

IS EUROPE READY FOR ALZHEIMER'S?

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WHO: "The impact of dementia on caregivers, family and societies can be physical, psychological, social and economic." [Neil Moralee / Flickr]

Rising dementia numbers in EU causes alarm

The European Union is stepping up efforts to combat dementia, but is being urged to do more, as 18.7 million EU citizens are expected to suffer from the illness by 2050.

The World Health Organisation (WHO) says dementia develops slowly and is caused by a variety of diseases and injuries that affect the brain, such as Alzheimer's disease, and strokes.

Alzheimer's is a type of dementia that causes problems with memory, thinking and behaviour. Symptoms usually develop slowly and get worse over time, becoming severe enough to hamper individuals from performing everyday activities. However, consciousness is not affected.

Practically, patients with dementia have an increased level of dependency.

"The impact of dementia on caregivers, family and societies can be physical, psychological, social and economic," the WHO notes.

Policymakers emphasise there is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care. They are calling for global action.

Another aspect of dementia is its high cost. According to a 2015 report by Alzheimer's Disease International

(ADI), the total estimated cost of dementia in 2015 was €750 billion and projections forecast that it could reach €1.83 trillion by 2018.

Dementia in the EU

In 2015, the number of people with dementia was approximately 10.5 million in Europe. The projections are alarming, as the number of affected people is predicted to increase to 13.4 million by 2030 and to 18.7 million by 2050.

According to the European Commission, the most common causes of dementia in the EU is Alzheimer's disease (about 50-70% of cases) and the successive strokes which lead to multi-infarct dementia (about 30%). Other causes are Pick's disease, Binswanger's diseases, Lewy-Body dementia, and others.

Member states are responsible for the organisation and delivery of health services, including care for dementia. In December 2015, the EU Council of Ministers adopted a policy framework to help people living with dementia by improving care policies and practices.

Several member states have already adopted a national strategy to address the situation.

In an interview with EurActiv.com, the Director of Alzheimer Europe, Jean Georges, stressed that the number of countries with such plans in place has continued to grow. There are now dementia or neurodegenerative

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disease strategies in place in Austria, Belgium, Cyprus, Czech Republic, Denmark, Greece, Ireland, Italy, Luxembourg, Malta, the Netherlands, Norway, Slovenia, Spain, Switzerland and the UK (with separate strategies for England, Northern Ireland and Scotland).

However, there is still much to do to fully implement plans, and in many countries, to put a plan in place, analysts explain.

EU Commission action plan

European Commission spokesman Enrico Brivio told EurActiv.com that in recent years dementia has become a priority for more and more member states.

There is a huge investment in research on dementia and other neurodegenerative diseases under the EU research programs, he said.

"The interest of the topic for member states is also manifested during the Presidency of the Council of the European Union," the official stressed, adding that the Commission works closely with the member states through the Group of Governmental experts on Dementias.

"The support for the implementation of the Council conclusions will be discussed in cooperation with the member states," he stated.

The executive also supports work to address dementia by supporting member states via the EU Health Programme.

Following the completion of the first Joint Action on Dementia (ALCOVE Joint Action), a second Joint Action on dementia under the EU-Health Programme was launched in March 2016. The initiative focuses on post-diagnostic support, crisis and care coordination, and the quality of residential care and dementia-friendly communities.

Brivio said there was huge investment in research on dementia and other neurodegenerative diseases

under the EU research programs.

"The Commission further supports the European Innovation Partnership on Active and Healthy Ageing, which is facilitating the exchange of good practices in prevention of frailty, integration of care and age-friendly environments, areas which highlight the importance of early diagnosis and screening for physical and cognitive decline, coordination of health and social care and support to patients and carers," Brivio said.

Nurses: Commission is out of touch

Contacted by EurActiv, the European Federation of Nurses Associations (ENF) said the Commission's planned joint action with member states on dementia excluded stakeholders like the ENF.

"They miss out 3 million nurses," said Paul De Raeve, the ENF's general secretary. "It is high time the European Commission respects frontline actors, dealing every day with dementia."

According to De Raeve, EU politicians write policies but they have never seen or taken care of a dementia patient in real life. This is visible in EU Council recommendations, which he said includes empty sentences and contains no concrete actions to take account of the experience of frontline people working and caring for dementia patients.

"Look at Horizon2020. Millions are spent on dementia, nothing changes in daily practice. What about implementing the research findings?" he asked.

iSupport

The WHO also focuses on the impact of caregiving, such as the deterioration of the caretaker's physical and mental health and lost productivity when carers are forced to abstain from work.

In 2010, informal care costs stood at roughly at €230 billion, according to the WHO, which claims that "e-health"

solutions could be effective.

I-Support is an e-programme that the WHO is currently developing with the goal of supporting family members and friends taking care of people living with dementia.

Available via personal computers, tablets and smartphones, iSupport offers a training program through which caregivers learn about the basics of dementia, how to take on their role, how to cope with the emotional stress associated with caregiving, and the importance of self-care.

Special attention is also paid to challenging behaviours associated with dementia, such as aggression, depression, and wandering.

INTERVIEW

Alzheimer Europe chief: Holistic approach needed to tackle dementia

Alzheimer's disease and other forms of dementia remain underdiagnosed in most European countries, Jean Georges told EurActiv.

Jean Georges is the Executive Director of Alzheimer Europe, a non-profit organisation aiming at improving care and treatment of patients with Alzheimer's disease.

Georges spoke with EurActiv's Sarantis Michalopoulos.

According to the 2016 Alzheimer's Disease International report, dementia affects 47 million people worldwide and this number will treble by 2050. What are the reasons for that? Do you believe that the current care system for dementia should be redesigned?

Age is the primary risk factor for Alzheimer's disease and for that reason the numbers of people affected is increasing as our populations are ageing. Alzheimer Europe estimates that 8.7 million people are living with Alzheimer's disease or another type of dementia in the European Union alone.

In 2008, a group of researchers estimated the cost per person with dementia in the European Union to be €22,000 per year, with great variations across the EU since the societal costs were estimated to be eight times more in Northern Europe than in Eastern Europe. However, it is the growing numbers of people with dementia in all European



Alzheimer's disease and other forms of dementia remain underdiagnosed in most European countries. [Jean Georges]

countries will pose serious challenges to the sustainability of current health and care systems.

For that reason, Alzheimer Europe and its national member organisations have been actively campaigning to have dementia recognised as a public health priority at EU and national level.

Do you see political appetite among EU politicians to address this situation? Do you believe that EU politicians realise the seriousness of Alzheimer's disease and other dementias?

We are encouraged by the growing number of EU politicians who have supported our campaign over the past years. In 2007, a small group of MEPs helped us in setting up the European Alzheimer's Alliance which has since grown to 127 MEPs from 27 EU countries.

Thanks to their support, awareness of dementia has increased, the need for greater European collaboration has been recognised and we have seen a number of EU Presidencies making further progress.

One of the first EU presidencies to do so was the French Presidency of the European Union in 2008 which organised the first Presidency Conference dedicated to Alzheimer's disease and which led to the creation of the Joint

Programme on Neurodegenerative Diseases Research (JPND) and the adoption by the European Commission of its European Alzheimer's Initiative.

Since then, the EU Presidencies of Italy (2014), Luxembourg (2015) and the Netherlands (2016) have continued the focus on dementia and the current Slovak EU Presidency will organise a conference on 29 November entitled "Alzheimer's disease – epidemic of the third millennium – Are we ready to face it?"

What kind of initiatives do you think should be taken at EU level in order to put this chronic disease under control?

We have been campaigning since 2006 to have dementia recognised as a European priority. In our Paris (2006) and Glasgow (2014) Declarations, we called for the development of national dementia strategies in all European countries as well as the development of a European action plan.

Such a European action plan or strategy should be comprised of two key elements:

1. On the one hand, the European Union should develop a comprehensive and holistic

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research agenda, which encompasses and supports all types of research (basic, clinical, psychosocial, care, epidemiological, health systems and health economics). Funding for dementia research should be increased substantially and better coordinated at EU level.

2. On the other hand, the European Union should promote the collaboration between health and social ministries and encourage them to learn from one another by exchanging information on innovative initiatives and existing good practices.

I would also like to see the appointment of a dementia coordinator at European Commission level and the further development of the European group of government experts on dementia.

The EU Council of Ministers has urged member states to set up national strategies to address the situation as well as boost their multilateral collaboration. What is the current state-of-play? Which countries have made the most progress and which ones are still lagging behind?

We welcomed the efforts of the Luxembourg Presidency of the European Union which resulted in the adoption by health ministers of very ambitious Presidency conclusions on Supporting people living with dementia, which called for greater European collaboration and the development of national dementia strategies. It was great to see that Health Ministers thus gave a ringing endorsement to our own campaign.

When we issued our call to have countries develop national dementia strategies in 2006, France was the only EU country which had a very modest Alzheimer's plan. The number of countries with such plans in place has continued to grow and we now have

dementia or neurodegenerative disease strategies in place in Austria, Belgium, Cyprus, Czech Republic, Denmark, Greece, Ireland, Italy, Luxembourg, Malta, the Netherlands, Norway, Slovenia, Spain, Switzerland and the UK (with separate strategies for England, Northern Ireland and Scotland).

There are of course huge variations between countries as to the contents, funding and monitoring of these strategies. Also, some countries without strategies have very comprehensive guidelines or research programmes in place without these having been formalised into a strategic framework.

What do you believe should be done in order to improve diagnosis of dementia? Are you satisfied with the research initiatives taken at EU level?

Alzheimer's disease and other forms of dementia remain underdiagnosed in most European countries. Our national associations have estimated that between half and two-thirds of people with dementia do not have a formal diagnosis. Also, research has shown that people are diagnosed in the later stages of the disease and that timely diagnosis remains the exception, rather than the rule.

However, those countries which have adopted national dementia strategies all have identified timely diagnosis as a key priority area. Awareness campaigns therefore need to target the general population to identify the first symptoms and general practitioners to ensure they either diagnose or refer to specialists.

In addition, timely diagnosis was the focus of ALCOVE, the first Joint Action on Dementia which resulted in recommendations which should be taken up by health ministries. The new Joint Action on Dementia (2016-2018) coordinated by the Scottish Government is looking to build on these recommendations to further promote models for timely diagnosis.

Similarly, a number of EU-funded

projects focus on developing new diagnostic methods or in comparing diagnostic strategies. Alzheimer Europe is delighted to be a partner in a new IMI-funded project entitled "MOPEAD – Models for Patient engagement in Alzheimer's disease" which will compare different approaches to identify which strategies lead to earlier identification and diagnosis.

We fully support the campaign for a timely diagnosis of Alzheimer's disease and dementia, but we stress that timely diagnosis should always be accompanied by the adequate post-diagnostic support (information on the local or national Alzheimer's association, access to treatment and psychosocial interventions, peer support, advance care planning and advance directives, possibility to participate in research and clinical trials).

Denmark aims to become 'dementia-friendly nation' by 2025

Denmark has put forward a national plan aimed at making the country dementia-friendly by 2025, Minister of Health Sophie Loehde told EurActiv.com in Copenhagen.

Dementia has become a political priority for Denmark, where an estimated 35,000 persons live with this disease today.

"In reality, the number is much higher since many live with the disease without having been diagnosed and in the years to come many more people will be affected," Loehde said.

"Dementia is a terrible disease that turns the lives of those affected upside down," the liberal politician stressed, adding that considering the critical situation, the government decided to forge a new national action plan on dementia for 2025.

Three objectives

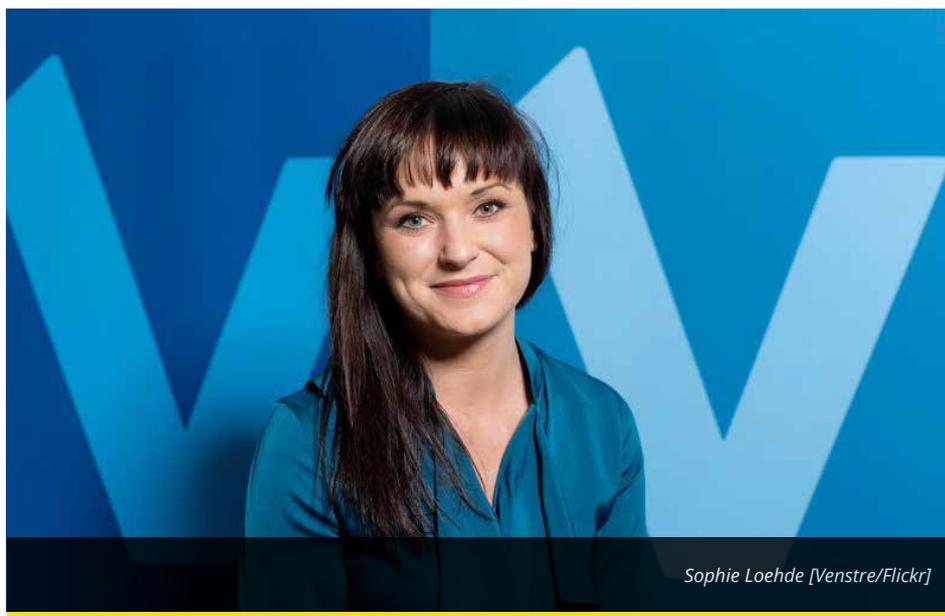
Denmark's plan was recently launched and inspired by best practices across Europe. It received funding worth over €60 million.

The strategy focuses on three overall objectives.

"Firstly, Denmark must become a dementia-friendly nation where people with dementia can live a safe and dignified life," Loehde said.

The second goal focuses on tailor-made care giving and prevention for dementia sufferers.

"The treatment and care of people with dementia must be based on the needs and values of the individual person, and treatment must be provided in a coherent way that focuses on prevention



Sophie Loehde [Venstre/Flickr]

and early intervention and is based on the newest knowledge and research," she explained.

The third objective is to support the friends and relatives of dementia sufferers, which she said should take center stage in the Danish strategy.

"Focusing on relatives is important when it comes to dementia since they face a very special challenge. Not only do they have to handle that a person close to them is severely ill, at the same time they also have to deal with their own grief of losing touch with a beloved person," she said.

Under the Danish national plan, 80% of dementia sufferers will have a specific diagnosis by 2025, Loehde said. Meanwhile, caregivers, nursing homes and hospitals will receive better training and skills development.

Reducing the amount of drugs administered to dementia sufferers is also an important part of the plan.

"The antipsychotic medication among people with dementia should be reduced by 50% toward 2025. It's not easy but I know that we can do it," Loehde said.

Fighting stigmatisation

Speaking at the 26th Alzheimer Europe Conference in Copenhagen, Sophie Loehde pointed out that her

country's national plan was collectively designed with the participation of relevant stakeholders, including persons affected by dementia.

The minister visited 35 municipalities in Denmark as well as in the Netherlands, the UK, Norway, and Sweden.

A key political objective is to make all 98 municipalities in Denmark "dementia-friendly" by making it "easier and safer for people with dementia and their relatives to live with this disease".

"Together [with stakeholders] we placed dementia on the top of the political agenda, as it should be," the minister pointed out.

She also cited an example of a relative of a person with dementia who said: "Sometimes, when we meet people we know, they cross the street in order to avoid us. We feel sorry for them. We know they do it because they don't know what to do or what to say."

"I want to fight this stigmatisation," Loehde said.

Inspired by the UK

Denmark's national plan on dementia was largely inspired by the United Kingdom, where more than 1.5 million dementia "friends" are currently registered.

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Britain has made efforts to set political targets, which are systematically followed up by data on how every region in the country performs, Loehde said.

"I'm impressed by the efforts of the UK to deal with people with dementia and their families. In Manchester, I was particularly impressed by the way civil society is involved."

The minister mentioned the example of a young British woman suffering from dementia who found herself challenged while shopping in a local supermarket. She was stressed out by "busy people" who lost their patience while queuing in line with her to pay, and she then contacted the director of the supermarket, who decided to make a

separate line for persons like her.

This, Loehde said, is "a little example indicating how much a small change can make a huge difference for people".

The role of local communities

Birgitte Vølund, the chairwoman of the Danish Alzheimer Association, told EurActiv that municipalities should be fully engaged in creating dementia-friendly local communities.

"Municipalities should form specific policies and set clear goals. The municipalities carry 80% of the economic burden so it's them that should change," Vølund stressed, adding that people with dementia should also be heard in this process, especially during the

implementation phase.

"Our goal is to provide a better quality of care in everyday life," she emphasised.

Vølund pointed out that when sufferers are diagnosed with dementia, "they are more or less left alone" as municipalities actually tell them "call us if you need any help".

"People are so confused when they receive a diagnosis. We need to take action to help these people from the very beginning," Vølund said, adding that the local administration should adopt more proactive strategies focused on visits and advice.

"The other thing is to have much more volunteering activity centers in Denmark which deal with social, cultural and physical activities," she said.

Study: Dementia healthcare services need to be redesigned

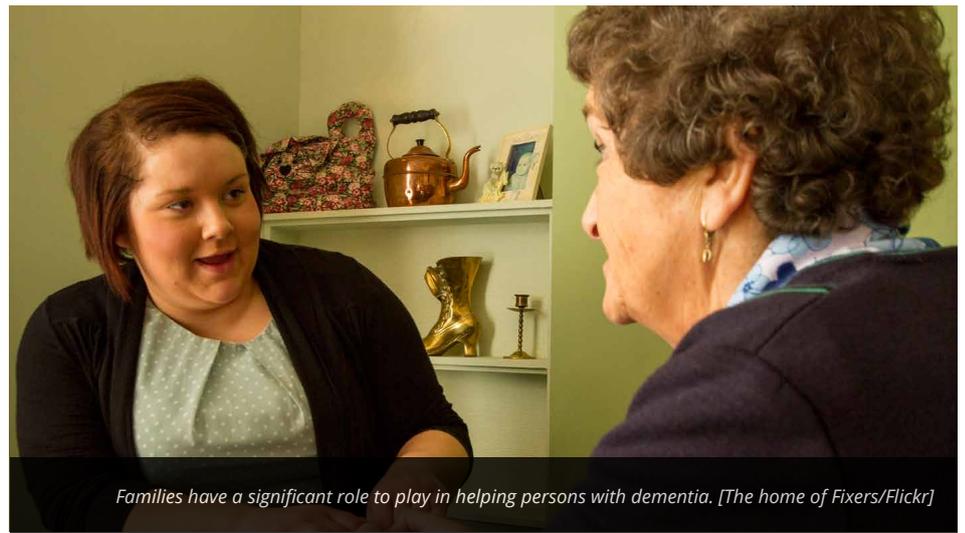
People with dementia remain under-diagnosed and lack comprehensive and continuing healthcare, a report has found, urging policymakers to focus on primary care services. EurActiv.com reports from Copenhagen.

A new report from Alzheimer's Disease International, authored by researchers at King's College London and the London School of Economics and Political Science (LSE), found that the vast majority of persons with dementia have yet to receive a diagnosis and calls for a global transformation in healthcare.

It also claims that strategies need to be developed that will focus on prevention and risk assessment, while rebalancing non-specialist primary care.

Diagnosis and cost

The report, Improving healthcare for



Families have a significant role to play in helping persons with dementia. [The home of Fixers/Flickr]

people living with dementia, rings the alarm about the rapid rise in dementia cases worldwide, which are projected to triple by 2050. A particular aspect of concern is the low levels of dementia diagnosis that prevent dementia patients from having access to care and treatment.

The researchers noted that around half of persons with dementia (40-50%) in high-income countries, and one in ten or less (5-10%) in low and middle-income countries have received a diagnosis.

In high-income countries, the costs of healthcare are higher for those suffering from dementia than age-matched controls, with a substantial proportion of

costs arising from hospitalisation.

Gilles Pargneau, a French Socialist MEP, recently told EurActiv that dementia costs Europe €123 billion per year, in terms of medical expenditures and social care.

According to the report, a radical change in the way healthcare is delivered to individuals living with dementia should be made, focusing more on non-specialist primary care.

"Greater involvement of non-specialist primary care staff can unlock capacity to meet increasing demand for

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dementia care, and could make the cost of care per person up to 40% cheaper," the report reads.

Primary care staff are non-specialist doctors and nurses based in the community who are typically the first point of contact with the healthcare system.

Primary care

Martin Prince, the lead author of the report at King's College London, told EurActiv that current specialist models of dementia care (where geriatricians, neurologists, and psychiatrists are providing dementia care) were unlikely to be able to scale up to care for the growing number of individuals affected by dementia – especially in low and middle-income countries.

"There is evidence that when primary care doctors take responsibility for dementia care they can achieve similar outcomes to specialists. Nurses can be case managers, and perform diagnostic assessments and reviews," he said.

Prince explained that training was crucial if primary care doctors are to take on an increased role in treating dementia patients. This, he said, can be achieved by defining a 'pathway' for dementia care with clearly defined roles for primary care doctors, specialists and others to work collaboratively.

"Specialists will need to take on a prominent role in training and supervising non-specialists in more general tasks," Prince said. "In low-resource countries, a greater commitment is needed to strengthen primary healthcare. These are elements that should be contained in a National Plan on Dementia, with allocated funding, in every country," he added, emphasising that more effort is needed to integrate dementia in primary healthcare.

Professor Craig Ritchie, who is the director of the University of Edinburgh Centre for Dementia Prevention, told EurActiv that primary or non-specialist care has two main roles: one linked to diagnosis and another related to

prevention.

"There are still a lot of people in the world who have not been diagnosed with dementia who are living with this condition; I think there is a particular role for primary care to play in making this diagnosis," he said.

"For instance, we need to see who does best during the whole evolution of the disease. Early disease possibly requires more specialist assessment in making a diagnosis but later in the disease primary care certainly will have a very prominent if not leading role," he noted.

Regarding prevention, he emphasised that although efforts have rightly focused on developing new drugs, there are probably a lot of things to do in risk mitigation, like the promotion of a better diet, exercise, and healthier lifestyle.

"Clearly, there is a role for the general practitioners in this as there is in other chronic conditions like diabetes or heart disease. So the general practitioners not only have a role in making diagnoses but also a very critical role in terms of prevention and maintenance of brain health."

What can the family do?

For Ritchie, families and close relatives have a critical role to play. Living with someone affected by dementia has a major impact on the wellbeing of family members who may need to sacrifice their professional lives to care for the patient, on top of the challenges of seeing a loved one's illness progress.

The family could also help identify the early symptoms, Ritchie said. "So family members have to be encouraged and given the opportunity to seek assistance if they are worried about a loved one's memory," he pointed out, saying the first point of contact is often the general practitioner.

Family members should also be involved in the therapy process, which helps optimise treatment, Ritchie said. But families cannot bear the entire burden, he warned. "Good care must also reflect and

manage the needs of family members who may have developed their own physical and mental health needs in their caring role," he remarked.

Raising awareness in the EU

The latest survey regarding the state of dementia care in the EU showed that half the carers spent at least 10 hours a day looking after their loved one and only 17% of them consider that the level of care for the elderly in their country is good.

They also noted that the information they received at diagnosis was "inadequate", and called for more information on drug treatments.

Four out of five said they wanted more information on help and support services and just two out of five were informed about the existence of an Alzheimer's association.

"Perhaps of greatest concern is that more than half have no access to services such as home care, day care or residential/nursing home care, and when these services are available, many carers have to pay themselves," the report reads.

Another report, Mapping dementia-friendly communities across Europe, commissioned by the European Foundations' Initiative on Dementia (EFID) and carried out in 2014-2015 by the Mental Health Foundation (a UK non-governmental organisation), specified the need for dementia-friendly communities across Europe.

The report aimed at providing practical information to support good practice around sustainable, inclusive and supportive environments for persons living with dementia and their carers.

Among the findings, researchers suggested that dementia sufferers should be actively included and involved in the communities they live in. Raising awareness about dementia was also highlighted by the researchers, who warned that "unclear information can be misleading and inadvertently risk adding to stigma".

INTERVIEW

People with dementia: 'We can still contribute to this society'

Europe needs a strategy to tackle dementia, two people with dementia told EurActiv.com, stressing that they have a role to play in research and society in general.

Helen Rochford-Brennan is Chair of the Irish Dementia Working Group and a member of the European Working Group of People with Dementia. Hilary Doxford is a volunteer for the Alzheimer's Society in England and also a member of the European Working Group of People with Dementia.

They spoke with EurActiv's Sarantis Michalopoulos at the 26th Alzheimer Europe Conference in Copenhagen.

Can you tell me about your personal experience of being diagnosed with dementia?

Helen: When I was diagnosed it was just a shock, a disaster to me because I was not prepared. I was still working, I was planning my retirement, I was enjoying my life and I was very involved in my community and on the boards of many organisations. I was deeply shocked. And I suppose for me, the most difficult thing was to let go all of that.

Hilary: It took me 6-7 years to get a diagnosis. I knew something was wrong with my brain seven years before I got the diagnosis. I went back to my general practitioner several times in that intervening period and when I got the diagnosis it was not a surprise to me



*"When I was diagnosed it was just a shock, a disaster to me because I was not prepared."
[Sarantis Michalopoulos]*

because I knew something was wrong. It's not the diagnosis you want to hear, but in a way, I found it as a relief to understand. I had something that told me what my problems were. Although I am still working now, it has a huge impact on your life.

Helen: Giving up everything is the hardest thing to do. You wake up in a morning, and you have nothing but isolation. You have no job, you have to step down as I did from all the organisations I was involved in. I was fully employed. These are difficult things. How do you tell your family? My husband often says he wants to have some of the Helen that was and not the Helen that is. When you are diagnosed, you are very alone and isolated.

Can you tell me about the kind of post-diagnostic support offered to you and how it could be improved? What should the main priorities be?

Helen: First of all, there is no cure, no medicine. I was under age 65 and there wasn't any post-diagnosis support for me. There is nothing, absolutely nothing. So I went home, I had no one to turn to. The general practitioner was supportive, the pharmacists understood my illness, but other than that I had nobody and it took me a long time to finally accept. I was fully aware of the stigma around the illness.

Hilary: For me, it was the same. There was no support. I was on my own when I got the diagnosis. I hadn't told my husband about my worries. So, when I went and told him it came to him as a real shock. In fact, the way I told him was really bad, because I had not thought about it. I had not prepared him for it. When I got the diagnosis, I was offered a follow-up appointment to bring my husband with me. After that, I was told to come back in a year, or (if I was worried) book an appointment when you feel like it.

This is not support. A year is too long. This disease can progress really quickly for some people. In fact, at the point of diagnosis, I was told I had 18 months to 2 years before I would need a lot of supporting care. And there is a medical professional telling me to come back in a years' time? This is half way through the time period he is telling me I'm going to be incapable. He got that wrong cause it is 4 years now and I am okay still. But I had no support whatsoever.

Helen: My consultant used to say to my husband, "Please try not to make Helen feel depressed", and he was saying, "How am I supposed to do it?" Then one day my consultant suggested to me to visit the Alzheimer's Society. He thought it could help me, so I went there and it was true. There was light.

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A nurse told me considering my background you should focus on research because research is really important today around dementia. A friend of mine was listening to the radio, a professor asking for people to be involved in research and she gave me his name. My son insisted I had to write a letter, but I didn't know what to say. It was eleven o'clock on Saturday night and we were writing a letter. The next morning at 09:00, Professor Robinson came back to me. That was the first step after a long time that got me out of my house, that there might still be a life for me.

Can you tell us about how you became involved with the European Working Group of People with Dementia (EWGPWD)? Are you also involved in national level advocacy?

Helen: I became a member of the research working group in Ireland, which has existed for 4 years now. From there, I was nominated to become chairwoman, very soon after I joined, I think.

Maybe because you deserved it.

Helen: Maybe! I immediately created structures in the group and after that, I was nominated to become a member of the European Working Group of People with Dementia (EWGPWD). All these things were wonderful and enlightening experiences and gave hope that I can live again and make a contribution to society.

Hilary: I was similar. My first question after I got diagnosed was "How long have I got?" My second question was "What research can I get involved in?" And the neurologist said, "I don't know." I went to the website of the English Alzheimer's Society and saw that they had an English network of volunteers and I joined that.

Now I am Ambassador for the Society and I joined the EWGPWD, like Helen. Happiness and hope were brought back to my life. We see now what is going on. Things are gradually changing.

What more can be done at European and national level to improve the lives of people with dementia?

Helen: First of all, every country should have a national dementia strategy. But not just have it, they must implement it. We also should have a European Strategy for dementia. It's the fastest illness globally. There is no cure. We need to be looking at how, even though there is so much research happening and I am optimistic that something is going to happen.

But we definitely need a European strategy. In every aspect of research, people with dementia should be involved, because we have the experience and knowledge.

Hilary: I totally agree. Now the World Health Organisation starts setting a framework that hopefully national societies and governments will then start to do something. It's great that it's on the agenda on this level. The real work is done on the ground. The people who deal with that every day need to have resources and strategies that will make their job easier and more effective.

How can policymakers, clinicians, and scientists, engage more with people with dementia in research and policy?

Helen: One of the main difficulties we people with dementia face is that most of us lose our careers, our jobs. So, a kind of a pension or disability allowance would be in order. When there is a requirement we would like, in particular for pharma for large conferences, to consider some kind of honorarium.

Because you are traveling a long distance and you want to buy a bottle of water and you might forget it. I will forget it. I will forget that I will need something. Expenses must be paid. Most of the time I travel alone. We want to be appreciated and respected as people who can make a contribution. I am still the same Helen like the one before I got my diagnosis. I

want to contribute as much as I can.

Hilary: We need to build working groups of people with dementia and the European one is great. We are just setting one up in England now, but every country needs one. We need to develop networks of people with dementia, which will be good for us, for professionals. People with dementia need to have access to a group where they will be granted the assistance they need.

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