for cognitive assessment in clinical trials for AD and other neurodegenerative diseases.
- ◆ **Massive Open Online Courses** (MOOC) are a recent and widely researched development in distance education that have emerged as a popular mode of learning.

Core messages



The natural history of AD begins several years before the onset of the clinical symptoms. It is now possible to detect biological changes related to AD in the brain of cognitively healthy subjects using different biomarkers.

The drive to develop therapies that will target the early stages of the disease will seek volunteers to participate in clinical trials at earlier stages of the disease.

Building dementia-friendly environments

- ◆ **Dementia Friends** (UK) aims at changing people's perceptions of dementia. A Dementia Friends Champion is a volunteer who runs Information sessions in their community to encourage others to make a positive difference to people living with dementia in their community (giving them information about the personal impact of dementia, and what they can do to help). A wide range of supporting tools are available online.
- ◆ **Dementia Friendly Communities** (DFC) (UK): the programme focuses on improving inclusion and quality of life for people with dementia. There is a recognition process that encourages communities to support people living with dementia, sign up and work towards becoming dementia-friendly.
- ◆ **EU Joint Action Act On Dementia 'Dementia-Friendly Communities' Work Package:** the findings from the pilot sites showed it is important to engage a robust network of organisations (from local stakeholders to local authorities and politicians). The DFC activities were mainstreamed in local plans.
- ◆ **A Friend for Rachel** (USA) is a learning experience and volunteer opportunity to provide companionship to people with early-stage dementia. It paired future healthcare professionals with people diagnosed with dementia. The goal was to change perspective and reduce stigma.

Collaborating with other healthcare professionals to improve the diagnosis

- ◆ **EU Joint Action Act On Dementia 'GP-Nurse cooperation project':** this project aimed at improving the detection rate of neurocognitive disorders in primary care to improve the diagnosis quality, reduce delay and improve patient management in three countries (Bulgaria, France and Italy). GPs and nurses were trained on how to use detection scales for assessing cognitive, behavioural and autonomy impairment. The pilot revealed that the GP-nurse cooperation was an efficient way to improve cognitive disorders detection and diagnosis. This collaboration model seems to be adapted to the needs of the population and could represent an alternative to detection and assessment in a hospital setting. The main barrier was the primary care professional's lack of knowledge about neurocognitive disorders the absence of consensus on detection tools, potential opposition of the medical profession, funding and legislation issues regarding nurses' activities.
- ◆ **Alois Network:** founded in 2005 in France by the Alois Association, the Alois network is a neuro-cognitive expert centre that manages a community-based pathway that organises remote memory consultations for the diagnosis and care of adult patients and children with cognitive disorders. This network is at the same time fully complementary to the existing system and more flexible and less traumatizing for patients. The diagnosis and care process is also performed at a lower cost, which is beneficial to the community and the public finances. The Alois Network also offers face-to-face or distance training. It has a research department (epidemiological studies, impact studies, adaptation of neuropsychological assessments). In 2006, a consultable patient database was created to better exchange information with the medical profession. This service is now also available to the French living over-seas and abroad.

<https://www.mopead.eu/>
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