Helena Dalli
Equality Commissioner outlines the new European Disability Rights Strategy

Helen Rochford-Brennan
member of the European Working Group of People with Dementia shares her experience of bereavement during the COVID-19 pandemic

Michael Hornberger
Professor of Applied Dementia Research at Norwich Medical School comments on the link between traumatic brain injury and dementia

Deirdre Clune, MEP
chairs Alzheimer Europe’s online European Parliament Workshop on the importance of data for dementia research
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Welcome

It gives me great pleasure to introduce issue 36 of Alzheimer Europe’s Dementia in Europe magazine, which highlights our efforts and those of our member associations to make dementia a European priority, and provides updates on the latest national- and European-level policy developments in the dementia field.

The first section of the magazine includes coverage of the online European Parliament workshop we co-hosted earlier this year with Charité – Universitätsmedizin Berlin. At the event, which was chaired by Deirdre Clune, MEP and explored the theme of “Digital data for dementia research and innovation”, we launched a report setting out recommendations to improve data sharing in dementia research. We recently published a position paper, also, on the importance of prioritising people with dementia and carers in COVID-19 vaccination programmes, and have dedicated an article to this topic. Other articles in this section share details of a recent Alzheimer’s Association Academy online event on sports and dementia, as well as our involvement in three different European research projects.

In the Policy Watch section, we are delighted to have an interview with EU Commissioner for Equality Helena Dalli, who introduces the EU’s new disability rights strategy.

At the national level, we speak to the Coordinator for the Czech Republic’s new National Action Plan for Alzheimer’s Disease and Related Illnesses 2020–2030, Marketa Svejdová Jandová and to Martina Mátlová, Director of the Czech Alzheimer Society, who shares her organisation’s views on this, the country’s second dementia plan. From the Czech Republic, we head to the Netherlands, where a fourth national dementia strategy has been launched. Anne de Boer, Advocacy Officer at Alzheimer Nederland, examines the strategy from her organisation’s perspective. Ms De Boer also discusses some of the issues surrounding voting for people with dementia in her country, in the Dementia in Society section of this magazine, and highlights some of the work Alzheimer Nederland has been doing to support them in exercising their democratic rights.

Alzheimer Scotland’s Director of Policy and Research, Jim Pearson, then provides an update on the organisation’s Fair Dementia Care Campaign and how this formed the basis of their recent Scottish Parliament Election Pledge Campaign, which sought the support of candidates standing in the Scottish Parliamentary election in May. Finally, at the national level, Mario Possenti, Secretary General of Federazione Alzheimer Italia, highlights the recent commitment from the Italian Government to provide funding for the country’s National Dementia Plan, which was first launched in 2014.

At a global level, the World Health Organization (WHO) is in the process of developing an “Intersectional global action plan on epilepsy and other neurological disorders”, which is discussed in the closing article of the policy watch section of this magazine, by Stéfanie Freel and Katrin Seeher of the WHO.

Up next, we hear from a researcher on the MOPEAD (Models of Patient Engagement for Alzheimer’s Disease) project, Lena Sanneman, who was interviewed by the Neuronet initiative (Efficiently Networking European Neurodegeneration Research), as part of its series of interviews with Early Career Researchers.

One of the expert speakers at our previously-mentioned Alzheimer’s Association Academy online event on sports and dementia, Renato Walkowiak, shares details of the “Ping4Alzheimer” initiative which involves giving special table tennis sessions for people with dementia and carers, while a second speaker at the event, Professor Michael Hornberger, rounds off the 36th edition of our magazine with an in-depth look at the link between contact sports-related head injuries and dementia.

I would like to warmly thank all the contributing authors, interviewees and our sponsors, without whom our Dementia in Europe magazine would not be possible.

I wish you good health and happy reading!

Iva Holmerová, Chairperson
Alzheimer Europe co-hosts European Parliament Workshop on “Digital data for dementia research and innovation”

Alzheimer Europe co-hosted an online European Workshop, chaired by Deirdre Clune, MEP, about how developments in the use and application of data were being used in the field of dementia research to improve our understanding of the condition, as well as the sharing and reuse of data.

On 23 February, Alzheimer Europe co-hosted an online European Parliament workshop with Charité – Universitätsmedizin Berlin. Chaired by Deirdre Clune MEP (Ireland), Vice-Chairperson of the European Alzheimer’s Alliance (EAA), the workshop featured presentations from speakers working in the field of dementia, at Alzheimer Europe and for the European Commission.

The event was attended by a total of 100 delegates. This included EU policymakers, representatives from national Alzheimer’s associations, national health ministries, pharmaceutical companies, researchers and members of the European Working Group of People with Dementia.

Opening remarks
In her opening remarks as chair, Ms Clune thanked members for their attendance and spoke of the need for a common European approach to the issue of dementia research, noting that the EU had undertaken some work in this area to date, including through the funding of dedicated research projects, as well at the Open Science approach embedded in the research programme.

Ms Penkova also thanked speakers for attending, citing the importance of the issue given the figures from the World Health Organization (WHO) about the increasing number of people living with dementia. She highlighted the importance of dementia as a cross party issue and offered her continued support.

Virtual Brain Cloud
Petra Ritter, BIH Johanna Quandt Professor for Brain Simulation at Charité – Universitätsmedizin Berlin and leader of the Virtual Brain Cloud project. The Virtual Brain Cloud was introduced, setting out the objective of the project as a way to develop and validate a dedicated cloud-based environment to utilise the potential of big data and high-performance computing. In doing so, it is expected that the Virtual Brain Cloud will achieve generalisable results that help individual patients in the detection and management of dementia.

One of the ways this will be achieved is through the integration of the data of large cohorts of patients and healthy controls, through multi-scale brain simulation using The Virtual Brain (or TVB) simulator. However, it was explained that to achieve this, there are a significant number of challenges in relation to both the required infrastructure for the sharing and processing of health data at a large scale, as well as the complications of doing so in a way which is compliant with the EU’s General Data Protection Regulation (GDPR).

Human Brain Project and EBRAINS
Paweł Świeboda, Director General of the Human Brain Project and CEO for EBRAINS, introduced these two programmes of work, outlining how they were addressing the challenges in infrastructure and interoperability related to the sharing of data in brain health research, as well as addressing issues of collaboration and scale. The EBRAINS research infrastructure (created by the EU-funded Human Brain Project), which specifically aims to allow researchers, through the use of collected and embedded tools, to collect, analyse, share, and integrate brain data, as well as performing modelling and simulation of brain function.

Looking towards the forthcoming work of the EU in relation to a European Health Data Space, it was suggested that there is a strong case to be made for a dedicated Brain Health Data Space embedded within this work.

Alzheimer’s Disease Data Initiative
Tetsuyuki Maruyama, Executive Director, Alzheimer’s Disease Data Initiative (ADDI), introduced the ADDI and ADDI’s AD Workbench, explaining that both the organisation and initiative are relatively early in their development. It was explained that ADDI’s aims include developing a data sharing platform and associated data science tools to provide
researchers with access to data from dementia research, as well as connecting data globally to allow access for researchers working in the dementia field.

Launched in November 2020, the AD Workbench aims to increase data sharing and support between researchers in the fields of dementia, through the development of new tools and analytics. At the time of the presentation, over 700 users across the world had begun to make use of the platform.

**Alzheimer Europe data sharing report**

Angela Bradshaw, Project Officer, Alzheimer Europe, launched Alzheimer Europe’s new report “Data sharing in dementia research – The EU landscape”, which outlines the legal and policy context that dementia researchers working in the field must navigate. The report identifies that whilst open access and data sharing is widely agreed upon in principle, practices vary widely between sectors and Member States, with the General Data Protection Regulation (GDPR) also not fully delivering on its aim of facilitating research data sharing. Key recommendations within the report include the development of pathways for faster, secure sharing of research data between sectors and across borders, support for researchers to maintain datasets and platforms after projects end, and embedding academic reward systems that place a greater value on data sharing and transparency.

You can read an article on Alzheimer Europe’s report on data sharing on pages 6–7.

**European Commission activity**

Saila Rinne, Head of Sector for policy, Unit H.3 eHealth, Wellbeing and Ageing, DG CONNECT, provided a focus on some of the different work being undertaken by the European Commission in relation to digital health and ageing. Much of this work is built around three points: secure access and exchange of health data; health data pooled for research and personalised medicine and digital tools and data for citizen empowerment. In addition to projects and work which has been undertaken so far in relation to digital health and ageing, future workstreams with relevance for better sharing and use of data for health research were highlighted, including Horizon Europe, EU4Health and the Digital Europe programmes.

Concluding the Workshop, Iva Holmerová, Chairperson of Alzheimer Europe, noted the importance of data, highlighting that the process of meta-analysis in research, beginning with the Cochrane process in clinical research decades ago, had laid the foundations for many of the more recent developments in the synthesis and a foundation for the current context. In addition, she thanked the speakers for their presentations, Deirdre Clune MEP for hosting and Ms Penkova MEP and Ms Pietikäinen MEP for their contributions, as well as attendees for joining the event.

The next European Parliament Workshop will take place virtually on 15 June 2021, with a focus on the spectrum of Alzheimer’s disease and the developments in research which have improved our understanding of the disease.

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Alzheimer Europe publishes report on Data Sharing in Dementia Research

At an online European Parliament workshop in February, Alzheimer Europe launched its new report “Data Sharing in Dementia Research”, which reviews recent changes in EU research policy and sets out recommendations to improve data sharing in dementia research. Angela Bradshaw, Project Officer, Alzheimer Europe, shares its key findings.

Researchers, funders and policymakers all agree that data sharing can accelerate and improve science, paving the way for new discoveries and improving the understanding, diagnosis, treatment and care of dementia. Such discoveries and advances are sorely needed. In our 2019 Dementia in Europe Yearbook, “Estimating the prevalence of dementia in Europe”, we found that the number of people with dementia in the wider European region is likely to double by 2050, increasing from 9,780,678 to 18,846,286. Despite its growing prevalence and high cost to health and social care systems, dementia attracts a disproportionately low amount of research investment compared to other chronic and life-limiting diseases. As a result, there is an urgent need to maximise the utility of data from dementia research.

The dementia datascape has expanded dramatically over the last century. When Alois Alzheimer first identified the disease that bears his name in 1906, he collected data on a single participant: a 51-year old woman named Auguste Deter. Nowadays, clinical trials often recruit hundreds of participants, while cohort studies can involve thousands of individuals across many different countries. Thanks to the development of new digital technologies and analytical techniques, clinical research studies routinely collect vast quantities of data on each participant, from genetic sequences to brain imaging scans and neuropsychological test measures. However, the sharing of this valuable data is far from being common practice; data often remains behind the firewalls of institutions, pharmaceutical companies and medical centres. In our report, Alzheimer Europe sought to understand why.

In the report we evaluated the legal and policy landscapes that dementia researchers have had to navigate since the launch of Horizon 2020 in 2013. In addition, we mapped the Horizon 2020 dementia research portfolio, assessing the scale of EU investment in dementia research and the use of clinical research data. Finally, we reviewed recent surveys of researchers, research participants and patients, collating their perceptions and concerns regarding data sharing.

The key findings from the report include:

- To date, over EUR 570 million has been invested through Horizon 2020 in dementia research projects, over 75% of which involve the use of clinical data. Many projects include partners from both public and private sectors, such as the IMI-funded EPAD (“European Prevention of Alzheimer’s Dementia”) project. This underscores the importance of systems that support secure data sharing between partners and sectors, as well as across borders.
- EU Open Science policies have helped promote the development of platforms and services for hosting and sharing data.
- The General Data Protection Regulation (GDPR) has made Europeans more aware of their rights to privacy and data protection. However, there is a perceived lack of clarity and regulatory divergence between Member States, which can impede data sharing both within the EU and beyond its borders.
- Researchers face obstacles to data sharing at many levels, citing technical, financial and motivational issues that make it harder to develop and implement data sharing plans.
- Although most research participants strongly believe that their data should be shared for greater societal benefit, many are concerned about the potential for loss of privacy.

The key recommendations to improve data sharing include:

- Research stakeholders should work on co-creating a “shared research knowledge” system, with clear policies and legal frameworks that promote greater transparency, trust and reciprocity.
- GDPR codes of conduct, standard contract clauses and guidelines (e.g. detailing...
which pseudonymisation methods to use) would make it easier for researchers and institutions to share research data between sectors and across borders.

- Researchers need more support to maintain and share datasets and platforms after their project funding period ends. Funders and research institutions should work to embed academic reward systems that place a greater value on data sharing and transparency.
- To increase awareness and trust in health data use, reuse and sharing, the EU and its Member States should work to increase data and digital literacy in the general population, ensuring that older adults and vulnerable groups are not left behind.
- Decisions on sharing data from clinical research should be ethically sound, justified and transparent. Researchers should therefore involve people with dementia in the design and conduct of research, as well as in data governance.

To ensure people with dementia benefit from the progress made in recent years, all stakeholders working within the field of dementia research must work together to overcome the remaining obstacles to data sharing. Lessons can be learned from the COVID-19 pandemic, which has illustrated how data can become a pillar in the fight against a global public health threat. Over the past 18 months, governments have shared virus surveillance and public health datasets; and institutions have created data repositories and platforms for sharing data from COVID-19 vaccine and treatment trials. Standardised protocols, procedures and data collection methods have helped trials such as SOLIDARITY quickly identify treatments that benefit people with COVID-19 – and rule out those that don’t.

Dementia, like COVID-19, is a public health crisis. In addition, people with dementia have been disproportionately affected by COVID-19, with social isolation and lack of access to care leading to a worsening of symptoms in many cases. We need to ensure that dementia is not overshadowed by the COVID-19 pandemic, and that dementia research is maintained as a priority for the EU and its Member States, paving the way for new dementia diagnostics, treatment and care.

Horizon 2020 funding allocation to dementia projects involving clinical data, by funding scheme

<table>
<thead>
<tr>
<th>Funding Scheme</th>
<th>Allocation (€)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SME Instruments</td>
<td>13,706,173.25</td>
</tr>
<tr>
<td>Marie Skłodowska Curie Actions</td>
<td>31,463,778.76</td>
</tr>
<tr>
<td>Innovative Medicines Initiative</td>
<td>112,748,307.35</td>
</tr>
<tr>
<td>European Research Council</td>
<td>225,734,591.28</td>
</tr>
<tr>
<td>Total funding:</td>
<td>309,083,122</td>
</tr>
</tbody>
</table>

We need to look beyond the treatment of established disease, and towards the maintenance of brain health: to do this, we need better mechanisms to collect, analyse and share real-world data across the lifecourse.”

Prof. Craig Ritchie, University of Edinburgh

A fundamental problem is that the landscape of dementia research data remains fragmented. To resolve this, we need more local support for researchers to prepare and share data; clearer regulations for legal departments to follow; and greater harmonization between platforms.”

Prof. Pieter Jelle Visser, University of Maastricht

Acknowledgement

Alzheimer Europe’s development of this report was made possible thanks to the support of Gates Ventures.
The PARADIGM project presents its Patient Engagement Toolbox

One of the main outcomes of the recently-concluded PARADIGM project (2018–2020) is its “Patient Engagement Toolbox”. Alzheimer Europe is proud to have contributed actively to this important work.

PARADIGM – Patients Active in Research and Dialogues for an Improved Generation of Medicines – a European project funded by the Innovative Medicines Initiative (IMI), kicked off in March 2018 and came to a close at the end of November 2020. It was a public-private partnership co-led by the European Patients’ Forum (EPF) and the European Federation of Pharmaceutical Industries and Associations (EFPIA). One of the main outcomes from this project, which included Alzheimer Europe as an active partner in all work packages, is the “Patient Engagement Toolbox”.

PARADIGM Patient Engagement Toolbox

The toolbox comprises the recommendations, guidelines and tools developed by PARADIGM to support patient engagement activities in medicines development. The tools were developed based on a gap analysis which helped to identify some of the more relevant gaps in current practices.

The toolbox includes tools related to:

- Planning patient engagement activities
- Conducting patient engagement activities
- Reporting and evaluation.

All tools and related materials (e.g. methodology used for each tool, contributors, related blogs) are available online: https://imi-paradigm.eu/petoolbox/

We present, here, some of the tools which might be particularly relevant for patient organisations. The Toolbox also includes tools with a focus on industry (e.g. pharmaceutical companies) and health technology assessment (HTA) bodies.

Topic: Monitoring and evaluating patient engagement

The Patient Engagement Framework can be used by people who directly plan and conduct patient engagement activities. It provides a map for monitoring and evaluation of patient engagement activities in medicines development, including 87 metrics organized across the following components:

1. Input metrics (e.g. whether the conditions for meaningful patient engagement are in place)
2. Activities/process metrics (e.g. how the implementation of patient engagement is progressing and areas for improvement)
3. Learning and change metrics (e.g. short-term, direct results of patient engagement which give an indication of the progress made towards impacts)
4. Impact metrics (e.g. long-term impacts for medicines development and stakeholders)
5. Context (e.g. contextual factors which may facilitate or inhibit success).

Steps to evaluate impact:

- Step 1: Decide on the primary objectives
- Step 2: Select metrics
- Step 3: Identify methods
- Step 4: Create a feedback loop.
Topic: (Organisational) Capabilities for patient engagement

This tool provides recommendations on the competencies (i.e. knowledge, skills and behaviours) and the resources that each stakeholder organisation should aspire to have in place in order to plan, implement and evaluate meaningful and sustainable patient engagement activities across the medicines lifecycle. It doesn’t include the competencies of the patient involved in patient engagement activities.

The key topics addressed are:

1. Purpose, roles and responsibilities of all stakeholders
2. Respect and accessibility
3. Representativeness of all stakeholders
4. Transparency in communication and documentation
5. Continuity and sustainability
6. Engaging with potentially vulnerable populations.

Topic: Legal agreements in patient engagement

This tool was developed to address the need for a legal framework within which collaboration between the pharmaceutical industry and patients could happen in a mutually respectful way.

In 2019, the “Reasonable agreements between patient advocates and pharmaceutical companies (RAPP) project” developed a Guiding principles document and four reference agreement templates (i.e., consultancy agreement, community speaker agreement, collaboration agreement and advisory board agreement). PARADIGM reviewed the RAPP documents and produced “annotated” versions which include additional descriptions and definitions of terms or sentences in lay terms.

Topic: Reporting and dissemination in the public domain

The tool provides practical guidance and support to help organisations involved in patient engagement to develop adequate reporting and dissemination plans so that the outcomes and learnings from patient engagement activities are more readily available in the public domain. It suggests that patients should be invited to, and supported in, taking part in the reporting and dissemination of the patient engagement activities where they have been involved.

It consists of the following elements:

1. Guiding principles
2. Accompanying checklist to help users in the planning phases, summarising the key considerations and principles to follow
3. A template with the core elements to be included in the reporting materials
4. An appendix with signposting information to resources from key stakeholder groups.
Topic: Managing competing interests
Tools developed:

1. Raising awareness on managing competing interests in a multi-stakeholder environment: Guidance to patients and engaging stakeholders
2. Short guidance on managing competing interests and conflicts of interests
3. Log of patient engagement activities
4. Educational scenarios on competing interests and conflicts of interest.

These tools were developed to raise awareness and understanding of this topic among all the different stakeholders involved in the process of developing medicines. It can support patients in taking informed decisions before participating in a patient engagement activity in medicines development.

Acknowledgement

The PARADIGM project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777450.
AI-Mind – New initiative to develop artificial intelligence tools for dementia prevention

The AI-Mind project with its intelligent digital tools for screening brain connectivity and dementia risk estimation in people with mild cognitive impairment will facilitate a paradigm shift in clinical practice.

The AI-Mind project kicked-off in March 2021 with a consortium meeting of 52 collaborators setting up a multidisciplinary approach to address the challenge of effective dementia prevention. Funded by Horizon 2020 with a duration of five years, the project has an initial budget of around EUR 14 million distributed across a total of 15 partners from multiple sectors including academic institutions, medical centres, SMEs, spin-off companies and patient associations. In this project, Alzheimer Europe is representing the patient perspective and will be involved in the ethics and communication activities of the project.

More than 10 million Europeans show signs of mild cognitive impairment (MCI), a condition defined by deficits in memory but not severe enough to significantly impact activities of daily life. Although people with MCI have clinical symptoms but limited disability, MCI is associated with a very high risk of dementia. It is estimated that around 50% of people with MCI will develop dementia within five years (risk more than 20 times higher than in the healthy elderly population).

Current clinical practice (e.g. diagnose, examination) lacks the necessary screening tools to identify those at 50% of risk. The patient’s journey typically takes many years and involved several clinical visits before a conclusive diagnosis of dementia is finally reached. A timely and early diagnosis can help people take control and would result in numerous benefits (e.g. early support, health improvement, early-stage intervention). AI-Mind will radically shorten this journey to a week, through a digital solution that is able to provide a fast and accurate (>95%) prediction for the individual dementia risk. This would give doctors and patients a window for preventive interventions, therapies and rehabilitation measures early in the course of the disease. AI-Mind aims to use artificial intelligence to enable clinicians to perform early population-based screening assessment of dementia risk for all people with MCI.

AI-Mind will develop an “Intelligent diagnostics toolkit” for brain connectivity screening and dementia risk estimation in people with MCI containing two new artificial intelligence-based digital tools: the AI-Mind Connector and the AI-Mind Predictor. The AI-Mind Connector will identify dysfunctional brain networks (e.g. synaptic malfunction and loss of connectivity which characterise signs of dementia) and the AI-Mind Predictor will assess dementia risk using data from the Connector, advanced cognitive tests and genetic biomarkers.

These two tools will be delivered to clinicians through a digital platform designed to analyse and process routinely collected data in an innovative manner. With the goal to distinguish people at risk and not at risk of dementia in a group of MCI subjects, the AI-based platform will be tested and validated in five European clinical centres:

- Complutense University of Madrid (Madrid, Spain)
- Helsinki University Hospital (Helsinki, Finland)
- Oslo University Hospital (Oslo, Norway)
- Scientific Institute for Research, Hospitalization and Healthcare, San Raffaele Roma (Rome, Italy)
- Università Cattolica del Sacro Cuore (Milan, Italy).
Ira Haraldsen, the project coordinator, presents the overall vision of AI-Mind

**What are the benefits of artificial intelligence for dementia prevention?**

Thanks to using artificial intelligence in well-established technologies, such as electrocardiogram (ECG) or electroencephalogram (EEG), we reach beyond the state of the art where more information becomes available to us. For example, in ECG and EEG the human eye has for over 100 years identified important information like the risk of acute heart attack/stroke. Until recently, most analyses of technologies were built on our own experiences alone.

“Using artificial intelligence in EEG interpretation will not only reduce the amount of time needed for manual calculations done by computer but will enhance the quality of our understanding of electrical phenomena and its correlation to dementia.”

Using artificial intelligence in EEG interpretation will not only reduce the amount of time needed for manual calculations done by computer but will enhance the quality of our understanding of electrical phenomena and its correlation to dementia. We know from research that one of the earliest signs of pathological dementia-like processes is of an electrical art, noticeable a long time before structural changes occur. Therefore, artificial intelligence will help us to open up a new window of opportunities in dementia treatment.

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

The first one that comes to my mind is to get access to sufficient data. Artificial intelligence needs big data; traditional storage of files connected to each journal file in one traditional hospital won’t be sufficient for machines or deep learning. Therefore, we have to establish international and European databanks where such analytical models can be developed and serve as a benchmark for results of individual patients. This would require fast adaptations in our health care system journal file procedures.

Interactive solutions with the outer world are demanded but they have to be secure and take care of our personal rights. One important pre-conditioning will be the harmonisation of the different national legal frameworks to have a European model understanding and implementing our human rights into AI based algorithms. Our willingness to adapt will be utterly important. Artificial intelligence is changing the world as we know it. Part of the fourth industrial revolution, AI is just as challenging as the use of electricity for lighting, or railway expansion were in another century. Not everybody liked using light bulbs, in the beginning some preferred candlelight, but now in the long term it enabled us to make substantial new discoveries.

**How did you come up with the idea to launch this innovative AI-Mind project?**

One of my PhD students was interested in functional and electrical brain network analyses. I respect very much his interdisciplinary and his technological knowledge but watching him every day working so hard and achieving so little, pushing constantly one or another computer button, writing another instruction on how the computer should calculate, was already for me exhausting to watch. Due to the demanding expertise in data processing, he submitted his first paper after 2.5 years. I thought, that even though all this information is of great importance, no patient would ever enjoy the journey. If we do not change the approach and benefit from AI revolution, this will be a standard research method used forever and I cannot accept this! There is another way.

My first job at the Max Planck Institute at Cologne in Germany taught me a lot in this regard. Back in the beginning of the ‘80s, Positron Emission Tomography was introduced to the clinic. There we were only successful by locating research facilities close to the hospital. We introduced physicists, mathematicians, engineers to the clinical research world by building strategical interdisciplinary teams. I love observing other experts looking at my knowledge background from a completely different angle. A friend of mine always says: “Education is looking at the same thing from different angles, like humans or birds differently experience water”. I love being part of projects where one can learn from others. The AI-Mind project gives us the opportunity not only to exchange knowledge but to develop AI-based technology that reaches beyond the state of the art and can be used for dementia prevention.

“**The AI-Mind project gives us the opportunity not only to exchange knowledge but to develop AI-based technology that reaches beyond the state of the art and can be used for dementia prevention.”**

**What are your expectations from and hopes for the project?**

I hope that AI-Mind team will contribute to the change in the health system. By developing a new screening method we can make one step forward in the fight against dementia.
forward into taking care of our brain. Dementia is still stigmatised like cancer was in the ‘60s-’70s. If we look now at cancer disease, a lot of changes happened. We regularly join preventive programmes, like mamma, prostate and cervix cancer screening programmes. However, we are not screening our brain function regularly, and not early enough to be able to intervene at the earliest possible time point, when cognitive changes are starting becoming pathological.

Unfortunately, today we are investigating brain function when it is too late. We are only able to diagnose dementia when structural changes are obvious. Functional methods like functional Magnetic Resonance Imaging and Positron Emission Tomography are only used in about 15% of the European dementia cases. It is an extremely expensive method and we note an inequity for those who have access to it. I really wish that AI-Mind can contribute to change this.

By developing an artificial intelligence-based prediction tool that is accessible, affordable, and non-harmful, we will do our duty to work for equity in health. It is irresponsible that only high technology-driven countries can have access to the latest innovative methods. Aging is a worldwide phenomenon and artificial intelligence will contribute in many areas such as dementia’s prevention to increase equality.

Acknowledgement

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LETHE project looks at digital cognitive biomarkers

LETHE is a personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on AI and distributed Machine Learning. Alzheimer Europe asked project coordinator Sten Hanke to discuss the details of this new EU-funded project.

What is the problem you are aiming to address with the LETHE project?

Cognitive impairment is common among elderly adults. Dementia, the most severe expression of cognitive impairment, represents the main cause of disability in elderly people. Globally, about 47 million people were living with dementia in 2015, and this number is projected to triple by 2050.

Dementia is the greatest global challenge for health and social care in the 21st century, and increases in numbers and costs are driven, worldwide, by improved longevity resulting from the welcome reduction in people dying prematurely.

As the world’s population increases in age, the number of people living with dementia grows, and this number is projected to continue to rise. Dementia has long been considered to be neither preventable nor treatable, but while the underlying illnesses are not curable, today we know that the disease course might be modifiable with good preventive interventions at an early stage.

With LETHE we want to identify risk factors at an early stage, project their development based on Artificial Intelligence methods, and apply early interventions to modify these risk factors. The aim is to shift the onset of dementia and cognitive decline to later stages."

"With LETHE we want to identify risk factors at an early stage, project their development based on Artificial Intelligence methods, and apply early interventions to modify these risk factors. The aim is to shift the onset of dementia and cognitive decline to later stages."

In parallel, we will implement an information and communications technology (ICT)-based intervention framework, inspired by the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) protocol which allows a semi-automated lifestyle intervention for people at risk of dementia. The ICT framework will, on the one hand, collect several types of passive and active behaviour data, through app-based questionnaires, wearables and other sensors; and on the other hand, provide some personal lifestyle guidance, to help keep the person adherent to the individual intervention protocol. LETHE will also make use of some interfaces which go beyond a normal app, such as robots or smart glasses.

What are the concrete objectives and actions that will be undertaken in LETHE?

Based on a data pool of 130,000 datasets from clinical centres in Europe, we will try to develop an initial prediction model of dementia-related risk factors and factors influencing the progress of cognitive decline. These datasets include prevention trial data, observational and longitudinal data, as well as insurance data.

"We will try to develop an initial prediction model of dementia-related risk factors and factors influencing the progress of cognitive decline."

Based on the data collected during a trial spanning more than two years, we will train an AI prediction model, first to gather knowledge about the influence of lifestyle parameters on the dementia risk factor progression, and then to adapt the individual lifestyle guidance in real-time to prevent the progression of the
risk factors and, by so doing, shift the onset of dementia to later stages in life.

What are the benefits of a personalised prediction and intervention model?

The clear benefit of automating the FINGER protocol is that, if LETHE is successful, theoretically anyone at any age could start to follow this tailored lifestyle intervention to shift the potential onset of dementia in later life. In the future, we might even be able to identify possibilities more easily, to understand our personal predisposition to certain chronic diseases before the first symptoms are even visible. This is the moment where ICT based interventions which can close to whole loop of measuring the progress and providing the guidance can bring a benefit to help people to stay healthy. The effects and the progression of the disease or the risk factors can be very individual, depending on several factors such as genetic predisposition and social background, among others. It is becoming clearer that a one-size-fits-all intervention may not be the best approach, particularly as we are all individuals and have our own preferences and habits. For example, one person might find it easier to walk 10,000 steps every day, while another finds it more convenient to follow a vegetarian diet. The important thing is that we manage to keep each person adherent to their individual protocol.

Another important thing we can do, also, when we collect data, is to see which intervention protocols and therapies are successful for which individuals, and to learn from that and apply it to other individuals with the same pre-disposition.

What are your expectations from and hopes for the LETHE project?

We have many hopes for the project. As mentioned, one goal would be to achieve an ICT-based intervention setup which can also be applied to prevent other chronic diseases. Then, we hope to find more insights into the relationship between different dementia risk factors and, by so doing, gain knowledge about the factors which are influencing dementia progression or the development of the disease in general – especially in the early stages.

Furthermore, it would be great to see that the personal ICT intervention, together with the ICT-based lifestyle guidance really prove the positive impact that lifestyle interventions can have, even in such a short period of time as the 2–3 years in the project.

Another aim is to collect a behaviour data set during the project, which will help us to further develop so-called ‘digital biomarkers’, which in the future might replace traditional biomarkers to diagnose and monitor dementia and risk factors. We expect a future shift to more information being taken from quantitative data measured in real-life settings, rather than from clinical data examinations.

Over all, the project has many hopes and expectations, both on the research and technical side, regarding data, algorithms and ICT intervention, but also on the clinical side regarding knowledge about dementia and its influencing factors.

In the long term, it should be possible to build a healthcare system that aims to prevent diseases and to keep people healthy for as long as possible, thus providing better quality of life for everyone.

In the long term, it should be possible to build a healthcare system that aims to prevent diseases and to keep people healthy for as long as possible, thus providing better quality of life for everyone.

Acknowledgement

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https://www.lethe-project.eu/
@lethe_project
Alzheimer Europe hosts Alzheimer’s Association Academy session focusing on sports and dementia

On 18 May 2021, Alzheimer Europe held an online session of its popular Alzheimer’s Association Academy series. These Academy sessions have been running since December 2015, and have been online since the start of the COVID pandemic. The theme for this session was “Sports and Dementia”.

Ping4Alzheimer

The first speaker, Renato Walkowiak, presented Ping4Alzheimer, a joint initiative of the French Table Tennis Federation and France Alzheimer. According to some scientific studies, table tennis is one of the most suitable and recommended sports for older people, and may help to slow cognitive decline. With this in mind, Mr Walkowiak, whose grandmother passed away with Alzheimer’s dementia some years ago, began giving special sessions for people with dementia and carers at his table tennis club, and the “Ping4Alzheimer” Initiative was born. The programme has been such a success that a partnership has now been created between the French Table Tennis Federation and France Alzheimer, with the aim of deploying the initiative nationally. Karine Teow of the International Table Tennis Federation and Lorène Gilly of France Alzheimer joined Mr Walkowiak for this presentation, each highlighting that their respective organisations were delighted to be involved in such a promising project. You can read more about this initiative on pages 40–41.

Partnering with the German Olympic Committee on sport and dementia

The second speaker, Sabine Jansen from the Deutsche Alzheimer Gesellschaft (DAlzG), described the partnership that has developed between her organisation and the Deutsche Olympische Sportbund (German Olympic Sports Confederation), aiming to involve as many people with dementia as possible in sports clubs throughout Germany. The programme, called “Sport bewegt Menschen mit Demenz” (sport moves people with dementia) emerged from Germany’s National Dementia Strategy, which was launched in 2019. The first of the four fields of action in the strategy is “Developing and establishing dementia-inclusive communities to enable people with dementia to participate in society”, which includes sports and sports clubs. A box of materials was developed in 2020, which is available to sports clubs and Alzheimer associations, in order to motivate and support their participation in this initiative.

Football memories

The next presentation was given by Chris Kelly from Alzheimer Scotland and Richard McBrearty from the Scottish Football Museum. They described a joint project called Football Memories, which has been running for over ten years. Chris Kelly presented an off-shoot of the project, which he created: a dementia-friendly walking football league, developed to help give people living with dementia the opportunity to remain involved with football. It offers slow-paced five-a-side games, played at Scotland’s national stadium. The project, “Hampden Heroes”, also gives participants the chance to compete and win the Alzheimer Scotland Walking Football League and Glasgow Cup. Richard McBrearty introduced delegates to Scotland’s Football Archive, which represents thousands of images from Scottish football history. The website enables groups to access these digital collections for “reminiscence activities”.

Sport and dementia risk

The final talk was on “Sport and dementia risk”, given by Michael Hornberger, Professor of Applied Dementia Research at the Norwich Medical School, University of East Anglia, United Kingdom. His talk was mainly focused on the link between traumatic head injury and dementia. The clinical evidence of a link between traumatic head injury and dementia has been known since the 1920s and the initial evidence was based mostly on boxers, whose post mortem brains showed similar protein changes to those with Alzheimer’s disease. These changes, named Chronic Traumatic Encephalopathy (CTE) have also been found in professional players of sports such as rugby, American football and ice hockey.

The key injury to avoid, he noted, is concussion and in particular repeated concussions. However, it is not only concussion that can cause neuroinflammation, but also “sub-concussive” events. These may be caused, for example, by heading the ball in football. For this reason, heading the ball has been banned in children’s football, since the young brain is more prone to injury.

Prof. Hornberger also made sure to stress the importance and benefits of sports, both for general wellbeing and for dementia risk-reduction, which he said can be reduced by up to 30% through regular exercise. You can read an interview with Prof. Hornberger, about CTE and dementia, on pages 44–46.
Prioritising of people with dementia and their carers for COVID-19 vaccination

Alzheimer Europe recently worked with its member associations to understand whether people with dementia and their carers were identified as priority groups for COVID-19 vaccination, developing a position statement based on their responses.

The COVID-19 pandemic has meant that people with dementia, their families and carers are facing unprecedented challenges. Severe COVID-19 predominantly affects older adults and those with underlying health conditions, with people aged over 65 years accounting for 95% of deaths related to COVID-19 in Europe. People with dementia have almost twice the risk for COVID-19 compared to people without the disease, with high rates of hospitalisation and an estimated 20% risk of mortality within 6 months.

Beyond the direct, often devastating impacts of COVID-19 infection, people with dementia and their carers have also experienced harmful consequences of public health measures designed to halt the spread of the virus. Reduced access to support, disruption of routines, enforced social isolation and lack of cognitive stimulation have caused increased anxiety, agitation, stress and depression, also accelerating cognitive decline for some people with dementia. Family members and carers have had to shoulder additional care responsibilities, causing increased psychological and physical stress.

Vaccination represents an important cornerstone of global efforts to contain the COVID-19 pandemic, alongside mask-wearing and physical distancing. Vaccination strategies developed by EU/EEA countries share common goals, namely to reduce COVID-19 mortality, and to relieve pressure on strained health and care systems. However, the vaccine prioritisation varies considerably between Member States.

Whilst many countries have identified risk groups linked to severe health conditions such as cancer, kidney and heart disease, prioritising people with these conditions for COVID-19 vaccination, dementia is not commonly listed as a risk factor. As a result, people with dementia in many countries may not be prioritised for COVID-19 vaccination, particularly those who are living in the community and are not in the oldest age brackets.

Alzheimer Europe survey

To understand whether people with dementia are referenced or prioritised in national COVID-19 vaccination strategies, Alzheimer Europe performed a survey of our member associations in March this year. We also asked whether they were aware of extra practical support that could be provided to facilitate vaccination for people with dementia, such as transport to vaccination centres, or support for making appointments.

In total, 25 responses were received, from member associations based in 24 different countries, from across the European region. Approximately half of the associations surveyed reported that their national vaccination strategies referenced neurodegenerative diseases or dementia.

However, only a quarter noted that people with neurodegenerative disease or dementia were specifically identified as a priority group, despite the fact that most vaccination strategies included some disease-based prioritisation (cancer, respiratory or cardiac disease). Encouragingly, however, two members (Austria and France) reported that adjustments had recently been made to include people with dementia and/or special cognitive needs as a priority group.

We also sought to understand whether carers (professional or informal) were identified as a priority group for COVID-19 vaccination. Similarly, almost half of the associations surveyed reported that professional carers were being prioritised for vaccination. However, fewer than 20% of responses indicated that informal or family carers were a priority for COVID-19 vaccination. This was identified as a significant issue by several associations, with some stating that informal carers had to be certified as such in order to receive priority vaccination.

More positively, most associations surveyed stated that national or local health authorities provide practical support to facilitate vaccination, such as vaccinations in the home or in care facilities, transport to vaccination clinics and/or helplines.

Together, the responses we collated from our members revealed a fragmented picture of vaccine prioritization across the wider European region. Many were concerned that people with dementia and their carers were not receiving COVID-19 vaccines as a priority, particularly those not falling into risk categories based on age and place of residence, such as people with early-onset dementia living in the community.

In response, on 7 May, Alzheimer Europe published a position and briefing statement calling for the prioritisation of people with dementia and their carers for vaccination, recognising the disproportionate effect of the pandemic on these groups.

The papers can be accessed at: https://www.alzheimer-europe.org/Policy/Our-opinion-on/2021-COVID-19-Vaccinations-and-People-with-Dementia
Alzheimer Europe speaks to Equality Commissioner Helena Dalli about the EU’s action on disability rights

On 5 March 2021, the European Commission launched the “Union of Equality: Strategy for the rights of persons with disabilities 2021–2030”, setting out how the Commission aims to uphold the rights of people with disabilities across the EU. In this article, Equality Commissioner Helena Dalli explains what this means for people with dementia.

What are the key commitments in the new “Union of Equality: Strategy for the Rights of Persons with Disabilities 2021–2030”?

Persons with disabilities must be able to participate in society on an equal basis with everyone else. The new Strategy for the rights of persons with disabilities 2021–2030 aims to ensure their full participation and address any discrimination based on the grounds of disability. It also provides a framework for the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) at the EU level, and supports and complements Member States’ actions to implement the Convention.

The strategy contains eight headers, including accessibility, EU rights, quality of life, living independently, equal access, non-discrimination, promoting the rights of persons with disabilities globally, and leading by example.

To ensure rights in practice, the Strategy sets out 7 core actions and 57 additional measures at EU level for the coming 10 years. To name a few examples: by 2023 the Commission will issue guidance recommending to EU Member States improvements on independent living and inclusion in the community, thus enabling persons with disabilities to choose where and how to live. We will also present a framework for social services of excellence for persons with disabilities.

I must clarify that the European Commission does not have the power to enact the necessary changes on its own, in all the areas concerned. The objectives of this Strategy can only be reached through coordinated action at both the national and the EU levels, with a strong commitment from Member States. For this reason, the Strategy includes 23 calls

“Persons with disabilities must be able to participate in society on an equal basis with everyone else. The new Strategy for the rights of persons with disabilities 2021–2030 aims to ensure their full participation and address any discrimination based on the grounds of disability.”
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for action by EU Member States in the areas where they bear the responsibility.

Dementia and other cognitive impairments are hidden disabilities, which are often overlooked in policy work – how will this strategy help to uphold their rights?

I am well aware of the challenges faced by persons with hidden disabilities. This is why the Strategy expressly encompasses invisible disabilities. It takes into account the diversity of disability as well as the increased prevalence of disabilities with age. To leave no one behind, the strategy has an intersectional approach, addressing the increased barriers at the intersection of different personal characteristics, or based on socioeconomic or other vulnerable situations.

I also recognise that persons with invisible disabilities do not always receive the tailored support they need. The COVID-19 crisis made even clearer how much more needs to be done. In this respect, it is worth pointing out that the European Commission is building a strong European Health Union, which will support EU Member States to improve the resilience of their health systems, including for persons with disabilities.

As part of our Strategy, we will address issues on health and disability through a steering group where EU Member States will share good practices. Finally, the Commission will keep on working with Member States to raise more awareness around disability and to combat stereotypes.

How does the Strategy tie into other relevant areas of the EU’s work such as the Pillar of Social Rights and the Green Paper on Ageing?

The European Pillar of Social Rights is our beacon guiding us towards a stronger social Europe and shows the goal: the full inclusion of persons with disabilities. As such, the objectives of the Strategy are coherent with the European Pillar of Social Rights and its newly adopted Action Plan. It is quite telling that the European Commission adopted both the Social Pillar Action Plan and the Strategy in the same week.

The Green Paper on Ageing launched a wide debate on the challenges and opportunities of Europe’s ageing society. It underlined the overlap between ageing and disability, as almost half of persons aged above 65 report some form of disability. It also highlighted a need for more accessible working environments for persons with disabilities in the workforce, and the opportunity to extend their autonomy. A public consultation was held and the Commission is currently analysing the results, which will help identify the support needed for people.

Within the Strategy, what role is envisaged for patient organisations and civil society in supporting persons with disabilities?

Civil society organisations, notably those representing persons with disabilities, will continue to play a key role in the development and implementation of disability policies. Indeed, the support and cooperation with such organisations at EU level is important to ensure that persons with disabilities and their representatives participate in all relevant processes through specific and inclusive structured dialogues. We know and understand that nothing about persons with disabilities should happen without their involvement.

The Commission will explore EU funding possibilities within the Citizens, Equality, Rights and Values programme to foster engagement of citizens with disabilities. We also call on EU Member States to ensure partnerships with representative organisations of persons with disabilities, civil society and other stakeholders in the design and implementation of EU funds. We are doing so because we know that civil society plays an important role in making sure that EU funds are used in line with the UN Convention on the Rights of Persons with Disabilities.
Czech Republic launches its second national action plan on dementia

In this article, the Coordinator for the Czech Republic’s new National Action Plan for Alzheimer’s Disease and Related Illnesses 2020–2030, Markéta Švejdová Jandová, explains some of the key points in the new Plan. In the second part of the article we hear from Martina Mátllová, the Director of the Czech Alzheimer Society, about her organisation’s reaction to the new Plan.

On 12 April 2021, the government of the Czech Republic approved the National Action Plan for Alzheimer’s Disease and Related Illnesses 2020–2030. The Plan was developed according to the recommendations of the World Health Organization’s (WHO) Towards a dementia plan: a WHO guide. The content, identified through a situational analysis and debated by a broad stakeholder platform, reflects the needs of people living with dementia and their caregivers, as well as professional care providers. Importantly, the Plan was developed in cooperation of two ministries, the Ministry of Health and the Ministry of Labor Social Affairs, to bridge existing barriers between health and social services. Beside national experts, we built on experiences and feedback provided by our colleagues during meetings organised by the WHO and Alzheimer Europe.

Situational analysis

A situational analysis was developed using the WHO’s Global Dementia Observatory instrument. It revealed that, according to data from Czech healthcare registers, 102,000 people were living with an official dementia diagnosis in the country in 2017. Epidemiological models estimate that the true prevalence was about 142,000 people showing that a diagnosis gap exists and needs to be addressed.

Moreover, diagnosis seems to be made only in the later stage of the disease, as only 45% of people with dementia survive more than one year and 16% more than five years from the point of diagnosis. This finding goes hand in hand with the fact that the network of post-diagnostic support and services enabling people with dementia to live at home as long as possible, are not well developed in the country. At the same time, the social care system is generally overwhelmed in relation to nursing home applications; in 2016, there were a total of 62,000 beds in nursing homes and about 20,000 applications which were not granted due to the limited capacity.

Strategic objectives

The Plan reacts to the situational analysis by setting five strategic objectives:

1. Developing interdisciplinary recommendations and strengthening the network of health and social services accordingly
2. Providing appropriate education to both professional and informal caregivers
3. Setting a system of continuous epidemiologic surveillance and research agenda
4. Increasing dementia awareness and promoting prevention
5. Better protecting rights of people living with dementia.

These objectives will be achieved through approximately fifty specific activities implemented in this decade.

COVID-19 delays

Although the approval of the Plan was delayed due to the COVID-19 pandemic, the implementation of some of the projects has already started or are currently being prepared. Examples include the national adaptation of the iSupport tool that helps informal caregivers, development of the prevention strategy...
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based on Risk reduction of cognitive decline and dementia: WHO guidelines, and preparation of a new online information portal.

Importantly, an implementation partner for the project creating interdisciplinary guidelines will be selected in the first half of 2021. This project will cover the journey of a person with dementia from the point of diagnosis and will ensure that timely diagnosis and post-diagnostic services are available in the country.

Coordinator of the Plan

The position of a national dementia coordinator was officially anchored within the Ministry of Health. Ms Markéta Švejdová Jandová will be responsible for supervising the implementation effort. In addition, an advisory stakeholder group appointed by the Minister of Health that will be regularly consulted about progress made to inform necessary changes in the implementation plan.

For more information on the plan, please contact Marketa.Svejdovajandovamzcr.cz

“I am very grateful to my Czech colleagues who participated in the preparation of the Plan as well as for the fruitful collaboration with WHO and Alzheimer Europe. I believe that the Plan is a strong basis for improvement of the living conditions of people with dementia and their families, and that the Czech Republic will harvest its first fruits soon.”

Markéta Švejdová Jandová

Martina Mátllová, Director of the Czech Alzheimer Society, shares the organisation's views on the new strategy

What is the reaction of the Czech Alzheimer Society to the new strategy?

It is great that the Czech Republic has a new strategy for managing Alzheimer’s disease and other types of dementia. The duration of the strategy is set for the years 2020–2030, so its approval by the government, which took place only in April 2021, was significantly delayed.

It is our hope that the fact that after the approval of the strategy, neither the Prime Minister, nor the Minister of Health, nor the Minister of Labour and Social Affairs, gave any significant speech, as well as the lack of media attention to the approval of the Plan by the government, does not predict the future success of the whole strategy.

It is, of course, necessary to recognise that the government had other concerns last year. At the same time, however, it is our view that the Plan could and should have been approved before the onset of the pandemic.

Significantly, the vague promise of funding within the Plan (“the Deputy Prime Minister and the Minister of Finance to take into account the costs associated with the implementation of NAPAN 2020–2030 in the negotiations on the state budget according to the relevance of the requirements and possibilities of the state budget”) can be considered a big shift compared to previous similar documents.

Furthermore, the shift of the agenda to the government level could bring positive results.

How was the Czech Alzheimer Society involved in the process of developing the strategy?

Hana Janečková, the Chairwoman of the Board of the Czech Alzheimer Society, was one of the members of the working group which worked on the creation of a new strategy. We are very proud that Hana devoted herself to working in a group with great enthusiasm and erudition. For example, the variation of the forget-me-not flower created by Mr. Starý, a Czech gentleman who lives with dementia, was included on the cover of the title page of the Plan, thanks to Hana. According to Hana, she represented the interests of people with dementia and their families, and we think that worked.

We also consider it as a very positive development that the Strategy commits to addressing the problem of a lack of data, which we have been drawing attention to for a long time. It is clear that without a thorough description of the needs of people with dementia and without quantification of the whole “problem”, it is not only unlikely that adequate solutions will be proposed, but it is also impossible to evaluate the success of possible measures.
We are watching as efforts are being made to create and build new things from the ground up. However, from our point of view, it would be more useful to cooperate and build on what has already been invented and created.

**Has the development of the strategy become even more significant in light of the COVID-19 pandemic?**

The COVID-19 pandemic and its management showed the limits of current public policy and public health. Problems with strategic management, working with data or communicating with the public or involving experts were very visible. The capacity of state structures seemed to be limited to solving a single problem. In one year, four Ministers took turns at the Ministry of Health!

Despite the above-mentioned shortcomings (which led to debates on the role of the state and its structures), it is necessary to agree that the pandemic showed the need for quality problem-solving tools. A strategy that describes the problem well and proposes a solution, has a realistic and binding timetable and a budget, should guarantee that attention will not be diverted from fundamental long-term problems, as a result of current and acute threats.

However, the question remains how, not only Czech society will be able to recover from the pandemic, but above all the Czech healthcare system, which has borne greatest burden of the pandemic. PTSD and burnout syndrome are already being talked about as a direct consequence of long-term overload of Czech healthcare professionals. This condition will affect all patients, including people with dementia.
The Netherlands launches its fourth national dementia strategy

At the conclusion of 2020, the Netherlands launched its fourth national dementia strategy, setting out the commitments of the country to dementia policy for the next ten years (2021–2030). In this article we look at some of the key highlights from the strategy and hear from Anne de Boer, Advocacy Officer, Alzheimer Nederland, who has shared the organisation’s views on the new strategy.

On 21 September 2020, the Dutch Ministry of Health, Welfare and Sports presented its National Dementia Strategy 2021–2030, the fourth such strategy published by the Government in the Netherlands. The strategy provides three overarching themes which structure the approach of the document:

- A world without dementia (focused on research)
- Persons with dementia matter (focused on dementia friendly societies)
- Tailor-made support when living with dementia (focused on high quality and personal dementia care and support).

Under each heading, further analysis and detail is included, identifying the key challenges which exist, as well as the goal and targets which the government aims to achieve. In the following article, we provide a high-level overview of the strategy.

A world without dementia

As with the previous strategy (the DeltaPlan Dementie), there is support for a dedicated research programme delivered by ZonMw (an independent research organisation in the Netherlands), which aims to provide greater synergies across the fields of dementia research. It is envisaged that this will provide focus across five areas of research:

- Basic research
- Diagnostics
- Risk reduction
- Promising technological developments
- Integrating research, care and education.

The goals set out under this theme are as follows:

- By 2025, a tailor-made diagnosis will be available for every person with dementia as well as a treatment that focuses on the individual and their specific needs
- By 2025, greater insight will have been obtained into the causes that are responsible for 60% of dementia cases (assuming that approximately 40% of dementia cases could have been prevented via lifestyle factors).

Persons with dementia matter

Under this heading, the strategy notes that with support and adjustments, persons with dementia can continue to live and participate in the societies in which they live for quite some time. However, it identifies that prejudices and stigma often result in assumptions that a person diagnosed with dementia has limited or no capacity.

The strategy identifies two specific programmes to address these issues. The first will focus on encouraging people with dementia to take up meaningful activities and make use of meeting centres within their communities, whilst the second will build upon the previous Dementia Friendly Together programme, seeking to use it as a basis for a more structured training course for professionals in various sectors and for private individuals.

For this theme, the strategy outlines the following targets:

- By 2030, 80% of persons living at home have access to a meeting centre for persons with dementia in the vicinity of their home, where they are able to participate in meaningful activities
- By 2025, the number of “dementia friends” will have doubled to 750,000 persons, with a focus on young people, with dementia friends being able to offer help to persons in their neighbourhood.

Tailor-made support when living with dementia

The strategy notes that the quality of dementia care in the Netherlands is high, whilst acknowledging the potential for further improvement. As part of this, the recent completion of the revised dementia care standard is highlighted, with the strategy explaining that this must now be implemented on a national level.

Furthermore, the government commits to continuing its work around the development of the register for dementia care and support, as well as working with regional dementia care networks to improve the availability of care and supports.

Two goals are included within this section:
As soon as possible (no later than 2025), all professionals in every regional dementia network are working in accordance with the dementia care standard, across domains, person-centred, efficiently, proactively, and in a timely fashion.

From 2025 onwards, every regional dementia network has a strong foundation via defined collaboration agreements and structural funding.

**Additional elements**

In addition to the three overarching themes, a number of cross-cutting elements are identified, including innovation, the specific needs of younger persons with dementia, international cooperation and communication (with a specific focus on the availability of information and risk reduction).

Furthermore, the strategy highlights importance of collaboration with international organisations and platforms, referencing the collaboration with Alzheimer Europe, as well as the European Group of Governmental Experts on Dementia.


### 7.6 Schematic overview

The organisation of the strategy can be summarised schematically as follows:

- **Management group**
- **Sounding board group**
- **Steering group**
- **Programme for “A world without Dementia”**
- **Programmes for “Persons with dementia matter”**
- **Programmes for “Tailor-made support when living with dementia”**

**Anne de Boer, Advocacy Officer, Alzheimer Nederland, shares the organisation’s reaction to the new strategy**

**Pillar “prevention” is missing**

An important pillar that is missing in the strategy of the Ministry of Health, Welfare and Sports is prevention. Alzheimer Nederland believes this is a missed opportunity, as we have been pleading for prevention for quite some time now; a healthy lifestyle improves brain health and lowers the risk of dementia. Prevention has the potential of postponing the incidence dementia to a later age. Therefore, it should be an important part of the minister’s new strategy, not only regarding research on relevant risk factors, but also on improving brain health and encouraging a healthy lifestyle through regional and national campaigns.

**Much more money needed for research**

The research pillar is well-elaborated in the national strategy, including research on diagnosis, treatment and the causes of dementia. The strategy contains not only objectives but also investments for the next ten years. This long-term investment is unique, because it is longer than the government’s term of four years. The budget is increased from EUR 10 million to EUR 16 million per year, twice as much as the government invested in the past five years in total.

At the same time, it is a fraction compared to the current total costs of dementia, which is more than EUR 6 billion. Dementia has developed into public disease number one and comes with huge healthcare costs. The urgency to invest in dementia is therefore greater than ever. Alzheimer Nederland believes that at least EUR 25 million per year is needed for research and therefore will co-fund the national dementia research programme and continues to encourage the Ministry to increase the budget.

**Dementia friendly societies**

To be able to participate in society as long as possible, support is essential. The aim of Ministry is to create more meeting centres and activities for people with dementia accessible for people living at home. However, due to the COVID-19 pandemic, the opposite is currently happening. Due to cutbacks and attempts to contain corona outbreaks, daycare activities are still not well organised, causing a lot of people with dementia living at home having no access to these services. In addition, the society plays a crucial role in the participation of people with dementia in the Netherlands, without stigma’s and prejudgments.

The Minister listened carefully to our advice and the goals in his strategy are ambitious.
and highly relevant. With this strategy, Alzheimer Nederland and the Ministry have a partnership. The dementia friendly programme of Alzheimer Nederland will receive a budget for the coming five years. The focus of the continuation will be on young people, municipalities and the neighbourhood.

Accessibility of care and support

The accessibility of care and support remains a point of attention. This was also one of the findings in the European Dementia Monitor 2020 and in our own Dementia Carers Monitor of 2020. Both studies show that people with dementia and carers often do not receive the care they need because of regulation and insufficient supply. We therefore believe that more attention should be paid to the provision of good and accessible care and support for people with dementia and their carers.

The fact that a budget is missing for this pillar is concerning.

The strategy in light of the COVID-19 pandemic

During the COVID-19 pandemic, the Minister has indicated that dementia will receive a lot of attention in the coming years: “We will be talking just as intensively about dementia as we are now about corona. After all, it will be public disease number one.” Alzheimer Nederland is pleased that the urgency and challenge are acknowledged by the Minister.

However, as the COVID-19 pandemic continues, Alzheimer Nederland is worried that the implementation of the national strategy will be delayed. This is a major concern because the need of adequate support and care is of crucial importance and falls short at the moment. The COVID-19 pandemic has shown that a lot of work needs to be done to improve the quality of life of people with dementia and their carers.

Alzheimer Nederland will continue to emphasise to the Ministry and the involved stakeholders that swift implementation of the national strategy is necessary. We can only improve dementia care and support if we work together and start now.

**TauRx** has a mission to discover, develop and commercialise new products for the diagnosis, treatment and cure of neurodegenerative diseases caused through protein aggregation.

Tau pathology is widely recognised as a principal driver of clinical dementia in Alzheimer’s disease and TauRx’s Tau Aggregation Inhibitors (TAlis) target the formation or aggregation of tau ‘tangles’ in the brain.

GT Diagnostics, a joint venture between Genting Bhd and TauRx, aims to transform the diagnostic pathway by launching cost effective and accurate assessment tools for dementia.

Learn more about our research and progress at www.taurx.com.

Alzheimer Scotland builds on Fair Dementia Care Campaign during national elections

In this article, Alzheimer Scotland’s Director of Policy and Research, Jim Pearson, provides an update on the organisation’s Fair Dementia Care Campaign and how this has formed the basis of their recent Scottish Parliament Election Pledge Campaign, which sought the support of candidates standing in the Scottish Parliamentary election on 6 May 2021.

Background to campaign

In 2019, Alzheimer Scotland published the “Delivering Fair Dementia Care for People with Advanced Dementia” report. The report highlighted the inequality in access to health care and the disproportionate impact of social care charges faced by people with advanced dementia, their families, and carers in Scotland. Since its publication, Alzheimer Scotland has continued to campaign to bring about change so that people with advanced dementia have equality of access to free health and nursing care on a par with people with other progressive life-limiting illnesses.

Dementia is caused by progressive and terminal neurological diseases such as Alzheimer’s disease. In advanced dementia, people experience complex physical and psychological symptoms which require specialist health and nursing care. Scotland’s current social care model does mean that people with advanced dementia do not always have access to the health and expert nursing care they require. In addition, they face an estimated GBP 51 million each year in social care charges, can be considered as primarily health and nursing care needs. Alzheimer Scotland’s Fair Dementia Care Campaign seeks to end these inequities.

To date over 18,000 people have supported it, as have Members of the Scottish Parliament from across all political parties, during debates throughout 2019 and 2020. Over the course of the weeks running up to the Scottish Parliament election on 6 May 2021, Alzheimer Scotland campaigned to gain the support of all the main political parties in Scotland.

Recent developments

The COVID-19 pandemic has further demonstrated the inequity experienced by people living with advanced dementia in Scotland. Tragically, many have died during this pandemic, and those who live in care homes have been denied the comfort of having meaningful contact with their families and friends because of the public health measures in place to prevent the spread of the virus. There is irrefutable evidence of the direct and indirect harm of COVID-19, yet people with advanced dementia continue to face care home charges despite their needs primarily being health and nursing care needs.

A positive development has been the recently published Independent Review of Adult Social Care report, which sets out a transformational and positive vision for a new future for social care in Scotland, including the creation of a new National Care Service. The Scottish Government has committed to implementing the recommendations of the report in full. These include recommendations to end all

Fair Dementia Care Election Pledge

I fully support Alzheimer Scotland’s call for Fair Dementia Care for people with advanced dementia in Scotland.

If elected to the Scottish Parliament, I pledge to help deliver fair dementia care by:

1. Working to ensure that every person with advanced dementia, living in a care home, has an individual assessment of their health and nursing care needs.
2. Supporting an increase in free personal and nursing care payments to a level which is equal to the actual cost of the care people with advanced dementia need.

To find out more visit www.alzscot.org/fairdementiacare

Alzheimer Scotland created a graphic for candidates to show their support on social media.
non-residential social care charges (for social care provided in the community) and a substantial increase in the level of Free Personal and Nursing Care payments for people living in care homes.

Alzheimer Scotland welcomes those proposals. However, people living with advanced dementia in Scotland today do not have time to wait several years for the type of transformation set out in the Independent Review to be implemented. Nor do we believe that the proposed increases in Free Personal and Nursing Care payments go far enough. While this is a substantial step in the right direction, Alzheimer Scotland is calling for every person with advanced dementia to have an individual assessment of their health and nursing care needs, and a corresponding increase in Free Personal and Nursing Care payments which reflects the actual cost of providing that care.

Only then will people with advanced dementia be treated equally with those who have other progressive and life-limiting illnesses.

**Alzheimer Scotland’s Scottish Parliament Election Pledge Campaign**

During the Scottish Parliamentary Election campaign, we have been asking our members and supporters to contact their candidates and ask them to pledge to deliver Fair Dementia Care for people with advanced dementia.

Alzheimer Scotland is calling on candidates from all political parties to end this inequity and pledge to deliver Fair Dementia Care for people with advanced dementia by committing to:

- Ensuring that every person with advanced dementia, living in a care home, has an individual assessment of their health and nursing care needs
- Support an increase in Free Personal and Nursing Care payments to a level which is equal to the actual cost of the care people with advanced dementia need

In addition, we have written to all party leaders asking that they include a commitment to deliver Fair Dementia Care in their election manifestos.

At the time of writing, three of Scotland’s main political parties have made manifesto commitments relating to our campaign. We now look forward to building on these commitments and working with the newly elected Scottish Government, with cross party support, to deliver Fair Dementia Care in Scotland for all people living with advanced dementia, their families, and carers.

More information on the Fair Dementia Care Campaign can be found at:

Italian Government commits to providing funding for its national dementia plan

In this article, Mario Possenti, Secretary General, Federazione Alzheimer Italia (FAI), highlights the recent commitment from the Italian Government to provide funding for the country's National Dementia Plan, which was first launched in 2014, as well as the campaigning work which led to this point.

In December 2020, the Italian Parliament approved, within the 2021 budget law, a fund of EUR 15 million over three years for the National Dementia Plan. The amendment included in the budget law was inspired by the bill of Senator Barbara Guidolin written with the collaboration of Federazione Alzheimer Italia (FAI).

This is a decisive step forward in protecting the rights of people with dementia and their families and in improving their quality of life: an objective for which FAI has been committed for over 25 years.

The “National Dementia Plan – Strategies for the promotion and improvement of the quality and appropriateness of care interventions in the dementia sector” was created with the objective of providing strategic indicators for the integrated management of dementia:

- The promotion of appropriate and adequate interventions to combat against stigma
- The protection and guarantee of rights
- Updated knowledge
- Coordination of activities.

Approved in 2014, it has never been made fully operational due to the lack of economic resources necessary for the realisations and implementation of its objectives.

FAI campaigns

In recent years, FAI has carried out numerous advocacy actions so that the National Dementia Plan does not remain solely full of good intentions but is transformed into concrete actions and meaningful support for people with dementia and their families.

Among the various actions taken, one proved to be particularly significant: at the end of 2018, a petition was launched on “change.org” to ask the Minister of Health to allocate funds to the National Dementia Plan. In a few days, the petition collected over 130,000 signatures, demonstrating how necessary and urgent action was. This initiative allowed the public to become aware of the fact that dementia was not adequately supported as a political priority but also created direct links with parliamentarians who have shown themselves to be proactive in supporting the objective of funding the National Dementia Plan.

At the same time, local associations and dementia-friendly communities have worked hard to contact local representatives to communicate the urgency and importance of a fund that can no longer be deferred.

It was the demonstration that a public initiative of great importance can actually create the conditions to influence the political agenda but even more, the ability to bring stakeholders together and propose a common strategy was fundamental.
Next steps

Now that the funds are available, it is the task of the Ministry of Health, having heard the opinion of the Permanent Table on Dementia – of which FAI is a member – to provide an indication on how to distribute the funds according to the objectives of the National Dementia Plan. Certainly, one of the priorities will be to provide Italian regions with the necessary tools to carry out research and pilots aimed at creating national best practices. The topics will range from the enhancement of early diagnosis to the spread of telemedicine interventions, as well as psycho-educational, cognitive and psychosocial treatments.

Another important aspect that will find space in the initiatives financed by the National Dementia Plan, is to address concerns regarding training programmes to strengthen specific knowledge and skills of all health, socio-health and social figures involved in the diagnosis and care of people with dementia.

Thanks to this first funding, the Permanent Table on Dementia will also be able to begin work on an update of the National Dementia Plan, in order to keep up with the needs of 1.2 million people living with dementia in Italy.

This moment is crucial because there is the will to transform the objectives of the Plan into concrete actions, however, given the numbers of people with dementia, it is difficult to think that a fund of EUR 15 million over three years can meet all the needs of the entire country. For this reason, FAI believes that this fund represents only the first step to be able to initiate interventions that cannot be postponed and it is already working to ensure greater dedicated funding.

As stated by FAI’s President, Gabriella Salvini Porro: “We know that the financing of the National Dementia Plan is not an end point but the beginning of a path that will not be easy and that involves a great deal of work in identifying the correct way to allocate economic resources. However, an important step has been taken and now more than ever it is essential that our institutions demonstrate unity and give a concrete signal, listening to the voice of people with dementia.”

Gabriella Salvini Porro, President, Federazione Alzheimer Italia

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World Health Organization developing new global action plan for epilepsy and other neurological disorders

The World Health Organization (WHO) is in the process of developing an “Intersectional global action plan on epilepsy and other neurological disorders” following the decision of the 73rd World Health Assembly. In this article, Stéfanie Fréel and Katrin Seeher of the WHO explain what this means for dementia policy.

Background

In adults, neurological disorders are the leading cause of disability-adjusted-life years (11.6% of DALYs) and the second leading cause of death (9 million deaths per year). The largest contributors of global neurological DALYS in 2016 included stroke (42.2%), migraine (16.3%), dementia (10.4%), meningitis (7.9%) and epilepsy (5%). As of 2016, 52.9 million children younger than 5 years had developmental disabilities, the majority living in low- and middle-income countries (LMICs).

As is the case for dementia, access to services and support including to diagnosis, treatment and essential cost-effective medicines, for neurological disorders is insufficient, particularly in LMICs. For example, 1 in 10 people with dementia receive a diagnosis, while only 1 in 4 people with epilepsy receive treatment. There also continues to be a lack of knowledge around neurological disorders, which in many countries is associated with high stigmatisation and discrimination. Dementia and other neurological disorders are associated with a significantly increased risk of mortality in patients with COVID-19 and are the second most common comorbidities in patients with COVID-19.

Multilateral response

To address the growing burden of neurological disorders, a meeting of the 146th Executive Board in February 2020, requested the World Health Organization (WHO) to expand the scope of its technical report on epilepsy by adding a new section on Synergies in addressing the burden of epilepsy and other neurologic diseases. This section was presented as part of agenda item 11.6 on epilepsy during the Seventy-third World Health Assembly (WHA) in May 2020. Resolution WHA 73.10 requests the Director-General to develop an Intersectoral global action plan on epilepsy and other neurological disorders 2021–2031 in consultation with Member States to ensure a comprehensive, coordinated response across multiple sectors.

To support the development of the new action plan, WHO – through its Brain Health Unit – organised formal virtual consultations on the discussion paper for the Intersectoral global
action plan on epilepsy and other neurological disorders with Member States, United Nations agencies, and non-State actors including academic institutions, civil society and private sector in March and April 2021. The draft Intersectoral global action plan on epilepsy and other neurological disorders will be submitted to the 150th session of WHO’s Executive Board in January 2022, for consideration by Member States at the 75th World Health Assembly in May 2022.

Alignment with the Global action plan on the public health response to dementia 2017–2025

Through its life-course approach, the Intersectoral global action plan on epilepsy and other neurological disorders will help reinforce dementia as a global public health priority, within the broader context of neurological disorders. It will present many synergies with the Global action plan on the public health response to dementia 2017–2025, its seven action areas and cross-cutting principles. This includes for example promotion of healthy behaviours across the life course, integrated, person-centred approach to evidence-based prevention, diagnosis, treatment and care, and focus on investment into research, innovation and health information systems.

Similar to the global dementia action plan, the Intersectoral global action plan on epilepsy and other neurological disorders will seek to prioritise neurological disorders within national policy agendas, harmonise a comprehensive response across health and social care systems and stakeholders, and ensure sustainable funding to support programming for people living with neurological disorders, their families and carers. A strong focus will also be set on gender, equity and human rights, including to reduce stigma and discrimination, and empowering people with neurological disorders, their families and carers.

The intersectoral global action plan on epilepsy and other neurological disorders will share many strategic interlinkages with the global action plan on dementia, including its alignment with the United Nations Political Declaration on Universal Health Coverage (2019), the Declaration of Astana on Primary Health Care (2018), the Comprehensive mental health action plan (2013–2020), the Global action plan for the prevention and control of noncommunicable diseases 2013–2020, the United Nations Decade of Healthy Ageing (2021–2030) and many other resolutions, decisions and declarations.

These intersections will maintain and raise dementia as a key public health priority on national political agendas, ensuring that people with dementia, their families and carers are treated with equality and dignity, receive the treatment and care they need, and enjoy the highest quality of life at home in their communities.
Living with dementia and bereavement

Helen Rochford-Brennan is a member of the European Working Group of People with Dementia (EWGPWD) and was Chairperson of the group from 2016–2020. In this article, she tells us about her experience as a person living with young-onset dementia, having lost her husband and partner of nearly forty years. Helen and her husband Sean lived together in a rural area of Ireland, where she is now living alone, navigating bereavement and grief during the COVID-19 pandemic – an already difficult and isolating time.

Last autumn, as I thought my life was beginning to settle down after COVID ‘cocooning’ (isolating), my husband Sean was diagnosed with lung cancer. We were home alone, as our son Martin works in London. There are no words to describe how both of us felt. Sean worried about what was going to happen to me and I could not bear to think of how painful his illness might become.

"I became a person with Alzheimer’s caring for somebody who was dealing with a serious illness and a rigorous treatment plan. It was daunting.”

We spoke to Sean’s consultants about various options of treatment and put a plan in place, which meant that I became a person with Alzheimer’s caring for somebody who was dealing with a serious illness and a rigorous treatment plan. It was daunting, as we live 65 miles from the hospital.

Worried and frightened during lockdown

We decided to stay at a hotel which, luckily enough, we found open near the hospital, so Sean could have his treatment. Staying there meant I did not have to drive every day and it was less strain on Sean. But it was not easy; I found cocooning in a hotel bedroom with somebody who was very ill extremely difficult.

It was really impacting on my brain and even though I tried to write everything down, I had trouble keeping his medicine plan in order. We took a walk when Sean was able, but for many, many days it was just us cocooning together through a pandemic, in one room, worried and frightened. There was nowhere for me to turn, I felt that I needed to forget about my needs and focus on the person I had loved for almost 40 years. The hotel staff were amazing, when they saw Sean’s health diminish and how I struggled each day. In a way, they became my new family, my bubble.

Family support

Our son Martin came home from London and was able to work from home and take care of our dog Lexy. He spent as much time as he possibly could with us and we were so grateful to see him. I am conscious that, as an only child, during those months, Martin’s world was either at home alone during a pandemic, or at home with two people with changing medical conditions, a job to do and a dog. Neither situation was easy.

Nowhere to turn to

I found there was nowhere to turn after Sean died. I googled and googled and wondered where I could find help for somebody with dementia dealing with grief but there is nothing. There was a lot of information about breaking the news to the person with dementia about a loved one’s death but nothing about how I might cope after that initial moment. Luckily, I live in a wonderful community and the community reached out to me as best they could in times of COVID.
In Ireland, funerals are a ritual and neighbours and friends come to your home and to the church service. In non-COVID times, you are held and supported by your community. At Sean’s funeral, however, only ten people were allowed to attend physically, while others had to join by live-stream on YouTube, so I was deprived of the ritual and the support. My neighbours stood on the street with candles and their presence was beautiful and so welcome, but not the same as a hug or a visit in my house.

“It was unimaginably difficult” – Bereavement during COVID

Grief is difficult and for me, to be honest, it was unimaginably difficult. I thought going through COVID was bad enough, but life without Sean was devastating. COVID lockdown with Sean was overwhelming but I faced the most recent lockdown without my husband. I now face life without my husband and when Martin returns to London, I am alone with my dementia.

COVID has made my loneliness and grief more extreme, but I remind myself to think of Sean’s words, telling me to stay positive.”

This loneliness is made worse with the isolation of COVID – nobody can visit me. I am faced with people offering me sympathy in the grocery store, while trying to buy groceries, and hearing the sadness of others via phone or teleconference, as I cocoon. I am grateful for technology but it’s just not enough. COVID has made my loneliness and grief more extreme, but I remind myself to think of Sean’s words, telling me to stay positive. I think, also, of the words of John Steinbeck: “It’s so much darker when a light goes than it would have been if it had never shone.” Well, I was lucky, the light shone on my life for almost 40 years.

Strength and hope from around the world

I am blessed to have received lots of kind words from my friends around the world, my personal friends, as well as my friends from the dementia world, of which there are many and for whom I am so grateful. To anyone reading this, who reached out to me during that time, please know that, wherever you are around the world, you gave me strength and hope to get through each day. The messages meant so much to me, as did the words from the teams at The Alzheimer Society of Ireland and Alzheimer Europe. The messages from those I worked with at Alzheimer’s Disease International (ADI), Dementia Alliance International (DAI) and on the World Health Organisation (WHO) Global Dementia Observatory (GDO) Knowledge Exchange Platform, were also very supportive.

In non-COVID times, you are held and supported by your community. At Sean’s funeral, however, only ten people were allowed to attend physically, while others had to join by live-stream on YouTube, so I was deprived of the ritual and the support.”

Slowly, I was able to return to advocacy. With the support of Martin and my extended family, I dipped my toe into a new life and new routines. I walked my dog and did my best to maintain my hobbies and interests.

I started by returning to my advisory work with the WHO GDO Knowledge Exchange Platform and to meetings with the European Working Group of People with Dementia (EWGPWD) in January, as the meetings were small and I knew the people involved well. I knew that they would be supportive and it gave me the confidence to do more.
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A new advocacy question

I returned to Google with a fresh eye, a critical eye! I saw lots of information on dementia and grief with regards support for telling a person whose dementia is more progressed that a loved one has died. But there was no appropriate support for me and for someone in my situation, so this is my new advocacy question: How do we support people living with mild dementia who are bereaved? What I needed was one-to-one, dementia-specific grief supports; a plan to talk about the impact of grief on my life, before it happened; and a support group for people living with mild dementia who are bereaved. There must be an acknowledgement that not all people living with dementia are the same. My needs are quite different to a person whose dementia has progressed and does not remember that their loved one has died.

We must also remember practical supports: I needed a plan to cook, to walk the dog, to organise my medication. How lucky am I to have Martin? But I want him to live his own life. I am so proud of the life he has created for himself and I know he will support me from afar, but I must be able to access professional support to remain independent for as long as possible.

No matter how resilient people with dementia are, we require a pathway and guidance to find the appropriate psychological supports for grief.

We read and hear every day about a rights-based approach to dementia and grief and managing loss should be part of this approach. No matter how resilient people with dementia are, we require a pathway and guidance to find the appropriate psychological supports for grief.

Until all of this is available for other people living with dementia, then get ready to listen! I intend to tackle this subject, to be open about my grief, just like I have been open about my dementia.

As you read this, I ask you to take steps in your country to ensure that a rights-based approach is taken, for people with mild dementia who cared for and are grieving for their departed loved one.

HOPE IS ALL I HAVE!

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Changing seasons – A year with dementia during COVID

Petri Lampinen was diagnosed with frontotemporal dementia in 2015, but he refuses to let the difficulties associated with his dementia defeat him. In spite of them, he continues to live an active life, and is a member of Finland’s national dementia working group and of the European Working Group of People with Dementia. In this article, he shares what it has been like for him, living with dementia during the global COVID-19 pandemic.

I’ve been thinking for a long time now, about the question of what I would like to write next. I don’t want to repeat the same things in my writings, but I want to try and develop as a writer despite dementia. I think I have been advancing in writing and it gives me great joy. I have also been particularly pleased that my writings have spread widely through the media.

A year of many changes

A great deal has happened in recent days. Illness has affected our family and loved ones. Inside me came a strong sense for writing and a desire to write about the past year. The past year brought a lot of changes in our lives.

My parents are already elderly and the years have brought many problems, as we all will someday have our own problems. However, by our own actions, we can influence this. We can eat healthily, remember to exercise and look for social contacts. My father has been doing so, and at the age of almost 90, he goes shopping independently and lives an active life. He also helps my mother at home. She is almost the same age, and I have been very concerned about how tired he may be as a result of all this. A year ago, I talked with them both, about how they were doing at home, and I persuaded them to get help from home-care services as well. At first, they were strongly against the idea, but now, after a year, they think the decision was very good. Home care visits have made life easier for all of us.

Immediately after starting home care, my mother became more seriously ill and, as a person with dementia myself, I had to help my father a lot. I personally wanted to take responsibility and reciprocate the care I received from him when I was a child.”

By our own actions, we can influence potential health problems. We can eat healthily, remember to exercise and look for social contacts. My father has been doing so, and at the age of almost 90, he goes shopping independently and lives an active life.”

“ My mother became more seriously ill and, as a person with dementia myself, I had to help my father a lot. I personally wanted to take responsibility and reciprocate the care I received from him when I was a child.”

Spring

Luckily, my mother got better when spring came and there was more light in the day as well with this new season. I treated myself, going outdoors every day into nature and it was good to gather my thoughts there. Many times, being there meant I was able to work on my thoughts and remove stress.

“I treated myself, going outdoors every day into nature and it was good to gather my thoughts there.”

Although I thought my living environment was safe to live in, my wife and I didn’t really like it there. For some reason, we caught our neighbours’ negative attention and we were kind of bullied by them and pushed out. However, I will not let things get me down, instead, I look for solutions to overcome the situation.
For 10 years, my wife has been trying to convince me to move to her home region, about 200 miles from where we were living. I was not willing to move at all, but due to other difficulties in my region, I decided to think things through again. I am curious about change and am looking for new directions in life. The biggest difficulty I could see was moving away from my parents, and also claiming new disability benefits from another city. I had been receiving good transport services where we lived, provided by the city’s disability services, and my wife had also been granted an informal care allowance. We were afraid about whether we would be left without these services if we moved to a new location.

Another consideration was our 15-year-old son Eetu. Moving would mean a lot of changes in his life, such as a new school and new friends. My wife would also need to find a new job. The decision involves all of us, and I don’t want to go ahead and think it’s all about me and the disease.

I am pleased that I have information about my symptoms and I want to make decisions a little in advance and to make a difference in my own way. My illness is progressing and I must also think about my wife’s future and how she will cope. She also has ageing parents who need care.

In the midst of all of this, came this COVID-19 pandemic, which made our lives difficult in many ways. We had to keep our distance from our parents and Eetu also had to homeschool. It actually suited me very well to homeschool him, and it allowed me to have company. I was also able to give him support in his school assignments and to feel useful, through this.

Summer

When the summer came, we found ourselves living in Seinäjoki, South Ostrobothnia. We had found a nice apartment, my wife found a good job and our son was at a new school. It was going very well, but the move took a heavy toll on my cognition. While packing boxes, I took a tumble and hurt my neck. The next day I went to the doctor and when I left there, I forgot to put on my shoes. As I walked down the hall, the doctor called after me: “You left your shoes in the room, Petri”.

I had settled in Seinäjoki and decided to discover important things for me straight away in this new city. For me, exercise is a very important tool when it comes to maintaining my functional capacity. When I am cycling, safety comes first and I use as many bike paths as possible. I was satisfied after a few cycling trips, because there are plenty of these. I also asked the property manager of our apartment building, if I could keep the garden in order, because I had worked as a gardener before retiring. Throughout the summer, I mowed the lawns and tidied the bushes. At the end of the summer, the superintendent...
told me that he was pleased with work I’ve done. These words mean a great deal to me! I feel appreciated, which raises my self-esteem.

After processing my application, disability service workers made a home visit. They mapped out my ability to function and the need for family support. The discussion with them was very constructive after about a month we got news that the transport service was granted but they refused support for informal care. We decided to lodge a complaint that it was not granted on the same grounds as the former place of residence. It felt tiring, especially living in a completely new place, to have to fight for my rights and when the complaint was not upheld, it felt very unfair. We are not bitter about it, though, but rather we decided to move on positively.

Autumn

By the autumn, I had worn out my bicycle. A manufacturer had read in the media about how I maintain my ability to function through cycling and that I felt unsafe cycling with my bicycle in poor condition, so they decided to support me and the memory work that I do, by sponsoring me with a new bicycle. This was a very nice gesture from them, for which I am very grateful.

I also maintain my ability to function by gardening, both at my parents’ cottage and in my parents-in-law’s garden. My green fingers and gardening knowledge have not been taken away by this dementia!

Many people thought that when the summer went, the pandemic would calm down, but unfortunately it did not. I had to distance myself from loved ones again and stay home as much as possible; avoid crowds and wear face masks, among other measures. Sometimes, it seems a little strange to me that I, as someone with dementia, seem to understand better how to follow the measures than a lot of healthy people!

It is a shame that almost all the events we were going to speak at have been cancelled for the year, but I am pleased to have been re-nominated as a member of the EWGPWD. Our team meetings have worked well remotely and we have become really good at working online.

Winter

At the end of 2020, our parents’ illnesses worsened again. My wife’s father fell seriously ill, and so did my mother. As I am writing this, I am going through some sad thoughts about the work I am going through for them. This writing is my own kind of therapy and I am venting my feelings this way. I want to show readers that someone with dementia, and especially a younger person, can experience similar challenges to a healthy person of the same age. My wife takes care of me and both our parents and I will try as hard as I can to help her, while I still can. As well as gardening, I also help her parents with carrying the firewood and doing snow shovelling, as well as helping my own parents with maintenance and cleaning at their cottage. All of this has brought my wife and I closer to each other. We feel like we are a good team and share a wide range of things together.

It has been snowing daily in the last few days and I have kept the yard areas of our apartment building clear of snow. I take advantage of all the situations I can, to help maintain my ability to function.

A few times, I have had to rely on the health care unit of our new hometown. I have been welcomed there and I am satisfied with the treatment I have received. When we moved, I was a little bit afraid because my long care relationships with familiar nurses and doctors broke down. I am also glad that the Memory Association of South Ostrobothnia warmly welcomed us and, through them, my wife and I attend a variety of activities. COVID has taken some parts away from my life, though, and because of the isolation measures, I have not been able to build new social relationships in my new hometown. I hate that I can’t meet new people but I am not going to let it get me down. I believe that better times will come and hopefully the members of the EWGPWD and Alzheimer Europe will soon be able to meet face-to-face, and not just on the screen. For now, though, we have to make do without familiar contact and hugs, so we have to replace them somehow – maybe with a big smile.
Spotlight on early-career researchers: a Neuronet interview with Lena Sannemann

The Neuronet initiative (Efficiently Networking European Neurodegeneration Research) is a coordination and support action that connects research projects launched by the Innovative Medicines Initiative. Neuronet conducts interviews with Early Career Researchers on the projects it connects and in this context, has interviewed one of the researchers on the MOPEAD (Models of Patient Engagement for Alzheimer's Disease) project, Lena Sannemann.

A number of research projects launched by the Innovative Medicines Initiative, Europe’s biggest public and private collaboration in life sciences, aim to better understand and develop treatments for neurodegenerative conditions such as Alzheimer’s disease and dementia. By establishing the Neuronet platform and connecting these projects, Neuronet hopes to aid progress and expedite the delivery of novel treatments.

Neuronet aims to help scientists to identify gaps in research, to make findings more visible for society as a whole and create links between Innovative Medicines Initiative projects and other international research initiatives. In order to do so, Neuronet also conducts interviews with Early Career Researchers.

In this Neuronet interview, we talk to Lena Sannemann who is a doctoral candidate at the University Hospital Cologne’s centre for memory disorders. Lena is a psychologist by background and is fascinated by the brain as well as neuropsychology in general.

Alongside her PhD, Lena started to work on the EU-funded, EUR 4.5 million multi-stakeholder project MOPEAD. The acronym stands for Models of Patient Engagement for Alzheimer’s Disease and represents a collaborative effort of 14 public and private partner institutions who set out to test ways that could help to detect Alzheimer’s disease (AD) earlier in the disease course.

**What motivated you to pursue a career in science?**

Neuropsychology has always fascinated me! During an internship at the centre for memory disorders, it became clear to me that the combination of working with data but also in direct contact with patients, as part of a PhD, was a career path worth pursuing and I enjoyed this balance and working in a multidisciplinary team a lot.

I was privileged to be able to join the MOPEAD kick-off meeting in Barcelona and to start working on the project. During that time, I witnessed a great working atmosphere, and I was looking forward to being able to work with international experts, as well as getting to learn from them. Witnessing the passion that they have for the research that they are doing was very motivating and inspiring.

**Could you tell us a bit about your PhD?**

I had the pleasure to start my PhD at the end of 2017. My work focusses on neurobehavioural changes in at-risk states for AD dementia (such as subjective cognitive decline) and their relationship with AD biomarkers. I believe that research on prodromal or at-risk states of AD is important, especially considering the growing significance of preventive interventions and clinical trials that target individuals at the very early stages of AD, to minimise risk or delay disease onset. For this, I analyse data from the longitudinal multicentre “DELCODE” study.

**What did your work on the MOPEAD project involve?**

In MOPEAD, we tested four different engagement methods in different settings. They included a neuropsychological online test, a neuropsychological test at memory clinics (as part of an open house initiative), a pre-screening carried out by general practitioners in the primary care setting and a pre-screening by endocrinologists in the tertiary care setting, given to patients that are diagnosed
with type 2 diabetes (who are at higher risk of developing dementia).

We noticed different reactions when we approached general practitioners to ask for a collaboration with MOPEAD to apply the pre-screening strategy in their offices. It was therefore a logical next step to better understand general practitioners’ attitudes/opinions (benefits vs. risks) towards an earlier diagnosis of AD and to explore possible barriers in this setting. Consequently, we launched a survey that was carried out at all MOPEAD sites (Germany, Netherlands, Spain, Slovenia and Sweden) and we recently published a paper about it.

**What did you learn through your survey on general practitioners’ attitudes towards early and pre-dementia diagnosis of AD?**

Looking at the results of our survey, we noticed that the majority of the general practitioners thought that an early diagnosis was actually of value. On the other hand, we also identified some barriers to earlier diagnosis. These were mostly of a logistical nature, such as a lack of time. Less than a third of the 343 respondents said that they had sufficient time to manage a patient with very early dementia or MCI.

Looking at country variances, we found that there were strong differences with regard to reimbursement perceptions, but also regarding the knowledge about early diagnosis. Around a third of the respondents did not feel confident in the diagnostic procedures for very early dementia or MCI.

We also asked about their opinions on pharmacological treatment options that are currently available and noticed that the majority was of the opinion that they have no or low benefit for patients. At the same time, results highlighted that the majority thought that non-pharmacological options do come with a benefit, although results indicated that they are not sufficiently available.

**MOPEAD’s study protocol also included questions about subjective cognitive complaints. Could you tell us more about the reasoning behind this?**

The concept of subjective cognitive decline (SCD) is defined by consistent self-experienced decline, without objective evidence of cognitive impairment in standardised cognitive tests. Studies show that people with SCD tend to be at higher risk of developing MCI or dementia in the future.

Although occasional cognitive concerns are common in older individuals and the majority will not progress to MCI or dementia, memory concerns should be taken seriously, as there might be underlying medical causes. In addition, questions about patients’ lived experience of their memory are meaningful and provide an opportunity to talk with patients about cognitive decline and prevention methods that are tied to potential lifestyle changes. Even in the absence of a disease-modifying drug, people can do something to decrease their individual risk and potentially delay disease onset.

**What do you think needs to happen to get people to receive a diagnosis earlier in the disease process?**

One well-known aspect is that general practitioners often don’t have sufficient or only very little time for their patients and that is something that needs to be addressed at a structural and policy level.

Even if conditions to work towards a timely diagnosis are in place, we need to raise awareness about timely detection of dementia and cognitive complaints, among general practitioners as well as the general public, since there is still a lot of stigma around the diagnosis of dementia.

I think this is especially important, keeping in mind that we see a rising impact of prevention strategies, these days. There are various modifiable risk factors of dementia, with about 30% of dementia risks being attributed to potentially modifiable risk factors, and general practitioners can play a role in raising awareness about these, among their patients.

As part of our work on the MOPEAD project, we therefore also developed infographics in the languages of the different participating countries. Apart from providing insights into the study, and background information on AD and dementia, one of them specifically addresses risk factors for dementia.

**What were your personal highlights working on MOPEAD?**

In addition to the collaboration with different experts in the field and learning a lot, my highlight was receiving feedback from the patients and seeing a real impact on their lives. We received very positive feedback, especially on the open house initiative. We noticed that there is a lot of interest in easily accessible cognitive testing. People were very grateful to get the opportunity to participate in our study. Getting this feedback and seeing that what we were doing actually helped people was my major personal highlight.

You can find the MOPEAD infographics here: [https://www.mopead.eu/infographics](https://www.mopead.eu/infographics)

Translations of the infographics are available for download here: [https://www.imi-neuronet.org/materials/](https://www.imi-neuronet.org/materials/)

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Ping4Alzheimer – Table tennis to help slow cognitive decline

According to some scientific studies, table tennis is one of the most suitable and recommended sports for older people, and may help to slow cognitive decline. With this in mind, Renato Walkowiak began giving special sessions for people with dementia and carers at Levallois Sporting Table Tennis Club in France, and the “Ping4Alzheimer” initiative was born. It is now being deployed nationally in partnership with France Alzheimer and the French Table Tennis Federation.

Table tennis may help slow or protect against Alzheimer’s and other dementias. According to studies, including that of Dr Daniel Amen (American neuropsychiatrist, specialist in brain disorders), table tennis helps stimulate and maintain the cognitive system. Another study, in Japan, showed brain changes before and after a ping-pong session, supported by brain imaging: it was shown to stimulate five specific areas of the brain, including the hippocampus, the area of the brain responsible for memory, which shrinks as Alzheimer’s disease progresses.

Table tennis, also known as ping-pong, is one of the most suitable and recommended sports for older people and may help protect against cognitive decline. At Levallois Sporting Table Tennis Club, in the Hauts-de-Seine region of France, coach and manager Renato Walkowiak created special sessions for people with dementia and their carers and so began the “Ping4Alzheimer” initiative.

“This sport requires permanent concentration. It improves visuospatial perception and strengthens hand-eye coordination” says Mr Walkowiak, whose grandmother had Alzheimer’s dementia.

It is also a highly inclusive and non-aggressive sport. “It’s like walking, everyone plays at their own pace, according to their age, level and physical abilities, but with the advantage of causing strong cognitive stimulation” says Mr Walkowiak, “You can even play in a chair”.

Mr Walkowiak started the initiative in Levallois, in 2018, with the aim of helping people with dementia and their carers, both in terms of partaking in an enjoyable activity on a regular basis, but also to help slow cognitive decline as much as possible. It was tested for two years (2018–2020) and the initiative convinced Alix de Chaumont, the General Secretary of the France Alzheimer association in the Hauts-de-Seine region: “Scientifically, it seems that the ping-pong exercise restores strength and volume to the hippocampus. We know that in Alzheimer’s disease it is the hippocampus that shrinks. I admit that I was a little skeptical but we have seen patients undergoing a metamorphosis.”

The programme has been such a success in its first two years that, in 2020, a partnership was created between the French Table Tennis Federation and France Alzheimer, with the aim of deploying the initiative nationally. The objective is twofold: to bring together a table tennis club and a France Alzheimer structure in each region of France and to identify a group that can scientifically assess the impact of this sporting practice on Alzheimer’s disease.

Renato Walkowiak

This sport requires permanent concentration. It improves visuospatial perception and strengthens hand-eye coordination and has the advantage of causing strong cognitive stimulation.”
The game of table tennis is fun, inexpensive in terms of equipment, practicable at any age and almost without contraindications; table tennis also has many advantages for health. It is a fast and intermittent sport which calls on the cardio-respiratory system and helps develop endurance. It is perhaps, however, in the brain that its effects are the most interesting with potential benefits on attention, concentration, coordination, balance, skill and reaction speed.

“Each ball trajectory is unique, and the players must constantly adapt. This is also true in tennis, but table tennis is faster with more spin, and it is a more suitable activity for someone who is getting back to the sport than tennis, where the contact is more violent with the ball” enthuses Mr Walkowiak.

Professor Claire Paquet, Head of Service of the Center for Cognitive Neurology, is also involved in Ping4Alzheimer. She asserts that attending table tennis sessions such as those set up by Renato Walkowiak at the Levallois club which include passionate table tennis players, people living with dementia and carers, carries a number of benefits:

1. It allows people with dementia and carers to engage with others both socially and intellectually, through playing and through conversations in-between games.
2. It provides cognitive stimulation, activating all the cognitive functions around visuospatial awareness.
3. It provides an excellent and accessible form of all-important physical activity.

For Joël Jaouen, President of France Alzheimer, “this programme, led by Renato, is a wonderful initiative. Playing ping-pong, beyond the benefits on health, brings joy to people living with dementia and their caregivers. Moreover, our partnership with the French table tennis Federation is fully in line with our fight against the prejudices that affect the families concerned on a daily basis. All of the actions implemented will enrich the support and well-being of people with Alzheimer’s disease and their caregivers.”

Testimonial from a participant

We have the interesting story of Etienne, 65, who has been a sportsman all his life. His wife tells us that he can’t concentrate at home and he always starts an activity without finishing it. When he arrived at the ping-pong club, however, he immediately played for two hours without losing his focus. The rhythm of the exchanges in table tennis has a mesmerising effect.

“We find ourselves laughing and playing like kids and we forget reality, so it puts us in a good mood. It has quite an amazing effect. We realise that we are laughing again, though we had stopped laughing and in our daily lives we don’t laugh as much. When we play, there is nothing but that little ball and everything else falls away.”

Find out more about the initiative and hear testimonials, here (in French with English subtitles): http://bit.ly/Ping4Alzheimer
Voting for people with dementia in the Netherlands

The elections in the Netherlands took place in March 2021. People with dementia have the right to vote for the elections, just like any other citizen of the Netherlands. But voting is not as easy for people with dementia as it is for others. Anne de Boer, Advocacy Officer at Alzheimer Nederland, tells us about how they are working to change this.

In 2018, together with the working group of people with dementia in the Netherlands, Alzheimer Nederland made helpful tools to make voting easier for them. Our tools focused both on people with dementia and on the municipalities, who arrange the polling places.

Voting with dementia

Voting during the elections is perhaps the most direct way to participate in a democracy. The right to vote is part of the International Covenant on Civil and Political Rights. For people with a disability, this right is emphasised again in article 29 – participation in political and public life – of the UN Convention on the Rights of Persons with Disabilities. This includes people with dementia. Because it is so important that every person with dementia has the chance to vote, Alzheimer Nederland aims to vote without obstacles and as independently as possible. Voting has to be physical accessible, for example voting booths on the ground floor. But accessibility also means that people know how to vote, when to vote and what to vote.

To help people with dementia to vote, the working group of people with dementia shared their experiences on voting. Together with the working group, we created an informative video about voting. In addition, we made an easy to read step-by-step plan that a person with dementia can bring to the voting booth. The tips that people with dementia have for others are:

1. Go at a quiet time. You might need some extra time to vote, and people waiting behind you can make you feel anxious which makes it more difficult to vote.
2. You cannot bring someone into the voting booth. Do you have questions about voting? Make sure you ask them beforehand.
3. Bring the step-by-step plan. Voting consists of a lot of steps. This overview helps you to vote on your own.

Because of COVID-19, voting was extra challenging this year. To prevent further spread of the virus, the government allowed voting by mail. Alzheimer Nederland provided people with dementia with information on how to vote by mail.

The college of human rights in the Netherlands supervises whether the elections have been complied with the UN convention. They set up a hotline where people could report their voting experiences so they could monitor if voting was accessible for everyone. We included this hotline in our communication to people with dementia to encourage them and their carers to report complaints about voting, if needed.

Dementia-friendly voting booths

Since voting is a human right, Alzheimer Nederland thinks it should not be the responsibility of people with dementia to make it possible for them to vote. That is why we put a lot of effort in dementia-friendly voting booths. Our toolkit for municipalities to provide accessible voting consists of a card about how to recognise people with dementia, a training about dementia and instructions on how to arrange the setting of the voting booth in a way that it is accessible for people with dementia. For example, using clear signs and instructions.
It would be helpful for people with dementia to have a relative helping them in the voting booth. However, this is not allowed by law. Only people with a physical disability are allowed to have support in the voting booth. Together with other patient organisations, Alzheimer Nederland pleads to let people with dementia have this support from a relative as well.

How dementia-friendly are the election programmes of the political parties?

Besides the voting itself, it is important for people with dementia to be well informed on who to vote for. Prior to the voting, Alzheimer Nederland informed all political parties about six of our statements concerning people with dementia. Namely:

1. Create an inclusive society where people with dementia can take part in.
2. Build houses for people with dementia to enable living longer at home.
3. Support caregivers. We would be nowhere without caregivers. Take responsibility to support them.
4. Invest in prevention of dementia. Stimulate the younger generation and the risk groups on living a healthy life to improve brain health.
5. Make healthcare and support accessible. Keep it simple for people with dementia.
6. Use e-Health and technology to improve communication and to relieve the pressure on the healthcare system. Not to replace human-centred and personal care, but to add to it.

We also met with the new potential members of the House of Representatives. With these meetings, we were able to inform the potential members beforehand about the statements of Alzheimer Nederland and offer our help with solutions for dementia as a social challenge.

When the parties published the election programmes we rated them on our six statements. It turned out that only in two election programmes dementia was mentioned as a separate theme. This is striking, especially because people with dementia and their carers comprise 1 million of 17 million potential voters in the Netherlands. Dementia is a social challenge and that needs to get specific attention in the policy of the Netherlands.

Since the number of people with dementia will increase while the number of healthcare providers will decrease, healthcare will not be manageable in the future if attention is not given now. A positive note to the election programmes was that housing, an inclusive society and prevention of diseases in general where represented in almost all programmes.

We summarised our findings in a so called “bingo card”. The purpose of this card is not to give specific voting advice, rather it shows that elections can have a direct influence on your personal situation and that you need to inform yourself on who to vote for. In addition, it shows the people with dementia and their carers what the themes are that Alzheimer Nederland is working on.

What’s next?

Currently the formation of the coalition is taking place. That means that the chosen parties are discussing on who will govern for the upcoming four years. But not only who will govern is of our interest, but also what their goals will be. What will they do for people with dementia in the four years to come? We will invite the new chamber members to visit Alzheimer Cafés and meeting centres so they will experience the importance of this type of support. In addition, we will send the new members all the important data concerning dementia in the Netherlands. With this, we aim to have a good relationship with them and to be the authority on dementia in the Netherlands.

The previous government created a National Dementia Strategy which will be operative for the coming four years. We want to make sure that this National Dementia Strategy is embedded in the coalition agreement, with a proper budget and an approach on how to implement the steps described in the strategy. Alzheimer Nederland will keep a close eye on the formation process and will make the voice of people with dementia resonate in the policy.
Behind the headlines: What is the link between contact sports-related head injuries and dementia?

Michael Hornberger is the Professor of Applied Dementia Research at the Norwich Medical School, where his research focuses on improving diagnosis, disease progression tracking and symptom management in dementia. He is passionate about dementia science communication and has spoken to Alzheimer Europe about the link between traumatic head injury and dementia, which has recently received a lot of media attention.

There have been many reports in the media, both recently and over the past few years, suggesting a link between head injuries incurred during contact sports and dementia in later life. Could you explain the clinical evidence for a link between traumatic head injury and dementia?

The clinical evidence between traumatic head injury and dementia has been known since the 1920s. The initial evidence was based mostly on boxers who often develop dementia-like symptoms later in their life. Investigations of the boxers’ post mortem brains showed that they have similar proteins changes in their brains to people with Alzheimer’s disease. These changes in boxers were named Chronic Traumatic Encephalopathy (CTE) to differentiate them from more general traumatic brain injury.

It took until the early 2000s to establish that CTE is not only common in boxers but also in other high-impact contact sports, such as American Football, Ice hockey and Rugby. The research evidence shows that professionals from these sports have an up to four-fold increased risk of developing CTE and dementia in the future.

More recently, research has shown that not only high-impact contact sports lead to CTE and dementia but even sports considered lower impact might increase sports people’s risk for dementia. Specifically, there has been evidence that former football/soccer players seem to be also at 2.5-fold increased risk for CTE and dementia. The current suggestion is that heading the ball might be the main contributor for CTE/dementia risk in former professional football players. However, this remains at this stage speculation and there are currently several ongoing studies investigating in more detail the impact of football on dementia risk and which aspects of football might increases the risk.

Finally, there is also an increasing recognition that female professional sportspersons might be particularly vulnerable to CTE and dementia. The exact reasons for this are unclear, however, professional women sport is – in general- much younger than their male counterpart and therefore fewer female professional sportspersons have aged to develop such symptoms. Again, this is an area of ongoing research to establish the risk for female professional sportspersons specifically.
How does head injury affect the brain, and how are these brain changes linked to pathological drivers of dementia such as amyloid, tau and vascular changes?

To understand how head injuries, including CTE, affect the brain, we need to first understand that the brain is surrounded by a fluid (the corticospinal fluid – CSF) which allows it to ‘float’ in the skull. This floating function of the CSF protects the brain from bouncing against the skull during any movements or minor impacts. However, during more severe impacts, such as having a fall or a car accident, which induce a sudden deceleration or torsion (twisting) of the head, the brain can still hit the inside of the skull. The CSF is simply not sufficient to protect the brain from these more severe impacts. The consequence if the brain hits the skull from the inside is that it leads to a localised damage in that brain region as the nerve cells get damaged and might die.

Damage to the brain always triggers a neuroinflammatory response which can affect the wider brain. This neuroinflammatory process can also increase the accumulation of amyloid and tau – two key proteins for the development of Alzheimer’s disease.”

There is not only direct damage to the brain but also more indirect damage. In particular, damage to the brain always triggers a neuroinflammatory response which can affect the wider brain. This neuroinflammatory process can also increase the accumulation of amyloid and tau – two key proteins for the development of Alzheimer’s disease. The exact mechanism of how neuroinflammation affects the accumulation of amyloid and tau are still being explored. However, what the research has shown so far is that the neuroinflammation seems to ‘fan the fire’ for the accumulation of amyloid and tau. In essence, it seems to speed up the process of protein accumulation, which might explain why repeated head injuries, even if they are minor head injuries, can lead to a chronic neuroinflammation which in turn increased the rate of amyloid and tau accumulation. However, again, at this stage this remains a hypothesis and is currently being investigated.

Still, what is clear is that not only severe head injuries, such as concussion and loss of consciousness can cause such neuroinflammation but also more minor head injuries. This is increasingly relevant for sport as a potential risk for CTE and dementia, since, for example, football rarely leads to concussion but heading the ball might lead to ‘sub-concussive’ events leading again to neuroinflammation and potentially an increased accumulation of amyloid and tau. The key question is of course which ‘sub-concussive’ events in sport might lead to this cascade, which clearly needs to be investigated in the future.

The final aspect to mention is that head injury can also cause vascular changes in the brain. Vascular changes in the brain are a key contributor to the development of dementia and need to be taken therefore quite seriously. They key vascular changes due to head injury are related to leakage of the blood brain vessels. The sudden deceleration or torsion of the head can lead to very small blood vessels in the brain rupturing and leaking. Such micro-bleeds in the brain are also referred to as mini- or silent strokes, as they only affect a small area in the brain. They are called ‘silent’ because they often do not cause symptoms, since these mini-strokes are so small that the brain can compensate for the loss of function in that brain region. Having such as mini-strokes has been shown to increase our risk for dementia significantly, as the mini-strokes can accumulate over time and eventually lead to symptoms.

Taken together, the exact mechanism how head injuries caused by sport lead to CTE and dementia are still being explored. But what has emerged so far is that there are likely multiple factors (inflammation, proteins, vascular changes) which contribute to the increased risk for dementia due to sport.

What type of injuries could put people at higher risk of developing dementia and in which sports are they most likely to occur?

The key injury to avoid is concussion and in particular repeated concussions. Concussion is commonly defined as a head injury which leads to a loss of consciousness or temporary confusion of the person experiencing it. Now many sports have concussion protocols in place, as it is increasingly recognised that concussion can have a significant impact on brain health and future dementia risk.

Unfortunately, despite concussion protocols now being used more commonly, players often themselves want to go back onto the field as quickly as possible. This clearly poses a conundrum since from a clinical point of
view a player who had a concussion on the field, should be taken off and monitored longer term. There is a question whether further education of players, managers and team doctors as to the health risks of head injuries and concussion might improve the long-term brain health of sportspersons.

All high-impact sports have a high risk of concussion, in particular American Football, Rugby and Ice Hockey are known for concussion to be common. Interestingly, concussion rates are often higher for women than men in these sports, which again raises the question as to whether sportswomen might be at particular risk of future CTE and dementia.

Despite concussion being the most established injury to increase the risk for dementia, ‘sub-concussive’ events, such as heading balls or hitting another player without loss of consciousness are increasingly investigated to establish whether they increase the risk for dementia. If such ‘sub-concussive’ events are proven to increase the risk for dementia, it might change high-impact sports quite significantly. But even lower impact sports would be affected, since heading the ball during football would also potentially fall under this category.

Sports bring us many benefits, and indeed exercise is highly recommended to keep our hearts and brains healthy, thus helping reduce our risk of dementia. What advice would you give to people currently practicing contact sports, to ensure they are getting the benefits, while mitigating the risks?

It is very important to highlight that physical activity and sports in general is extremely beneficial for our brain health. In particular, cardiovascular health is strongly linked to healthy ageing and dementia risk. We should, therefore, encourage people to be physically active and doing sports, as physical activity itself has shown to potentially reduce the future risk of dementia by up to 30%.

The other important point to emphasise is that virtually all the studies investigating the link between sport and dementia have been conducted in professional sportspersons. To my knowledge, there is no existing evidence that the risk for dementia is similar in amateur sportspersons. The risk for amateur sportspersons is currently still being investigated. For now, the benefits of sport clearly outweigh its risks for future dementia development and everyone should be encouraged to stay as physically active as possible during their lifetime.

The only aspect I would advise people to be careful about is when they experience a concussion during their sports activity. Having a concussion needs to be further investigated by a medical specialist and the person should refrain from conducting their sport until they are given the all clear by the specialist.

Is there any action that people can take now, if they played contact sports in their younger years and are worried about the impact this may have on their risk of dementia in the future? Can they adapt their lifestyle to reduce the likelihood of developing dementia?

We have to carefully distinguish here professional from amateur sportspersons. For professional sportspersons from higher impact sports, there is an established higher risk of dementia in later years. Professional sportspersons are therefore recommended to discuss their concerns directly with their professional sports affiliations, many of whom have now dedicated support for these concerns.

For amateur sportspersons, there should be reassurance that for now there is no evidence that participation in higher impact sports leads to a higher risk of dementia. The only exception is repeated concussions. If you have experienced repeated concussions during your amateur sports time, then you should discuss your concerns with your family doctor. In general, try to keep as fit as possible as it will not only will make you feel better but also reduce your future risk of dementia. Time to dust off those trainers!
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