

DEMENTIA IN EUROPE

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Svandís Svavarsdóttir
Icelandic Minister of Health discusses Iceland's newly launched national dementia strategy



Christophe Hansen, MEP
moderated the lunch debate on Innovative Medicines Initiative funded projects on dementia



Senator Fiona O'Loughlin
sets out her priorities following her election to the Seanad Éireann



Mischa Kamp
discusses "Romy's Salon", her award-winning film about dementia

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Welcome



Iva Holmerová, Chairperson of Alzheimer Europe

I am pleased to welcome you to the 33rd edition of *Dementia in Europe* - the Alzheimer Europe magazine. This is the first time we have had a fully electronic edition of the magazine. I hope you enjoy it! The decision to go electronic, for this issue, was made due to the uncertainties around the COVID-19 pandemic and its impact on service providers.

The first section of the magazine highlights some of our efforts to ensure dementia remains a European priority. It begins with coverage of our February 2020 lunch debate, organised together with the Neuronet project and focusing on research collaborations at a European level. The debate was hosted by European Alzheimer's Alliance Vice-Chairperson, Christophe Hansen, MEP (Luxembourg). I would like to thank him for the interest he has shown in the work we are doing to support dementia research.

The Alzheimer Europe section then looks at some of the work we are doing with the European Working Group of People with Dementia (EWGPWD) in the area of Patient and Public Involvement (PPI) in research. We are also pleased to announce the start of two new JPND-funded projects, in which we are participating: EUROFINGERS and ADAIR. The project coordinators share more

information about these exciting new initiatives, both of which our team is looking forward to supporting.

The Policy Watch section presents the newly-launched national dementia strategy from Iceland, with input from Icelandic Minister of Health, Svandís Svavarsdóttir, as well as from our member, Alzheimer Iceland. We then take a closer look at Spain's recently-published strategy, with feedback from our member, Confederación Española de Alzheimer (CEAFA). Also at the national level, we spoke to The Alzheimer Society of Ireland, which recently ran a campaign for change during the Irish General Election.

At the European level, we include an interview piece with new EAA Office Bearers, MEPs Christophe Hansen, Hilde Vautmans and Sirpa Pietikäinen.

The final article in the policy section reflects on the key issues around continence care for people with dementia and identifies some of the ongoing efforts to improve the quality of their care and treatment, including work Alzheimer Europe has done on this topic in recent years.

Our third section, *Dementia in Society*, begins with a piece about Alzheimer's associations throughout Europe which have implemented Dementia Friends programmes in their countries and about how successful this movement has been, as well as about how such programmes continue to engage people after they become "Dementia Friends".

Next, we have an article written by Finnish member of the EWGPWD, Petri Lampinen, who shares his thoughts on life since a diagnosis of Frontotemporal Dementia and on the importance of exercise, diet and careful planning.

For our final "society" article, Dutch film director Mischa Kamp tells our readers about her award-winning movie "Romy's Salon", released at the start of this year. The movie shines a spotlight on the changing relationship between hair salon owner Stine and her granddaughter, Romy, as Stine's dementia progresses.

Our final section pays special attention to some of the changes that have been happening for people with dementia, their carers, and for the associations and organisations that are working to support them, during this COVID-19 pandemic. The section covers our own activities in response to the crisis, as well as some of those of our members, who continue to work tirelessly to find new and creative ways to ensure people living with dementia and their supporters can continue to access much needed care and services during this time of confinement, closures, and social distancing.

On the subject of changes due to COVID-19, Alzheimer Europe's 30th Annual Conference #30AEC, which was planned to take place in Bucharest, will now be a virtual conference, under the banner "Dementia in a changing world". This decision was taken by the Alzheimer Europe Board at an online meeting on 19 May 2020, in light of the continuing pandemic. It was also decided by the Board that, rather than cancelling it, the Bucharest conference "Building Bridges" would move to 29 November to 1 December 2021. More information about the 2020 virtual conference is available on our website.

I wish you all good health!



Lunch debate explores the work of the Innovative Medicines Initiative (IMI) in advancing Alzheimer’s research through private-public partnerships

Alzheimer Europe and Neuronet co-organised a lunch debate, moderated by Vice-Chairperson of the European Alzheimer Alliance (EAA) Christophe Hansen, MEP, examining the work of the Innovative Medicines Initiative (IMI) in relation to dementia research.



Alzheimer Europe co-hosted the lunch debate with the Neuronet Coordination and Support Action

On 18 February, Alzheimer Europe held its first lunch debate of 2020, entitled “The Innovative Medicines Initiative (IMI): Advancing Alzheimer’s research through public-private partnerships”. The lunch debate was organised by Alzheimer Europe, in partnership with the Neuronet Coordination and Support Action. A total of 70 people attended the debate, including national member organisations, members of the European Working Group of People with Dementia (EWGPWD), academics, industry representatives and policy makers.

Christophe Hansen, MEP (Luxembourg), Vice-Chairperson of the European Alzheimer’s Alliance (EAA), opened the session, welcoming attendees and thanking them for taking the time to attend the meeting.

He acknowledged that dementia should be a research priority since there is no disease modifying treatment and no cure for the

underlying conditions, such as Alzheimer’s disease. In relation to how dementia is understood, Dr Hansen briefly outlined some of the changes in recent years, including developments in pre-symptomatic detection and development of new ways of detecting the condition (e.g. through biomarkers) shifting the focus in relation to diagnosis and detection of the disease.

He further highlighted that the focus of research had not solely been on basic science or drug discovery, but also on how health records and data can be better utilised to facilitate high quality research. However, this had also led to the need for data and information generated to be better coordinated, to ensure data did not remain fragmented and difficult to access.



(left to right) Pierre Meulien, Bart Vannieuwenhuysse, Christophe Hansen, MEP, Jean Georges and Carlos Diaz

Dr Hansen noted that progress could only be made with investment in research, with a significant source of funding being public-private collaborations such as IMI 1 (2008–2013) and IMI2 (2014–2020).

Mr Hansen concluded his remarks by noting that it was essential that Horizon Europe continued this collaborative approach to research.

The Neuronet Coordination and Support Action

Carlos Díaz, Project Coordinator for Neuronet, opened his presentation by providing an overview of the project and its role in supporting the neurodegeneration portfolio of the second IMI.

He elaborated that Neuronet aimed to better support and integrate 16 different projects from the IMI neurodegeneration disorders portfolio, boosting synergy, preventing projects from working in isolation, identifying gaps across the neurodegeneration portfolio and enhancing the visibility of the findings of projects.

He then provided an overview of the current landscape in relation to research projects on neurodegeneration within the IMI portfolio. In particular, he explained the complex nature of the five key components which impact upon each project: Targets; Timescales; Knowledge; Hierarchies; and, Funding. Within the IMI projects, Mr Díaz noted that this translated into hundreds of institutions and thousands of researchers, each bringing their own considerations with regards to these five areas.

Neuronet therefore aims to avoid a top-down approach, instead operating a “switchboard” model, connecting people, tools and technologies, as well as supporting synergies between projects. As part of this, a just in time approach ensures timely linkages between projects and their outputs, aligning to other projects which may have related or relevant work.

Mr Díaz outlined the governance structure of Neuronet, setting out the roles of the Scientific Coordination Board (SCB), the Working Groups (WG) and Task Forces (TFs).

He explained that the SCB is composed of leaders of the IMI projects, who set the overall direction and strategy for Neuronet. He further outlined the role of the four thematic WGs which contain expert members from the projects and which are tasked with drafting guidelines and white papers on the subjects of data sharing and reuse, regulatory issues, ethics and patient privacy, and sustainability. Finally, the TFs are designed to be small cross-project teams which will implement specific work on synergies within a set time frame.

A key area of work for Neuronet is the development of a knowledge base, a resource providing an overview of projects and activities within the IMI neurodegeneration portfolio in the form of a dashboard. As part of this, an asset map will provide a visual overview of the outputs of each project.

Mr Díaz concluded by noting that the future landscape should be one where there are joint perspectives, embedded ideas of leadership (which recognise that not everyone has to



Lenny Shallcross of the World Dementia Council speaks to Alzheimer Europe Vice-Chairperson Charles Scerri

try and lead) and which cultivate a problem solving culture.

The European Medical Information Framework

Bart Vannieuwenhuysse, the Senior Director of Health information Sciences for Janssen, presented on the European Medical Information Framework (EMIF) project, which had been undertaken as part of the IMI 1 partnership.

This project stemmed from recognition of the many silos of data which were not being utilised in an optimal way for research. The work was a precursor for and provided much of the data and infrastructure for later projects and programmes, such as a Big Data for Better Outcomes (BD4BO).

Mr Vannieuwenhuysse outlined the EMIF project, which ran between 2013–2017, involving 58 partners from 14 European countries and had a total budget of EUR 56 million.

The project had three components: EMIF-Platform; EMIF-Metabolic; and, EMIF-AD. The overarching platform aimed to develop a framework for evaluating, enhancing and providing access to human health data across Europe, whilst also supporting the condition-specific areas of obesity and Alzheimer’s disease.

For the EMIF-AD component of the project, the goal was to identify predictors and diagnostic biomarkers for AD; identify and link AD cohorts; define phenotypes and develop a prediction model for cognitive decline; and, acquire data to discover biomarkers and genetic markers for pre-dementia AD.

Mr Vannieuwenhuysse described the AD Catalogue, which had been developed as part of the project to create a publicly available tool allowing researchers to find AD cohorts of interest based on cohort metadata, aiming to stimulate the re-use of data and establish



A total of 70 people attended the lunch debate

new research collaborations, as well as providing a comprehensive overview of all available AD cohorts, with tools to search, select, and compare different AD cohorts.

He further explained the AD cohort explorer process which allows for group level queries to identify subjects and variables of interest, on harmonised datasets, in addition to enabling researchers to easily find the right subjects, stimulating and facilitating the re-use of AD cohort data. Key to this area of work was the common data model of variables, which is also compatible with projects such as the European Prevention of Alzheimer's Dementia (EPAD) project.

Mr Vannieuwenhuysen also highlighted the EMIF 1000 cohort, which aimed to establish large sample sets for biomarker discovery in EMIF-AD, by re-using data and samples of existing AD cohorts spread over Europe. In doing so, this created a digital cohort of over 1000 people, incorporating data from MRI scans, Cerebrospinal Fluid (CSF), DNA profiling and amyloid measurement. This digital cohort continues to be used by researchers, even after the conclusion of the project.

The presentation concluded by highlighting a successor project to the EMIF, the European Health Data and Evidence Network (EHDEN), which aims to harmonise 100 million health records, create an ecosystem of certified harmonised data sources and create a system of federated analytics.

Neurodegeneration in the Innovative Medicines Initiatives

Pierre Meulien, the Executive Director of IMI, presented on the work of public-private partnerships in neurodegeneration research to date, as well as looking towards future collaborations.

The presentation highlighted that the nature of the IMI partnership was unique and that it was unlikely that such a collaboration would be possible elsewhere in the world. It was explained that the IMI portfolio covers many different areas of work including brain disorders, drug discovery, cancer and data knowledge and management, amongst others.

Dr Meulien continued by noting that about 20% of active IMI projects have patient organisations as full partners, about 50% have a strong patient voice (either as full partners or through having a role in the project) and about 30% have patient organisations represented on advisory boards or have consulted with patient organisations. He also noted that IMI had developed a pool of patient experts, 118 patients and 39 family carers, including 3 members of the EWGPWD.

He articulated the IMI as an ecosystem for innovation, allowing for multi-sector and multi-disciplinary engagement at the forefront of cutting-edge research, providing the necessary scale for funding, expertise, knowledge, skills and resources.

The difference in the funding mechanisms between IMI 1 and IMI 2 was explained, with a new concept of "Associated Partners", providing an opportunity for other organisations to contribute to and play an active role in the research programme, with 36 having done so, contributing over EUR 200 million, so far.

In relation to neurodegeneration, Dr Meulien noted that diagnosis and therapeutic research had shifted earlier in the disease process, moving the focus towards the pre-symptomatic diagnosis based on biological aspects of the condition. Long term, this shift will continue as developments are made into pre-symptomatic risk prediction.

In relation to the dementia portfolio specifically, Dr Meulien highlighted AETIONOMY, EMIF, EPAD and AMYPAD as some of the most prominent and successful projects. Respectively, these projects address issues around the underlying cause of dementia, the risk factors in developing the condition, improving clinical trial design and the uses of brain scanning.

In concluding his presentation, Dr Meulien outlined some of the broad themes which have so far emerged in relation to a future public-private partnership on health. The focus will go beyond medicines development, with prevention and early detection at its core, as well as integrating big data and digital solutions. Additionally, he explained that the voice of patients and citizens would continue to be prominent within the future collaboration.

Open discussion

An open discussion followed, with attendees raising questions and comments. Nelida Aguiar, supporter of Idalina Aguiar from the EWGPWD, shared her experience of struggling to participate in research due to her location on an island and urged the panelists to ensure that people in rural areas and islands were able to participate.

Lenny Shallcross, Executive Director of the World Dementia Council (WDC), addressed the issue of the difference between the messaging for people with a diagnosis of dementia and those at future risk of developing the condition. Dr Meulien noted that



Members of the European Working Group attended the lunch debate



Alzheimer Europe launched two reports at the lunch debate

health systems are not currently sustainable and discussion around prevention must be part of the discussion around dementia.

Chris Roberts, Vice-Chairperson of the EWG-PWD, spoke of the need to start at school and to educate young people in relation to dementia.

Jean Georges, Executive Director of Alzheimer Europe, asked what could be improved for future research projects and programmes. Dr Meulien highlighted the need to have more small and eastern European countries involved in projects. Mr Vannieuwenhuysse noted that there was a need to find a better balance on reporting for projects, as well as a better way of establishing consortia between public and industry partners.

The discussion also covered the sustainability and legacy of projects after the initial period of funding, with the suggestion of an approach with national “nodes” contributing funding to ensure continuity. Mr Díaz proposed longer funding periods of 10–15 years, with clearer targets for deliverables or objectives which would have to be met at set intervals.

Christophe Hansen addressed questions to each of the presenters, asking:

- Mr Vannieuwenhuysse how data sharing could be facilitated given the difficulty with data which was often coded, protected or subject to IP rights
- Mr Díaz how collaboration could be encouraged more widely, beyond Europe, for issues which had a global impact
- Dr Meulien for his thoughts on the future of the UK within the Horizon Europe research programme.

Mr Vannieuwenhuysse reiterated the importance of public-private collaborations but noted that research in this area was still in its early stages, with new science and new therapeutic interventions needed. He noted that as progress was made towards a treatment, it may lead to stronger collaboration and greater sharing of data.

Mr Díaz noted that too often researchers/ organisations approached research in terms

of possessing data, research, etc. and that there was a need for projects such as Neuronet to play an ambassador role, emphasising the mutual benefits of collaboration.

Dr Meulien commented that Horizon 2020 would continue to fund UK partners for the duration of the projects, not just until the end of the transition period. He noted that as the UK received 25% of all IMI money, coupled with the research expertise in the UK, Brexit was a lose-lose situation for the future programme.

Launch of Alzheimer Europe reports

Jean Georges launched two reports at the meeting: the Dementia in Europe Yearbook 2019 on the prevalence of dementia and a discussion paper entitled “Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research”.

Closing remarks

Charles Scerri, Vice-Chairperson of Alzheimer Europe, brought the session to a close by thanking attendees and speakers for their contribution to the event. Christophe Hansen, MEP reflected on the need to reduce the fragmentation in research, as well as maintaining significant funding in the future of research at the European level.

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Christophe Hansen, MEP – Innovation and research are key if we want to fight diseases such as dementia and Alzheimer's

As Vice-Chairperson of the European Alzheimer's Alliance, I was honoured to host Alzheimer Europe's lunch debate on research collaborations at EU level.

New numbers from the Alzheimer Europe Yearbook 2019 report on the prevalence of dementia in Europe finds that even though a reduction in the prevalence of dementia can be observed, the number of people with dementia is set to double by 2050.

Demographic changes are among the main reasons for this increase: The population in Europe is getting older. Consequently, more people are likely to get Alzheimer's disease or dementia.

Today, there is no cure or disease modifying treatment for Alzheimer's or dementia. For this reason, they must be a priority when it comes to research and the development of new medicine or treatment.

Innovation and research are indeed key if we want to fight diseases such as dementia and Alzheimer's. Therefore, we also need better cooperation between researchers in the EU.

Over the past decade, the Innovative Medicines Initiative (IMI) has already proven to be a successful tool for public-private partnerships. Through cooperation between the European Union and private partners in the pharmaceutical industry, better and safer medicine is being developed.



However, the Initiative has also made clear that cooperation and the exchange of data and information are just as important. Sharing findings from research and working together on innovative projects, Neuronet and EMIF have shown how collaboration can work.

It is good to see that this flagship, established under the EU Horizon programme for Research and Innovation, is working and that there will be a successor, the "European Partnership for innovative health" under the new Horizon Europe.

The successful continuation of the initiative however requires sufficient funding. The negotiations on the Multiannual Financial Framework (MFF) 2021–2027 are therefore essential. Discussions are currently ongoing and have proven to be

quite challenging in the current political and economic context. The UK, one of the biggest net contributors to the EU budget has left the European Union, global challenges such as climate change and trade tensions with the US and China are a strain on Members States economies.

The Coronavirus crisis has put additional stress on the EU. At the same time, these challenges call for an ambitious EU budget in order to tackle them as a Union. Unfortunately, many Member States are reluctant to raise their contributions. It is therefore of utmost importance to ensure that the budget for Horizon Europe is not reduced. If the Coronavirus pandemic has made one thing clear, it is that funding for innovation and research are essential in order to support a health sector which is able to react to new challenges.

“Innovation and research are indeed key if we want to fight diseases such as dementia and Alzheimer's. Therefore, we also need better cooperation between researchers in the EU.”

Patient and Public Involvement in research

In early 2020, an article entitled “Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia” was published in the journal *Dementia*. Alzheimer Europe spoke to three of the co-authors – Chris Roberts, Helen Rochford-Brennan and Jayne Goodrick – about the article and about their own experiences of PPI.

Since 2012, when the European Working Group of People with Dementia (EWGPWD) was set up, Alzheimer Europe has increasingly involved people affected by dementia in Patient and Public Involvement (PPI) activities, in particular in the context of large European research projects.

In 2017, and in collaboration with the pan-European network of researchers, INTERDEM, Alzheimer Europe and its EWGPWD developed a position paper on PPI in dementia research. The position paper was approved by the Boards of Alzheimer Europe and INTERDEM and published in an academic journal (*Aging and Mental Health*) so that other organisations could use or adapt it. The 2017 position paper highlighted seven key areas

which form a framework for the development, implementation and monitoring of PPI work in the context of dementia research.

As a follow up, in early 2020, a new article entitled “Our reflections of Patient and Public Involvement in research as members of the European Working Group of People with Dementia” was published in an international peer-reviewed journal (*Dementia*). The article was co-authored by Chris Roberts, Helen Rochford-Brennan (both living with dementia and members of the EWGPWD), Jayne Goodrick (supporter, Chris’s wife) and Dianne Gove, Ana Diaz and Jean Georges (Alzheimer Europe staff). To write the article, all the co-authors worked together and identified three of the seven areas of the framework

“It is very important for experts by experience to be involved in all relevant research and that they are given what is their right: a say in what and how research is undertaken. Our inclusion in PPI provides a unique and valuable perspective of the lived experience.”

Chris Roberts

which tend to receive less attention in the literature. Based on their own preferences and interests, each person affected by dementia decided to review one of them. In the article:

- Chris Roberts presents his experience and views on the issue “Recognition and acknowledgement of the contribution made by people with dementia”
- Helen Rochford-Brennan presents her experience and views on the issue “Promoting and protecting the rights and well-being of people with dementia”
- Jayne Goodrick presents her experience and views on the issue “Training and support”

The article was selected by the website committee of INTERDEM as the January ‘article of the month’, due to its relevance for researchers working in dementia.

Chris Roberts, first author

What did it mean to you to be first author of this peer-reviewed journal article and how important was it, for you, to write such an article, recognising and acknowledging the contribution made by people with dementia, in the area of PPI?

It was and always is a great pleasure and experience to work with Alzheimer Europe as a member of the European Working Group of People with Dementia (EWGPWD) and it was a real honour to be asked to be the lead author on this journal article. Usually we, as people living with dementia, are asked for advice, feedback and comments for articles but hardly ever are we asked to



Helen Rochford-Brennan (L), Chris Roberts and Jayne Goodrick (R) attending Alzheimer Europe lunch debate, 10 December 2019

be lead authors. It is an important statement that people living with dementia are still capable members of our society after their diagnosis. It is very important for experts by experience to be involved in all relevant research and that they are given what is their right: a say in what and how research is undertaken. Our inclusion in PPI provides a unique and valuable perspective of the lived experience.

Papers such as this are an important reminder to continue to include and promote the collaboration of people with dementia. Such papers also serve to inspire other experts by experience to also take part in PPI and to assure them of the value of their potential contribution.

Helen Rochford-Brennan, co-author

As a co-author of this article, can you tell us more about one of its main focal points: promoting and protecting the rights and well-being of people with dementia taking part in PPI?

For too long, people living with dementia have been involved in research by simply answering questions. However, to ensure that we are represented and that our voices are heard, we need to set the question and have a seat at the table when that question is being refined.

Equality is critical during PPI. People living with dementia need to be equal partners – we must be listened to and have shared power for decision making. An integral part of this is appropriate support to participate – support

“PPI is so vital. We can demonstrate that whatever assumptions people may have about dementia, and about all those affected by dementia, are just assumptions and do not apply in each individual case of dementia.”

Jayne Goodrick

“Equality is critical during PPI. People living with dementia need to be equal partners – we must be listened to and have shared power for decision making. An integral part of this is appropriate support to participate.”

Helen Rochford-Brennan

to review documents, travel and expenses. Equality is practical as well as theoretical!

Can you also comment on the principle of involving people with dementia as authors and co-authors in peer-reviewed journal articles?

This is important for recognition. If our work on the project is important, then we need to be involved in writing up the work. I believe there are clinical experts, academic experts and experts by experience. People with dementia are experts by experience. If you leave out one group of experts, the article will be the weaker for it.

I find a great joy in collaboration and the writing process, but I need support to do that. It is really important to have practical support to consider ideas and type them up.

On a personal level, being involved gives me a wonderful hope and a sense of purpose. Getting recognition is empowering, not just for myself, but for others, in particular those newly diagnosed.

Jayne Goodrick, co-author

As a co-author of this article, can you give us some insights into your personal and ongoing experience of PPI?

I was extremely pleased and very proud to be asked to contribute to this article. As carers, we can sometimes be overlooked. That's nobody's fault, just the way it is, so to be included meant so much. It is particularly important as people with dementia are often considered incapable of anything, even today. As my husband Chris says, there is a beginning and a middle before you get to the late stages of dementia.

This peer reviewed article showed just how intelligent and capable people with dementia can still be. Dementia does not compromise your intelligence. Chris has retained many of his cognitive abilities and I am still astounded by his ability to work around any difficulties he encounters in that respect.

It is for these reasons that PPI is so vital. We can demonstrate that whatever assumptions people may have about dementia, and about all those affected by dementia, are just assumptions and do not apply in each individual case of dementia. It is especially important that organisations, which are producing or developing products and services for the very people who will be the beneficiaries of those products and services, understand this basic concept.”

You can read the full article on PPI here: www.bit.ly/PPI-article



The EWGPWD was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia, nominated by their national Alzheimer associations. They work to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia.

www.bit.ly/EWGPWD

EURO-FINGERS: Europe at the forefront of Alzheimer’s dementia prevention

Alzheimer Europe is part of the newly-launched JPND project “EURO-FINGERS: multimodal precision prevention toolbox for dementia in Alzheimer’s disease”. We spoke to Professor Miia Kivipelto, scientific coordinator of EURO-FINGERS, to discuss the project’s aims and expectations at the time of the COVID-19 pandemic.



The EURO-FINGERS project starts at a historical moment for Europe and many other world regions, which are focused on halting the COVID-19 pandemic while ensuring adequate medical care of people with chronic non-communicable disorders (NCDs), who are mostly seniors. Older adults are a large and fast-growing portion of the population; they are the most vulnerable to the SARS-CoV2 infection, and they also have increased risk to develop Alzheimer’s disease (AD) and dementia. Curative drugs for dementia and AD are not yet available, and repeated negative results of randomised controlled trials (RCTs) testing pharmacological interventions make the timeline for a cure uncertain.

Prevention for AD and dementia has been identified as a global public health priority. In this landscape, the EURO-FINGERS project brings together European top researchers to develop the next generation of RCTs for the prevention of AD dementia. EURO-FINGERS is supported by the EU Joint Programme – Neurodegenerative Disease Research (JPND), the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. EURO-FINGERS officially started on 1 March 2020 and is a 3-year project. Alzheimer Europe is a key partner in this project and is contributing towards the patient and public involvement and communication activities. Alzheimer Europe will also have a key role in the scientific dissemination of the EURO-FINGERS results to key stakeholders and the general public.

What are the concrete objectives and actions that will be undertaken by the project?

EURO-FINGERS builds upon the successful experience of FINGER: the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (led by Prof. Kivipelto, Ed.). In this pioneering RCT, we demonstrated that a 2-year multimodal lifestyle intervention consisting of nutritional guidance, exercise, cognitive training, and control of vascular risk factors benefitted cognition in senior community dwellers at increased risk of dementia. In EURO-FINGERS, we aim to develop tools to advance, optimise and scale-up the FINGER model across Europe. These tools include methods to accurately measure the level of AD risk in seniors, as well as their prevention potential, in order to identify subjects with different risk profiles, who are more likely to benefit from specific preventative interventions.

We will also develop an innovative RCT model, where for the first time, multimodal lifestyle interventions can be tested in combination with drugs that might halt AD. Although no disease-modifying drug has so far been approved for AD, we are working to identify medications that can synergise with the benefit of the multimodal intervention. Additionally, we will build the EURO-FINGERS online registry, which will facilitate the recruitment of participants in AD prevention RCTs across Europe. So far,

we have 7 countries involved, but we envision the consortium will grow over time and include more nations.

What are some of the main challenges you are facing with this research?

AD and dementia prevention is a relatively new field, and we have learned from other recent multimodal prevention RCTs that there is no “one-size-fits-all” solution. Late-life AD is a complex and heterogeneous disorder. Only by deciphering this complexity and heterogeneity, can we find effective preventative solutions. We need to implement Precision Prevention, which means defining preventive strategies tailored to specific risk groups, identified by clinical and biological features and environmental risk factors exposure. To achieve this, EURO-FINGERS will leverage unique European long-term data from observational studies and RCTs, covering the full spectrum from at-risk states to early-symptomatic AD. These studies provide multidimensional data (lifestyle, clinical, genetic, omics), that will be analysed with novel AI-based methods, able to translate complex and large data into fingerprints of individual AD risk and prevention potential.

Precision Prevention is already developed in oncology, and we are learning from this field. In progressing Precision Prevention strategies for AD dementia, we focus on the “what”, which risk factors to target, the “why”, the biological mechanisms that mediate prevention effectiveness, and the “how”, the most cost-effective implementation approaches. Indeed, another big challenge is that Precision Prevention strategies must be developed and implemented in ways that will make them accessible to all who may benefit from them. This is especially important as the sustainability of many healthcare systems can be challenged by acute crises such as the current pandemic. In EURO-FINGERS we have unique ready-available long-term data from prevention RCTs, that can be used for cost-effectiveness analyses, to assess the sustainability of prevention strategies in targeted populations who are most likely to benefit.

What are your expectations from and hopes for the project, also bearing in mind the current pandemic?

The AD research field is heavily affected by the COVID-19 outbreak, with many activities being delayed or paused. In EURO-FINGERS, a large amount of data is already available, and activities have started as planned. Depending on how the pandemic and its control measures will evolve, we will adapt to prevent and minimise delays in delivering the project.

EURO-FINGERS synergises and builds upon cutting-edge studies to produce crucial knowledge for effective and sustainable prevention. The project will bridge the gap between non-pharmaceutical and pharmaceutical trials by designing the first combined lifestyle + drug prevention RCT protocol. Additionally, through the creation of EURO-FINGERS online registry, we can address the recruitment challenges in AD trials. Finally, thanks to the JPND widening concept, the EURO-FINGERS consortium includes Hungary, often under-represented in this research field. In the future, we aim to expand the consortium so that more European countries can participate in harmonised efforts for AD prevention.

In relation to the current pandemic, we expect that EURO-FINGERS results can benefit the management of risk factors, including NCDs (e.g., hypertension, diabetes) and lifestyle-related factors (e.g., diet, physical activity), which are relevant to AD dementia but also to the overall morbidity burden of seniors. The pandemic has negative effects on the management of all these factors, because of changes in the functioning of the healthcare system, seniors being reluctant to seek care due to infection risk, and lifestyle changes due to the outbreak control procedures, such as limited physical activity due to home isolation. In this context, EURO-FINGERS is a very timely project which can inform sustainable healthy lifestyle and management of NCDs in seniors, with benefits beyond AD dementia prevention.

As an example, we will develop e-tools (e.g., remote visits, online surveys) suitable for seniors with cognitive impairment, and the PPI activities led by Alzheimer Europe will ensure inclusion of the users' preferences.

How will this project collaborate with other projects in the field?

EURO-FINGERS follows another successful JPND-funded project, MIND-AD, in which we tested for the first time the feasibility of a multi-domain intervention in subjects with early-symptomatic (prodromal) AD. Many of the MIND-AD consortium members participate in EURO-FINGERS, and they collaborate also within the IMI-EPAD project, a large European initiative focused on AD dementia prevention, with relevant insight on large cohorts and RCT design for early stages of AD.

Overall, EURO-FINGERS brings forward a successful research pipeline through a well-established European network. EURO-FINGERS will provide a common framework and align the main European cohorts in the AD field, to deliver results easily implementable in Europe. Additionally, EURO-FINGERS is closely linked to the recent World-Wide FINGERS initiative (WW-FINGERS, led by Prof. Kivipelto, Ed.), aiming to test the FINGER multimodal precision prevention model in various geographical, cultural and economic settings (e.g. trials now in the planning stage in Europe, North and South America, Asia and Australia). EURO-FINGERS represents the scientific engine of WW-FINGERS, providing tools and methodology that ensure synergy, harmonisation, and more effective and targeted interventions across WW-FINGERS trials, ultimately leading towards the identification of globally effective prevention strategies.

How will this project benefit people at risk of Alzheimer's disease dementia?

According to a recent Alzheimer Europe report, despite a reduction in the age-specific

prevalence of dementia, the total number of affected individuals in Europe is expected to double by 2050, consistently with global estimates. Current data suggest that about 1 in 3 cases of AD may be attributable to modifiable risk factors, including lifestyle, metabolic and vascular factors. This indicates the presence of a prevention potential, which might be even larger than the current estimates. Results from EURO-FINGERS are expected to benefit people at risk of AD dementia by creating knowledge on effective and sustainable prevention strategies for seniors, as well as a solid framework for AD prevention Europe. This includes a tool (EURO-FINGERS online registry) to easily direct research-interested citizens/patients to the most suitable prevention trials. Furthermore, through their active engagement in EURO-FINGERS, individuals at risk (or at early-stage) of AD dementia are empowered by integrating their views and preferences in guidelines on how clinicians should disclose the at-risk status. The project will also identify strategies for shared decision-making to improve patients' and caregivers' involvement in the diagnostic process and the choice of preventive strategies, ultimately bringing dementia prevention closer to society in general.

EURO-FINGERS project partners

Karolinska Institute, Sweden (Coordinator); Alzheimer Europe, Luxembourg; Combinostics Ltd., Finland; Finnish Institute for Health and Welfare, Finland; IIS Instituto Hospital del Mar de Investigaciones Mèdicas, Spain; National Institute of Clinical Neurosciences and Semmelweis University, Hungary; Saarland University (Germany); VU University Medical Centre, Netherlands.

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Luxembourg National
Research Fund



ADAIR: Examining the link between air pollution and dementia

Using the most advanced research methods, models and cohort studies, the ADAIR project hopes to unravel the link between air pollution exposure, brain health and Alzheimer’s disease (AD), with the end goal of finding ways to identify at-risk individuals and to prevent the disease. Alzheimer Europe spoke to project coordinator Katja Kanninen to learn more.



According to Katja Kanninen, Alzheimer’s disease (AD) is a devastating disorder without a cure, but remarkably little attention is paid to the involvement of environmental factors in AD research.

Air pollution, a massive public health issue, is an important, ever-increasing global concern. Every year, about 7 million premature deaths from cardiovascular and respiratory conditions occur as a direct result of exposure to air pollutants, especially to particulate matter

(PM). Yet, epidemiological studies and controlled animal studies show that exposure to air pollutants also impairs the brain. Recent epidemiological research demonstrates a link between cognitive dysfunction/AD and exposure to high levels of air pollution in humans. Inhalation exposure to diesel engine exhaust or PM has been shown to aggravate AD-like pathology in mice. However, detailed understanding of the connection between air pollution and AD does not exist.

What are the concrete objectives and actions that will be undertaken by the project?

Despite some progress in the field, many questions remain unanswered as mechanistic information on air pollutant effects in brain is scarce. Importantly, biomarkers for air pollution and AD risk prediction do not currently exist, thus hindering the identification and stratification of individuals at risk for harmful air pollution effects. Researchers involved in the highly innovative ADAIR project will use the most advanced research methods, models and cohort studies to unravel the link between air pollution exposure, brain health and AD.

The ultimate goal of the project is to develop strategies for early identification of people at risk of developing AD, and to discover new approaches for disease prevention. For this purpose, ADAIR uses three clinical, population cohorts: 1) Betula Study in Sweden, 2) Rotterdam Study in the Netherlands, and 3) the Pearl River Delta study in China for in-depth investigation of pollutant effects in healthy individuals as well as those diagnosed with AD. In addition to using these three large population-based cohorts, ADAIR utilises highly translational human-based in vitro research models for biomarker discovery and functional studies. The clinical and in vitro data will be combined using emerging new technologies including integration of omics in a systems biology platform, for the identification of novel biomarkers for air pollutant effects and risk prediction. This will allow us for the first time to identify altered molecular and functional interactions, and key pathways associated with air pollutant effects and AD for better understanding of this complex disease.

What are some of the main challenges you are facing with this research?

One of the main challenges in this research is deciphering which exact type of air pollution exposure is harmful for brain health. The duration and level of exposure are likely to be critical in determining the consequences on health. In addition, deciphering how genetically determined predisposing factors may play a role in the risk of health impairment is another complex challenge that requires intensive investigation.



ADAIR consortium at kick-off meeting in Prague, Czech Republic, 16 January 2020

What are your expectations from and hopes for the project?

We expect that this project will produce important information on the impact of air pollution exposure on brain health. We hope that this information can in the future be used for identification of at risk individuals and for preventive interventions. We also hope that the information generated during the project will generate strong interest within relevant stakeholder communities both in Europe and beyond, including policy-makers, health and safety sector, patients and advocacy groups, and research communities.

The results of the project can be used to make informed decisions that create better and safer settings and policies for protection of human health.

How will this project collaborate with other EU projects in the field?

ADAIR is a multi-national collaboration between neuroscientists, environmental scientists, clinicians, epidemiologists, informaticians, and non-profit organisations. We collaborate with several national and international projects in the field, most notably with the InCo flagship on reduction of transport

impact on air quality project called “Transport derived Ultrafines and the Brain Effects” (TUBE), which started in May 2019 and continues until April 2023.

How will this project benefit people with dementia?

We hope that the results of this project will in the future aid in early identification of individuals at risk of air pollution effects. We also hope that the results will lead to increased understanding of AD disease mechanisms that can form the basis for new therapies in the future.

Acknowledgement



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Iceland launches first national dementia strategy

Following the publication of Iceland’s first national dementia strategy in April 2020, Alzheimer Europe spoke to Icelandic Minister of Health, Svandís Svavarsdóttir, about the strategy and to Árni Sverrisson, Chairperson of Alzheimer Iceland, about their response to the strategy how it aims to change the lives of people with dementia and their carers.

It is fantastic that Iceland has launched its dementia strategy – what was the key driver for the development of the strategy?

Iceland has a long history of specialised services for people who are diagnosed with dementia, with many specialists – geriatricians, nurses, social workers and psychologists – working in this area. The country’s first specialised day-care centre for people with dementia was established more than 30 years ago; this was a progressive move in international comparison, and still is.

In spring 2017, a parliamentary resolution was adopted by the Althingi (the Icelandic Parliament), commissioning the Minister of Health to draw up a strategy on persons with dementia; this was to include raising public awareness and understanding of the issues, give greater prominence to the gathering of statistics, encourage focused research programmes and launch a campaign aimed at greater quality of care for what is a rapidly growing patient group in the community. The resolution received cross-party support and the creation of the strategy was adopted as one of the priorities of the government that took power at the end of 2017.

In spring 2019, I submitted to the Althingi the Health Policy until 2030, which was passed unanimously. It is on the basis of that policy that strategies in individual areas are being developed.

Work on a strategy on persons with dementia began early in 2019 when I commissioned one of Iceland’s most respected geriatricians, Jón

Snædal, to draw up a policy draft. He submitted his report in summer 2019. This was then placed in a web consultation portal where anyone could submit criticisms, comments and suggestions on it. Contributions were received from the main stakeholders, including healthcare professionals and Alzheimer Iceland; these were of great value in formulating the strategy. Work then followed on drawing up an implementation schedule based on the proposals in the report and the comments received. The strategy has now been unveiled.

Can you give us an insight into some of the key areas of focus for the strategy?

The key points in this strategy could be said to be the same as those in other countries. They include seamless support for individuals

and their families from the time of diagnosis to the end of the patients’ lives. Emphasis is also placed on individually tailored, non-institutional services which take account of the needs of the individual and the family, both as regards daily training services and services in the home.

Priority is given to upgrading education and awareness of dementia for staff in both primary health centres and nursing homes, and on improving people’s health literacy. One important aim is to establish, and then use, a range of treatment methods including art and handicraft therapy of various types. The strategy includes setting up a database on dementia disorders, with an emphasis on integrating and coordinating services. In Iceland, social services come under local government, while all health services are the responsibility of central government. The division has long meant that certain administrative complications have to be dealt with, and here, it is essential to integrate services as far as possible.

Does the strategy have a dedicated budget to implement its objectives/commitments?

The strategy covers a five-year period, ending in 2025, and the aim is that all components in it will be funded during this time. Many of them do not entail great expense, being centred rather on shifts in emphasis in collaboration between parts of the health and social service infrastructure that already exists.



Icelandic Minister of Health, Svandís Svavarsdóttir



Icelandic Dementia Strategy

How will the government be monitoring the implementation of the strategy and measuring the impact it has for people?

The strategy has been set out in an outcome sequence chart where each of the main target areas is broken down into modules with measurable goals. It should therefore be easy for the Ministry of Health to monitor implementation of the strategy and assess its results. We will rely on the involvement of stakeholders via the consultation portal when it comes to revising and updating the strategy at the end of this five-year period. At that point, it will be possible to arrive at a comprehensive assessment of what has been achieved and to identify new priorities.

Will you work with Alzheimer Iceland and people with dementia to ensure their voices are heard?

Alzheimer Iceland was actively involved in drawing up the present strategy by contributing its comments, and it has already been assigned important tasks in the implementation of the strategy as regards awareness-raising and education, both in the community at large, the administrative sector and in nursing homes. This includes, primarily, the production of educational materials for public services covering the forms that

dementia takes in patients and how it affects clients and service-providers in their day-to-day work, and also how service-providers can best deal with patients and clients.

Alzheimer Iceland has also been commissioned to set up peer-to-peer educational programmes on dementia in nursing homes, whereby non-specialised employees can share their knowledge and experience, as well as the methods they use in dealing with and caring for patients. It is by no means the case that this knowledge and experience can all be imparted through formal study and training; personal elements play a large role in positive and successful handling of dementia patients. It is important to harness this knowledge on the part of non-specialist staff in a deliberate way and to make sure that it is shared by other staff. Alzheimer Iceland has now been entrusted with helping nursing homes to disseminate these insights and skills to workers in all nursing homes.

What do you see as being the most important factor in the success of the strategy?

The strength of this strategy lies in many factors. One of the most important is that all interested parties had the opportunity of taking part in designing the strategy by means of their contributions via the web consultation portal. Another valuable point is that there is a high level of general interest in the community regarding people with dementia, as well as a broad cross-party consensus in the Althingi and in society at large on the importance of upgrading services to this patient group.

International collaboration, both with other European countries and, particularly within the Nordic countries, is of immense importance for a small country like Iceland, complementing the excellent professionals we have here at home. The infrastructure of our health and social services is strong and many people take an interest in, and have

knowledge of, the plight of dementia patients and their families. Our strategy is, first and foremost, a matter of integrating these various factors.

Further comment from the Minister regarding COVID-19

The current circumstances resulting from the COVID-19 pandemic have forced everyone to re-think priorities in our health services. In Iceland, the emphasis has been on maintaining services to vulnerable groups in the community; for example, we have kept the specialised daily training centres for dementia patients open despite the restrictions on movement and gatherings.

Our view is that disruption of these services could quickly lead to a deterioration in the health of the individuals concerned and result in the necessity of more people being hospitalised. This policy was adopted not least in the light of recommendations from Alzheimer Iceland, which operates some of the daily training centres in the metropolitan area. These centres admit up to 20 individuals at a time, which is also the maximum number allowed under the current restrictions on gatherings to combat the COVID-19 hazard in Iceland. Monitoring of elderly people, and those who have not been able to attend the daily training sessions, takes place by phone calls from staff of the social services on a daily basis.

So far we have succeeded reasonably well in protecting the older generation from COVID-19. It was decided early on to prohibit visits to nursing homes and hospitals and clear guidelines were issued for the elderly and other vulnerable groups. Official guidelines issued by the authorities in connection with the pandemic can be found on the website www.covid.is, including information in various languages and also information on the age distribution of those who have been diagnosed with the virus and other statistical data.

“International collaboration, both with other European countries and, particularly within the Nordic countries, is of immense importance for a small country like Iceland, complementing the excellent professionals we have here at home.”

Árni Sverrisson, Chairperson of Alzheimer Iceland responds to the new Icelandic dementia strategy



Iceland has launched its first dementia strategy

Alzheimer Iceland welcomes the “Action Plan on Services for Individuals with Dementia”.

The Action Plan is set for the year 2025, and it lists many of the main policies of the association, most notably: Rights of people with Dementia, Education - Information Flow, Friendly Communities, Service Center, and Registration of Statistical Information.

The Action Plan is divided into 6 categories, which are:

1. Self-determination, patient involvement and legal framework.
2. Prevention.
3. Timely diagnosis of dementia in the right place and follow-up after diagnosis.
4. Activity, self-help and support.
5. Proper service based on the level of dementia.
6. Scope, research, knowledge and skills.

Within each subject area in the 6 categories, it is defined: What are the Minister's priorities – what action needs to be taken – what impact it has on society - what will be the situation in 2030.

The Action plan will be revised in 2025, taking into account the Health Plan until 2030. All 6 elements of the programme are

expected to be fully implemented by 2030 but funding will be ensured for all aspects of the plan by 2025 at the latest. Some elements are already underway, others are in preparation, and there are several elements that need to be launched. The aspects that Alzheimer Iceland has come to, include: education, prevention, working with the opinions and wishes of the patient and their relatives, professional assistance of various types and professional and specialised day training centres. Other major factors that Alzheimer Iceland has begun to work on and prepare, are:

New educational programme

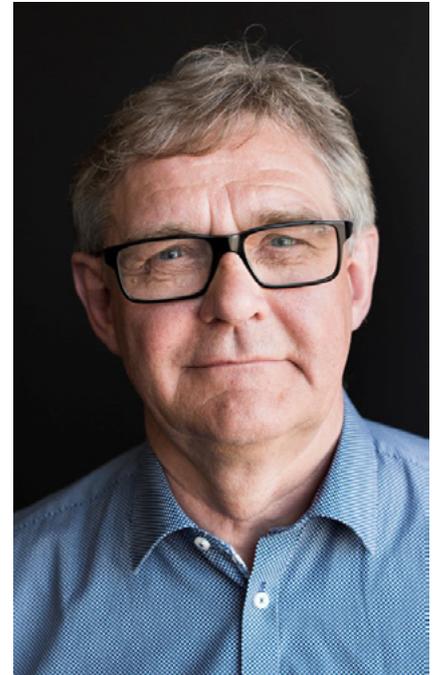
Alzheimer Iceland has been tasked by the Minister of Health to initiate peer-to-peer education and training on caring for people with dementia. This training will take place in Nursing homes for those employees who do not have specialised training to care for these individuals.

Friendly communities

One cooperation agreement has already been made with one of the largest municipalities in the country on the development of a Friendly community and four other municipalities have already requested cooperation with the association on such projects.

Service Center

The organisation has been in talks with a municipality in the Greater Reykjavík area about long-term lease of housing that is



scheduled to become a Service Centre. It assumes that the main activities of the association will be housed together with special services for young diagnosed persons with dementia.

Now that the Action Plan has become official, the entire work of the association will be much more focused and direct cooperation with the health authorities will increase. All of this makes it easier for people with dementia and their families to know about their rights, hopefully all of them for a better future.

“The association has been working for many years to come up with a recognised policy on these issues, and this is a major step on the vision of improving and clarifying the rights of this patients group and their immediate relatives. Iceland now joins a group of European nations that have already formulated policies on these issues.”

Spain publishes national dementia strategy

Following the announcement of the Spanish Government towards the end of 2019 regarding the agreement of the country's national dementia strategy, Alzheimer Europe looks at the content of the strategy and hears from Jesus Rodrigo of Confederación Española de Alzheimer (CEAFA) on their reaction to the strategy.

The Spanish Government has published its "Plan Integral de Alzheimer y otras Demencias" (Comprehensive Plan for Alzheimer's and other dementias), setting out its national strategy to improve the lives of people living with dementia in the country.

Although the Plan was confirmed by the Spanish Government last year, at the time of its announcement, it had not been published and the full details were not known. Intended to cover a period of four years, the Plan has four axes along which the actions of the plan are based. Under these sections, 20 "objectives" which outline more specific action points, detailing how the objectives are to be achieved. The four main sections of the Plan are:

1. Awareness raising and transformation of the environment

The first section focuses on transforming the societal perception and understanding of dementia and Alzheimer's disease, increasing the level of knowledge, acceptance and compassion towards people affected by the condition (both the person with the condition and the informal caregiver).

In doing so, the Plan aims to reduce instances of stigma, rejection and exclusion experienced by people with dementia and their carers, so that they may continue to have opportunities to participate and contribute to the community in which they live, as full active citizens.

2. The person at the centre of social and health care: prevention, diagnosis and treatment

Under the second axis, the strategy sets out measures to enhance the early, accurate and timely diagnosis of dementia by modernising the attitudes, techniques and processes involved. As part of this, the Plan identifies the need to promote good clinical practice (including diagnosis, treatment etc.) based on current available scientific evidence.

Additionally, the Plan addresses the implementation of dementia prevention strategies from the perspective of the current state of medical and social science. Specifically, it identifies the need for a supportive approach, with coordinated social and health care services around each person, which should be specialised and adapted to the needs of the person at each stage of the disease. Furthermore, it highlighted that such an approach must be based on the specific condition of and must enhance the participation and self-determination of the person.

3. Rights, ethics and dignity of the person

The third section underscores the importance of measures to improve the understanding of the role of informal caregivers of people with dementia, to ensure the prevention of situations of overload and stress. In relation to services, supports and benefits, these should avoid the

Plan Integral de Alzheimer
y otras Demencias
(2019-2023)

SANIDAD 2019
MINISTERIO DE SANIDAD, CONSUMO Y BIENESTAR SOCIAL

Spanish Dementia Strategy

institutionalisation of the person and enable them to remain within their natural environment for as long as possible.

This section of the strategy seeks to establish conditions for better knowledge, access and exercise of rights, both for the person with dementia and their informal caregiver, encouraging the incorporation of ethics in interventions and the elimination of situations of abuse or abandonment.

4. Research, innovation and knowledge

The final axis of the strategy is concerned with the promotion of biomedical, social and health research on dementia, particularly from a translational research approach. This will be based on the establishment of a research framework which is regulated by quality and rationality criteria, introducing scenarios of funding (both public and private), optimising the resources available from collaboration and network research. The strategy additionally identifies the need to generate information and knowledge related to the size and situation of people affected by the disease.

Jesús Rodrigo, Executive Director of CEAFA responds to the new Spanish dementia strategy



It is fantastic that Spain has launched its dementia strategy – what was the key driver for the development of the strategy?

The first thing to say is that Spain has a Strategy for Neurodegenerative Diseases of the National Health System in which dementia has a special consideration, and the Comprehensive (National) Plan of Alzheimer’s and other dementias 2019–2023, approved in October 2019.

The Plan has been made possible by the involvement of actors from all sectors linked to the approach of this socio-health issues, as well as the central government, through the involvement of the Institute of Migration and Social Services (IMSERSO).

All of them have formed the State Dementia Group, which has developed the plan by putting the person (patient and caregiver) in the care centre; the Plan has the highest political and social consensus.

Does the strategy have a dedicated budget to implement its objectives/commitments?

Unfortunately, there is not a budget allocated yet. The political instability that the country has suffered in recent months has made it impossible to have general state budgets, under which the plan should be adequately funded.

How will the government be monitoring the implementation of the strategy and measuring the impact it has for people?

The State Dementia Group is expected to assume this role, as a continuation of its primary responsibility, which was the development of the Plan. It is assumed that once the budget is approved, the group adapts to the new functions.

Will CEAFA work to ensure that people with dementia have their voices heard?

CEAFA has taken an active and responsible role from the outset in the elaboration of the Plan, making available the knowledge acquired during 30 years of history. In addition, the Panel of Experts of People with Alzheimer’s has reviewed, valued and provided its first-hand vision, as representatives of the recipients of the Plan.



What do you see as being the most important factor in the success of the strategy?

The Plan has been approved by the territorial and interterritorial councils, which means that it has the clear support of the autonomous communities, ultimately responsible for its implementation. It also has significant social support. However, it must have the necessary budgetary allocation.

“CEAFA has taken an active and responsible role from the outset in the elaboration of the Plan, making available the knowledge acquired during 30 years of history. In addition, the Panel of Experts of People with Alzheimer’s has reviewed, valued and provided its first-hand vision, as representatives of the recipients of the Plan.”

European Alzheimer's Alliance (EAA) members reiterate importance of dementia as a European policy priority

Following the #DementiaPledge2019 campaign last year, Alzheimer Europe has been working with members to grow the European Alzheimer's Alliance (EAA). In this article, we provide an overview of the current position of the EAA, as well as speaking to the Chairperson and Vice-Chairpersons for the group.



Following its successful #DementiaPledge2019 campaign in May 2019, Alzheimer Europe has been working closely with its national member organisations to develop the European Alzheimer's Alliance (EAA). Established in 2007, the purpose of

the EAA is to ensure that dementia remains a key area of focus at a European level and to ensure that Members of the European Parliament (MEPs) remain informed about the work taking place in relation to dementia across the domains of health, research and social policy.

The EAA currently has 94 Members from 26 Member States of the European Union. As part of its engagement, Alzheimer Europe

contacted members of the group who have been active in raising dementia as a policy priority over the years or who had expressed particular interest during the campaign, inviting them to hold the position of Chairperson and Vice-Chairpersons for the group. The following MEPs are currently hold these positions:

- Sirpa Pietikäinen, MEP (Finland), Chairperson
- Deirdre Clune, MEP (Ireland), Vice-Chairperson
- Christophe Hansen, MEP (Luxembourg), Vice-Chairperson
- Marisa Matias, MEP (Portugal), Vice-Chairperson
- Hilde Vautmans, MEP (Belgium), Vice-Chairperson.

In the following section, three of these members outline where they see dementia within the existing framework of the policy work of the EU, and how the EAA and Alzheimer Europe can ensure dementia is prioritised. They also make a specific commitment about how they will do this as parliamentarians.

Sirpa Pietikäinen, MEP (Finland), Chairperson



Where do you see dementia fitting within the current agenda and work of the EU?

Memory disabling diseases should be kept as a priority in EU's health agenda in the future as well. Memory disabling diseases like Alzheimer's should be taken strongly and seriously as a part of disabilities. Thus the disability rights the UN Convention on the Rights of Persons with Disabilities (CRPD) should be guaranteed for memory disabled people also; as well as user-driven design, the right to be heard, the right for self-determination and the right to access to services including digital services and devices, not forgetting inclusion in urban infrastructure and housing.

What is your view on the opportunities for Alzheimer Europe and the EAA to ensure that dementia is prioritised in the work of the EU?

Alzheimer Europe is the key spokesperson for memory diseases and people having them, as well as the needs of formal and informal caregivers. It is the leading actor to stimulate political debate in the European Parliament, European Commission and Council, and guide and propose needed programmes, actions and projects.

The EAA brings together MEPs, memory-disabled people, their carers and experts from different Member States in the Parliament. As well as advocating hopefully for strong

support by the Member States to common European policy in the Council.

What is your personal commitment in this parliamentary term to help ensure dementia is prioritised as a policy priority?

As the Chairperson of the European Alzheimer's Alliance group in Parliament I am committed to advocating for a better understanding of memory disabling diseases and better commitment to resourcing the research and better services. I will keep on fighting for the constitutional and other human rights of memory-disabled people. EU should renew its commitment to improving the research, care, and rights of memory disabling diseases.

Christophe Hansen, MEP (Luxembourg), Vice-Chairperson



Where you see dementia fitting within the existing work of the EU?

Dementia is one of the few diseases where there is no cure or disease modifying treatment, but which has far-reaching consequences on health systems. The care for patients with dementia is not only time consuming and expensive, its diagnosis is also a nightmare for the families involved. Finding a cure requires investments in research that cannot be granted by a single company or country alone. EU funding programmes such as the Horizon programme for Research and Innovation are therefore key to allow for better cooperation and exchange between researchers, establishments of private-public partnerships and data sharing.

What is your view on the opportunities for Alzheimer Europe and the EAA to ensure that dementia is prioritised in the work of the EU?

The work of Alzheimer Europe and the EAA is vital in raising awareness on this disease among European stakeholders. In order to secure the necessary funding in light of the discussions on the MFF, representatives from the EU Commission, the Council and the European Parliament need to be convinced of the magnitude of the disease and the need to invest in research. Considering the current budget strains due to the Brexit and the unforeseeable consequences of the Corona pandemic, this will not be an easy task. On the other hand, the current COVID-19 outbreak might become an example of how concerted efforts and allocation of resources might lead to the development of a drug in historical speed.

What is your personal commitment in this parliamentary term to help ensure dementia is prioritised as a policy priority?

As Vice-Chairperson of the European Alzheimer's Alliance I will continue to raise awareness among my colleagues by supporting and organizing events in the European Parliament. Campaigns and other initiatives on social media are also an important tool to secure support for the fight against dementia. I will also do my utmost to ensure support for prioritisation of dementia and Alzheimer in policy strategies and, most importantly, to secure the necessary funding in the responsible budget committee for individual research programmes as well as the Horizon programme in general.

Hilde Vautmans, MEP (Belgium), Vice-Chairperson



Where you see dementia fitting within the existing work of the EU?

As the life expectations of the European population continues to increase, the number of older people will rise and with that comes a significant rise in the number of people affected by dementia. As there currently is no cure for dementia, this will undoubtedly put a lot of pressure on societies and healthcare systems.

Through its research and innovation framework programmes, the EU can add value by supporting joint research into neurodegenerative diseases and data analysis or by coordinating brain research projects between EU Member States, academia and industry. But even globally, the EU should take the lead in fostering joint research into the causes and possible treatments of dementia, prevention or better care and in exchanging best practices.

Due to huge investment costs and little return on investments, duplication of efforts, resources and funds should be avoided as much as possible and additional incentives to stimulate dementia research should be considered. Furthermore, the EU could support the Member States by raising awareness about healthy lifestyles and their impact on reducing risk factors for many diseases, including dementia.

What is your view on the opportunities for Alzheimer Europe and the EAA to ensure that dementia is prioritised in the work of the EU?

Due to the COVID-19 pandemic, public health issues will be high on the political agenda again. The corona pandemic will be a key driver for increased investments into healthcare systems, an adjustment of work programmes and an update of the EU's long-term budget for the period 2021-2027.

This could be an opportunity to raise awareness about the challenge of dementia in the context of demographic change, about its huge (economic) burden on societies and hence about the urgent need for increased research efforts and breakthrough innovation.

What is your personal commitment in this parliamentary term to help ensure dementia is prioritised as a policy priority?

I have witnessed the impact that dementia has, not only on the life of people who suffer from the disease but also on their carers and families. I will contribute to the best of my abilities to ensure that the political attention to dementia is kept up with the scale of the challenge. More specifically, I want to raise more awareness about dementia as one of Europe's biggest challenges in the context of demographic change and about the importance of patient-centred care and a dignified life for people with dementia.

The Alzheimer Society of Ireland campaigns for change during Irish General Election

During the General Election in February 2020, The Alzheimer Society of Ireland (ASI) campaigned on the theme “Deliver on Dementia – Time for Change”, asking candidates to commit to a pledge on dementia. Avril Easton, Advocacy Manager, shares the ASI’s approach to the campaign and speaks to Senator Fiona O’Loughlin about her plans in relation to dementia.



We also issued 27 press releases incorporating national and local figures about dementia in their area and also the details of candidates in every constituency who had signed our pledge. These press releases were sent to every press and media outlet in the country.

In total, over 5,000 e-mails were sent to candidates and thanks to the engagement of our grassroots network over 190 candidates pledged their support and 92 of those were elected. This is close to 60% of the new TD (Teachtaí Dála) in the Dáil (the directly elected chamber of the Irish Parliament) that have pledged to Deliver on Dementia. In addition, dementia was specifically highlighted in six of the seven political party Manifestos.

However, Ireland and the world have changed dramatically since the election that took place in early February. In the election, the Irish electorate did not vote for a majority party; indeed, the emergence of Sinn Féin as a leading party with a key electoral vote was both surprising and unexpected.

By the time of the onset of COVID-19 in Ireland, a Government had still not been formed. The existing Government had to take on a caretaker role to direct the country through the early days of the pandemic. COVID-19 has shifted the focus and has meant that the pace has had to quicken on Government formation with pressure mounting on parties to come together in the national interest.

Fine Gael and Fianna Fáil have been working on a joint policy document, with the two parties having 72 seats combined – eight short of a majority. At the time of writing, Taoiseach (Prime Minister) Leo Varadkar has said that the two traditional parties need a ‘third party’ as well as Independents to form a stable Government, explicitly mentioning Labour,



the crisis in dementia care among the election candidates.

As part of our campaign we also asked people to share their personal stories of caring for a loved one with dementia to connect with the public and show that people are living in crisis. One of these stories featured two sisters, Louise and Rachel who care for both their parents with dementia. “We don’t have time to get sick in our families as our parents, Tom and Carmel, need us to look after them and be on call 24/7. We are their voice, their protection and their care”.

Through social media, we highlighted five real life case studies to demonstrate the challenges of caring and living with dementia and the urgent need for Government action. The video soundbites were used on Facebook, Twitter and our website to encourage members of the general public to contact their candidates to call for action on dementia.

Earlier this year in February, the Republic of Ireland held a General Election where the country voted to elect their next Government. The Alzheimer Society of Ireland election campaign “Deliver on Dementia – Time to End the Crisis” aimed to ensure that dementia is included in the new Programme for Government so people with dementia and their families can get the support that they need.

The campaign focused on asking over 500 election candidates to pledge to Deliver on Dementia in the next Programme for Government to ensure three key things:

1. The National Dementia Strategy is fully implemented
2. Home care for everybody
3. Dementia is in the Chronic Disease Management Programme

We used our extensive grassroots network to distribute 3,000 voter prompt cards to staff, clients, families, volunteers and advocates across the organisation. Voters were asked to use these prompt cards for when they meet a candidate to help outline the challenges and struggles they face. The campaign aimed to get as many people as possible to highlight

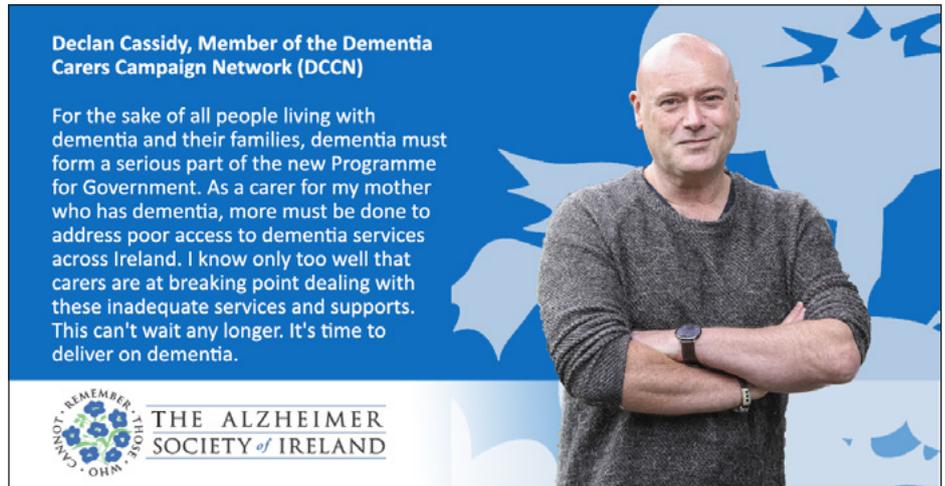


Voter prompt card

the Social Democrats and the Green Party as potential partners.

While none of the potential third parties are greatly enthused by the idea of going into Government with Fine Gael and Fianna Fáil, the increasing pressure of the COVID-19 crisis and the current legislative deadlock will probably have an effect on their outlook.

COVID-19 has been a perfect storm for people with dementia. With the closure of our day centres, social clubs, Alzheimer cafés and face-to-face carer training, the people we support have been hit very hard. They have nowhere to go each day to keep them active and stimulated. This means that thousands of people with dementia and their carers cannot access crucial services at this time. Everyone’s lives have been turned upside down during this health crisis – but people with dementia are particularly vulnerable here.



An example of the carers stories shared as part of the election campaign

Throughout all this disruption, the advocacy work of the ASI continues. We have been lobbying all politicians and key party negotiators about the importance of dementia being included in the Programme for

Government. This has never more been important, as people with dementia are severely impacted by COVID-19: now is the time that we must address the crisis in dementia care.

Senator Fiona O’Loughlin sets out her plans for dementia



In early April 2020, Fiona O’Loughlin (Fianna Fáil) was elected to the Administrative Panel of Seanad Éireann (the upper chamber of the Irish Parliament).

Here Senator O’Loughlin outlines her vision and interest in dementia and what she hopes to achieve in her time as a Senator:

Aside from my work in the Education and Disability sector, I have been a public representative since 1994, serving as a County Councillor, Mayor, TD for Kildare South and now Senator. I was delighted to be nominated by The Alzheimer Society of Ireland

to the Administrative panel for the 36th Seanad.

In the previous Dáil, I was a member of the All Party Oireachtas Group on Dementia which aims to build understanding and galvanise support for long-term planning and resources for people with dementia.

My interest in the area stems from my involvement with the day care centre in my hometown of Rathangan and with the Moore Abbey Alzheimer Day Care in Monasterevin, part of my South Kildare constituency. Here, I witnessed families and neighbours struggle to keep these services open and funded, and the tireless work of carers looking after loved ones with dementia. With 55,000 people living with dementia in Ireland, I want to do my part to get better funding and supports for people affected.

I was also inspired by those that I met who spoke about their own personal experiences with dementia – either as a person diagnosed with the condition or as a family carer. I was moved by our own local ‘forget

me not’ choir in Kildare, and by the ‘butterfly’ approach to living in a residential setting in St Josephs, Shankill.

In my time in the Seanad, I want to give a voice to people with dementia and work to implement the National Dementia Strategy. I will highlight the fact that dementia is a global public health priority. We must prioritise dementia care support in communities and within the home.

My goals are:

- An increase in the number of Dementia Advisers
- Better provision of Home Care packages and community support
- Increased funding and support for Dementia Day Care Centres
- Better use of assistive technology
- Work with Carers Organisations to support family members
- Push for earlier diagnosis, better GP training and Health Service Executive awareness programmes.

Continence care matters for people living with dementia

In this article, Alzheimer Europe reflects on some of the key issues around continence care for people with dementia and identifies some of the ongoing efforts to improve the quality of their care and treatment. Dianne Gove, Director for Projects, then provides some reflections on the work of Alzheimer Europe on this topic in recent years.

Incontinence is a widespread condition affecting some 50 million people across the EU, with more than 15 million informal carers taking care of some of these people living with the condition. A significant number of people living with dementia in the EU are likely to experience issues with incontinence at some stage, with no total cure currently available, despite medical and pharmaceutical research into this area.

Approach to continence care

Despite the scale of the number of people affected by the condition, it is an area which is often not discussed or adequately considered in the context of dementia. There are four key aspects which must be considered in relation to addressing incontinence:

- Prevention
- Detection
- Assessment of incontinence
- Management of continence problems with toileting and containment

Continence care must always be in accordance with the needs of people with dementia and carers. It is essential that the primary consideration in any approach must be to do what is best for the person with dementia, taking into account their individuality, their wishes and the promotion of their individual autonomy, wellbeing and independence.

This requires awareness, training and education of informal caregivers and professionals so they may appropriately assess the toileting and containment needs of the person with dementia, as well as identifying and

suggesting suitable management or preventative measures. Health and social care professionals must also take into consideration the needs and wishes of informal carers who often play a vital role in ensuring good continence care for people with dementia living at home. Due to the progressive nature of dementia, regular re-assessment is essential to ensure the suitability and effectiveness of the measures put in place.

As part of this process, people with dementia (and where appropriate their informal carers) must be involved in all aspects of their assessment and the delivery of continence care. Where proxy decision-making powers are in place, procedures should be followed in line with policy and legislation in that country to involve the proxy.

Looking to the future of toileting and containment care

Research and development processes in this field have advanced, aiming at improving the care pathway for toileting and containment care, especially for people who require care services, with the ambition to keep people self-managing for as long as possible. The optimisation of the care pathway is helped by the use of technology enabling a good assessment and an improved delivery of person-centred care.

New technologies have the potential to assist people with advanced dementia who experience difficulties in expressing their need to go to the toilet or have their pad change managed. One such example of a recently developed assessment tool is a digital health

technology product that monitors the voiding pattern and the volume of urine lost, providing the base for developing a person-centred toileting and containment care plan. Another approach which utilises digital health technology is a change indicator, which can inform an informal carer or professional that the pad is saturated and need to be changed.

Digital health technologies, in combination with other incontinence products, can help ensure the good quality care for persons with dementia which meets their needs. This way good outcomes can be achieved for the person with incontinence and for informal carers, whilst ensuring effective use of available budgets provided by health care payers. If a care pathway with the support of digital health technologies are to be implemented as part of care for people with dementia, a significant shift both in policy and practise is required.

Towards the implementation of good practice

In the policy context, Alzheimer Europe joined a roundtable event in 2019, facilitated by Essity Hygiene and Health AB, along with AGE Platform Europe, Eurocarers and the European Institute for Women's Health. The group identified key issues affecting the populations they represent, the required solutions and the policy and decision makers who were best placed to affect change.

This discussion culminated in a call for action, calling on decision makers at local, regional, national and EU levels to take action to put in place the necessary person-centred care provisions that can help manage incontinence, to support the best possible quality of life and make the best possible use of existing budgets and care resources.

Recommendations within the call to action were broad in nature, including:

- Urging health authorities to promote the World Health Organization (WHO) Integrated care for older people (ICOPE) framework.
- Demanding that health care payers ensure that out-of-pocket expenses for individuals are minimised and ensure that individuals and informal carers have

choice and control over the selection of containment products and overall care with respect to toileting needs.

- Encouraging education bodies to ensure that the training of health care

professionals responsible for assessment and delivery of care are sufficiently skilled and knowledgeable about prevention and daily management strategies for incontinence.

The Call to Action can be accessed at: www.bit.ly/ContinenceCallToAction

Dianne Gove, Director for Projects, explores the importance of good continence care and highlights Alzheimer Europe’s work in this area



Just over five years ago, Alzheimer Europe set out to explore the issue of continence care for people with dementia living at home. At the time, little work had been done on continence care for this group of people. Recommendations and guidelines for the continence care of other groups (such as older people, people with cognitive impairments or frail older people) in other settings (e.g. hospital or residential care settings) cannot simply be applied to people with dementia living at home.

Together with a team of clinical and academic experts in continence care, policy making, general practice and dementia, including a person with dementia, and with the support of Essity (formerly SCA Hygiene Products AB), we developed guidelines on continence care for people with dementia living at home.

The report and recommendations emphasised the need to promote independence, as far as possible, and to avoid assumptions about dementia, the abilities of people with dementia and their wishes. Continence care must always be based on an individual assessment. Incontinence should not be seen as an inevitable aspect of dementia. It should always be investigated and a diagnosis of dementia should not, on its own, rule out any specific approach.

The experts recognised the importance of appropriate and affordable, good quality

continence products, but also that these must not be the only solution offered to people with dementia. Rather appropriate continence products may be one part of a comprehensive continence care plan. This includes looking at how the environment contributes towards incontinence, at techniques to help prevent actual incontinence, and at treatment and even surgery.

Following on from this work, Alzheimer Europe has contributed towards the development of key performance indicators (KPIs) to measure outcomes for the daily management of toileting and containment within a range of care settings. It is hoped that these KPIs will contribute towards improving the quality of continence care for people with dementia. Another, important area of work has been the development of policy recommendations, as mentioned above, and Alzheimer Europe is currently a member of an advisory board for a study to



Continence Care Report

compare the efficacy of different types of continence products.

Good continence care is key to respecting the human rights and dignity of those affected by continence problems but incontinence remains a stigma in many parts of Europe. Alzheimer Europe is keen to promote open discussion about this topic and encourages health and social care professionals, as well as policy makers, to take a proactive approach to addressing this sensitive topic so as to provide appropriate and timely support for people with dementia and carers.

“ Good continence care is key to respecting the human rights and dignity of those affected by continence problems but incontinence remains a stigma in many parts of Europe.”

Dementia Friends – keeping up the good work

There are 25 Alzheimer’s associations throughout Europe which have implemented Dementia Friends programmes in their countries. We spoke to some of them about how successful this global movement has been, since its inception in the United Kingdom in 2013, and about how they continue to engage people after they become Dementia Friends.

United Kingdom – paving the way

Alzheimer’s Society Dementia Friends programme

Launched in England and Wales in 2013, the Dementia Friends programme of the Alzheimer’s Society is the UK’s biggest ever initiative to change people’s perceptions of dementia. Dementia Friends are those who have watched our video or attended a session delivered by a Dementia Champion, at which they learn more about dementia and the ways in which they can help. There are over 3.7 million people taking action as Dementia Friends across England and Wales.

Dementia Friends receive a welcome email with a reminder of their learning and actions, as well as a monthly newsletter with opportunities to get involved and the latest programme announcements. On social media, Dementia Friends can also engage with each other, discuss key messages, ‘like’ photos and stories. Dementia Friends have also been involved in campaigns where they

are encouraged to be ambassadors for the programme in England and Wales.

The success of the Dementia Friends programme is measured via a theory of change brought together with the Dementia Friendly Communities initiative. Dementia awareness, empathy and understanding of the rights of people affected by dementia as programme outcomes are further evaluated by in-depth interviews.

Dementia Friends are also surveyed on a regular basis. It has been identified that 86% of Dementia Friends in England and Wales have an improved understanding of dementia and 84% feel the programme is inspiring communities to take action. Personal stories of impact also demonstrate the success of the programme and are celebrated at the annual Dementia Friendly Awards.



Dementia Friends England and Wales

Global Dementia Friends Network – the beginning and end of an era

Until spring 2020, Alzheimer’s Society coordinated the Global Dementia Friends Network (GDFN), supporting other countries to develop their own Dementia Friends programmes by providing capacity-building support and fostering a global network. Under the GDFN, national Alzheimer’s associations and other organisations in over 67 countries and territories worked together to share, support and collaborate for a truly global dementia friendly movement. The GDFN created over 19 million Dementia Friends worldwide.

Alzheimer’s Society International work is mostly funded by the UK Department of Health and Social Care. This funding was withdrawn in early 2020 and no additional source of funding was secured. This has led to the decision to permanently disband the international team and the GDFN.

The GDFN was a project part of the Implementation Plan for the Prime Minister’s Challenge on Dementia 2020, where Alzheimer’s Society committed to, “turning Dementia Friends into a global movement including sharing its

Some important points to note:

1. The national programme and all associated activities (Dementia Friendly Communities, Programme Partnerships, etc.) in the UK will continue.
2. All existing programmes with a license (a signed agreement) for the use of Alzheimer’s Society Dementia Friends logo and Alzheimer’s Society Dementia Friends materials will continue to be able to use them as part of their national Dementia Friends programme in accordance to the current agreement.
3. Programmes using their own brand and materials should not be affected by changes to the network.
4. If a new country (via its Alzheimer’s association) wants to launch a Dementia Friends programme, they should contact Alzheimer’s Society Head of Policy, Gavin Terry, Gavin.Terry@alzheimers.org.uk to enter into an agreement to use the brand and materials. This is to avoid misuse of the brand.



Global Dementia Friends Network meeting

learning across the world and learning from others". As this project comes to an end it cannot be transferred to another partner in its current shape and purpose. Alzheimer's Society is working with Alzheimer's Disease International (ADI), to help manage the communication around the cessation of the programme and to provide advice for the network in terms of how it can stay connected.

In Europe, 25 Alzheimer's associations, part of the former GDFN, continue paving the way to help realise the rights of people affected by dementia in Europe. Success stories include using Dementia Friends as a hook to influence key decision makers; creating a dementia friendly generation via Dementia Friends; launching successful awareness campaigns with celebrity ambassadors;

multi-sector partnerships combined with dementia awareness training and raising the profile of dementia as a European and global health priority. Every programme is unique and tailored to its cultural context. More and more Dementia Friends programmes are being adapted to reflect the cultural diversity of countries in Europe and the world.

Sharing learning and good practice was key to the success of the GDFN and according to a survey by Alzheimer's Society, 83% of countries reported feeling part of a global dementia friendly movement and that they have benefitted from the experience of other countries. The legacy of the Global Dementia Friends Network continues via the programmes in Europe and the rest of the world. Alzheimer's Society is proud to have contributed to the success of this global movement.

For more information visit: www.dementia-friends.org.uk



Global Dementia Friends Network map, March 2020

Denmark



The Danish Dementia Friends programme, “Demensven”, is highly inspired by the UK Alzheimer’s Society initiative, Dementia Friends. The Demensven programme was launched by Alzheimerforeningen, the Danish Alzheimer’s association, in May 2015, at a national conference for health professionals and researchers in dementia care. At the launch, 1,000 people signed up to become Dementia Friends. Almost 90,000 people are currently living with Dementia in our country and the initial goal was to reach 100,000 Dementia Friends. This was accomplished in May 2019.

In Denmark, the focus of this programme is to acquire knowledge of dementia and to understand how to use that knowledge in order to support people with dementia in living a good life. You become a Dementia Friend by signing up on our website www.demensven.dk or by taking part in a local Dementia Friends information session arranged by one of our Dementia Friends Champions. We have also developed a digital platform for companies and organisations, so that their staff can become Dementia Friends. When a company has completed the online training, it will appear on a digital map of dementia friendly places. Currently, there are almost 600 dementia friendly places across Denmark.

Netherlands



In the Netherlands, a country of 17 million citizens, the number of people living with dementia will double in the coming twenty

The numbers

As of April 2020, we have more than 110,000 Dementia Friends. Every Dementia Friend receives a purple Demensven heart-shaped badge, together with information about dementia and ideas on what actions to take. Through partnerships, we have managed to attract a lot of attention to the Dementia Friends initiative. In particular, a partnership with TV2 (a commercial TV station in Denmark), which allowed us to reach thousands of new Dementia Friends during 2017 and 2018. In collaboration with TV2, we organised a week of special events focused on dementia. We produced short films of people with dementia, explaining why public knowledge of the disease is crucial, in order for them to be met by understanding and patience. The videos aired on social media and TV. Together with young children of people with dementia, they encouraged the public to become Dementia Friends. The result was that almost 25,000 people did so. The TV2 partnership helped raised awareness of the fact that it is not only older people who are diagnosed with dementia. It also helped to shine a light on some of the many challenges a family faces when a mother or father is diagnosed with dementia.

Success and continued engagement

We can see an increase in the general level of knowledge around dementia in Denmark. From 2016 to 2019, we conducted an annual YouGov population study, to establish people’s knowledge of dementia. Through these studies, we were able to ascertain that the proportion of people in Denmark with a high level of knowledge about dementia is two and a half times greater among those who are Dementia Friends, than those who are not.

years, to more than half a million. As more and more people with dementia live at home, they depend heavily on their family carers. Family carers can get overwhelmed, experience feelings of loneliness and generally even die at an earlier age. The number of informal carers will decline in the near future. This growing problem demands a more inclusive and dementia friendly society. To meet this

We send out monthly Demensven newsletters which focus on knowledge of dementia and testimonials from other Dementia Friends. We publish many such testimonials, for example from someone who spotted a person who seemed lost and confused and helped them find their way home; and another who assisted a person at the supermarket with getting the right groceries. We have created a lot of video material and infographics, which we use on social media to spread knowledge and awareness.



Birgitte Vølund

“Dementia Friends is a great way for the Danish Alzheimer’s Association to raise awareness of the disease in Denmark. Getting to know more about dementia is the first step to become a dementia friendly society. We are very pleased with how people have supported the Dementia Friends initiative and after reaching the first 100,000, we have increased our goal to reach 500,000 Dementia Friends over the coming years”, said Birgitte Vølund, Chairperson, Alzheimerforeningen.

need, in 2016, Alzheimer Nederland started a dedicated five-year Dementia Friends campaign, “Samen dementievriendelijk”, in cooperation with the Dutch Ministry of Health, Welfare & Sport and PGGM, a pension administration organisation.

The objective of Samen dementievriendelijk is to encourage Dutch society to become



Samen dementievriendelijk

dementia friendly through year-round campaigns on national television, on social media and by using an extensive training programme. This approach is focused on a learning strategy; learning how to recognise the signs of dementia will help people to act in an appropriate and supportive manner. Generally, we have found that people are willing to help people with dementia, once they understand better how to provide that support.

The numbers

There are currently 280,000 people with dementia living in the Netherlands. Since the start of the programme Samen dementievriendelijk, nearly 343,000 people have registered as Dementia Friends, so there is at least one Dementia Friend for every person with dementia. The goal is for this number of Dementia Friends to grow even more. Sixty percent of our Dementia Friends followed a fifteen-minute online training in which they increased their knowledge about dementia and learned skills in dealing with someone with dementia. There are two general online training courses and twelve specific courses for employees of companies with a high frequency of customer contact. These online training courses were developed in close cooperation with the companies involved, with the possibility of then offering this training to their own employees. Today nearly 37,000 employees of these companies have followed this programme. Wishing to make a difference for people with dementia, more than 350 companies have joined the programme, with care organisations and supermarkets being the largest participants.

In addition, Samen dementievriendelijk offers an on-site two-hour training course to employees of companies. These customised trainings are given by 200 trained volunteers. The number of on-site trainings is growing rapidly and is a huge success with 1,788 courses having already taken place.

Success and continued engagement

To keep our Dementia Friends engaged and motivated, more than 140,000 of them receive a monthly newsletter which includes inspiring stories, information about newly-developed trainings, and tips and campaign activities. Between this newsletter and our Facebook campaigns (26,000 followers), the Samen dementievriendelijk campaign continues to inspire our Dementia Friends to turn their knowledge into action.

Samen dementievriendelijk is certainly a success in terms of numbers. On top of this, the programme regularly measures its impact. The campaign has reached 98% of the target population, and recognition among the general public has increased from 29% to 83%. Repetition is necessary to stimulate action, such as taking a training course. The amount of people that say they know what dementia is, has increased from 64% in 2016 to 82% in 2019. A recent study of Dementia Friends (N=500) shows that 82% of all Dementia Friends feel more confident in interacting with someone with dementia after following the online training. This is an important result in the chosen Dutch learning strategy.

The national survey, “Dementia Monitor of Alzheimer Nederland” (www.alzheimer-nederland.nl/dementiemonitor), which is conducted among 4,500 family carers, every other year, has also shown us that relatives and family carers are now experiencing more understanding and support within their social environments (an increase from 70% to 78%).

Campaigning during COVID-19

The recent pandemic has clearly shown an enormous willingness to help other people in need. It was a good reason for Samen dementievriendelijk to change focus, from learning to doing; moving towards a more active programme in

which we call upon everyone to help people with dementia, and their carers, in a safe way. Inspiring initiatives to offer help and dementia friendly tips in Corona-times are being promoted on a new platform, “how to help”, and shared with Dementia Friends and the Dutch public, through social media. The attention this has received is enormous and the platform has already been visited by more than 33,000 people in the space of 2 weeks. At Easter time, Samen dementievriendelijk joined forces with the successful Alzheimer Nederland campaign #wevergetenjullieniet (“we won’t forget you”), in which the Dutch public was asked to support their loved ones in times of isolation. Thousands of people visited the platform and lent their support by posting heart-warming messages on social media, sending a postcard, cooking an extra meal, offering to do grocery shopping and displaying our campaign poster, which was also included in all the national and regional newspapers.



Samen dementievriendelijk

The future

The ultimate goal, of course, is to have impact among family carers and people with dementia. All the above mentioned results show that, although we still have a long way to go, we are making progress in the Netherlands. The COVID-19 crisis has really shown us the huge willingness of the Dutch people to help others who become isolated, and to show real solidarity. Life after COVID-19 will never be the same. The Samen dementievriendelijk programme plays an important role in keeping this sentiment alive and contributes to the more inclusive society that the Netherlands aspires to.

The Dutch Dementia Friends website can be visited, here: www.samendementievriendelijk.nl

Finland



The Finnish Dementia Friends programme, “Muistikummit”, was launched by Muistiliitto, the Alzheimer Society of Finland, in September 2018. There was even a session of Muistikummit in the Finnish Parliament on World Alzheimer’s Day, 21 September 2018.



Muistikummit – Dementia Friends in Finland

The numbers

Since the launch 13,253 people have become Dementia Friends. In 2019, we launched an internet version, which helped us to reach even more potential Dementia Friends. You can access the website, here: www.muistikummit.fi/verkkotuokio.

Success and continued engagement

The programme was an instant success in Finland, and we have had very

encouraging feedback from the people who have taken part in sessions. The participants have told us, for example, how their attitudes have changed towards relatives with a memory illness, or how they now find it a lot easier to communicate and to be patient with friends who have dementia. We have also started to collect written feedback from participants and also from the people who participated in online sessions. We simply ask them whether the session has/or has not changed their

attitude towards people who have memory illnesses. About 82% says that it has made a positive impact on their attitudes.

After each session, we collect participants’ email addresses and send them our Dementia Friends newsletter, four times per year. We give them information and encourage them to do dementia friendly deeds. For every newsletter, we also try to find a Dementia Friend to share their experiences and their dementia friendly actions.

Slovenia

Spominčica – Alzheimer Slovenia joined the “Dementia Friends” movement in September 2018. We officially launched our campaign at the 10th International Conference on Dementia – ASK 2018, which we organised together with the Faculty of Medicine, Ljubljana, and at which Iva Holmerova, Chairperson of Alzheimer Europe, and Paola Barbarino, CEO of Alzheimer’s Disease International (ADI), were honorary speakers.

The numbers

Since the launch, Dementia Friends in Slovenia has been very well accepted and the membership is constantly growing. In Slovenia, there are now more than 600 Dementia Friends and 100 of them are

Dementia Champions. Our hope is that our Dementia Friends will help to create a more dementia friendly Slovenia, by raising

awareness and reducing the stigma often still attached to dementia.



Igor Šoltes, MEP, joins Slovenia’s Dementia Friends programme



Human Rights Ombudsman Vlasta Nussdorfer, clinic head Vida Drame Orožim and minister Ksenija Klampfer sign up

Engaging public figures in Slovenia

To promote the programme, we use our webpage, social media, printed Spominčica magazine and all our public activities like

Alzheimer Cafes, Memory walk, stands at fairs and festivals. The programme is also supported by public officials becoming members and promoting Dementia Friends, including: MEP Igor Šoltes, Ombudsman



Secretary of State for Health Uros Prikl is a Dementia Friend

for Human Rights Vlasta Nussdorfer, head of “pro bono” clinic Vida Drame Orožim, Minister for Social Affairs Ksenija Klampfer, Minister for Public Administration Rudi Medved, Minister for Internal Affairs Boštjan Poklukar, President of the Slovenian Parliament Dejan Židan, and Secretary of State for Health Uroš Prikl. Slovenia’s police force also has a number of Dementia Friends.

Italy



Federazione Alzheimer Italia officially joined the Dementia Friends network in December 2019.

Italy’s approach – starting with communities

We had already started the Dementia Friendly Community (DFC) programme in 2016, which grew to create 26 DFCs scattered throughout Italy. This ground work is now being enhanced by the Dementia Friends programme so that each new Dementia Friend, having received extra training and knowledge, can use this knowledge within their own community. Only where the community path had already been laid down by the DFC programme, did we wish to also start the Dementia Friends programme, so that the training and concepts of this additional programme can be more effectively integrated into a neighbourhood that has already started and so can better

continue the long path to becoming a more inclusive community.

This careful planning has made it possible for us to now proudly count 4,415 Dementia Friends in 26 Dementia Friendly Communities, as at the end of 2019. This significant growth is mainly thanks to the local effort of small towns in the northern hills, villages in the southern mountains and individual neighbourhoods in larger cities.

Introducing the Dementia Friends initiative

In early 2020, just before the disruption of the COVID-19 pandemic, the new Dementia Friends initiative was introduced and discussed at the Annual meeting of the DFCs. It was envisioned that the Dementia Friends programme would build upon what has already been achieved by each DFC and would add value in terms of assistance, training, support and awareness of



DFC Arzignano



DFC Abbiategrosso

dementia. Starting from their own city, town and neighbourhood, each Dementia Friend would be a spokesperson for positive behaviour and would encourage simple changes in behaviour such as, “be more patient”, “visit a person with dementia”. For all citizens, who live in those communities that are working to become dementia friendly, knowing that this attitude is shared by millions of people around the world is a driving force that itself creates even more help and support for the project. These are the everyday small actions

that count and that can make the difference in the life of a person with dementia: showing patience when you are at the checkout, telling friends and neighbours what you learned about dementia, making yourself available for a home delivery. Small actions that, in each course and seminar organised locally by the DFCs, are encouraged by the experience of professionals and family members so that the citizen can bring home practical knowledge to make himself available to the community.

The future

Our next steps will be to support the communities by creating even more opportunities for interaction, so that not only will the number of those who understand and support people with dementia grow more and more, but greater importance and value will also be given to inclusive initiatives, involving as many people as possible, which we hope should develop long-lasting friendships.



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Exercise and dementia – Petri Lampinen’s story

Petri Lampinen, a member of the European Working Group of People with Dementia (EWGPWD), shares his thoughts on life since his diagnosis of Frontotemporal Dementia and on what exercise, a healthy diet and careful planning have done to help him.

I was diagnosed with FTD (Frontotemporal Dementia) at Tampere University Hospital in 2015. Receiving the diagnosis was a great relief for me as well as my family and friends. It meant I was finally able to connect many of my symptoms and personality changes to an underlying issue.

When I received the diagnosis, my neurologist gave me some instructions on how to slow down the progression of the disorder. People with FTD don’t usually receive any medication, since there really aren’t any drugs for this slightly rarer form of dementia. However, after some careful thought, I was prescribed a type of drug used for treating Alzheimer’s disease, in order to help boost my cognition. The most important piece of advice my neurologist gave to me was: “The best thing you can do in this situation is to start exercising actively.” I am happy I paid attention and marked the doctor’s words. I have been living by these instructions for a few years now, and it has worked out very well for me.

“FTD has made me impulsive, and exercise allows me to get rid of any excess energy I may have. It also improves my psychological well-being.”

Understanding the importance of exercise

After the diagnosis, my wife and I were allowed to attend an adjustment training programme for people with memory-related diseases and their families, which was

organised by the Social Insurance Institution of Finland, Kela. That is when I really understood the importance of exercise. I started exercising a lot more after the training, going on long walks and cycling.

After a few months, I applied for another training programme from Kela. At that point, I was given the wrong advice by a number of health-care experts, who said that I could not apply for this ‘multidisciplinary medical (neurological) rehabilitation for the severely disabled’. Luckily I was proactive and figured things out myself. I contacted Kela’s rehabilitation services directly and was told that I could, in fact, apply for the training. I found a doctor who knew about these things and drew up a rehabilitation plan for me. He understood how vital exercise was for my well-being, so I sent the application to Kela and was fairly quickly granted access to a 13-day rehabilitation programme. Once again, my proactivity paid off!

“The most important piece of advice my neurologist gave to me was: ‘The best thing you can do in this situation is to start exercising actively.’”

Rediscovering my youth

At the first meeting of this new programme, I set myself a goal to improve my ability to function through new forms of exercise and occupational therapy. With some excellent guidance from the staff, I was able to rediscover activities from my youth. When I was young, I used to play table tennis and badminton quite often. The rehabilitation brought the sports back into my life. As I got older, I had forgotten about them.

On the last day of rehabilitation, I felt a bit sad that it was all coming to an end. I had come to realise how much I was getting out of this programme. I also remember thinking that the rehabilitation would only be useful if I continued actively taking care of myself. An active approach to rehabilitation would allow me to reap the benefits at a later stage and leave no room for second guessing about the possible advantages of exercise later on. The decision to take care of myself has been one of the best life choices I have ever made!



Petri enjoys playing table tennis



Petri prefers his basic bicycle to the 'fancier' models

“When I ride my bike, I use cycle paths and, in the countryside, paved roads. I enjoy my trips through the countryside and take great pleasure in observing the seasons changing. There is always so much to see along the way.”

Exercise really pays off

I really started to get into exercising, and my daily routines became more varied. Fortunately, I am conscious of my symptoms. It makes me realise which types of exercise are good for me and which are not.

FTD has made me impulsive, and exercise allows me to get rid of any excess energy I may have. It also improves my psychological well-being.

After both programmes I attended, my exercise routine consisted of walking, table tennis, badminton and cycling. In the three years prior to this, I had also occasionally taken part in strength and balance training groups organised by the service unit for senior citizens in the city of Hämeenlinna. I received some guided training from their physiotherapist, including physical ability testing. As well as the physical benefits, there was an added benefit which was the opportunity to socialise with the other participants.

My condition has some parallels with ALS (amyotrophic lateral sclerosis), which is why I find it important to strengthen my muscles. I take particularly good care of my leg muscles, because, as my neurologist advised me during my diagnosis, towards the final stages of FTD many people tend to experience symptoms that resemble those of Parkinson's disease.

My love of cycling

Nowadays, the most suitable form of exercise for me, and the one that is closest to my heart, is cycling. The past summer, I managed to cycle a little over 4,500 kilometres, but I don't cycle at all in the winter time.

After the neurological rehabilitation, I wanted to keep myself active in the winter, so I booked a badminton court at the local school. This winter, I am going to try skiing again, after a long time away from the sport. I also bought myself an exercise bike some time ago. I am self-rehabilitating my life!

As I have got into better shape, my bike trips have got longer month by month. I started out by cycling 10 to 20 kilometres a day, but was soon doing 30 a day, and the trips still kept getting longer. Today, my typical daily stretch is 40 to 60 kilometres. I have even cycled more than 100 kilometres a couple of times, having only short drinking breaks along the way. I always remember to take enough to drink and some high-energy food with me when I go on my trips.

Planning and support

I use a sports watch which allows me to monitor my heart rate so that it doesn't get too high. I also know how to take breaks from exercising and the sports watch helps me judge how long I need to rest for, during and after training. In addition, my wife keeps an eye on me and my training and supports my efforts. She also comes to my rescue on occasion. This summer, my pedal came off in the middle of nowhere. I phoned her while she was cooking, and she was luckily able to set aside what she was doing to come and help me. Had I needed to push my bike, it would have been a very long walk home!

I do my bike trips within the local taxi operating area. Fortunately, I have a taxi card, which was given to me by the disability services, so if I get into a tricky situation during one of my trips, I am always able to get home by calling a taxi.

I also avoid cycling in the city centre. That would almost certainly mean a run-in with a car, since I have some trouble with concentration and short-term memory. I easily forget things that have just happened. For instance, I might think that I have just looked left even if in fact I haven't, then I take off straight into the path of an oncoming car.

When I ride my bike, I use cycle paths and, in the countryside, paved roads. I enjoy my trips through the countryside and take great pleasure in observing the seasons changing. There is always so much to see along the way. In the spring, I marvel at the budding of trees and hedges. In the summer, I like looking at flowers and, later, the autumn colours. As you can probably tell from my enthusiasm, I don't travel along with a frown on my face!

I feel safe while exercising, because I make sure I am prepared. As well as bringing a drink with me, I always take a small first-aid kit. In the future, I plan to bring along some tools, to allow my wife do her cooking in peace. I use Google Maps, which helps me with route planning and I can also use it to pinpoint where I am, if I need to. I have installed the 112 mobile application, which can be used for calling the emergency services and emergency geolocation. Planning is really important.

Back to basics

There is a lot of humour in exercise. I ride an old, three-speed bike, and a couple of times, I have taken a more advanced cyclist by surprise. They have been riding along on their expensive bike in their fancy cycling gear, getting far ahead of me on a straight stretch or while going downhill. Then, I have surprised them while cycling uphill, overtaking them like a formula one driver! Afterwards they catch up to me and start to wonder why I ride such a basic bike. I have told them that I have a memory-related disease and use a slightly simpler bike, so that I may be able to fix it myself, if needed. I wouldn't know how to fix a multi-speed bike, as he disease has taken its toll on some of my skills.

In my childhood and youth, I used to do competitive orienteering. The skills I acquired then are valuable to me as get older, I have noticed. Luckily for me, my condition doesn't involve getting lost, as in Alzheimer's disease. It gives me the freedom to exercise as I like. I always leave a note on the whiteboard at home, saying where I am going. In the future, I can also start using various mobile applications to let my family know where I am.

Road safety

So far, I have managed to avoid scratches and bumps, but I have had some encounters with wild animals. Last summer I almost hit an elk, a deer, a dog, some birds and even a grumpy cockerel, whose territory I must have invaded with my bike. My encounters with drivers have usually gone well, though. There's one thing that puzzles both me and the drivers, though: rules for yielding at the intersection of a cycle path and a road. Neither of us seems to know who is supposed to give way. Even healthy people have trouble



Petri Lampinen (left) gave a presentation at the EWGPWD symposium during the 28th Alzheimer Europe Conference, with a translation by Chris Roberts (right)

with this situation, let alone a cyclist with a memory-related disease. As I have travelled around Europe doing work related to my illness, I have noticed special traffic signs for cyclists, that in similar places clearly show the obligation to give way. It would be great to see these signs in Finland as well.

Unexpected benefits

I have taken matters into my own hands when it comes to preparing my own exercise-based rehabilitation routine. I feel like I have made good decisions when it comes to maintaining my ability to function. However, I have also received some negative, even mocking, feedback. Some people just can't seem to understand that frequent exercise allows me to take care of myself.

On top of all these benefits, active exercise, has also allowed me to sleep better than before. I have also changed my diet to a healthier one. There wasn't too much to improve there, though, as I was already quite a healthy eater.

At the moment, I would like to get a personal rehabilitation instructor. They could give me some exercise tips and keep track of my activity levels. Due to my impulsive behaviour, I might at some point put too big a strain on myself – especially if I become less aware of my symptoms as time goes on. It would be wonderful to come up with a dietary plan and a follow-up system, too.

Gratitude

I have been living my life as a person with dementia (or: a 'memory-related disease' as we call it in Finland) and following the model outlined in the "FINGER" study (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) for a couple of years now. I have exercised a lot, acquired social contacts and taken part in various activities that have come my way. I have maintained a healthy diet and also remembered to rest when needed.

During the past few years, I have taken immense pleasure in my life. Life has had a lot to offer, and my condition has also brought me a lot of new friends. Together, we are able to change old preconceptions about what it is like to live with dementia. Fortunately, we have been provided with channels through which we can make a difference in society. I have noticed that there is genuine interest in what we have to say and that our opinions are being taken seriously and appreciated.

Thank you to Alzheimer Europe and Muustiliiitto – The Alzheimer Society of Finland, for giving me the opportunity to be a part of the European Working Group of People with Dementia (EWGPWD) and Finland's "Memory Activists", which gives me the space to share my experiences with others.

Dementia in the arts: An interview with “Romy’s Salon” director Mischa Kamp

Dutch film director Mischa Kamp spoke to Alzheimer Europe about her award-winning movie “Romy’s Salon”, which looks at the changing relationship between hair salon owner Stine and her granddaughter, Romy, as Stine’s dementia progresses.



What made you decide to direct the movie “Romy’s Salon”? Is the subject-matter particularly close to your heart?

The scriptwriter, Tamara Bos, told me about her idea for this film about 10 years ago. We had just finished shooting “Winky’s Horse”, a film about a Chinese girl who emigrates to the Netherlands and who hears about “Sinterklaas” (Santa Claus) for the first time. It was a big success in our country.

Tamara’s idea was to tell the story of a young girl and her grandmother, who is coping with Alzheimer’s disease. When Tamara was 19 years old, her own grandmother had

Alzheimer’s and this was the inspiration behind the story. Although, of course, the character in this film, Romy, is much younger.

Even up to 10 years ago, there were no family films about this subject. It is so important for young people today, to understand a little more, especially since this disease is becoming more and more common.

For me, the interest was not family related. Rather, the way Tamara described the dynamic relationship between Romy and her grandmother, really got my attention. It was very original and therefore an interesting way to talk about dementia.

The story takes place in a hair salon; a place everyone can relate to and where people often speak quite openly and honestly. Is that why this particular location was chosen for Tamara Bos’ story to unfold, or was there another reason?

Tamara wanted the grandmother to still be working and to be in a sociable environment. A woman still in the middle of an active, vivid life. It was important to show in the film that the grandmother was losing her memory bit by bit. She was slowly losing her grip. The other good thing about a hairdressing salon is that Romy could easily come by after school and stay upstairs in her grandmother’s house. It is good when a film can show the main characters getting closer to each other and becoming more involved in each other’s lives in an easy, natural way. Part of Tamara’s inspiration for the setting had come from her own neighbourhood memories, where a child used to go to her grandmother’s after school, who ran a hairdressing salon.

How were you able to make Stine (the grandmother)’s character, played by Bepie Melissen, so believable? Did you and screenwriter Tamara Bos research Alzheimer’s dementia and how it can affect different people, to help achieve this result?

We read a lot about Alzheimer’s disease and saw a lot of documentaries, which was very



Romy doing her grandmother’s hair



Romy, Stine and Romy's mother Margot – three generations impacted by Alzheimer's dementia

inspiring. While Tamara was writing, she already had the actress, Beppie Melissen, in her mind. At that point, Beppie was still a bit too young for the role. So, in that way, it was a not such a bad thing that financing the film took quite a while because Beppie got older and more believable in the role of a grandparent.

Beppie Melissen is a very good actress and she plays a lot of comic roles. I think, as a director, if you can play comic roles successfully, you understand the importance of timing really well. This was one of Beppie's first times playing a lead in a serious role. During the shooting of the film, we worked closely together to create each scene. We would shoot several 'takes', each with a different approach to how Stine's role should be played; to which stage of confusion she was in at that moment in time – was she very confused or just a little? Beppie can improvise very easily, so her acting gave us a lot of input and it then came more naturally, straight from the heart.

Romy, who helps her grandmother in the salon, takes on a lot of responsibility at the young age of 10. It is moving to watch her relationship with her grandmother develop, through supporting and trying

to understand her better, but she goes through a lot of pain and confusion along the way. Was part of your aim in making this movie to help children understand how dementia might affect a relative, and so to lessen the pain and confusion they might encounter?

There is a difference in experiencing the film for adults and children. Adults know more about the disease and how it will develop as time goes on. Children live more 'in the moment'.

In the case of Grandma Stine, she becomes more open and less strict towards Romy. We wanted to tell a story about a young girl, who was strong and independent. Romy had to be able to cope with some quite difficult issues but, in movies, you don't want to show a child suffering too much, which is why we chose Romy as the character, because her strength and independence allowed her to cope.

I also believe that we, as parents, should not be too frightened of showing our children, films depicting real life issues like a family member struggling with the effects of Alzheimer's disease. Kids can handle far more than people think and it is important

to talk about such subjects with each other. A film can help in that way. Especially if you not only show the negative, but also some of the positive sides.

The movie was very well received and has won a number of international film awards. Congratulations! Which are you most proud of and why?

We are very proud because we won many prizes. Some were voted on by kids only, some were voted for by adults only, some were the general public voting. So it is great to see that it is a film for a big and broad audience – a family film for those 8 years of age and upwards. Besides that, it is nice to see that people from all around the world love the film. It has been a success at festivals in Europe, but also in China and other Asian countries too.

Despite the sometimes heart-breaking aspects of Alzheimer's dementia that are portrayed in "Romy's Salon", there are also some positives that are shown: Romy is able to find a lot of courage and strength within herself; Stine, who has previously been very strict and distant, is able to develop a warmer relationship with her granddaughter; and Romy's parents, who had become

quite absent in her life, become more involved and the whole family becomes closer again. What, for you, was the most important message in the movie?

That is a very difficult question, to choose what is the most important message. Because that's why I think the film is so interesting. All these aspects are so well intertwined in the lives of Romy and Stine. Of course, the fact that Stine has dementia is the focal point of the story, but so is their relationship, which is so meaningful for the story. The balance of these subjects make the film complete. It all starts with the script, and during the editing phase you work on that balance again. It is important to tell a sad story with some humour and to give people some hope and strength at the end. Especially for children, this is an important support for life. We wanted to tell a story, and of course we know that Alzheimer's can be a very awful and cruel disease, but sometimes it can also bring families closer to each



Granddaughter Romy helps out at Stine's hair salon after school

other. For children to understand that things change with an illness, but that this change is not only a loss but can also bring something

new and positive, such as a closer relationship and special memories, is one of the most important messages.

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Alzheimer Europe responds to COVID-19 pandemic

As a result of the COVID-19 pandemic, Alzheimer Europe has worked to ensure that the rights of people with dementia and carers are recognised in the policy responses and measures put in place to curb the virus. Here, we provide an overview of some of the actions we have coordinated and undertaken in the first half of 2020.

Collated webpage of resources

In light of the spread of COVID-19 across European countries, various restrictions have been put in place ranging from the closure of important services such as day care or respite care to the prohibition of visits to nursing and old people's homes. This situation and some of these restrictions also adversely affect people with dementia and their carers.

To support carers and associations providing support and help for people with dementia in these difficult times, Alzheimer Europe created a specific section within its website, collating information and resources from a variety of sources.

Sub-divided into 11 sections, the list of resources that has been put together reflects the seriousness of the situation, as well as the breadth of information and resources which have been created in response to the pandemic. The important and invaluable work of national Alzheimer's associations, governments, European and international organisations has been brought together under the following sections:

- Information for people living with dementia
- Advice for caregivers and families
- Information for minority ethnic groups
- COVID-19 and intellectual disabilities
- COVID-19 in numbers: epidemiology
- COVID-19 and Ethics
- Global resources
- European Union resources
- National resources
- General and scientific resources
- Mental health resources

By including such a broad range of themes, Alzheimer Europe has aimed to ensure a comprehensive collection of resources across a range of disciplines. This section of the website will continue to be updated on a regular basis.

Online meeting of Government Experts on Dementia

On 24 March, following the suggestion of the Scottish Government, Alzheimer Europe organised and hosted an online meeting of the European Group of Governmental Experts on Dementia to discuss how countries across Europe were responding to the COVID-19 pandemic.

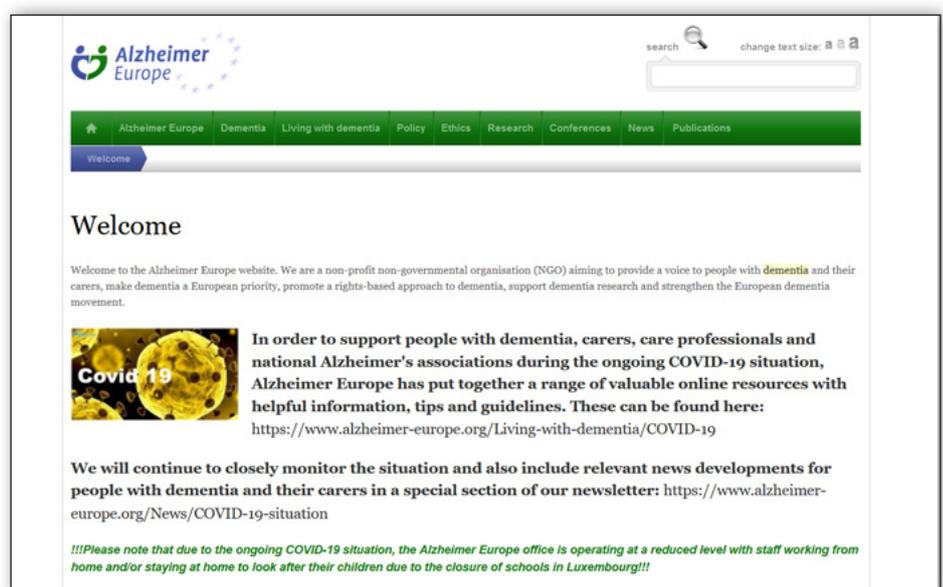
A total of 20 people were present on the call, with representatives from Austria, Belgium – Flanders, Czech Republic, Estonia, France,

Germany, Ireland, Netherlands, Poland, Sweden and the United Kingdom – Scotland, all participating in the online meeting. Additionally, observers from Alzheimer Europe, the European Commission (both DG RTD and DG SANTE), the Organisation for Economic Cooperation and Development (OECD) and the World Health Organization (WHO) were present.

Countries exchanged information and resources which had been produced and utilised in their respective countries, as well as providing a high-level overview of the context of the country and good practice examples for people with dementia or other vulnerable populations. This included the publication of easy read information, the development of guidance to support people to use video conferencing in care homes and the targeting of information to population groups who were deemed to be vulnerable.

In addition, the group discussed how to ensure that people with dementia and their carers living at home did not become isolated in places where lockdown measures were in place. Furthermore, they identified the crucial role for national Alzheimer's associations in communicating and supporting people with dementia and their carers during the pandemic.

Alzheimer Europe collected the links and resources exchanged in an online platform to allow members of the group to have a single reference point for resources and actions in each country. Members will be able to share



Alzheimer Europe home page

and upload resources on an ongoing basis on this platform.

Online meeting of Alzheimer Europe's national member organisations

On 2 April, Alzheimer Europe hosted an online meeting of its national member organisations members to discuss their responses to the COVID-19 pandemic. The meeting, attended by 22 associations, allowed members to discuss how they were operating during the crisis, as well as sharing examples of how they were continuing to support people with dementia and their carers throughout the pandemic. During the meeting, Alzheimer Europe updated members on the work it had undertaken, including providing an overview of the meeting of the Governmental Experts, as well as the dedicated website section.

During the discussions, it emerged that whilst national organisations were unable to deliver services such as daycare or in-person supports, many were continuing to provide support through the use of telephone helplines, video conferencing and publishing information and resources online. Additionally, examples of members using local networks to help with deliveries of food, medicines etc. to people confined to their homes, were also highlighted.

A number of organisations also highlighted that they continued to engage with decision makers during the pandemic to ensure that the rights of people with dementia were upheld, particularly in relation to decisions on health and social care.

Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD)

“On behalf of the EWGPWD and a person cocooned, taking part in the online meeting was a wonderful example of leadership, connection and sharing of much needed knowledge and good practice of how countries are supporting people with dementia. It was inspiring to hear the creativity in how countries are reaching out, especially to those who cannot use a computer or telephone and that live in remote areas.”

Additionally, members were asked to contribute to the development of a position paper that Alzheimer Europe was drafting in relation to the allocation of medical resources for intensive care during the pandemic.

Alzheimer Europe position statements

Following the online meetings with the Governmental Experts and national members, Alzheimer Europe has adopted two position statements in relation to COVID-19 and its potential impact on people with dementia.

Allocation of intensive care resources Intensive Care Unit

The first statement was adopted by Alzheimer Europe on 3 April, calling for people with dementia to be treated fairly and equitably in the allocation of resources in intensive care. The statement was issued following reports from countries which were significantly affected by COVID-19, suggesting that as a result of limited resources and intensive care beds, triage decisions would be taken that would see older people and people with chronic conditions (including people with dementia) refused treatment, care and support.

Its statement, Alzheimer Europe emphasised its commitment to a human rights-based approach to dementia and its belief people with dementia can live meaningfully for many years with a high quality of life. As such, the statement reiterates that a diagnosis of dementia on its own should therefore never be a reason to refuse people access to treatment, care and support.

Furthermore, Alzheimer Europe's position sets out that governments and healthcare systems should take all necessary measures to ensure that the needed infrastructure (in addition to sufficient human resources) is in place to avoid the need for triage decisions.

To date, 48 organisations, both nationally and at a European level, have expressed their support for this position.

Promoting the wellbeing of people with dementia and their carers

A second statement, adopted by Alzheimer Europe on 14 April, identified some of the key issues and challenges faced by people with dementia, informal carers, and health and social care professionals, in relation to the COVID-19 pandemic and dementia.

The position statement outlines whilst having dementia is not believed to increase the risk of contracting COVID-19, people with dementia may find it more difficult to adopt or comply with various protective measures (e.g. hand washing, coughing, distancing, isolation and lockdown). It further notes that as a result of physical distancing, as well as the closure and cessation of many care and support services, people with dementia and their carers are at a heightened risk of isolation and loneliness, as well as other poorer mental health outcomes, including depression or anxiety.

The statement contains specific recommendations targeted at three groups, including health and social care professionals, governments and national Alzheimer's associations, about how they can ensure the wellbeing of people with dementia and their carers.



“We never close!”

During the COVID-19 pandemic, Alzheimer Europe has been in awe of the response of its members. National Alzheimer’s associations across Europe have found new and creative ways to continue providing the best possible support to people with dementia and carers, during confinement. In this article, we highlight just some of this work, but we would like to congratulate and thank every single one of our members for their vital efforts and their resilience in such difficult times.

Italy

Italy has been badly affected by the coronavirus pandemic sweeping across the world. Everything literally just stopped on 23 February 2020. This was the date of the first governmental decree, that effectively closed all schools, recreational and work activities and asked Italians to remain confined at home.

Ever since that fateful day, when people with dementia and their families saw their entire dementia support structure vanish, countless care workers, volunteers, local associations and Dementia Friendly Communities have worked tirelessly to rekindle an alternative support structure. Over time, new activities and initiatives have developed which have done a lot to continue the support of those most in need in our dementia community.

After the initial chaos and confusion, Federazione Alzheimer Italia started to slowly restore some order by acting as a coordinator of the many local initiatives that were emerging. New ideas or actions were promptly updated on social media; help and support lines were restored; a handbook of practical advice dedicated to caregivers was shared on a national level with the media and with families, to help them better face the confinement period at home with their loved ones.

Most local associations and Dementia Friendly Communities have activated new telephone contacts in order to continue to guarantee support for caregivers. Such support has gradually been implemented through video calls and online meetings. In

Verona, for example, videos of music therapists and occupational therapists have been published on Facebook, thus transforming a social platform into a service provider. New services have also evolved to meet new needs, such as home shopping for those who are confined. Cicala, a small village in southern Italy which is a member of the Italian Dementia Friendly network, produced and distributed 12 posters with clear and simple instructions, to improve awareness of the virus and to protect the elderly and vulnerable. In many cases, direct contact has been made with families living with dementia. Individual programmes of assistance have been created. Also encouraged are activities which lift up community spirit and involvement, such as a competition between wives in cutting the beards of their husbands, or perhaps creating new Easter greetings with different shapes made from typical sweets of the town. Thanks to the previous collaboration within the Dementia Friendly Community project, in another city in southern Italy, Bari, it was



“Mask and gloves”

possible to activate a home delivery service for all the families in the neighborhood. The last concrete example from southern Italy is from Villaricca, on the outskirts of Naples, where a booklet called “Caterina’s advice” was launched. This booklet contained solid advice and good suggestions regarding the correct use of the PPE and how to reduce and manage stress related to confinement.

Also interesting are the initiatives that have been created to connect people and their needs, while still respecting personal distance. Through internet social platforms, it has been possible to locate unused PPE (personal protective equipment) and to make such resources available instead for those who need it most. This is the possibly the answer to a new model of solidarity, typical of dementia-friendly communities, which will ensure the care of people within the community.

Initiatives are also happening in northern Italy, for example in two of the most industrialised regions and also those regions most affected by COVID-19. The Dementia Friendly Community of Arzignano communicates through short videos sent to families who have a relative with dementia: a greeting from the mayor and the local priest, the physiotherapists who perform some exercises, volunteers and/or operators who sing popular songs. The response of these families was equally rich, immediate, spontaneous and surprising: greetings, photos, videos, songs, recited poems, streaming news of concerts. Numerous acknowledgments have been received in return, as even this distant mode



“Funeral”

of interaction makes those families feel that someone is thinking about them and trying to take care of them. Finally, from the province of Bergamo, in Lombardy, the region that alone accounts for two thirds of the deaths for COVID-19 in Italy, the “Alzheimer’s office” of the Dementia Friendly Community in Scanzorosciate has replaced personal consultations and home visits, with telephone calls. Stories and advice emerging out of these calls to the office, are shared on social media in a column entitled “Alzheimer’s in the time of COVID-19”. The media posts are enriched with the drawings of a caregiver, who had previously collaborated artistically with the Dementia Friendly Community during the last World Alzheimer Month.



“New technology”

In conclusion, with so many examples of solidarity to show, we can honestly say that the intricate network created over many years by local associations and the Dementia Friendly Community, has enabled neighborhoods and villages to survive this crisis and be able to rely on the help of volunteers and sensitive people, to activate a network of solidarity for those families who need it most. Those people with dementia and their families who have been reached by all these initiatives, clearly appreciate this support and look forward to new activities through new means of technological communication. Relationships previously built on trust and long experience can survive through the use of new technologies that facilitate smooth communication, which have been tried and tested in these strange times, and they have been a vital part of maintaining trust and routine, for many people with dementia. However, we must always keep in mind that not everyone

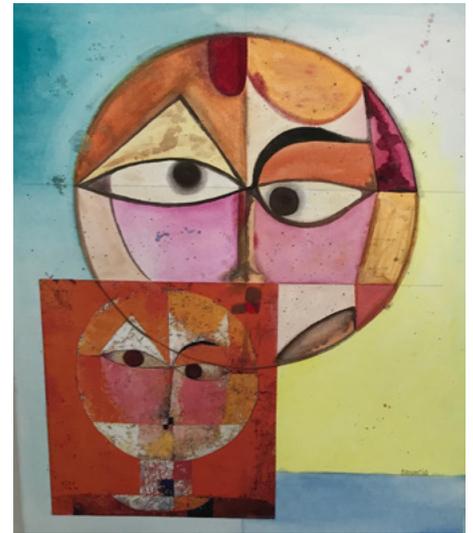
with dementia receives the support they need and deserve. We all must learn from this pandemic, and we must also continue to strive to reach all those who rely on us.

Luxembourg

On 26 March, Association Luxembourg Alzheimer (ALA), posted a number of photographs on its Facebook account, showing members of staff at work during these difficult times, with the slogan “we are working, so you can stay at home”. Association Luxembourg Alzheimer continues to provide its vital services and also aims to raise awareness of the need for other people to stay home, to help protect vulnerable populations and care workers.

On 7 April, Michèle Halsdorf, director of the ALA’s « Beim Goldknapp » care home, was interviewed by national television and radio station, RTL. Speaking about how best to support people living with dementia during the pandemic - particularly those who are no longer in the early stages of dementia – she said that this was “a real challenge”. She stressed the importance of supporting the person with dementia and of reassuring them, in terms they could understand, so as to ensure that they feel safe.

At the initiative of the German Alzheimer association (Deutsche Alzheimer Gesellschaft), several associations came together to support



Artwork from the “Konschtatelier” art workshop in Luxembourg

carers of people with dementia, by publishing guidelines and information for carers around the topic of care at home, during confinement. They particularly emphasised the importance of planning and of daily routine and gave suggestions as to how to do this and what might be important to include in a daily schedule. ALA compiled these various guidelines, in both German and French, on its website www.alzheimer.lu. For any questions carers might still have, the ALA helpline is still available 24/7. The number is: 26 432 432 (national calls only).



Association Luxembourg Alzheimer employees hard at work during the pandemic

Finally, to bring a bit of colour and fun to its Facebook page during these sombre times, the ALA organised a virtual art exhibition, presenting works from its «Konschtatelier», an art workshop which uses art therapy methods. The artists themselves chose to focus the works around a quote from Swiss artist Paul Klee, who said “Art does not reproduce what is visible, it makes things visible”.

France

In response to the coronavirus pandemic, France Alzheimer created several resources aimed at supporting people with dementia, their families and caregivers. On 18 March 2020, France Alzheimer announced that its 99 departmental associations would be setting up additional telephone helplines staffed by trained volunteers, aiming to provide support and information to those in need.

France Alzheimer has also published advice for carers and caregivers of people living with dementia, highlighting ways in which they can provide support in the home or in care institutions. These include demonstrating good hand washing techniques, ensuring a good supply of prescription medication, and making sure that people with dementia can keep in touch with their family and caregivers via phone calls, emails or letters.

To support people with dementia who are isolated at home, France Alzheimer suggests creating a structured routine that can be



“We are working, so you can stay at home”

followed, offering reassurance and stability and reducing anxiety. The importance of remaining physically and cognitively active is emphasised, and several suggestions for physical and cognitive activities are provided, such as doing craft projects, listening to music, doing stretching exercises and walking on the spot. France Alzheimer also encourages people to use technology, devices and telephone conversations, where possible, to remain connected with friends and family.

For more information, visit: www.francealzheimer.org/covid-19-conseils-pour-les-aidants-et-personnes-malades-dalzheimer-ou-dune-maladie-apparentee/

Finland

In Finland, the novel coronavirus outbreak started in March. People started working from home, care homes closed their doors to visitors and all individuals over 70 were asked to avoid contact with others. Local associations and “Muistiluotsi” expert and support centres of the Alzheimer Society of Finland cancelled all activities, events and peer support groups, for the time being.

This meant a significant change for the people with memory-related diseases and their families. The Alzheimer Society of Finland wanted to know more and sent a survey to local associations asking about the situation.

The survey showed that the situation is difficult in many ways:

Since visits to care homes have not been allowed, people are missing their loved ones and are worried about them. People with memory-related diseases living at home and their families are having trouble as well. Carers do not get any free time because all activities for the people needing their support are cancelled, so they are getting tired. People with memory-related diseases living alone are cut off from the world and are lonely.

There have, however, been some positive sides as well. As soon as all activities were cancelled, local professionals started thinking



France Alzheimer published COVID-19-related resources on its website



Katariina Suomu

about new ways to reach their members. Peer support groups were organised virtually, using a variety of online platforms. These meetings were well-received. Some associations have been making videos and publishing them on YouTube, encouraging people to sing or to exercise. Others have been calling their members and asking how they are doing, as well as sending letters and work packages to help them remain active.

The “Muistineuvo” memory advice phone support answers questions regarding memory-related diseases. Before the outbreak, the phone-line was open three days a week. The opening times have now been extended to five days a week, to ensure more coverage and support at this difficult time.

“Despite all the challenges COVID-19 has brought to both people with memory-diseases and their carers and our organisation, I feel happy and proud, when I see the agility and innovativeness of our professionals. They really are doing their best to help our clients in these difficult times”, said Katariina Suomu, Executive Director of the Alzheimer Society of Finland .

Ireland

Research carried out by The Alzheimer Society of Ireland (ASI) to identify the current challenges brought about by the COVID-19 health crisis, as experienced by people with dementia and family carers, found a rise in the cases of isolation, loneliness, boredom, anxiety and fear. The ASI’s Dementia Advisers reported an increase in responsive behaviour from people with dementia including confusion, paranoia, delusions, agitation, and other behavioural changes, with one Dementia Adviser comparing the

deterioration of one person with dementia to “falling off a cliff edge”.

The research, published on 1 April and which included the views of 160 people with dementia, family carers, Dementia Advisers, and Dementia: Understand Together Community Champions, found that 73.3% of people with dementia felt they needed some support during the crisis, with most requiring both practical (e.g. shopping) and emotional supports (e.g. regular telephone check-ins). Of note, only 31.3% were comfortable using the internet.

77.6% of family carers reported needing supports including practical supports (e.g. shopping, information) and emotional supports (e.g. peer support). Many cited heightened anxiety and stress, with feelings of helplessness, worry for their loved ones with dementia, and concerns about the impact of social isolation. In particular, carers expressed that they were worried about getting sick themselves and not being able to care for loved ones.

In addition, almost 95% of Dementia: Understand Together Community Champions felt that with local services such as daycare, Alzheimer Cafes and community activities

suspended, people affected by dementia required alternative practical or emotional support, or both (e.g. advice on local supports, dog walking and regular check-ins). Community Champions were also asked about alternative sources of support that were already in place in their communities, with respondents identifying volunteer networks offering practical assistance and meals-on-wheels services that are currently in action.

The ASI has continued to support people with dementia and their families, insofar as its Home Care, Dementia Advisers, Alzheimer National Helpline and Online Family Carer Training all continued to operate. In addition, The ASI implemented new ways of providing supports remotely, such as regular telephone calls and activity packages for people to use in their own homes.

The full report can be found here: www.alzheimer.ie/wp-content/uploads/2020/04/FINAL-Research-survey-results-on-need-1st-April-2020.pdf

In addition to this, a new resource on “At Home Activities” was published, aimed at people living with dementia and their supporters, during the COVID-19 confinement period.

This extensive resource, which contains many suggested activities together with clear and concise information and instructions, was the result of a collaboration between The Alzheimer Society of Ireland and Ireland’s Health Service Executive (HSE), as part of the “Understand Together” campaign.

You can read and download the resource, here (free): www.understandtogether.ie/Training-resources/Helpful-Resources/Publications/At%20Home%20Activities.pdf

Elsewhere in Europe

Alzheimer associations across Europe are working tirelessly, during this pandemic, to support people with dementia and carers, at the local and national levels. You can read a selection of articles about what they have been doing, here: www.alzheimer-europe.org/News/COVID-19-situation



The ASI and HSE jointly published a resource on home-based activities

Living with dementia during the COVID-19 pandemic

Chris Roberts was diagnosed with early onset mixed dementia (vascular and Alzheimer’s) in 2012, when he was in his early 50s. He is the Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and his wife, Jayne Goodrick, is his supporter. They each give us their perspective on life since the COVID-19 pandemic began and on the impact it has had for them as individuals and on their family.

Chris Roberts

We had just picked up our, new-to-us, motor-home on 4 March and went away for a couple of days to get to know it better. While we were away, we were watching the news about COVID-19, how it was spreading and the increase in numbers of those who had contracted it. We saw that a potential lock-down was coming and decided to return home back to Wales.

Restaurants and bars were starting to be closed and public gatherings were also being limited or stopped, to try and slow down the risk of spreading the virus. We discussed the impact it might have on us. I have a lung disease, emphysema, a form of chronic obstructive pulmonary disease (COPD), which puts me in the ‘severe risk’ group and so we decided to start isolating ourselves a week before the official lock-down in the UK.

Most, if not all, of our appointments were being cancelled, and rightly so, but our previously busy schedules doing advocacy work around dementia had suddenly become empty. I was worried about a lack of purpose and focus in my life, as I’m sure that being busy has helped slow down the progression of my dementia. It has progressed, but not as quickly as anticipated.

I started making myself busy in the garden to try reduce my anxiety levels and worries, which were a bit overwhelming at first! I soon got into my new role as a gardener and realised I was actually enjoying doing very little in comparison to previously. I felt quite

comfortable in myself but yet also a bit concerned and slightly guilty that being isolated did not actually seem to be having much of a negative effect on me, despite having an impact on most people.

Once I realised that self-isolation hasn’t been bothering me that much, I fell to wondering why...and here is what I came up with:

I think I’m fairly practical and resilient anyway; I have not been a ‘people person’ since I’ve been living with dementia; I like my own company (and Jayne’s, luckily!); I have usually worked mostly on my own; I have never needed or thought to ask for help from anyone; I’ve always looked for solutions and not dwelt on the problems; since my diagnosis of dementia, I have not been very socially active, so I have been self-isolating to help

my own mental health for a few years already and have become used to not seeing most of my friends anymore; I don’t have a driving license, so no transport, car, van or motorcycle to get out and about; I don’t function very well in big groups or noisy places, so I usually keep away or sit to one side; and I haven’t been fully in touch with reality for some time, the ‘real world’ being just out of my reach as it were.

So...living with dementia symptoms really does prepare you for these trying times - welcome to my world, everyone!

I do miss my family and close friends but thanks to technology we have kept in touch quite regularly, even having family quiz nights. We have had online meetings, using conference software, with the members and friends in the EWGPWD and at Alzheimer Europe. After all, work and projects concerning global awareness and research have to carry on, as dementia will still be here when COVID-19 has gone!

Jayne Goodrick

The COVID-19 confinement measures started for on 17 March, St Patrick’s Day.

We had picked up our motorhome on 4 March, and brought it home, very excited to try out our new vehicle. What plans we had for the summer! The Lake District of Wales, Scotland, plans to travel all over the UK. We have a very busy schedule and so were struggling to find



Chris and Jayne

time slots to travel such vast distances, whilst still honouring our commitments. Such 'First World problems'!

We were indirectly impacted early on, with various conferences and meetings all over the world being cancelled/postponed, meaning we suddenly had a very empty diary.

We were due at a research meeting on 10 March, in London. Signs of infection were there, but no-one was unduly worried. However, we couldn't get there as there was some problem in the train signalling office - a fire or alarm - and by the time we approached the last stop before London, the UK's Coronavirus epicentre, all trains were halted into and out of Euston station. Looking back, I genuinely believe that it was 'the gods' looking after us, when we had to turn and go home. It took us 10 hours from leaving the house, to arriving back. After that, chaos reigned around us, with the full realisation of the seriousness of this pandemic.

With our new free time we jumped in the van and headed off to self-isolate in the beauty spots of North Wales, and met some friends in their motorhome at a reservoir in the middle of nowhere. On 16 March, Boris Johnson, the UK Prime Minister, made a national announcement that was very sobering, and it all became more real. We headed back home the next day, St Patrick's day, 17 March.

Due to Chris' emphysema and therefore being classed as 'high risk', we went straight into self-imposed isolation. Our adult daughter lives with us, and so we all practiced social distancing in the house. We have a large house, so luckily it wasn't too difficult. Not long after this, the regular daily update changed time from 5pm to 8.30. That was on Monday 23 March. It was obvious to us what this meant - an announcement that we were going into lockdown.

Within 15 minutes of the announcement, our daughter left home. She is a key worker looking after young children and she was not prepared to risk bringing the infection into our house, and so moved out. That was a very surreal moment, and I insisted on hugging her tight as I didn't know when I would next be able to do so. Our son's wedding on 13 April had to be postponed until November.



The new campervan

The funeral of a friend who had young onset dementia was attended by family only, and also five of us wives who, when asked if we were family, chorused as one, "Yes!"

But...Chris' anxiety ramped up to the next level. He had been busying himself in the garden, but now he went into overdrive. Pruning bushes ended in them being cut to the ground (I think it's called coppicing), the drive was scraped of all weeds, then weed killer applied, then cleared again after a few days. I left him to it, because to be honest, the driveway needed it! But Chris would come in dripping in sweat, filthy with dust, scratched, bruised, and unsure of where or what was going on, in that moment.

He hadn't had water or been to the toilet. He only stopped when I called him in for sustenance of some sort. His sleep patterns became very disturbed again.

I found out I am a pretty good cook! I even baked custard tarts, which were delicious!

Our daughter Kate brings us fresh food as we need it, bread, milk, veg. That's all we generally need as I have always had a very well stocked store cupboard and freezer (thanks, Mum!).

And so, we settled into routine. It has been described by some as Groundhog Day, but we see it differently. We are living in the moment.

Wake up. Coffee. Dress, or not. Eat. Potter in the garden/house. No commitments.

No demands on our time. And it is true to say that we are enjoying that. We are very comfortable with it. And that has become our new routine, and routine is very dementia friendly. No demands on time.

But Chris' vocabulary has decreased. His fluency has lessened. He struggles now to speak a full sentence without stammering, struggling to say a word, that's if he can find the right word, the one he wants. Because he is not using those conversing skills. When out at meetings, at conferences, at the 'de-briefs' afterwards, there are many different conversations, questions, opinions being asked of him. Of us all. And our brains have to work, the synapses have to fire, and when a blockage is met, re-route to find a new way to convey the response. Lots of stimulation and using of skills. And then by the time overload comes, he, we, can withdraw and recuperate ready for the next one.

And that, for now, is on hold. We hope that we can get him back to where he was pre-lockdown, but we don't know that he will. We do know that once a skill is lost to dementia, it doesn't come back, but this is an artificial de-skilling, so we live in hope. Because hope is all that we have. And a lovely garden. The garden is once again looking great!

***Side note:** We found out our motorhome friends were infected, he very nearly being admitted to hospital, and we believe our daughter may have had a very mild case of COVID-19, but we remain very healthy.

Our members are helping people with dementia and their carers in 35 countries

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EMDA – The Alzheimer's Association of Israel



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SLOVENIA – LJUBLJANA
Spominčica – Alzheimer Slovenija



SPAIN – MADRID
Fundación Alzheimer España



SPAIN – PAMPLONA
Confederación Española de Alzheimer (CEAFA)



SWEDEN – LUND
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