ALZHEIMER’S DISEASE IN THE EU DURING AND AFTER PANDEMIC

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The COVID-19 pandemic has had a severe impact on health services across the EU and one public health condition that was sidelined, among others, was Alzheimer’s disease.

The World Health Organisation (WHO) has spotted serious malfunctioning in dementia diagnosis and assessment.

According to the WHO, it is estimated that the crude prevalence of dementia in those aged 65+ is 8.5%, or 13.1 million (population over 65 years in the WHO European Region is 154.3 million).

Stakeholders caution that urgent and coordinated action is needed to help EU patients and their carers cope with the challenges of Alzheimer’s disease.

Meanwhile, promising new technologies and innovative therapies in the field are constantly emerging, which patients want to take full advantage of.
WHO official: COVID-19 seriously worsened dementia's state-of-play in Europe

Dementia: everyone has heard the word, but no one understands

‘Increasingly popular’ patient engagement in Alzheimer research is bearing fruit

European health systems must prepare for Alzheimer’s

Alzheimer’s researchers do not want to get lost in digital translation
WHO official: COVID-19 seriously worsened dementia’s state-of-play in Europe

By Sarantis Michalopoulos | EURACTIV.com

The COVID-19 pandemic has had and will continue to have a negative impact on people suffering from dementia, Dr Natasha Azzopardi Muscat from the World Health Organisation (WHO) told EURACTIV in an interview.

“Because of the pandemic and the effect it has had on other essential services, more people with dementia are living without a diagnosis, unable to access emotional, practical, legal and financial advice, as well as vital support services and pharmacological and non-pharmacological interventions,” said Dr Muscat, Director of Country Health Policies and Systems at WHO Regional Office for Europe.

These effects, she stressed, are even more serious if one considers that symptoms may be worsened by social distancing and the closure of community services.

“Ensuring access to a dementia diagnosis must be a central consideration of primary and secondary care as we move forward, during COVID-19 and beyond,” she said.

According to WHO data, 55.2 million people worldwide lived with dementia in 2019. Of these, 14.1 million were in the WHO European Region.

Dementia is among the top ten

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causes that lead to losing years of healthy life due to disability, and over the past 20 years, the loss of disability-adjusted life years due to dementia has more than doubled, the WHO says.

Another impact, according to Dr Muscat, is that there has been a considerable delay in diagnoses and/or treatment of those living with dementia.

“This was undoubtedly partly due to fear or inability to seek primary or hospital care during the virus’ outbreak. This meant that patients and families were unable to benefit from the post-diagnosis support, care and respite that should have been available in their community.”

In 2020, she said, three out of four countries reported disruptions in services for older adults with mental health conditions or disabilities, including dementia.

**DEMENTIA PATIENTS DIED DUE TO COVID**

The drama of the pandemic does not limit to dementia-related services, but it has had serious effects on dementia as a health condition.

She said the burden and losses in terms of mortality and morbidity have been particularly high among older people, and especially people with dementia.

“People with pre-existing neurological conditions, including dementia, are more vulnerable to SARS-CoV-2 infection, including having higher risks of severe outcomes and mortality,” Dr Muscat noted.

She added that a WHO survey showed that cerebrovascular disease and dementia/neurodegenerative diseases were most frequently associated with severe COVID-19 disease.

**EU COUNTRIES STILL HAVE ‘LARGE GAPS’**

Several EU countries have developed national dementia strategies and plans. However, Dr Muscat emphasised there are still large gaps between the demand for public support to people living with dementia and the services actually provided.

“This gap has been exacerbated by the pandemic, as we have seen very high mortality rates among people living in nursing homes, including in many EU countries,” she said.

In September, the WHO launched the Pan-European Mental Health Coalition, which consists of NGOs, institutions and individuals, and aims to improve mental health services in the European Region, including for patients living with Alzheimer and dementia.

“We know that improving the situation of people living with dementia (as well as investing more in preventative strategies, such as non-communicable diseases over the life course) requires cooperation across different sectors,” she said.

**THE ROLE OF NEW TECHNOLOGIES**

EURACTIV recently reported that the EU is unprepared to tackle Alzheimer’s disease as new treatments progress.

The industry and patients emphasise that new treatments are in progress, focusing on early stages of dementia, but even if they are approved, Europe lacks the proper infrastructure to take advantage of them, like medical training of GPs and specialists, or specialised diagnostics such as brain scans.

Asked if she shared this view, Dr Muscat replied that the WHO follows with interest the advancement of new technologies and medical products, as well as of innovative initiatives that aim at responding to the challenge of dementia in our region.

“While we applaud the renewed international focus on supporting countries to improve the lives of people living with dementia, their families and carers, also through better focus on patients’ access to timely and accurate diagnosis and adequate post-diagnostic support, we also stand by the EU and its recognition that more work needs to be done,” she said.

According to her, there is still much room for improvement in the coordination of care to help patients and their families navigate complex health and social systems.

“And we also need more progress in developing residential care models that actually reflect the specific needs of people with dementia,” she concluded.
Dementia: everyone has heard the word, but no one understands

By Sarantis Michalopoulos | EURACTIV.com

I will eventually have the luxury of forgetting, all those around me won’t have that luxury, they will never forget what dementia has done to us,” Chris Roberts, who has dementia, told EURACTIV.com in an interview, emphasising the need for increased awareness over a devastating disease is present in all corners of the world.

Dementia is among the top ten reasons people lose years of healthy life due to disability. Over the past 20 years, the loss of disability-adjusted life years due to dementia has more than doubled, the World Health Organisation (WHO) says.

Chris Roberts is a patient and the Chairperson of the European Working Group of People with Dementia.

EURACTIV contacted Roberts and his wife Jayne Goodrick, who is simultaneously his carer and a member on the advisory panel of Dementia Carers Count in the UK, with an aim to highlight the challenges both patients and carers are facing daily.

Roberts was diagnosed with Alzheimer’s and vascular damage when he was 50 years old. Before and during his dementia diagnosis, he also had emphysema.

“Getting mixed up with dreams and reality, not being able to write, facing problems with balance and mobility, not recognising friends and family and getting lost in your own house are just some of the daily challenges a dementia patient faces.

“Roberts

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and word-finding was sometimes quite difficult.

“I didn’t notice at the time, but sorting money, and loose change, was also becoming problematic. I compensated by paying with notes instead,” he said.

In the beginning, he thought it was down to my emphysema, but his doctor said, “no, that’s not emphysema”, and the testing started.

“My GP was very good and supportive, she referred me to our local memory clinic for testing. It took 13 months. I didn’t mind how long they took because we wanted a correct diagnosis, not a rushed one,” Roberts said.

During this time, he noticed that his driving was getting worse.

“I was looking down to see where my feet were supposed to be, forgetting where controls were, and kept getting lost in familiar places. I thought we lived in a world where everyone beeped their horns at each other[...] It turned out most were just beeping at me!” he said, adding that ultimately, he decided to give up his licence.

**DIAGNOSIS WAS A ‘RELIEF’**

Roberts stressed that he felt relieved after he was first diagnosed.

“At least, I now had a label that I wasn’t going mad, or it wasn’t a brain tumour. So we left the clinic with our welcome pack feeling completely lost and alone. We knew nothing about dementia. Why would we? I was feeling so guilty about putting my family in this position, and I was grieving”, he said.

Roberts said that after that, he immediately gathered all the family to discuss. After a diagnosis of dementia, the whole family also receives the diagnosis, and it becomes a team effort, he added.

“It has to be. With any life-changing illness, you have to change one’s life. Only then can you embrace, accept, and live with it!”.

He noted that mainly due to the misconceptions, myths, and what you see in the media, one is left thinking nothing can be done.

Asked about public support about the disease, Roberts said: “Everyone has heard the word, but not many actually understand it. It’s this lack of knowledge that makes us very fearful and afraid”.

“Just like that dark space under the bed when you are a child, but shine a light there, and it’s ok.”

Roberts also said patients should not fear of being stigmatised if they unveil their disease, as “people are very good when they know about my dementia and are very supportive in general, but more education and awareness is still needed.”

**PRO-ACTION, NOT REACTION**

From a carer’s perspective, his wife Jayne Goodrick said the main challenge is that all of a sudden, the caring role is takes up more time than the personal needs of the carer diminish in a “slow and silent” way.

“The role of caring can become all-consuming – without the carer noticing,” she said.

“This is why all of a sudden people can go into crisis without previously having asked for help or support. This is why we advocate for pro-action from services, to delay or even prevent these crisis moments,” she added.

On a policy level, she said there could be legislation where the authorities are obligated to contact the carer each month to see how things are and if any further support is needed.

But this, she said, could be seen as ‘Big Brother’ and intrusive, so it is a very fine balance between pro-action and interference.

“Also, so much input could make the carer feel judged, or watched, for any mistakes or perceived lack of skill, inducing fear of that help.”

She added that in Wales, there is a carers’ needs assessment, which is “an assessment of what I need, what matters to me”.

“This takes place (supposedly) once a year, which is fine in the early years, but as dementia progresses, so should the needs assessments”, she added.

“We need to have a whole rethink around the options and requirements of respite so that I have a break, and him a break from me, but not at the cost of his being incarcerated in a locked care home, with people who have far more complex needs than he, sat there looking at his future. That will do neither of us any good,” she concluded.
‘Increasingly popular’ patient engagement in Alzheimer research is bearing fruit

By Giedre Peseckyte | EURACTIV.com

Patient involvement in research on dementia has shown to be mutually beneficial, both to the quality of medical studies and to people’s rights to be involved in relevant research about their own condition, according to health experts.

The World Health Organisation (WHO) recognises dementia as a public health priority. While there are many different forms of dementia, Alzheimer’s disease is the most common form and may contribute to up to 70% of cases.

In May 2017, the World Health Assembly endorsed the Global action plan on the public health response to dementia 2017-2025, providing a comprehensive blueprint for action in many areas, one of which is research.

A recent push toward more people-centred health services is also affecting the way research is conducted and a dedicated panel at this year’s Alzheimer Europe Conference on 29 November dug more into how the research on dementia would benefit from public involvement.

Public involvement in research means that research is being carried out with or by the members of the public, rather than for them, with participants being involved during the whole research process.

Eileen Penman, who took part in the European Prevention of Alzheimer’s Dementia project (EPAD),
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said the experience of participating in the research was “absolutely fascinating” convincing her that more public involvement should be included in the research area.

“We don’t all just fall off a cliff at the end when we get the diagnosis of Alzheimer’s,” she said.

For Ana Diaz, project officer at Alzheimer Europe, public involvement is not just about talking to people living with the disease, bringing them to a meeting, or just trying to have a conversation.

“It involves a lot of planning and thinking and working along with them,” she stressed.

**WHAT ARE THE ADVANTAGES?**

Public involvement has advantages both for patients and for researchers and in recent years this approach has become “increasingly popular”, according to Johanna Graeber from the University Medical Center Schleswig-Holstein.

“Patients have the opportunity to advocate their interests through research, and researchers gain valuable insights through the unique knowledge about disease conditions, care and treatments that patients can provide,” she said.

Patient involvement and engagement have shown to be beneficial to the quality of medical research studies, particularly in big research projects that put a heavy burden on the participants, Graeber pointed out.

Alzheimer Europe’s Diaz presented two key arguments in favour of public involvement.

Firstly, it ensures people’s rights as they can be involved in research relevant to their own condition.

Secondly, patient engagement improves the quality, validity, relevance, and utility of research, both from a research and user perspective.

“This includes, for example, highlighting issues and asking questions about things that researchers have perhaps not considered,” she added.

**IT TAKES TIME**

To ensure that both research and participants benefit from public involvement, careful planning is needed.

Alison Keogh from the University College Dublin pointed out that public involvement is really time-consuming, therefore some structures are needed to have an effective engagement.

“It’s taken us a year to set up those structures. But we are very confident that those structures are what we need now going forward,” Keogh said.

Once the structures are in place, there are no other challenges as the participants start engaging with each other and exchange their experiences.

“Once you do that groundwork, it’s only beneficial,” Keogh concluded.

Another important aspect of patient engagement is providing the participants with feedback.

Having public involvement will bring about changes, Keogh said. “We had to become very used to the fact that participants’ feedback will help us change, but it will also force us to change.”.

Diaz explained that it is important to update participants on how their feedback has been used and what impact it had on the project.

“It’s not just […] having feedback from the people involved, from the people with dementia. It’s also about feeding back to them,” she said.

**COLLECTING DIFFERENT EXPERIENCES**

Dementia affects each person in a different way, depending on the underlying causes, other health conditions, and the person’s cognitive functioning before becoming ill.

This is why Stina Saunders, a fellow at the European Prevention of Alzheimer’s Dementia (EPAD) project, highlighted the need for diversity in the research groups.

“We want to diversify the child cohorts, and to make sure that there is an equal representation of people across different socio-economic groups, a racial representation.”

But not everything is about representation. Diaz said it is more about “trying to find people with different backgrounds and different experiences”.

Each contribution in research is equally important despite the level of involvement. “We don’t talk about the level of involvement, we talk about different types of involvement,” Diaz said.
By taking concrete steps today, Europe can be prepared for Alzheimer’s disease (AD). The burden of disease is growing, so there is no time to wait.

The COVID-19 pandemic has brought the need for health system readiness into sharp focus. It has taught us that we can better prepare for, and respond to, future pandemics by ensuring early detection, and having enough hospital beds and health care professionals in place to cope with surging demands on health services.

There is another looming crisis for which we are ill-prepared – Alzheimer’s disease. The number of people affected in Europe is estimated to be around 10 million – rising to 14 million by the end of this decade. The disease takes a heavy toll on quality of life for people living with AD, as well as their carers and families. The European costs of Alzheimer’s disease are forecasted to be over €250 billion in 2030.

While the predicted growth in the burden of AD may be startling, there is some good news on the horizon. Scientific understanding of dementia has deepened and there are now a significant number of disease-modifying treatments (DMTs) in late-stage clinical development[1]. It has been estimated that a DMT that delays onset of disease by five years would reduce the number of people affected by dementia by one third in 2050.

While the science is progressing, European healthcare systems still need to evolve to match and respond to the recent scientific advances.

Early detection is a key element of addressing this burden. Detecting AD at the earliest stages, and providing a timely diagnosis, would provide clinicians and people living with AD with more options in terms of effective interventions. This requires the greater use and reimbursement of diagnostic biomarkers and brain imaging within clinical practice.

There are other barriers that could limit the use of new potential DMTs. For example, some of the DMTs in development require intravenous administration. This would require greater infusion capacity in hospitals, as well as in primary care and

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By EFPIA
NATIONAL DIFFERENCES WILL SHAPE PATIENT OUTCOMES

While the World Health Organisation (WHO) and Alzheimer Europe have sounded the alarm on Europe’s lack of readiness for tackling the dementia challenge, there are significant differences in the approaches taken across Europe.

For example, France created a national plan in 2008 but has yet to achieve some of its goals, while Italy has demonstrated political support, but has faced criticism for not providing sufficient funding. The Italian government is now developing a new plan and is considering additional funding to support regional implementation.

The picture is a little brighter in Germany – even if there is still much to do to raise awareness and improve diagnosis. A German National Dementia Strategy, developed with more than 70 stakeholders and published in 2020, aims not only to improve the lives of today’s dementia patients but to create ‘sustainable structures for the future’.

Germany is also strong on infrastructure and has more specialists than their neighbours in France and Italy, but public awareness of early diagnosis remains weak, as does the use of diagnostic biomarkers for the confirmation of amyloid pathology. In order for disease-modifying treatments to have an impact on patient health outcomes, this will need to change.

There are also lessons to learn from Czechia, where a new action plan aims to address historic shortcomings in dementia care. Experts say most cases of AD in Czechia are detected in the advanced stages of cognitive impairment, and there has been a serious lack of data on disease incidence across the regions.

Czechia’s 2021 National Action Plan for Alzheimer’s Disease and Related Illnesses commits to addressing these gaps. It includes a new information portal and the creation of a network of monitoring centre to gather data. It also aims to support innovative approaches, including the use of automatic reminders for medication and enlisting pharmacists in community-based diagnosis.

Slovenia is also working on a new dementia strategy that will include the creation of a national dementia registry. While the strategy is designed to address future needs in dementia care, achieving this will require significant financial investment and action to effectively implement the proposals. Staff shortages and limited access to advanced diagnostics remain key challenges that will need to be addressed.

While the challenges of AD faced by European Member States are similar, the responses remain patchy. By learning from one another, and through greater collaboration, countries can accelerate the needed improvements to their health systems to provide quality care for people living with AD and a future with new treatments. The question is: what role can the European Commission play in knitting this patchwork together?

DOES EUROPE NEED TO ADOPT A BEATING ALZHEIMER PLAN?

Europe can and must take a lead in this crucial area of health. By developing a European plan to beat Alzheimer’s, modelled on Europe’s Beating Cancer Plan, the European Commission can provide the catalyst for action that is desperately needed.

There is also a strong role for the new EU4Health Programme. This initiative, with its unprecedented budget and scale, must foster collaboration between Member States in sharing best practices related to healthcare system readiness. Together, health systems can improve their capacity to prevent, diagnose, treat and care for people living with AD.

To ensure that people with Alzheimer’s in all regions of Europe can access high-quality care, the European Commission should disseminate independent and evidence-based detection, diagnosis and care guidelines, such as those developed by the European Academy of Neurology.

Finally, every Member State should adopt, implement and fund a comprehensive national dementia/Alzheimer’s plan designed to improve national healthcare systems’ readiness for the arrival of disease-modifying therapies in future.

The collective challenge Europe faces requires concerted action. Alzheimer’s will test European health systems. If we fail to prepare, we must prepare to fail. Let’s rise to the challenge. The time is now.

Alzheimer’s researchers do not want to get lost in digital translation

By Gerardo Fortuna | EURACTIV.com

Transposing research outcomes into digital products and services is a complex but stimulating process that could move the needle in diagnosing Alzheimer early but also in improving the quality of life of patients.

The digital revolution is set to change the health world as we know it and the EU executive jumped on the e-Health wagon already in 2018, with the communication on enabling the digital transformation of health and care in the digital single market.

But it was only with the COVID-19 pandemic that both doctors and patients experienced the benefits of digital channels of communications, particularly when people had issues in getting access to basic health services because of restrictive measures.

“Especially with the pandemic, more people used digital technologies in their daily lives, even in the health sector where patients directly engaged with such tools,” explained Jan-Philipp Beck, CEO of Europe’s leading health innovation initiative EIT Health.

Researchers are already looking at the potential of telemedicine as it could offer solutions that could help to cope with conditions like dementia.

“But it is hugely complex to transfer those findings. Biomarkers opened a whole new field of translating research into digital and useful applications to support care and diagnostics,” he said.

It is worth the effort though. Beck mentioned the project Alzheimer’s Disease Prediction Service (ADPS), which was spun off from ETH Zurich and developed together with the Trinity College in Dublin.

The project consisted of developing a pre-symptomatic biomarker to predict whether someone is likely to develop Alzheimer’s in the next six-year period. The final research result was a 10-minute test for smartphones.
“The outcome is something that looks quite simple – it is essentially a virtual reality-enabled game, but it supports diagnostics and the understanding of early cognitive impairment,” said EIT’s Beck.

This technology helps diagnose the early stages of Alzheimer in an easy, non-invasive manner, with 87-94% diagnostic accuracy. “But doing that was a six-year journey on the research side.”

“Beyond Alzheimer and dementia, I see more readiness and openness to also embrace new technologies amongst patients but also health professionals,” Beck said.

**THE REVOLUTION OF BIOMARKERS**

ADPS was among the first solutions in the world to assess cognition using virtual reality, but health researchers are already thinking of a world in which digital health practices will be adopted more broadly.

The biotech company Biogen is one of the pioneers of this. Before joining the company, Thorsten Lambertus worked at the Fragile Art Research Organisation, where he had first-hand experience of what it takes to generate research insights and convert them into something with value.

At that time, he worked with technologies that analyse micro-expressions on camera. “In general, we are able to understand age, sex, but also emotions through that,” he said.

Several startups and research groups are working on understanding how early stages of dementia and mild cognitive impairment may be detected this way, for instance through analysing the speech.

“At some point, all those research results might build services that enable diagnostics at a very early stage and also monitoring disease progression over time,” Lambertus added.

Biogen and the tech juggernaut Apple launched a partnership to develop digital biomarkers to help monitor cognitive performance, which is the ability to think clearly, learn and remember.

“There are many different components that could be detected very early on through wearables devices or smartphones,” Lambertus explained, mentioning biomarkers like motor function, breath and speech.

At the same time, digital tools have the potential to empower doctors, general practitioners and specialists to collect relevant data through digitalised cognitive tests.

Other approaches involve AI solutions for radiologists that make it easier to analyse and predict the progression of Alzheimer through magnetic resonance imaging (MRI).

**PATIENT-CENTRED APPROACH**

Digital health services could play a role not only in diagnostic but also in improving care and quality of life, a key component of Alzheimer patients’ journey.

“We always need to find ways to understand what is quality of life for each specific patient and having a personalised medicine approach is very important,” Lambertus said.

New technology advancements in virtual and augmented reality, for instance, help to have more immersive experiences alleviating comorbidities like depression and anxiety often suffered by dementia patients.

The e-Health game is played also on the EU turf with the proposal for a European health data space, a cornerstone for the digitalisation of the sector.

“It’s a bundle of potential policy and regulatory measures that could help to capitalise on those opportunities and really utilise data for research and innovation,” commented EIT’s Beck.

According to him though, Europe needs to get it right with proper data legislation to keep Europe both a front runner in the field and to create trust in the patients.

“To keep people on board and involved, they need to be trusting this,” he said, adding that it is crucial to ensure that people’s rights and their consent in giving their own health data are preserved.

“That’s a key feature of Europe, it’s part of our identity. We do not privatise people’s data. [Only this way] can we have a very citizen and patient-centred approach,” he concluded.