

DEMENTIA IN EUROPE

THE ALZHEIMER EUROPE MAGAZINE



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Valentina Prevolnik Rupel
Minister of Health introduces
Slovenia's new dementia strategy



Deirdre Clune MEP
hosts lunch debate on findings
of Alzheimer Europe's European
Dementia Monitor 2023



Margaret Northedge
and her husband Barry Northedge,
member of the European Dementia Carers
Working Group, tell us "Margaret's Story"



Jongjie Yon
talks about WHO Europe's Regional
Summit on policy innovation for healthy
ageing held in Lisbon, Portugal

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Welcome



Maria do Rosário Zincke dos Reis, Chairperson, Portugal

It is with great pleasure that I introduce the 44th edition of our Dementia in Europe magazine, which contains many important updates on European and national policy developments in the dementia field.

We open the Alzheimer Europe section with a report on our most recent European Parliament lunch debate, held in December 2023 and focusing on a new edition of our European Dementia Monitor as well as on our 2024 EU Elections Campaign. I would like to thank Deirdre Clune MEP (Ireland), Vice-Chairperson of the European Alzheimer's Alliance, for hosting this important event. Our next article takes a closer look at the content of the European Dementia Monitor 2023.

We then have a series of articles about four new publications from Alzheimer Europe: Our 2023 Yearbook on the topic of legal capacity and supported decision-making, our new guide on the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) review process, and two new position papers – one on disclosing dementia risk and one on anti-amyloid therapies for Alzheimer's disease.

The penultimate article in this section focuses on a recent collaborative event for Public Involvement in European brain health research, held in Luxembourg and involving six European research projects that joined together in a series of consultations, whilst

the final article looks back at the newly-closed EU-FINGERS project, a collaborative initiative developing tools to conduct new clinical studies for the prevention of Alzheimer's disease and dementia.

In the Policy section we start with important news from Slovenia, which has just published its second National dementia strategy. Minister of Health, Valentina Prevolnik Rupel, outlines more details about the new strategy, and President of Spominčica, Štefanija L. Zlobec, shares the association's response to the strategy.

Up next, we share details of our campaign work in the run up to the European Parliament elections 2024, aiming for dementia to be prioritised as a policy matter at a European level. Building on previous advocacy work, the campaign has been developed with three distinct elements: The Helsinki Manifesto; A Public Call to Action, and the Dementia Pledge 2024.

Going back to the national level, we speak to Dr Mairéad Bracken-Scally and Dr Seán O'Dowd from the Irish Health Service Executive to find out more about the publication of the Model of Care for Dementia in Ireland in 2023, and then to Jacqueline Hoogendam and Sara Elkiki from the Dutch Government, to learn about the country's recent international conference which took place under the banner "Defeating Dementia".

Closing off the policy section, we asked Yongjie Yon, Technical Officer on Ageing and Health at the World Health Organization (WHO) to tell our readers about the Regional Summit for Policy Innovation on Healthy Ageing in Lisbon, Portugal, co-organised by WHO Europe and the Directorate General of Health of Portugal.

Our third and final section, Dementia in Society, starts off with a personal account of living with dementia, written by Barry Northedge, Scottish member of the European

Dementia Carers Working Group, who shares his wife Margaret's story both before and after diagnosis.

We then find out about the "ABOARD" project in the Netherlands, the halfway point of which was marked by the "ABOARD Midterm Meeting" in late 2023. Project leader Wiesje van der Flier from Alzheimer Center Amsterdam shares the achievements so far and we also hear from some of the project's early stage researchers about their involvement.

The film "Waltzing Matilda" is the subject of the third article in this section. Directed by Czech screenwriter, renowned documentary and theatre director and author of several TV dramas, Petr Slavík and produced by his wife Nataša Slavíková, the film is an intimate family drama about bailiff Karel Jaroš, his mother the former choir singer Matilda, and Karel's teenage son Pavel. We interviewed producer Nataša Slavíková about the reasons for making the film and to learn more about the characters and the message.

We end this section and indeed the magazine with a look at a new book emerging from Scotland, called "Challenging Assumptions Around Dementia". The book seeks to challenge preconceived ideas about dementia and its co-authors are six people living with dementia and six who support or have supported someone with the condition. Their work was brought together by research psychologist Dr Rosalie Ashworth, so Alzheimer Europe asked Dr Ashworth and two of the book's co-authors, David Ross and Agnes Houston, to tell us more.

As a special supplement to this edition of our magazine, we are also delighted to present a new publication about the 33rd Alzheimer Europe Conference (33AEC) in Helsinki.

I hope you enjoy our magazine and trust you have all had an excellent start to 2024!

Maria do Rosário Zincke dos Reis

Alzheimer Europe hosts lunch debate launching the European Dementia Monitor 2023

Alzheimer Europe welcomed attendees to its lunch debate on 5 December 2023 in Brussels, Belgium. The session was focused on the organisation's work on the European Dementia Monitor 2023 and its EU Elections Campaign 2024. Stakeholders representing national member organisations, national ministries, industry partners, policy makers and non-governmental organisations were in attendance.



Left to Right: Andy Heffernan (CEO of The Alzheimer Society of Ireland), Deirdre Clune MEP, Jean Georges, Maria do Rosário Zincke Dos Reis

Alzheimer Europe welcomed attendees to its lunch debate on 5 December 2023 in Brussels, Belgium, hosted by Vice-Chair of the European Alzheimer's Alliance (EAA), Deirdre Clune MEP (Ireland). During the session, the organisation launched its new European Dementia Monitor 2023 and shared key messages for its forthcoming campaign around the 2024 EU elections.

Ms Clune opened the session by noting that these events were a welcome opportunity to bring together stakeholders from across civil society, industry, governments, academia and people with lived experience to share knowledge, experiences and information. She further expressed her view that coming together from different countries and backgrounds was essential to ensure

that dementia remains a political priority. She welcomed the work on the Dementia Monitor 2023, explaining that benchmarking the situation in countries across Europe allowed for the identification of the gaps in policies and services within countries, whilst also identifying trends across Europe. Ms Clune stressed the need to better coordinate efforts at a European level to better utilise the knowledge and resources from different levels, to drive improvements in policy and practice.

European Dementia Monitor

Alzheimer Europe Executive Director, Jean Georges, opened by introducing the objectives of the European Dementia Monitor, explaining that it was intended to provide a benchmark of national dementia policies in

order to compare and rank European countries in relation to dementia policies and practice. Two earlier editions of the European Dementia Monitor exist, published in 2017 and 2020.

Further information on the 2023 edition of the Monitor is available on page 7.

Panel discussion

Following Jean's presentation, attendees heard the thoughts and reactions from a panel comprised of people with lived experience of dementia and professionals working in the health field:

- Chair of the European Working Group of People with Dementia – Chris Roberts
- Chair of the European Dementia Carers Working Group – Sonata Mačiulskytė
- Executive Director of European Patients' Forum – Anca Toma
- Senior policy advisor international affairs and dementia research, Netherlands Government – Abida Durrani.

Chris stated that the report was an excellent resource and commended Alzheimer Europe on its work, welcoming that progress had been made in a number of areas. He noted that financing and resources was a key barrier to action and progress in a number of areas. Additionally, he expressed surprise that so many countries do not recognise dementia as a disability, as well as the lack of training and support for informal carers, despite them being key to supporting people with dementia. He also expressed disappointment that so many countries were failing to take action on the misuse of anti-psychotic medications, particularly given the potential harm that such drugs can have for people with dementia.

Sonata also welcomed the report, noting it was a useful exercise to compare and benchmark progress, especially for neighbouring countries, noting that the Baltic countries often compared their situation. She noted that it was helpful to have the "big picture" across Europe and to see the inconsistent progress across Europe – she highlighted that the presence of a dementia strategy wasn't necessarily a guarantee of progress in all areas. She expressed her

surprise at the lack of dementia-inclusive initiatives in so many countries, whilst also highlighting that availability and affordability of care services were crucial to the quality of life of individuals.

Anca shared that from her personal perspective, it was disappointing to see Romania ranked so lowly in many categories, reflecting on her own experience, with her mother caring for her grandmother who has Alzheimer's. She noted that it was surprising to see so many countries not having ratified human rights treaties and that the EU needed to take further actions to embed basic rights-based approaches across Europe. She further noted that despite conversations about ageing demographics and about preparations for the future, there was still a lack of services and supports for people with dementia and carers now. However, she welcomed that the situation was improved compared to three years ago.

Abida expressed that she was pleased to see the Netherlands do well in many areas but that there was still work to be done. She shared some of the activities ongoing in the Netherlands, including the 2021-2030 Dementia Strategy, which focuses on research and anti-stigma, as well as care and support, and assistive technologies. She further noted that the setup of the health and care systems and relevant legislation, was a key factor in ensuring people's needs were covered – in the Netherlands there are three complementary



Left to Right: Jean Georges, Sonata Mačiulskytė, Abida Durrani, Anca Toma and Chris Roberts

pieces of legislation which ensure that everyone's needs are covered. However, she also noted that as societies age, ensuring access to care will become more difficult and that as such, preventative approaches were becoming more important as well.

Alzheimer Europe election campaign 2024

Alzheimer Europe Policy Officer, Owen Miller, presented on the organisation's plans for the 2024 European Parliament elections. He provided a brief overview of Alzheimer Europe's previous campaigning activities, including the Paris Declaration 2006 and the Glasgow Declaration 2014, as well as the European Parliament election campaigns of 2014 and 2019.

Setting out Alzheimer Europe's approach to the election, he outlined the key messages of the campaign, which would highlight the increasing prevalence and cost of dementia across Europe, the need for greater focus on dementia within health and research programmes, the need for dementia to be recognised as a disability and the need for greater support for informal caregivers. He further explained that the campaign would have three distinct elements:

- The Helsinki Manifesto – a document outlining specific demands of the European Commission and national governments, which will be the basis of Alzheimer Europe's public affairs work in the coming years.

- A public Call to Action – a short statement highlighting the key figures associated with dementia cost and prevalence, to which members of the public will be invited to sign up to demand that European decision makers prioritise dementia as a priority issue.
- The Dementia Pledge 2024 – a short commitment to which candidates standing for the European Parliament elections will be invited to sign, pledging their support, upon their election, for dementia in the areas of health, research, disability policy and informal carers.

The campaign was officially launched on 15 January 2024 and more information on the campaign is available on pages 24-26.

Closing remarks

Alzheimer Europe Chairperson, Maria do Rosário Zincke Dos Reis, closed the session, thanking the attendees for their participation and the panel members for sharing their reactions to the Dementia Monitor, noting that the report had highlighted the inequities for the diagnosis and treatment of dementia across Europe. She further noted the importance of all associations taking part in the European election campaign to convince decision makers to prioritise dementia as a policy issue.

The videos of the presentations from the lunch debate are available at: <https://bit.ly/3ldDQpz>



Owen Miller spoke about the Alzheimer Europe's election campaign 2024

Snapshots from the lunch debate



New Alzheimer Europe publication highlights continuing inequalities in access to dementia care and treatment across Europe

On 5 December 2023, Alzheimer Europe launched the latest edition of its European Dementia Monitor, at a lunch debate hosted by Deirdre Clune MEP (Ireland) in Brussels. The objective of the Monitor is to provide a benchmark of national dementia policies in order to compare and rate the responses of European countries to the dementia challenge. The new edition highlights continuing inequalities in access to dementia care and treatment across Europe.



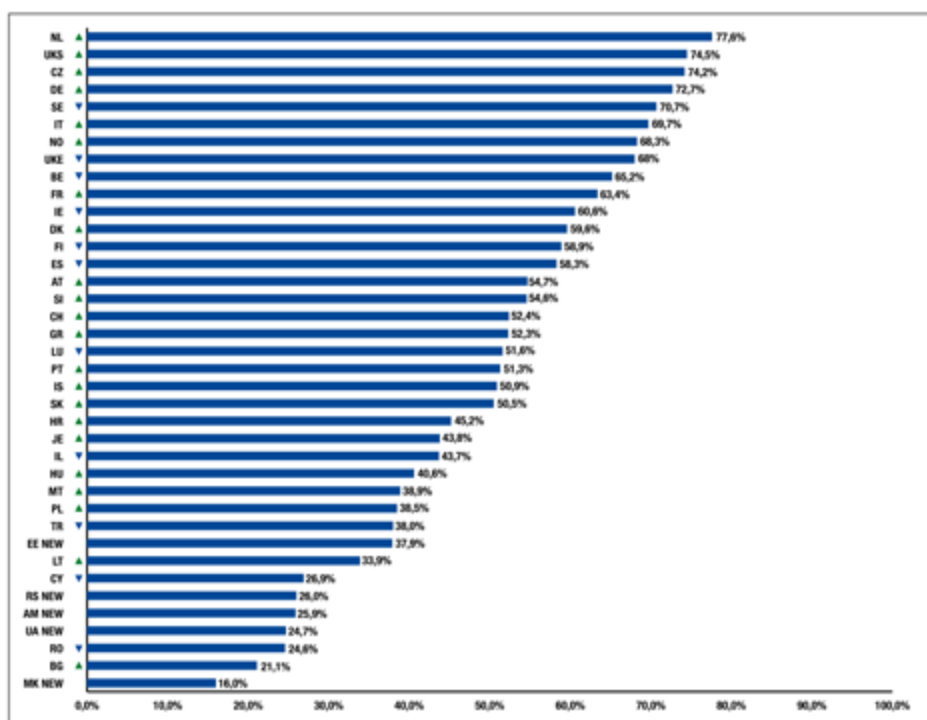
Jean Georges

dementia strategies. The aim of the European Dementia Monitor is to assess which countries provide the most dementia-inclusive policies and guarantee the best support and treatment of people with dementia and their carers. This third edition of our report shows continuing inequalities between European countries, and we hope that national governments will use this report to improve the lives of people with dementia and their carers in those areas where they are currently lagging behind."

The Monitor compares countries on 10 different categories

1. The availability of care services
2. The affordability of care services
3. The reimbursement of medicines and other medical interventions
4. The availability of clinical trials
5. The involvement of the country in European dementia research initiatives
6. The recognition of dementia as a policy and research priority
7. The development of dementia-friendly initiatives
8. The recognition of legal rights
9. The ratification of International and European human rights treaties
10. Care and employment rights.

According to the findings, no country excelled in all 10 categories and there were significant differences between European countries.

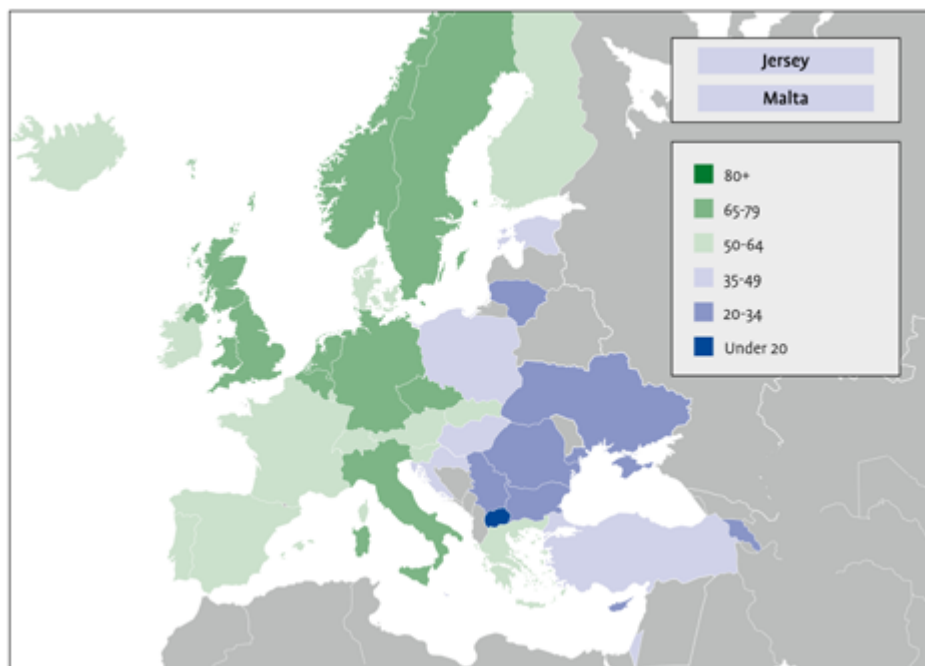


Overall ranking of countries in the 2023 European Dementia Monitor

The European Dementia Monitor, launched on 5 December 2023, covers all Member States of the European Union (with the exception of Latvia), as well as Armenia, Iceland, Israel, Jersey, North Macedonia, Norway, Serbia, Switzerland, Turkey, United Kingdom (both England and Scotland) and Ukraine.

Jean Georges, Executive Director of Alzheimer Europe, commented

"Our organisation has consistently called upon European governments to recognise dementia as a national public health and research priority, and to develop national



Overall scores of countries in the 2023 European Dementia Monitor

Some of the key findings were:

- Luxembourg scored highest on care availability with most services rated as sufficiently available, whereas Norway scored highest on care affordability as it ensured that these services were accessible and affordable for people with dementia and their carers. On both care availability and care affordability, Bulgaria ranked last.
- On the availability and reimbursement of medical interventions, Sweden scored highest as all included medical interventions (with the exception of Fortasyn Connect) were covered by the national reimbursement system. Armenia ranked last in this category as none of the medical interventions were reimbursed.
- As Europe is waiting for the authorisation by the European Medicines Agency of new anti-amyloid treatments for Alzheimer's disease, only Greece, Ireland, Slovakia, Sweden and the United Kingdom (England) had set up a working group or strategy to prepare for the introduction of these new treatments.
- France scored highest in the category of clinical trials as the only country where it was possible for people with dementia to take part in eight of the 10 phase III clinical trials which were studied for the report. The Netherlands, Spain and the United Kingdom came second, with seven clinical

trials active in these countries. Armenia, Lithuania, Luxembourg, Malta and North Macedonia were on the other end of the scale, with no clinical trials available for people with dementia in those countries.

- France, Germany and the Netherlands were the countries that were the most active in European dementia research collaborations scoring 100% in that category, whereas Armenia, Cyprus, Greece, Iceland, Lithuania, Malta, North Macedonia, Serbia and Ukraine were not involved in the Joint Programme for Neurodegenerative Diseases Research (JPND) or any of the calls for European research collaboration.
- For recognition of dementia as a national policy and research priority, the United Kingdom (Scotland) came first with full marks whereas North Macedonia, Serbia and Ukraine did not score any points in this category.
- The United Kingdom (England and Scotland) had the most dementia-inclusive initiatives and communities, but Luxembourg, North Macedonia, Portugal and Serbia did not score any points in this category.
- Regarding the protection of the legal rights of people with dementia, a growing number of countries complied with Alzheimer Europe's five recommendations in this field [Austria, Croatia, Czech Republic, Denmark,

France, Germany, Iceland, Ireland, Israel, Italy, Jersey, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden and the United Kingdom (England)]. However, Bulgaria, North Macedonia, Poland and Romania scored no points in this category.

- In relation to International and European Human Rights Conventions, there has been progress since earlier editions of the Monitor (2017 and 2020), with an increasing number of countries (Cyprus, Czech Republic, Estonia, Finland, France, Greece and Portugal) having signed and ratified all of the treaties. Israel was the country with the least number of conventions signed and ratified.
- The Czech Republic, the Netherlands and the United Kingdom (Scotland) were the three countries where all care and employment rights were recognised, whereas Armenia, Cyprus and Ukraine came last in this category with none of these rights recognised in legislation.



Deirdre Clune

Deirdre Clune MEP (Ireland) welcomed the findings of the European Dementia Monitor

"As a Member of the European Parliament and as Vice-Chairperson of the European Alzheimer's Alliance, I am interested in how European countries differ in their approaches to dementia care and treatment, and I hope that reports like this one can help identify good practices to be implemented in countries lagging behind. As an Irish MEP, I was happy to see that Ireland excelled in some key areas with the development of our national dementia strategy, the Irish Dementia Working Group and the recognition of legal rights. However, my country has some catching up to do in other areas, and more efforts need to be made to provide more accessible and affordable care services. Similarly, I would hope

that more clinical trials will be conducted in Ireland to allow people with dementia to participate in research for the development of new and better treatments.”

On the basis of the findings in the 10 identified categories, Alzheimer Europe established a ranking of countries (with each category contributing 10% to the overall score), with the Netherlands coming first with an overall score of 77.6%, followed by the United Kingdom (Scotland) (74.5%), the Czech Republic (74.2%), Germany (72.7%) and Sweden (70.7%). Compared to the 2020 edition of the Dementia Monitor, the Netherlands and the Czech Republic improved their scores and ranking the most, moving up from seventh to first and from 19th place to third place respectively. The United Kingdom (Scotland) and Germany also slightly improved their scores, but Scotland stayed in second place while Germany moved from fifth to fourth place. Sweden moved down from first to fifth place in this year’s ranking, whereas the United Kingdom (England) and Belgium dropped out of the top five and moved to eighth and ninth place respectively.

Gerjoke Wilmink, CEO of Alzheimer Nederland, also welcomed the findings

“I was delighted to see that the Netherlands came first in this extensive survey of Alzheimer Europe. There has been a very strong commitment in my country to finding practical solutions and concrete support for the many people living with Alzheimer’s disease and other types of dementia. We are happy to continue sharing our experiences and good practices with our partner organisations within Alzheimer Europe, and look forward to learning from those countries in categories where the Netherlands did less well.”



Gerjoke Wilmink

Chris Roberts, Chairperson of the European Working Group of People with Dementia, commented

“The 2023 European Dementia Monitor provides an update on the previous 2020 and 2017 publications. It is a very important policy tool for all countries, as it examines what changes and developments have taken place in 37 countries across Europe and allows countries to compare their national situations regarding dementia with that of other European countries, a sharing of knowledge which then shows good practice, what may be missing and how to improve. Alzheimer Europe shows how these changes can be addressed to improve the experience of all people affected by dementia, including their families and carers.”



Chris Roberts

Sonata Mačiulskytė, Chairperson of European Dementia Carers Working Group, commented

“The Dementia Monitor is perhaps the most comprehensive and systematic register of dementia policy dynamics and should inspire researchers to undertake further studies within and across countries. In addition, it is a powerful tool for analysing the impact of national dementia strategies on various dementia-related indicators within the countries which adopted them, and to encourage countries without such strategies to make progress”.



Sonata Mačiulskytė

Jean Georges concluded

“It was great to see that a number of countries were able to improve the situation of people with dementia and their carers. However, as in our previous editions, we can see that progress is not the same across all European regions. Our Monitor shows that there is still a clear East/West divide in Europe with most of the Western and Northern European countries scoring significantly higher than Eastern European countries. As a rule, countries with national dementia strategies scored better. It is time therefore that all European countries and in particular those in Eastern Europe recognise dementia as a national priority and develop national dementia strategies.”

The full report “European Dementia Monitor 2023: Comparing and benchmarking national dementia strategies and policies” can be downloaded for free, at: <https://bit.ly/DementiaMonitor23>

Acknowledgement

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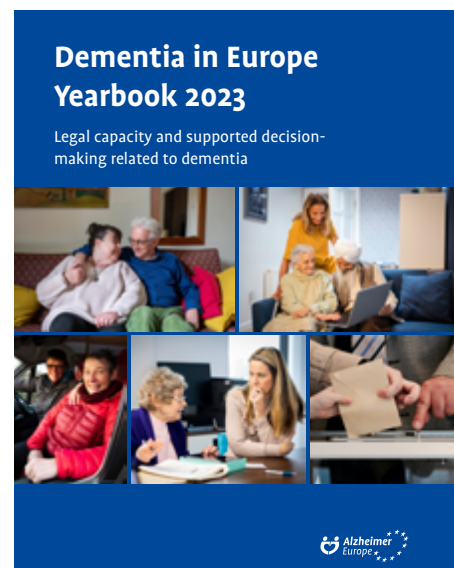
Alzheimer Europe launches Dementia in Europe Yearbook 2023 on legal capacity and supported decision-making

The Dementia in Europe Yearbook 2023 examines how the rights of people with dementia and their carers are detailed in European and International rights conventions, before examining how legal capacity and supported decision-making are implemented at a national level. The Yearbook also contains a number of good practice examples, as well as testimonies from people with dementia and carers.

On 31 January 2024, Alzheimer Europe published its Dementia in Europe Yearbook 2023, which was focused on legal capacity and supported decision-making throughout Europe, examining how the issue is addressed at a national, European and International level. The topic had last been visited by the Dementia in Europe Yearbook in 2016.

The Yearbook provides an overview of the provisions of the Charter of Fundamental Rights, the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD) and the Hague Convention on the International Protection of Adults 2000, which all address legal capacity and supported decision-making to some degree. In addition, it highlights some of the relevant areas of EU policy and legislation in this area, including the Commission's recent proposals on cross-border protections and the Hague Convention. In addition, based on the responses of 26 Alzheimer's associations across Europe, Alzheimer Europe was able to collate information on the current policies and legislation at a national level, identifying the way in which legal capacity was dealt with within countries, as well as any moves towards supported decision-making. The contributions of members demonstrate that there has been some progress in the promotion and upholding of legal

capacity in recent years both at a national level since the publication of the previous Yearbook in 2016. This includes legislative reforms and development of resources which aim to maximise the autonomy of the individuals who may not have full legal or mental capacity. However, many countries have not reformed their systems in recent years and even in instances where changes have been made, supported decision-making is still not widespread. Alzheimer Europe noted that in the Commission's proposals on cross-border arrangements, the language within the legislative proposal does not reflect a more rights-based approach and does not acknowledge the need for such systems to be UNCPRD compliant (for example, by including reference to supported decision-making). Additionally, Alzheimer Europe highlighted that the UNCPRD General Comment No.1 and its view that substitute decision-making is discriminatory and should be abolished, continued to be problematic. Specifically, this approach overlooks the progressive nature of a condition such as dementia and gives no consideration to the practical difficulties that arise where no mechanism exists to take decisions where an individual cannot make decisions for themselves. Even in countries which have tiered levels of guardianship and/or supported decision-making articulated in its legislation,



all recognise the importance of guardianship as a measure of last resort where supported decision-making is no longer sufficient. As such, Alzheimer Europe continues to believe that its model of supported decision-making, articulated in the 2020 Ethics Report (which examined ethical issues relating to supported decision-making and legal capacity), remains more appropriate and feasible.

The Yearbook also provides an overview of some key issues raised by European Working Group of People with Dementia (EWGPWD) and European Dementia Carers Working Group (EDCWG), which stressed the need to take into account the wishes of the individual, their families and carers. Indeed, during the discussions with these groups, few took issue with the concept of proxy decision-making itself, but more so with the information provided around processes, as well as support for individuals and family. Members of both groups spoke of the importance involving people in decisions as far as possible, even where a Power of Attorney or Guardianship was in place, with ongoing conversations and discussions between the individual, family members and carers seen as essential.

The final section of the Yearbook includes a number of recommendations for both European and national policy makers. For more information, the Dementia in Europe Yearbook 2023 can be downloaded at: <https://bit.ly/AEYearbook2023>



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Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or European Commission. Neither the European Union nor the granting authority can be held responsible for them.

Alzheimer Europe publishes guide on United Nations Convention on the Rights of Persons with Disabilities review process

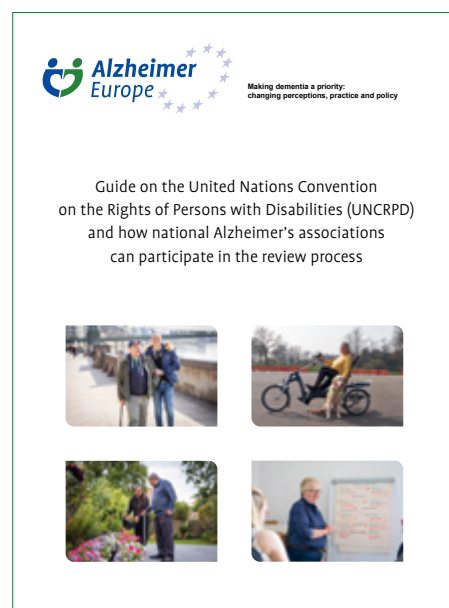
Dementia is recognised as a disability under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Yet 15 years since its inception, the UNCRPD's implementation remains variable and in many countries dementia is still not recognised as a disability, with the rights of people with dementia under the Convention not realised. As such, Alzheimer Europe created a guide to encourage its members to engage in the UNCRPD review process.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into effect on 3 May 2008. As an international human rights instrument, it was seen as an important milestone in transforming existing approaches to disability, moving from protectionist and discriminatory practices which aimed to act in the best interest of people with disabilities, to a paradigm of empowerment and autonomy, holding people with disabilities as equal citizens, with the same rights and entitlements as anyone else.

Under the definition of disability set out in the UNCRPD, dementia was recognised as a disability, placing obligations on governments to ensure that people living with dementia are supported, requiring that national policies and legislation aligned to the articles of the Convention and upheld the rights of individuals. Since coming into force, the UNCRPD has evidently been the catalyst for wide-ranging legal and political reforms across Europe, both at a national and EU level. However, this is not universally true, with many countries still refusing to recognise dementia as a disability and therefore, not recognising or upholding their rights under the Convention.

Alzheimer Europe is therefore keen for its member organisations to engage in the UNCRPD review process, whereby the UNCRPD Committee reviews the adherence of a country to its obligations under the Convention. Since the Convention came into effect, only one of Alzheimer Europe's national member organisations (the Alzheimer's Society – UK) has engaged in the UNCRPD review process. As a result of their engagement, within the UNCRPD Committee recommendations to the UK government, dementia-specific actions were included amongst these.

The Committee is reliant upon receiving information from a broad range of stakeholders, including non-governmental organisations, in order to formulate its List of issues/Concluding observations, and in particular of representative organisations of persons with disabilities. Although the process cannot itself force governments to change policies or legislation, by drawing attention to gaps in implementation of the Convention, it represents the opportunity for concerns and evidence to be presented to an independent and external actor.



Alzheimer Europe has therefore created a UNCRPD Guide, which outlines the purpose and background to the UNCRPD and the review process, with a specific focus on how the UNCRPD relates to persons with dementia. Additionally, it provides practical information about how Alzheimer's associations may involve themselves in the review process, with practical information about timescales, the format of contributions and the different types of opportunities for contributions (including Periodic Reviews, General Comments etc.). The guide also contains examples of where dementia has been specifically identified in the Concluding Recommendations of the UNCRPD Committee, demonstrating how issues relevant to people can be given a greater focus by engaging in the review process.

Alzheimer Europe is hopeful that by creating the UNCRPD Guide, its member associations will not only gain a greater understanding of why the UNCRPD process is highly relevant for their advocacy and campaigning activities but that it will also provide a useful and practical guide which enables them to be able to take part in the review process in future.

For more information, the UNCRPD Guide can be downloaded at: <https://bit.ly/AEUNCRPDGuide>

Alzheimer Europe calls for urgent action to disclose dementia risk in an open, honest, empathetic and compassionate way

In a position statement published on 30 November 2023, and following engagement with its national members and the European Dementia Carers Working Group (EDCWG), Alzheimer Europe calls for open, honest, empathetic and compassionate disclosure of dementia risk in both research and clinical practice. Soraya Moradi-Bachiller, Public Involvement Officer, tells us more.

Alzheimer's disease (AD) research has recently shifted its focus towards the development of diagnostic tools for earlier detection and risk prediction of dementia. There has also been increased attention on strategies to keep the brain healthy and reduce modifiable risk factors contributing to the disease's onset and progression. This shift would allow dementia researchers to recruit more suitable participants for clinical trials testing new AD treatments that would hopefully benefit more than just those in the latest stages of the disease.

Within this context, people with no known cognitive problems or in the early stage of AD [i.e. Mild Cognitive Impairment (MCI) due to AD], could have their risk of developing cognitive problems or progressing to AD dementia predicted and estimated as part of the research study in which they participate. These risk assessment tools could be ultimately implemented in clinical practice, where people could be tested for their risk of developing dementia.

Alzheimer Europe notes that although dementia risk prediction is happening in research and may be happening in clinical practice in the near future, very little focus has been on the disclosure of such risk. To address this lack of focus on risk disclosure, Alzheimer Europe developed general and specific recommendations, in collaboration

with Alzheimer Europe's national members and the EDCWG. They are grouped as follows:

- General recommendations when disclosing risk for cognitive impairment to cognitively healthy people, or disclosing risk for AD dementia to people with MCI due to AD.
- Specific recommendations when disclosing risk for cognitive impairment to cognitively healthy people.
- Specific recommendations when disclosing the risk for AD dementia to people with a diagnosis of MCI due to AD.

The recommendations are aimed at both clinicians and researchers, as the risk disclosure may happen during someone's participation in research or as part of a person's proactive search for their risk status in a clinical practice. Recommendations include:

- Clinicians should be transparent about the capacity of current therapies and interventions have to create beneficial change and about their limitations. When recommending the adoption of healthy lifestyle choices, clinicians should clarify that the healthiest of lifestyles cannot, unfortunately, guarantee that someone will not experience cognitive impairment or AD dementia.
- Clinicians should also be transparent about the uncertainty of the clinical progression toward cognitive impairment or AD



Soraya Moradi-Bachiller

dementia. Risk prediction for cognitive impairment or AD dementia does not bring certainty or information about the likely course or progression of the disease.

- Clinicians, researchers or counsellors should guide and inform the person on positive actions they can take upon receipt of results, such as positive lifestyle changes, support groups they can join and clinical trials from which they might benefit. Regular appointments should be offered to both monitor the person's clinical progression and support the person.
- Clinicians should consider the personal utility that risk prediction for cognitive impairment may have for the individual. Some people may want to use this information to participate in a dementia prevention clinical trial, and/or to prepare themselves and their families for a possible future with AD.
- Clinicians should also consider personal factors such as age, employment status and their views about available drugs to prevent the development of AD. These factors may contribute to the impact that risk prediction will have on a person's personal and working life, and how they plan to approach life such as accelerating travel plans, taking on new challenges, or devoting more time to voluntary work.
- If different factors such as time constraints make it unrealistic for clinicians to manage the disclosure process, then other professionals like counsellors should be involved in this process.

Our full position statement can be accessed on the Alzheimer Europe website: https://bit.ly/AE_RiskDisclosurePosition

Alzheimer Europe adopts position on anti-amyloid therapies for Alzheimer's disease, issuing a call to action for timely, safe and equitable access

As the first disease-modifying therapies for Alzheimer's disease, anti-amyloid drugs represent a new hope for people living with the condition. In our position paper, we discuss key challenges and highlight important areas for action to enable access. Angela Bradshaw, Director for Research and Policy, tells us more.

The growing prevalence and burden of Alzheimer's disease (AD) has catalysed huge investments in research on its causes, diagnosis, treatment and care. After many high-profile failures, recent clinical trials of anti-amyloid drugs have marked a turning point for the field, leading to the approval of the first disease-modifying therapies for Alzheimer's disease by US regulators. Marketing authorisation applications for two anti-amyloid drugs, lecanemab and donanemab, are currently being reviewed by European regulators. Disease-modifying therapies are potential game-changers for AD. Drugs such as lecanemab and donanemab can slow the processive, clinical decline associated with the disease, with the potential to give patients more time in the less symptomatic stages. However, the benefits and risks of initiating treatment with anti-amyloid drugs are multifaceted and complex, as are the patterns of evidence and effectiveness from clinical trials.

These studies show that anti-amyloid drugs can slow clinical decline – but with a risk of side effects such as brain swelling and bleeds, particularly for people carrying ApoE4 genetic risk alleles. There are also notable challenges that go beyond the core issues of benefit and risk. Access to anti-amyloid drugs hinges entirely on a timely and accurate diagnosis of AD, in the mild cognitive impairment or mild dementia stages, with confirmation of amyloid pathology in the brain. However, diagnosing AD remains challenging in clinical practice,

excluding many from accessing patient-centred support, care and treatments. Currently, European healthcare systems are inadequately resourced to provide a timely diagnosis, let alone equitable access to anti-amyloid drugs, for all people with early AD who could benefit from treatment. The Alzheimer Europe position paper was developed in collaboration with our member organisations and with the European Working Group of People with Dementia. In the position paper, we address questions of anti-amyloid drug efficacy, safety and cost, highlighting three priority areas to ensure equitable access to these innovative treatments.

Firstly, accurate communication of the benefits and risks of anti-amyloid drugs is crucial, to enable informed, supported decision-making for patients and their families. People with AD should receive an accurate and timely diagnosis, regardless of ethnicity, socio-economic status, language, or geographic location, enabling access to treatments, support and care. Finally, European healthcare systems must make concrete infrastructure and workforce investments, to prepare for a future where disease-modifying therapies should be readily accessible to all patients who could benefit. To address these challenges, and enable timely, safe and equitable access to these new drugs, the Alzheimer Europe position paper calls for concrete actions from industry, regulators, payers, healthcare systems and governments.



Angela Bradshaw

These include:

- Accessible, inclusive communication of the benefits and risks of anti-amyloid drugs, so patients can weigh the potential slowing of clinical decline against the side effects, financial costs and logistical burdens of treatment;
- The adoption of realistic, sustainable pricing policies for anti-amyloid drugs, coupled with clear reimbursement frameworks that reflect the true value of treatment for patients and society, without impacting the coverage of existing therapies that are hugely valued by people with dementia and their carers/supporters;
- Development of patient registries for long-term collection of real-world evidence on the efficacy and safety of anti-amyloid drugs, including data on outcomes that are meaningful for patients and their carers/supporters;
- Investment in infrastructures for diagnosis and treatment, with expansion of workforce capacity and capability supported by clear guidance on drug eligibility, and parameters for treatment initiation, safety monitoring and discontinuation;
- Implementation of biomarker-guided clinical pathways which support the diagnosis and treatment of AD in the early stages of disease, integrated alongside existing pathways focused on managing the symptoms of later-stage dementia;
- Continued investment in the development of diagnostics and treatments for other causes and stages of dementia, as well as support and care services that can help people live well with dementia at all stages.

Our full position paper can be accessed on the Alzheimer Europe website: https://bit.ly/AE_AntiAmyloidTreatmentPosition

Luxembourg hosts collaborative event for Public Involvement in European brain health research

At the first event of its kind, six European research projects joined together in a series of consultations focusing on Public Involvement in dementia and brain health research, organised by Alzheimer Europe.



EU-FINGERS, LETHE and Multi-MeMo Advisory Boards, Luxembourg, 14 November 2023

The event took place in Luxembourg from 14 to 16 November 2023 and was hosted and organised by Alzheimer Europe. It involved 44 members of the public (including members of project-specific Advisory Boards and of

the European Working Group of People with Dementia - EWGPWD and their supporters) and several researchers from the different projects involved. The feedback and discussions from these consultations will contribute

“The FNR is proud to support multiple projects that Alzheimer Europe work on, as part of the JPND European Consortium. It is very important for the FNR as a funder to participate in these meetings, to see the impact of such Advisory Boards on research and it's fascinating to see the difference that people make when they are involved and integrated into a project from the very beginning and throughout the lifespan of such a project.”
Sean Sapcariu

towards the work of these six EU-funded projects (EU-FINGERS, LETHE, Multi-MeMo, eBRAIN-Health, EPND and ADIS).

Members of the Advisory Boards are people at a higher risk of/or living with dementia, carers and supporters of people with dementia and other lay people with an interest in brain health and dementia. This was the first collaborative meeting of this type and scale, uniting projects working on different aspects of brain health and dementia research, funded through the three largest research and innovation programmes in Europe: The Joint Programme on Neurodegenerative Diseases, Innovative Medicines Initiative and Horizon Europe.

During this collaborative event, Alzheimer Europe produced a series of insightful video interviews. Advisory Board members discussed their vital contributions and emphasised the importance of Public Involvement. The videos are available on the Alzheimer Europe <https://bit.ly/PublicInvolvementEvent>

Multidomain interventions & communication tools for discussing risk of dementia

The first consultation held on 14 November gathered 17 members of the EU-FINGERS, LETHE and Multi-MeMo Advisory Boards who met for the very first time in person. Members came from nine European countries (Austria, Finland, Hungary, Italy, Luxembourg, Netherlands, Spain, Sweden and the United Kingdom) to discuss topics around multidomain interventions to reduce dementia risk and communication tools for discussing risk of dementia with patients. The meeting was co-facilitated by Alzheimer Europe (Ana Diaz and Cindy Birck) and several researchers representing the different projects: Francesca Mangialasche (KI), Anna Rosenberg (THL), Mariagnese Barbera (UEF), Leonie Visser, Tanja de Rijke and Heleen Hendriksen (Amsterdam UMC – Alzheimer Center Amsterdam).

Ana Diaz welcomed delegates, emphasised the importance of their presence and the pleasant spirit driving the meeting. Then, Sean Sapcariu provided valuable insights into the Luxembourg National Research Fund (FNR), the main funder of research activities in Luxembourg. Next, Francesca Mangialasche



Consultation with the EU-FINGERS, LETHE and Multi-MeMo Advisory Boards, Luxembourg, 14 November 2023

and Anna Rosenberg took the floor to provide a comprehensive update on the EU-FINGERS and LETHE projects. They reminded the aims and mission of each project and both emphasised the pivotal role of the Advisory Board members as essential partners to guide and influence relevant decisions on how the research activities are conducted. The heart of the consultation unfolded through four workshops in small groups, facilitated by Anna Rosenberg, Leonie Visser, Tanja de Rijke and Heleen Hendriksen and co-facilitated by Francesca Mangialasche, Ana Diaz, Cindy Birck and Mariagnese Barbera. Members were engaged in dynamic discussions, exchanging thoughts and ideas on: 1) social activities in digital multi-domain interventions; 2) information needs on future Alzheimer's disease medication; 3) a new tool to help patients and supporters to share personal information and 4) the implementation of tools to support preparation for memory clinic consultations. Mariagnese Barbera concluded the event by presenting the overarching goals of the Multi-MeMo project and highlighting the continuity of Public Involvement work from EU-FINGERS to Multi-MeMo.

Consent and data-sharing in dementia research

On 15 and 16 November, it was the turn of two further projects, EPND and ADIS. EPND, (European Platform for Neurodegenerative Diseases) is a public-private partnership project funded through the Innovative Medicines Initiative. EPND aims to accelerate the discovery of diagnostics and treatments for neurodegenerative diseases such as AD, by creating a collaborative platform for data and sample sharing. ADIS, which stands for "Early

Diagnosis of AD by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances", also has a focus on diagnostics, and is evaluating how immune profiling and sleep data can enhance the prediction of risk and early diagnosis.

Informed consent is an important topic for both projects. For ADIS, informed consent for participation in the ADIS study is crucial, while for EPND, informed consent for data and sample sharing is a fundamental requirement for the platform. The ADIS and EPND consultations brought together people with Mild Cognitive Impairment (MCI), people with dementia and their carers and supporters, to obtain feedback on key challenges for informed consent; the design of forms and processes; terminology and perspectives on sharing of data and samples.

The consultations were moderated by Ana Diaz, Cindy Birck, Soraya Moradi-Bachiller and Angela Bradshaw, and involved, on 15 November, members of the EWGPWD and their supporters, and on 16, members of the ADIS Advisory Board (people with MCI and their supporters). They emphasised that informed consent forms and processes should be flexible and adaptable, to meet individual needs and levels of understanding. Awareness of research, and the value of research participation, was identified as a key enabler of informed consent. In the latter half of the consultation, they reviewed clauses extracted from informed consent forms used in clinical research studies. They underlined the importance of using language that is precise and accurate, but also understandable, identifying terms that are unclear, or potentially confusing. Drawing the consultations to a close, they expressed their

“I really like to tell the Advisory Board members that with their contributions they do not only make our project better but they make us better scientists.”
Mariagnese Barbera

views on data and sample sharing, reinforcing their support for sharing to maximise the value and impact of research – to benefit the next generation and “make a difference” for people affected by dementia now, and in the future.

Feedback on a cognitive training application and on virtual reality tools used in the context of brain health and dementia

Another consultation, which also took place on 15 November, was related to the eBRAIN-Health project and involved members of the project's Public and Patient Advisory Group, two members of the EWGPWD and a member of another Alzheimer Europe Advisory Group.

Santiago Brandi and Aarushi Sharma, both from Eodyne Systems, a partner in the eBRAIN-Health project, also joined the meeting, together with Daphné Lamirel and Chris Bintener. The meeting started with an introduction from Daphné. Santiago then presented more information about the eBRAIN-Health project, including the RGS app used for cognitive training and rehabilitation which will make use of some of the data gathered through the eBRAIN-Health platform.

During the first part of the consultation, members tested the RGS app, engaging in memory-focussed games and then completing a written questionnaire sharing their experiences. Subsequently, they explored a set of Augmented Reality (AR) games, distinct from conventional 2D games. A specific questionnaire was then administered to capture their thoughts on this experience. In a group discussion, participants shared their overall impressions of the app, offering valuable



Spanish language ADIS consultation, Luxembourg, 16 November 2023

insights on improving user experience for individuals with dementia, MCI or with no cognitive problems but interested in mitigating dementia risk. Feedback included suggestions to enhance app functionality and insights into the disparities between experiences with 2D and AR games. Participants elaborated on the barriers to using these kinds of tools at home.

In the afternoon, attendees tested another technological tool developed by Eodyne: a virtual reality (VR) game designed to train spatial orientation and cognition, and act as a distraction from chronic pain. Some volunteers tested the VR tool in front of the group, while others observed on a screen. The group proposed ideas on how to improve this tool and make it more relevant to the preferences of different groups of people (e.g. people with dementia, women, etc.).

Overall, the eBRAIN-Health meeting proved highly insightful – the feedback of the Advisory Group will enable Eodyne to refine the RGS app and inform the development of additional VR experiences focussed specifically on cognition and dementia.

Information about the projects involved

ADIS stands for "Early Diagnosis of Alzheimer's Disease by Immune Profiling of Cytotoxic Lymphocytes and Recording of Sleep Disturbances". It aims to identify

novel signatures of the immune system and digitally recorded physiology for early prediction of the disease, potentially occurring early in the disease course and associated with rapid clinical decline. ADIS is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project and is supported by the Luxembourg National Research Fund (FNR). www.adis-project.eu

eBRAIN-Health aims to create a platform to facilitate the sharing of brain data and support the development of digital brain twins. Digital brain twins refer to virtual maps of human brains, and can be used

to help research into and clinical management of dementia. The project has received funding from the European Union's Horizon Europe research and innovation programme. www.ebrain-health.eu/

EPND (European Platform for Neurodegenerative Diseases) integrates existing initiatives to build, grow, and deliver a scalable and self-sustainable platform for storage and analysis of high-quality clinical samples and data collections. It is a public-private partnership and has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU). The JU receives support from the European



EWGPWD and Alzheimer Europe staff at ADIS and EPND consultations, Luxembourg, 15 November 2023



eBrain-Health Advisory Board, Luxembourg, 15 November 2023

Union's Horizon2020 research and innovation programme and EFPIA. <https://epnd.org/>

EU-FINGERS is working towards a novel multimodal precision prevention toolbox, based on an existing successful multimodal lifestyle/vascular prevention model, FINGER (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) and on a precision prevention and early detection (PPED) approach, adapted from cancer research. EU-FINGERS is an EU Joint Programme - Neurodegenerative Disease Research (JPND) project and is supported by the Luxembourg National Research Fund (FNR). <https://eufingers.com/>

LETHE aims to provide a data-driven risk factor prediction model for older individuals at risk of cognitive decline, building upon big data analysis of cross-sectional observational and longitudinal intervention datasets from four clinical centres in Europe including an 11-year analysis of the FINGER study. The project has received funding from the European Union's Horizon 2020 research and innovation programme. www.lethe-project.eu/

Multi-MeMo stands for "Shorter- and longer-term mechanisms of multimodal interventions to prevent dementia". Funded by the EU Joint Programme for Neurodegenerative Diseases Research (JPND) and supported by the Luxembourg National Research Fund (FNR), the project aligns experimental molecular, cellular, and animal models with a very strong array of

unique multi-national multimodal human trials which have already demonstrated multi-year cognitive and functional benefits across the entire continuum from at-risk to prodromal disease stages. www.multi-memo.eu/

Funding

Funding of the event came from the Luxembourg National Research Fund (FNR) (INTER/JPND21/15741011/ADIS, INTER/JPND/19/14012609/EU-FINGERS; INTER/JPND22/17107181/Multi-MeMo) under

“Public involvement in research is very important, especially those with the lived experience. We bring a wealth of knowledge to the professionals, and it's definitely a case of nothing about us, without all of us. We can contribute so much and it's great to work together. It gives me hope and it gives me confidence.”
Chris Roberts

the aegis of the EU Joint Programme – Neurodegenerative Disease Research (JPND), the European Union's Horizon 2020 research and Innovation programme under grant agreement No 101017405 (LETHE), the European Union's Horizon Europe research and innovation programme under grant agreement No. 101058516 (eBRAIN-Health) and the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 101034344 (EPND). The JU receives support from the European Union's Horizon2020 research and innovation programme and EFPIA.



EU-FINGERS – Collaborative initiative developing tools to conduct new clinical studies for the prevention of Alzheimer’s disease and dementia

As the EU-FINGERS project draws to a close, Alzheimer Europe looks back at the innovative project and the achievements to date.



EU-FINGERS General Assembly meeting, Stockholm, November 2022

The landscape

In recent decades, a lot of research has highlighted the impact of several modifiable factors on brain health, including lifestyles and factors related to vascular and metabolic health. The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) demonstrated for the first time that a two-year multimodal life-style intervention combining nutritional guidance, physical exercise, cognitive training, social stimulation and management of vascular and metabolic factors benefitted cognition in older people at increased risk of dementia.

An innovative project

EU-FINGERS builds upon the successful experience of FINGER and aims to develop tools to advance, optimise and scale-up the FINGER model across Europe. These tools include methods to accurately measure the level of risk in older adults, both in terms of developing brain pathology and cognitive decline, as well as their prevention potential, in order to identify subjects with different risk profiles, who are more likely to benefit from specific preventative interventions.

EU-FINGERS is a multinational interdisciplinary consortium that has been growing since

its launch in 2020 and is part of the global World-Wide FINGERS® network of multidomain trials for dementia risk reduction and prevention. The project, led by Karolinska Institutet in conjunction with 11 partners organisations, was funded by the EU Joint Programme – Neurodegenerative Disease Research (JPND) until 31 December 2023.

EU-FINGERS achieved several milestones: first and foremost, the consortium has grown with the inclusion of three research teams, from Hungary, Luxembourg and Spain, thus becoming even more representative of the European landscape and maximising the impact of this JPND-supported project. The expansion enriched availability of relevant data, with a total of about 2.000 participants from preventive trials and over 16.000 participants from observational studies on brain aging and Alzheimer’s disease. Secondly, the consortium developed tools supporting new intervention studies and the launch of two novel multidomain interventions (MET-FINGER, FINGER-NL). These innovative clinical trials are testing the FINGER updated life-style intervention with the drug metformin (MET-FINGER) or medical food (FINGER-NL). Finally, engagement of citizens has been achieved, establishing an Advisory Board which provided relevant input to carry on the consortium’s work.

The EU-FINGERS tools

The EU-FINGERS tools and methods are enabling a new generation of clinical trials, to find effective and sustainable multidomain programmes to reduce dementia risk or to slow down Alzheimer’s disease and other brain disorders leading to memory problems and dementia.

Tools and methods developed in EU-FINGERS include:

- Tools to measure the prevention potential of individuals and help early identification of people at risk of experiencing cognitive decline and/or of developing Alzheimer’s dementia, who can benefit most from specific preventive interventions
- Protocol to design and conduct new clinical trials combining lifestyle amelioration and medications (MET-FINGER, FINGER-NL) supporting brain health

- Online registry for the population to provide easy access to reliable information on projects related to dementia prevention, with possibility to sign-up and express interest in participating in intervention studies
- Guidelines for clinicians on how to best inform persons with no memory problems (or mild problems) about the results of medical tests related to Alzheimer's disease and how to empower the person with no memory problems (or mild problems) in deciding and engaging in an individualised plan to prevent dementia.

The Advisory Board

EU-FINGERS recognises the importance of Public Involvement in shaping its activities. At the heart of this initiative lies the Advisory Board, a unique group composed by 16 people from the general public, with and without cognitive problems (i.e. older adults who had participated in previous studies, who were at a higher risk of dementia, with Mild Cognitive Impairment or mild dementia, or informal carers) from seven different European countries (Finland, Hungary, Luxembourg, Netherlands, Spain, Sweden and the United Kingdom).

Led by Alzheimer Europe in close collaboration with project partners, the EU-FINGERS Advisory Board brought a unique perspective and actively and meaningfully contributed towards several aspects of the project. This helps to ensure that the voices of different people from the public, with an interest in the topics addressed in the project, were heard and taken into account. Members actively participated in regular discussions, providing valuable insights and recommendations that help shape the direction of the consortium's activities.

A few words from EU-FINGERS members



Miia Kivipelto

"We have developed innovative tools, which open new avenues in the field of Alzheimer's disease and dementia prevention, and we are testing them in pioneering trials. EU-FINGERS is also providing much needed guidance to healthcare professionals on how to support the increasing number of older adults who access memory clinics to have answers on their concerns about dementia risk. We have today many effective tools to support brain health, and we work to make them available across Europe", said Professor Miia Kivipelto, EU-FINGERS Project Coordinator (Karolinska Institutet).



Ana Diaz

"Alzheimer Europe is keen to promote the involvement of people with dementia and from the general public in research, in the context of Public Involvement. Collaborating closely with project partners in shaping the EU-FINGERS Advisory Board was a pleasure. The involvement of the EU-FINGERS Advisory Board was pivotal fostering a collaborative journey towards meaningful and relevant advancements. Their expertise and diverse perspectives served as compass points, ensuring that the projects activities were aligned with real-world needs", said Public Involvement Lead Ana Diaz (Alzheimer Europe).



Nick Montague

"Being part of the EU-FINGERS Advisory Board is very important and also very rewarding. It has taught me a lot. I have no medical background nor knowledge of medicine and I do not understand any medical acronyms, which is a perfect reason as to why people such as myself can contribute to the EU-FINGERS Advisory Board. We have first-hand experience of mental issues and combining our expertise with the wonderful work that the researchers do, make it a much more powerful and realistic form of research", said Nick, member of the EU-FINGERS Advisory Board.

"Brain health is very important and there is so much that we can learn about it. I am researcher by profession and I am really interested by research. It was important to be part of the EU-FINGERS Advisory Board and it has been a great pleasure to work together with European researchers.", said Sylvia, member of the EU-FINGERS Advisory Board.

Acknowledgement

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The project is supported through the following funding organisations: Finland, Academy of Finland; Germany, Federal Ministry of Education and Research; Hungary, National Research, Development and Innovation Office; Luxemburg, National Research Fund; The Netherlands, Netherlands Organisation for Health Research and Development; Spain, National Institute of Health Carlos III; Sweden, Swedish Research Council.





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Slovenia publishes second National dementia strategy

On 6 July 2023, the Slovenian Government adopted the Strategy for Dementia Management in Slovenia until 2030. The strategy pursues 10 goals aligned with the recommendations of the World Health Organization (WHO) and the principles of human rights protection, aiming to promote healthy ageing and improve the quality of life of people with dementia and their relatives. In this article, Minister of Health, Valentina Prevolnik Rupel, outlines more details about the new strategy, and President of Spominčica, Štefanija L. Zlobec, shares the association's response to the Strategy.



This is Slovenia's second National dementia strategy – how does this new strategy build on the first and what are its priorities?

The second National dementia management strategy is an upgrade of the first strategy from 2016. Most of the members of the working group at the Ministry of Health participated in the preparation of the first strategy. However, I must also highlight the fact that Slovenia is a small country, so documents from international organisations such as the World Health Organization (WHO), the Organisation for Economic and Co-operation and Development OECD (OECD), the Council of Europe, EU organisations and relevant non-governmental organisations are also very important for the effective planning and implementation of the National dementia strategy such as Alzheimer Europe and Spominčica – Alzheimer Slovenia. Documents created after 2016, such as the Global Action Plan on the Public Health Response to Dementia 2017-2025, Global Dementia Observatory, Care Needed: Improving the Lives of People with Dementia and Alzheimer Europe report were of great support to the working group.

Due to the experience during the COVID-19 epidemic, we have added "Appropriate treatment of people with dementia during epidemics and other emergency situations" to the goals of the strategy.

The strategy defines ten goals:

- Promotion of preventive programmes for reducing risk factors and for maintaining and strengthening health in the community with different approaches to individual groups and individuals
- Diagnosing the early stages of neuro-cognitive disorders, improving access to quality, safe and effective health care and treatment
- Improving access to appropriate and coordinated post-diagnostic multidisciplinary treatment for people with dementia, including integrated treatment, long-term care, social services, support for families or caregivers in the local environment, and access to palliative care
- Use of modern information and communication technologies for the treatment and support of people with dementia

- Respecting the dignity of people with dementia, reducing stigma and raising awareness of the wider society and the professional public for the development and establishment of dementia-friendly communities
- Education of all professional groups in the field of dementia management
- Establishing national dementia data collection
- Promoting dementia research
- Establishing a National Dementia Centre, and
- Appropriate treatment of persons with dementia during epidemics and other emergencies.

How was the strategy developed and how were people with lived experience (people with dementia, carers etc.) involved in the process?

The strategy proposal was prepared by a working group at the Ministry of Health, which included representatives of the Ministry of Health, the Ministry of Labour, Family, Social Affairs and Equal Opportunities, neurological and psychiatric professions, family medicine, nursing, the National Institute for Public Health. Other people with dementia, informal carers, experts and the interested public and other stakeholders participated in the public hearing, which lasted from 2 November to 2 December 2022.

What is the role of civil society organisations such as Spominčica – Alzheimer Slovenia in helping to realise the aims of the strategy?

Dementia is a disease that goes beyond the medical field, as people with dementia have the most problems in performing everyday tasks, in which they are generally more or less dependent on the help of others. Therefore, an interdisciplinary approach and intersectoral cooperation are important for managing dementia.

In order to create a dementia-friendly environment, in addition to integrated treatment in the local environment, we must also improve the literacy of the population about dementia and establish effective cooperation of all stakeholders in the chain

of care for people with dementia. We must offer special support to relatives and other informal caregivers of people with dementia, as they can also become ill themselves due to heavy burdens. In establishing a dementia-friendly environment, non-governmental organisations play an important role when they supplement the services of public services with their programmes. Spominčica is the most important non-governmental organisation in the field of dementia in Slovenia. Its network of activities is spread across all Slovenian regions, so its activities can significantly contribute to prevention measures, social inclusion and the reduction of loneliness, education of professional and lay stakeholders, awareness of various publics and destigmatisation of this disease. With its projects and programmes, Spominčica is an important partner of the Ministry in planning and implementing programmes for managing dementia. The Ministry of Health co-finance through public tenders those programmes of non-governmental organisations that are coordinated with the national programmes and guidelines of the Ministry. The last tender of this kind was carried out in 2021 for the co-financing of dementia management programmes in 2021, 2022 and 2023. Spominčica established a consortium of partners from the field of psychiatric or neurological professions, health professions at the primary level and social welfare professions.

Is there funding dedicated for delivering the aims of the strategy?

The Dementia Strategy is designed to complement other national health and social care programmes that affect healthy aging and access to dementia services. We must consider the adoption of the Law on long-term treatment, the Resolution on the National Mental Health Programme 2018-2028 (which establishes a network of adult mental health centres at the primary health care level, with mobile teams for home treatment, the Ministry's measures to supplement the network of personal/family doctors, the increase of the number of specialisations in psychiatry, neurology and clinical psychology, the Resolution on

the National Health Care Plan 2016-2025, the Resolution on the National Social Care Programme for the period 2021-2030 and other national programmes, which are also partly aimed at managing dementia and are financed from other sources.

The Strategy plans new measures for people with dementia and their caregivers also. For these measures, special dedicated funds are provided within the framework of the European financial perspective 2021-2027 in the amount of approximately EUR 15 million. In order to comprehensively manage the problem of dementia and effective planning of the use of financial and personnel resources, as set out in the strategy, in Slovenia we still need to obtain some data and prepare appropriate professional bases, which is the priority of the first action plan for the years 2024-2025.

What will be key factors for the successful implementation of the Strategy?

The key factors for the successful implementation of the Strategy are: good planning at the national level, a clearly defined management structure, good intersectoral cooperation between different professions, raising the population's literacy about dementia and a healthy lifestyle, the connection of all stakeholders in the chain of care for people with dementia at the national and local environment. Destigmatisation of this disease is also crucial for successful implementation.

For the effective implementation of the Strategy, the sui generis establishment of a National centre for dementia is planned. The centre will take care of the effective, professional, high-quality and cost-effective implementation of the Strategy and promote awareness and education of the general and target public. In the future, the National Dementia Centre will be a partner and professional support for the state administration and other stakeholders in planning or implementing measures to control dementia in Slovenia.

The new strategy is available at: www.gov.si/teme/demenca/

Štefanija L. Zlobec, President, Spominčica - Alzheimer Slovenija shares the organisation's view of the new strategy



Štefanija L. Zlobec

The Slovenian Government adopted the second Dementia Strategy in Slovenia until 2030 in July 2023. The second strategy was prepared by an interdisciplinary working group which was appointed by the Minister of Health in 2019. The working group consisted of experts from the Ministry of Health, Ministry of Labour, Family, Social Affairs and Equal Opportunities, Psychiatric Clinic of Ljubljana, Neurology Clinic of Ljubljana, National Institute for Public Health, GP's and Štefanija L. Zlobec, the president of Spominčica – Alzheimer Slovenia. Due to the COVID-19 situation and the change of the Government after the elections in 2022, there was a delay in the completion and adoption of the strategy. As the adoption of the strategy was at a standstill, the President of Slovenia, on the initiative of Spominčica, established the Slovenian Council for the Dementia Strategy in November 2022. The President of the Republic of Slovenia and members of the Council supported the proposed strategy and the Ministry of Health launched the activities for the adoption of the strategy.

The Dementia Strategy in Slovenia until 2030 is a fundamental document and represents a continuation of the first Slovenian dementia strategy. The first strategy was adopted in 2016 for the period 2016 – 2020. Slovenia has been one of the first countries in the EU to have this document. Spominčica and Dr. Aleš Kogoj, a psychiatrist and founder of Spominčica, were the initiators of the formation of an interdisciplinary working group by the Ministry of Health to start the preparation of the first Strategy. The first Strategy produced good results in reducing the stigma of dementia, awareness raising about dementia, timely diagnosis and prevention, and in the field of capacity building with training programmes and education of more than 10.000 healthcare professionals, formal and informal carers of persons with dementia.

To raise awareness about dementia, Spominčica started with the national programme Dementia Friendly Points (DFP) in 2017 and in 2023 we are close to 500 DFP in Slovenia. The first DFP was opened at the Human Rights Ombudsman Office after the training of their employees. The programme aims to get as close as possible to the people who live and work in local communities. We are getting an overwhelmingly strong response from a wide range of organisations. Before opening a DFP, we always organise training for staff on dementia and recognising the first signs, the appropriate approach and communication. Together with DFP organisations in local settings across Slovenia, we promote and facilitate the integration of people with dementia and their families into the community as active members and to maintain their autonomy. The DFP network consists of 124 different organisations like homes for the elderly, community health centres, pharmacies, libraries, museums, shops, banks, post offices, police stations, centres for social work, as well as Ministries, the Public health institute, the Medical Chamber and the Social Chamber and the Office of the President of the Republic of Slovenia. This also indicates that people and organisations

with a sense of social responsibility are willing to help create a dementia-friendly environment and, moreover, that we as civil society can make such initiatives national. The DFP programme was recognised by the WHO as a dementia friendly initiative best practice.

The Dementia Strategy in Slovenia until 2030 is built on the essential elements and commitments contained in the documents adopted at the level of the European Union and the World Health Organization, as well as strategies in the field of dementia management in other countries. It enables a coordinated and integrated approach of all stakeholders in solving the problem of dementia and related conditions. The strategy aims to ensure preventive measures, early diagnosis of the disease and an appropriate standard of medical and social care for people with dementia. It is based on the knowledge that people with dementia are a particularly vulnerable target group, which is rapidly increasing due to demographic changes and the aging of the population while focusing on the individual and their needs, which requires coordinated and responsive action by the State and a multidisciplinary treatment approach.

As a special achievement, we at Spominčica consider that, at our initiative and insistence, the Strategy includes an action point to regulate the legal framework for the disability status of people with dementia.

The adoption of the Long-Term Care Act in Slovenia is also an important development. Spominčica has consistently emphasised that the implementation of the Act must take into account the specific needs of people with dementia, the vast majority of whom live at home, so that they and their families have an adequate level of services. We are agreeing with the Ministry of Solidarity-Based Future, which covers long-term care, that Spominčica will be involved in the training of access points for the allocation of long-term care services.

Alzheimer Europe launches European election campaign 2024

In the run up to the European Parliament elections (6-9 June 2024), Alzheimer Europe has launched its European election campaign 2024, aiming for dementia to be prioritised as a policy matter at a European level. Building on previous advocacy work, the campaign has been developed with three distinct elements: The Helsinki Manifesto; A public Call to Action, and the Dementia Pledge 2024. In this article, we look in more detail at each part of the campaign.

In June 2024, people across Europe will go to the polls to elect their representatives in the European Parliament. The new term of the European Commission will start in the autumn, bringing together 26 Commissioners led by a President.

The election falls in the context of World Health Organization (WHO) figures showing that dementia is the third leading cause of mortality in Europe and the seventh globally, with an estimated societal cost of EUR 392 billion in Europe. By 2025, 9.1 million people

will be living with dementia in the European Union, rising to 14.3 million in 2050. Despite this, in recent years, a number of policy commitments made at international and European level, including those of the WHO Global Action Plan on the Public Health Response to Dementia 2017-2025, have not been met. Furthermore, dementia has been deprioritised as a policy issue at a European level in recent years.

As such, in advance of the 2024 elections and the new term (2024-2029) of the European

Commission, Alzheimer Europe has adopted a campaign with three distinct elements:

- The Helsinki Manifesto
- A public Call to Action
- The Dementia Pledge 2024.

As part of the campaign, Alzheimer Europe worked with members of the European Working Group of People with Dementia and the European Dementia Carers Working Group to create videos for use on social media, with members of the groups sharing their own experiences of dementia and calling for decision-makers to prioritise dementia as a policy issue.

You can view these videos at: <https://vimeo.com/showcase/10986239>

Once the campaign has concluded, Alzheimer Europe will work with its national member associations to follow up with elected MEPs who supported the Dementia Pledge, to identify where dementia must be prioritised and to ensure that the aims of the Helsinki Manifesto are embedded in the Commission's priorities for the new legislative term.

You can find more information about the campaign on the Alzheimer Europe website: <https://bit.ly/AE2024EUCampaign>





The Helsinki Manifesto was adopted at Alzheimer Europe's Annual General Meeting in Helsinki, Finland, on 16 October 2023

Helsinki Manifesto

Ten years on from the Glasgow Declaration (2014), dementia has been deprioritised at a European level and in many European countries. This has taken place despite the growing number of people living with the condition and the continued lack of access to diagnosis, treatment and care, which have been identified as long-standing challenges in countries across Europe.

In response, at our Annual General Meeting on 16 October 2023, in Helsinki, Finland, our members adopted the “Helsinki Manifesto”, which outlines the current position of dementia across Europe and lays the foundation for Alzheimer Europe’s campaigning activities over the next five years (2024-2029), in the run up to the European Parliament elections and the next term of the European Commission.

The Helsinki Manifesto is divided into the following policy areas:

- Health
- Research

- Disability and social rights
- Support for informal carers.

Under each policy area, a brief rationale for action is outlined, followed by a number of specific demands for European and national decisions-makers, including:

- Invest in improvements to support timely diagnosis, including access to imaging, bio-marker testing and new treatment options
- An increase in the funding allocated for dementia research which is proportionate to its societal cost, bringing the total funding to at least the level of other non-communicable diseases
- The prioritisation of dementia in future health programmes with dedicated funding for projects and actions in line with other non-communicable diseases (e.g. cancer)
- The development and implementation of a European Dementia Action Plan, to coordinate efforts and programmes across the domains of health, research and social affairs.

European and national organisations have been invited to endorse the Manifesto. At the time of publication, all of Alzheimer Europe’s members had endorsed the Manifesto, as well as the following organisations:

- AENMA Centro de día terapéutico
- Alzheimer’s Disease International (ADI)
- Council of Occupational Therapists for the European Countries (COTEC)
- Eurocarers
- European Federation of Neurological Associations (EFNA)
- European Institute of Women’s Health (EIWH)
- International Psychogeriatric Association
- Women’s Brain Project

The full Manifesto is available on Alzheimer Europe’s website at: <https://bit.ly/AEHelsinkiManifesto>

Public Call to Action

In the second strand of the Campaign, Alzheimer Europe has developed a Call to Action, asking for the support of the general public to demand that European decision-makers prioritise dementia as a policy issue and implement the actions of the Helsinki Manifesto. Alzheimer Europe is working with its members to distribute the call throughout its networks, to encourage members of the public to sign the call on its website.

The call has been translated into the different languages of Alzheimer Europe's members, to help the Call be understood more widely and to encourage people to sign up.

The text of the Call can be seen below: By 2025, 9.1 million people will be living with dementia in Europe. By 2050, this number is estimated to reach 14.3 million. According to World Health Organization's (WHO) it is the third leading cause of mortality in Europe and the seventh globally. Furthermore, the WHO estimates that the cost of dementia in the European region in 2019 was EUR 392 billion. As such, Alzheimer Europe and its member organisations are asking for your support to call for European Union leaders to make dementia a priority in the forthcoming term 2024-2029, implementing the actions of the Helsinki Manifesto.

Show your support by signing the call below!

The Call to Action is available to sign on Alzheimer Europe's website at: <https://bit.ly/AECallToAction2024>



Dementia Pledge 2024

The third strand of Alzheimer Europe's campaign is its direct appeal to candidates standing in the European Parliament Elections 2024, calling on them to support making dementia a European priority by asking them to sign the Dementia Pledge 2024.

Candidates who sign the Dementia Pledge, upon election, commit to joining the European Alzheimer's Alliance and to prioritising dementia during their work as parliamentarians.

Members of the European Parliament have the opportunity to play a key role in prioritising dementia in a number of ways, including:

- Asking questions of (prospective) Commissioners with responsibility for policy areas such as Health, Research and Social Affairs, to ensure dementia is prioritised
- Using their position as members of European Parliament committees or as Rapporteurs in order to improve legislation which will affect people with dementia and their carers

- Raising awareness through their communications activities to colleagues and stakeholders to ensure dementia is understood and addressed at a European level.

The Pledge is below, in full.

The Pledge and signatories can be viewed on Alzheimer Europe's website at: <https://bit.ly/DementiaPledge2024>



Sign the European Dementia Pledge 2024

#DementiaPledge2024

I pledge that, upon my election to the European Parliament, I will:

1. Join the European Alzheimer's Alliance

2. Support the campaign of Alzheimer Europe and its member organisations to make dementia a European priority, with specific actions in the following four key areas:

- Ensuring dedicated EU funding for dementia-focused research across all disciplines, commensurate with the societal and economic cost associated with dementia
- Responding to the scale of dementia as a health challenge by prioritising the condition as part of the next health programme of the EU
- Acknowledging dementia as a disability, affording people with dementia the rights guaranteed under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- Undertaking focused work at an EU level to provide greater support and protections for carers

Irish Health Service Executive outlines Model of Care for Dementia

Following the publication of the Model of Care for Dementia in Ireland in May 2023, Dr Mairéad Bracken-Scally and Dr Seán O'Dowd from the Irish Health Service Executive, spoke to Alzheimer Europe about the development of the Model of Care and what it means for people living with dementia, their families and carers.

Can you tell us about the development of the Model of Care for Dementia in Ireland?

The Irish National Dementia Strategy was published in 2014. Following this, the National Dementia Office was established within the Health Service Executive (HSE) in 2015 to oversee the implementation of the National Dementia Strategy through partnership and collaboration with key stakeholders including people living with dementia and family carers. In 2017, the National Dementia Office commenced dementia diagnostic and post-diagnostic projects to address one of the Strategy's priority action areas: timely diagnosis and intervention. The aim of these projects was to investigate current and good practice in relation to (i) dementia diagnosis and (ii) supports for people once they have received their diagnosis.



Mairéad Bracken-Scally

Utilising evidence from both of these projects, work commenced on developing the Model of Care for Dementia. National and international evidence informed the development of the Model of Care, as well as consultations with people living with dementia, family carers, clinical groups, health and social care professionals, and guidance from an expert advisory group from across disciplines and sectors. The Model of Care for Dementia builds on work undertaken to date in relation to the National Dementia Strategy, the Health Service Executive Corporate Plan, and has been developed in line with the Programme for Government objectives and "Sláintecare" (Ireland's health reform agenda), where delivering the right care, in the right place, at the right time, given by the right team, is a central principle.

The Model of Care aims to address system shortcomings, providing earlier recognition and intervention for those living with dementia, as well as their support networks. It provides an integrated framework to bring together a wide range of services into a coherent pathway for people living with dementia. Five key principals underpin the Model of Care: Citizenship; A person-centred approach; Integration; Personal outcome-focused and Timeliness. The model also takes into account the principles and approach of Sláintecare where people may receive care and support in different care settings and by different services but where "home first" is a primary focus.



Seán O'Dowd

Speaking at the launch of the Model in May 2023, Minister of State for Mental Health and Older Persons, Mary Butler explained: "This Model of Care underpins our values of placing people living with dementia at the centre of all considerations relating to their health and wellbeing. It is an innovative approach which ensures that people can be supported within their own communities. There has been a real dementia culture change in Ireland. People know more about dementia and we see communities coming together to include and support people with dementia. With the Model of Care, the emphasis is also on community integration of a wide range of post-diagnostic support services, not only for the person with dementia but also their families, carers and supporters."

What are the key components of the Model of Care for Dementia?

The Model of Care for Dementia sets out the optimum care and support pathways for people living with dementia, from the point of concern when first noticing symptoms (e.g. change in cognition, behaviour, memory, mental health, mood or personality) to receiving a variety of supports in the community and at home. It describes adaptable pathways of care that maximise the use of existing structures, the enhancement of current services and new service requirements.

It also outlines integrated working across services and personalised care to reach the outcomes most important for each individual. Specifically, the model includes guidance on:

- Dementia assessment and targets for diagnostic services.
- An outline of the dementia diagnostic pathway and the required assessment service infrastructure, describing three levels within the assessment and diagnostic pathway.
- Guidance on best practice and key steps in communicating a diagnosis of dementia.
- Recommendations on the key elements of personalised care planning.
- Targets and recommendations on early post-diagnostic support and details on the dementia post-diagnostic care pathway with examples of supports and interventions, which can be provided across five strands of support.

The Model of Care seeks to place Ireland to the fore internationally in our approach to brain health, cognitive impairment and dementia, and ensure the delivery of timely and effective assessment and the enhancement of integrated dementia services in Ireland.

What is the potential benefit for people living with dementia, their families and carers?

The core of the Model is ensuring a person-centred approach to the delivery of dementia services in Ireland, involving the person with dementia from the first stage of diagnostics through to post-diagnostic supports. Its purpose is to support people to navigate the system, addresses diagnostic and post-diagnostic supports for all stages of dementia and emphasises the importance of an individualised and flexible approach. It aims to reduce waiting times to specialist services with easier and timelier access to assessment, diagnosis and continuous post-diagnostic supports. The model supports practitioners to diagnose dementia and to identify and prescribe appropriate supports.

Family carers and supporters are the backbone of the care ecosystem for people living with dementia. It is estimated that for every one person with dementia, there are three others supporting those living with the condition and providing care. The Model of Care for Dementia outlines pathways of care that promote autonomy, timeliness, outcome-focused, person-centred and citizenship approaches for people living with dementia; the care pathways will also be enablers for family carers and supporters also. The Model

identifies assessment of family carer needs, and the provision of education and skills training in dementia for family carers and supporters, as key targets.

What does the Model of Care for Dementia mean for the Healthcare System in Ireland?

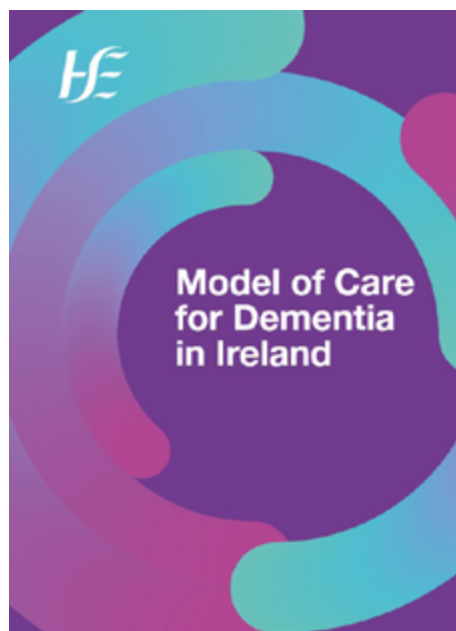
The Model of Care places the person with dementia at the centre of care planning and decision-making, promoting an outcome-focused approach that meets each of the aims of the Health Service Executive Corporate Plan (as illustrated below).

Implementation of this Model of Care will also assist Ireland in meeting the targets set out by the World Health Organisation's Global Action Plan on Dementia (2017-2025), across seven action areas:

- Action area 1: Dementia as a public health priority.
- Action area 2: Dementia awareness and friendliness.
- Action area 3: Dementia risk reduction.
- Action area 4: Dementia diagnosis, treatment, care and support.
- Action area 5: Support for dementia carers.
- Action area 6: Information systems for dementia.
- Action area 7: Dementia research and innovation.



The Model of Care was launched on 31 May 2023 by Minister of State for Mental Health and Older Persons, Mary Butler (4th from left)



The Model of Care sets out the blueprint for optimum care and support pathways for people living with dementia, from the point of concern when first reporting symptoms to home care in the community. As part of this, memory services will be enhanced across Ireland allowing quicker access and expert opinion for primary care and acute healthcare workers who may wish to refer their patients. The diagnostic model utilises three levels of assessment that will not only be integrated with each other, but more importantly will be integrated with existing community services.

“The core of the Model is ensuring a person-centred approach to the delivery of dementia services in Ireland, involving the person with dementia from the first stage of diagnostics through to post-diagnostic supports.”

Through the Model of Care, supports will work in a more integrated way with primary care and acute services to deliver end-to-end care, keeping people out of hospital and embracing a ‘home first’ approach. The implementation of the Model supports capacity building in the community and will assist with reorientation of service delivery towards primary care and community-based services.

What are the next steps to progress the Model of Care for Dementia in Ireland?

Funding was secured as part of the Health Service Executive National Service Plan in 2021, 2022 and 2023 to progress implementation of the Model of Care across the wider health setting. This has included the resourcing of:

- National Intellectual Disability Memory Service
- Four Regional Specialist Memory Clinics
- Ten Memory Assessment Support Services (MASS).

Other service developments which have been implemented or planned which will indirectly progress the Model of Care include, for example, Memory Technology Resource Rooms enhancement across 23 sites, a brain health project, development of a dementia registry, national auditing of dementia in acute hospitals, the Dementia: Understand Together campaign, and the Implementation of National Clinical Guideline No. 21 (Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia).

The Health Service Executive has also provided funding for a number of dementia-specific roles in the acute hospital setting, including Clinical Nurse Specialists and Dementia Quality Improvement Assistant Directors of Nursing, which are an important part of progressing the Model of Care.



Figure 1. Overview of the Aims of the Health Service Executive Corporate Plan

Dutch Government hosts global “Defeating Dementia” event

On 2 October 2023, in collaboration with the World Dementia Council, the Dutch Ministry of Health, Welfare and Sports, organised the international conference ‘Defeating Dementia’ at the Kunstmuseum in The Hague, Netherlands. Representatives from G20 governments, international institutions, and a number of international leaders from across the dementia field were invited to participate in the conference. Jacqueline Hoogendam and Sara Elkiki from the Dutch Government share details about the conference.

The goal of the conference was to generate renewed interest in the challenges dementia poses to society and the urgency of this issue and to highlight the swift progress that could be made in care delivery and drug discovery.

In her opening speech the host of the conference, Minister for Long-Term Care and Sport Conny Helder, called for a major change in thinking and increased funding for dementia research, so we get results more quickly and more affordable for countries that need it. Prof Philip Scheltens, chair of the World Dementia Council, highlighted the need for more funding in dementia research and improved diagnosis methods.

In the opening session a person living with dementia was interviewed by the moderator about his experiences living with dementia. This person emphasised the importance of



Jacqueline Hoogendam

focussing on what you can do, not on what is no longer possible. For instance, his wife takes care of financial affairs now, while he is responsible for the laundry. Later during the conference this person living with dementia was a soloist at the concert of the Participation Choir (Participatiekoor).

The conference had four plenary sessions, each introduced by a governmental representative and a scientist, followed by a panel discussion with four more experts.

The first session on diagnosing and treating Alzheimer's and other dementias led to a vivid discussion on the prognostic value of blood tests for amyloid and tau and the possibility of developing blood tests for other types of dementia. Another important issue was the guarantee for equity in treating dementia. The governmental representative from the US, Ms Tisamarie Sherry, shared the first experiences treating patients with Lecanemab. With this she stressed the importance of investing in clinical infrastructure to ensure treatments are accessible.

Dementia prevention created a stir among speakers and panel member in the second session. Easily accessible diagnostic methods and lifestyle improvements were named as crucial tools. All speakers agreed that “it is never too early nor too late to initiate preventive action”. At the same time, they emphasised the importance of understanding



Sara Elkiki

existing evidence, generating additional evidence and effective communication to inform policies and guidelines. The challenge of the ageing society was first addressed by the Japanese governmental representative, who stressed the importance of involving persons affected by dementia in policy development. A recent law in Japan promotes an inclusive society, focussing on maintaining the dignity of people with dementia, and the importance of creating a sense of purpose. This law is in line with the discussion during this third session: the effect of stigma and how people with dementia participate in society. Creating a community around people with dementia and strengthening local dementia organisations, is very important in keeping them cognitively healthy. Furthermore, raising awareness amongst employers that employees with dementia need adjustments in their work, and caregivers with dementia need more flexibility, is vital. This session was very complementary to the concert by the Participation Choir, immediately before the start of this session. This choir consist of chorists with and without dementia. Those without dementia assist their colleagues with dementia. Accompanied by professional musicians, they reach a high level in singing parts of J.S. Bach's St Matthew Passion. A very good example of the capabilities of people living with dementia.

Saudi Arabia was represented in the fourth session on technology in care and support, highlighting the promising solutions of technology and innovation. Advancements such as Artificial Intelligence, wearable tech, and telemedicine are transforming healthcare. However, technology's dual nature was



Left to right – Prof Philip Scheltens (chair World Dementia Council), Dr Sameera Maziad Al Tuwaijri (World Bank), Dr Masami Sakoi (Chief Medical Officer, Ministry of Health, Labour and Welfare, Japan), Conny Helder (Minister for Long-Term Care and Sport, Netherlands), Dr Tareef Yusuf Al-Aama (Deputy Minister for Curative Services, Ministry of Health, Saudi Arabia), Dr Tarun Dua (WHO), Mark Rutte (Prime Minister, Netherlands)

described by the panel as both cold and warm depending on its correct usage, emphasising its potential to improve society. Apart from the contributions to the four plenary sessions by governmental representatives from the US, the European Commission, Japan and Saudi Arabia, video messages were shown from China, New Zealand and by WHO's Director General, Dr Tedros Adhanom Ghebreyesus. All stressing the importance of increased and ongoing commitment to all aspects of dementia.

During lunchtime the conference participants had the opportunity to watch a shortened version of the documentary 'Human Forever'. In this documentary, the young nurse Teun Toebe explores how dementia is dealt with in several countries all over the world and what we can learn from each other to make the future more beautiful and inclusive. Being interviewed during the conference, Teun emphasises the important message that affects us all: "We cannot wait. We can start today to make the future more hopeful for all people. We can do this by changing the narrative: People living with dementia. We see dementia as the end; but I am hopeful that we can change the future of people with dementia".

The commitment of the Dutch government to dementia was highlighted by a speech given by Prime Minister Mark Rutte. In his speech, Mr Rutte expressed a sense of hope coming from the proceedings of the conference.

He also stressed the importance of inclusion and participation in society for persons with dementia. The Prime Minister's hope was prompted by the joint governmental statement, endorsed by the participating countries at the end of the conference. In summary, this statement laid down the following:

Research

- To promote and support international collaboration in research into all aspects of dementia, bilaterally and multilaterally.
- To emphasise the importance of a significant global increase in dedicated research investments and to call on all countries to accelerate the pace of this increase in efforts to prevent dementia and improve the lives of people living with dementia and their caregivers.

Global collaboration

- To set up a worldwide group of governmental experts on dementia and to promote and to contribute to the activities of this group. The aims of this group are to provide a solid foundation to ensure that dementia remains a global priority and to assist governments in reaching the G8 and WHO goals on dementia.
- To further develop ways to assist Low- or Middle-Income Country's in dealing with the challenges of dementia.

Inclusion

- To promote and support actions to raise awareness and general knowledge on dementia, both on a national and international level, and to create a dementia inclusive society.
- To recognise persons living with dementia as valued members of society, who can and should participate in society and meaningful activities, given the added value they have for society.
- To build communities and services that enable people living with dementia to take and keep their role in society.

Support and care

- To provide person-centred, high quality dementia support and care, according to the key principles of high-quality dementia care, set by the World Dementia Council in 2017.

The Dutch government will work with other governments, the World Dementia Council, WHO, Alzheimer Europe, Alzheimer's Disease International and other relevant organisations to attain the goals of this statement.



Participation Choir

World Health Organization (WHO) Europe hosts Regional Summit on Healthy Ageing

On 11-12 October 2023, WHO Europe hosted the Regional Summit for Policy Innovation on Healthy Ageing in Lisbon, Portugal, which was co-organised with the Directorate General of Health of Portugal. Yongjie Yon, Technical Officer on Ageing and Health, WHO, explains the background to the Summit and outlines the Lisbon Outcome Statement which was published at the Summit.

The Summit

As Europe's population continues to age, the need for innovative policies and practices to support healthy ageing becomes increasingly vital. Today, the WHO European Region has one of the highest shares of older people in the world, and it will continue to see increases over the next decades, especially in the number of people aged 80 and over. The Region also stands on the brink of a historic shift: From 2024, more older people will be living across its 53 countries than children and adolescents.

As the life expectancy of Europe's population extends, promoting healthy ageing becomes paramount. Challenges and opportunities arise, necessitating improved health care, a skilled health and care workforce, age-friendly environments, and a collective effort to combat ageism across all sectors.

To explore these issues, WHO/Europe hosted the Regional Summit for Policy Innovation on Healthy Ageing on 10-11 October in Lisbon, Portugal. Co-organised with the Directorate General of Health of Portugal, the Summit brought together over 250 participants



Yongjie Yon

consisting of government representatives, thought leaders, policy experts, academics, civil society representatives, carers, professional organisations and other partners to drive policy innovation and explore promising practices to address the implications of ageing populations. Innovative policies and practices were explored to improve healthcare, combat ageism and create age-friendly environments.

Areas of common interest

WHO is working with partners around the European Region and the world, including many who attended this event, to implement the Global Action Plan on the public health response to dementia (2017-2025). This Global Action Plan has several tools and resources to support countries in achieving their 2025 dementia targets. In the European Region alone, 10 million people currently live with dementia, and this number is projected to nearly double by 2050, reaching over 18 million. This alarming trend underscores the urgent need for collaborative efforts.

Despite these projections, people living with dementia and their families frequently encounter barriers to accessing essential services, including diagnosis, treatment, and support. Tragically, they often grapple with ageism, stigma, and social exclusion. To confront these pressing issues, countries must collectively prioritise and implement dementia policies, ensure universal access to diagnosis and care, foster age-friendly and dementia-inclusive environments, strengthen health information systems, and significantly increase investment in dementia prevention. This unified approach is crucial in enhancing the overall well-being of those affected by dementia.



Left to Right: Dr Miguel Arriaga, Head of Division of Literacy, Health and Well-being, Directorate General of Health, Portugal; Dr Natasha Azzopardi Muscat, Director of Country Health Policies and Systems, WHO Europe; Dr Mara de Belem Roseira, Minister of Health of Portugal (1995-1999)

Throughout the Summit, two additional areas were discussed, which overlap with the agenda of supporting people living with dementia:

1. **Caregivers:** participants were privileged to listen to two inspiring caregivers of people living with dementia. Their presentations were a personal insight into the challenges of caring for someone living with the disease, whilst also celebrating the incredible journey of the carer, including their resourcefulness, strength and resilience.
2. **Digital technology:** Digital health solutions also offer promising avenues to improve the health and well-being of older individuals and can be especially valuable for those living with dementia (and to support their caregivers). Leveraging these technologies can elevate care by facilitating early detection, personalised treatment plans, medication reminders, safety monitoring and remote patient monitoring.

The Lisbon Outcome Statement

Through a landmark Statement, participants of the Regional Summit for Policy Innovation on Healthy Ageing are calling for action to advance and promote healthy ageing across the WHO European Region.

The Lisbon Outcome Statement acts as a concise guide, encapsulating the key priorities and actions outlined during the Regional Summit, but also identifying key areas for work to ensure a good quality of life for older people. It advocates a life-course approach to healthy ageing, noting the importance of embedding the development and maintenance of functional abilities. Furthermore, it recognises the diverse capacities and life experiences of older adults, whilst noting the need to address persistent inequities tied to socioeconomic status, gender, disability, ethnicity and other social determinants of health. The Statement supports the UN Decade of Healthy Ageing by emphasising the need to support older people in staying active and healthy, being included in society, and by creating age-friendly environments.

The adoption of the Lisbon Outcome Statement is a significant step towards addressing the challenges and harnessing the



Left to Right: Dr Alexandre Kalache, former Director of Ageing Programme, WHO HQ; Dr Yongjie Yon, Technical Officer on Ageing and Health, WHO Europe; Dr Piroos Ostlin, Regional Advisor on Policy and Governance for Health Through the Lifecourse

opportunities of Europe's ageing population. It underscores the importance of a collective effort involving governments, organisations, and individuals from diverse sectors to promote healthy ageing.

The Statement highlights five key priorities to advance healthy ageing policies including:

- preventive measures, which focus on preventing health issues and promoting physical, social, and mental well-being throughout life;
- enabling continuous support, by providing accessible, affordable, and high-quality care throughout a person's life, and adapting to changing needs and across different care settings, including long-term care;
- age-friendly environments, by creating communities and cities that empower people of all ages to engage in community life;
- leveraging older people's potential, by recognising and utilising the valuable contributions and expertise of older people; and,
- data and evidence, which ensures that policy decisions are informed by evidence-based practices.

As we move forward, the Statement will serve as a valuable reference and source of inspiration for policy-makers, practitioners, and advocates dedicated to improving the quality of life for older adults. By working together and embracing innovative approaches, we can unlock the potential for healthy ageing, ensuring that current and future generations of older persons can enjoy the well-deserved benefits of a long and fulfilling life.

The Lisbon Statement contains two explicit references to dementia and cognitive issues, including the following:

- Point 3A (iii): development and implementation of comprehensive plans for mental and brain health, including neurodegenerative conditions and dementia, to ensure equitable access to prevention, diagnosis, treatment and care services;
- Point 3B (iv): addressing intersectionality of disability and ageing, and supporting individuals with physical, cognitive and mental impairments, along with their families and caregivers who provide a pivotal caring role for older people with comorbidities, including cognitive impairment.

Looking to the future, the next steps to build on this Summit and Statement can be synthesised with the overarching three key messages:

- Firstly, establishing age-friendly environments in creating an effective ecosystem for the implementation and delivery of services and programmes. Within these communities, a pivotal step also involves the development of robust health and long-term care systems to support the well-being of individuals.
- Secondly, we must actively involve older people. There's untapped potential in their wisdom, experience, and insights.
- And lastly, older people must be empowered by providing them with the space and resources to contribute effectively to planning and developing their health and well-being.

The Lisbon Outcome Statement is available at: www.who.int/europe/publications/m/item/lisbon-outcome-statement



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Margaret's story

Barry Northedge, a member of the European Dementia Carers Working Group, shares his wife Margaret's story. He tells us about Margaret, both before and after her diagnosis with dementia and shares some of her passions and experiences, as well as his own, on the journey they are taking together, through life.

The consultant settled himself behind his desk and told us, quite dispassionately, that Margaret 'had' Early Onset Alzheimer's disease and she had probably been experiencing symptoms for the last couple of years. Such few words delivered with devastating effect were at the same time perversely reassuring, because we had known for quite a while that there was 'something wrong' but no-one had been able to tell us what. At last, there was some confirmation of our fears. He went on to tell us that the average life expectancy of someone diagnosed with dementia was five years, but we could hardly comprehend that at the time with so many questions immediately flooding our thoughts. Margaret was just 54 years old.

In truth 'Margaret's Story' began at least a couple of years earlier.

So, who is Margaret Northedge?

This is Margaret (Meg), daughter, wife, mother of two fine sons, grandmother to three grandsons and a granddaughter. She loves her family. Margaret's parents, Maud and Tom McGinn, both had or have dementia. Tom died in residential care on 4 December 2022 after developing vascular dementia following a stroke a few years earlier. Maud, 88 years old, still lives at home with a good care 'package' supporting her, she is 'comfortable' but continues to decline. Dementia has become something of a family concern!

Life and Work

Margaret was born in Tillicoultry, Clackmannanshire, Scotland, 64 years ago and now lives in the beautiful Highlands of Scotland



less than 3 kms from the banks of Loch Ness. Her life has taken her from Tillicoultry to Blairgowrie, Doncaster, Grantham, Bracknell and Chesterfield before moving back to Scotland. She has sold houses, been a PA to a Company Director, taught IT and helped hundreds of unemployed miners retrain for new careers following the closures of the 'pits' (coal mines).

Margaret always worked and took pride in doing every job as well as she could. She particularly enjoyed the feeling that her work was helping people. She harboured an ambition to go to university and so, whilst teaching IT skills to adult students in Derbyshire, she studied for and achieved a first class honour's degree in Education and Training, ironically writing a dissertation on "The relationship between ageing and learning with particular reference to 'mature students'"! She was so proud of her achievement.

When we moved to Scotland she began a master's degree which, unfortunately, was overtaken by dementia.

We moved to the Highlands in January 2005 in some of the worst rain we had ever experienced - even the removals men ended up with webbed feet! Margaret got a job as an Employee Development trainer with the Highland Council and soon enjoyed the freedom to travel to all corners of Highland delivering the Council's training courses. When she set off from home in the morning she was just as likely to be driving 200 kms to deliver a course on the Isle of Skye as she was to be heading to her office in Inverness. She loved it!

She wrote new courses and delivered new qualifications, she had an ability to relate equally well to all members of staff from refuse collectors to the Chief Executive, who she regularly supported through Management Briefings. She was confident, professional and extremely able. She was also very independent, and still is today!

For a while she 'stepped up' to a Senior role to cover a manager. Everything looked bright and was going well and then it all changed. Margaret began to notice that she couldn't retain information; she would forget conversations or lose track of her thoughts during a conversation. She began to doubt herself and couldn't understand why. Work became stressful, even though her manager kept reassuring her that she was fine and doing a good job.

Margaret raised the concerns over several months during work supervision sessions, but her manager simply replied that she was doing well and there were no problems. The manager either didn't understand or recognise the difficulties and thought she was reassuring Margaret and being supportive, but it was anything but reassuring. Margaret would come home in tears after almost every course. She prided herself on her professionalism, and she knew that she wasn't able to do her best, so she resigned. She loved her job, loved all the places that she travelled to, but felt that she was letting people down and couldn't accept that.



Margaret with her sons and their partners

The diagnosis

At least eighteen months before resigning, once we were sure that Margaret was experiencing problems with her memory, we had sought help. Our doctor, who was excellent, referred Margaret to Psychological Services in 2014.

We attended regularly. Margaret did countless memory tests, drew endless boxes and tried, with diminishing success, to remember what street Mr Brown lived on, never mind his house number. We were obedient and compliant, never late but becoming increasingly frustrated with the lack of perceived progress. More than a year later Margaret was still doing the same tests, drawing the same boxes and wondering why she needed to remember Mr Brown's address - she was never going to send him a Christmas card! After all this time, there was no diagnosis and very little support.

Finally, we asked how to make a complaint. All of a sudden there was urgency. We got a new psychological consultant, had a new assessment and finally got that diagnosis. Margaret had Early Onset Alzheimer's. Oddly, regardless of all the negatives and ignorance about the disease, the diagnosis was a relief, a confirmation at last that there was 'something wrong'. Margaret had not been imagining things and the diagnosis began to open doors.

Margaret was able to access her pension through early retirement on health grounds, she qualified for the Personal Independence

Payment (a UK disability benefit) and we 'got' a Post Diagnostic Support (PDS) worker, Flora (who was brilliant!). Some 'doors' closed, Margaret desperately missed work, but others opened.

Moving on

Sometimes you have to 'plumb the depths before you appreciate the highs', and Margaret certainly plumbed the depths. Resignation, leaving a job that she loved, although it was the right thing to do, left Margaret with a lack of purpose and plummeting self-worth. She felt that her life was over and sank into depression. We visited some very dark places, places we never wish to visit again.

It was Flora, the PDS worker, who helped Margaret to find purpose again. Flora took Margaret to the local Alzheimer Scotland Resource Centre where she met people experiencing the same issues and found support. Margaret joined the local working group for people with dementia and began campaigning on behalf of people living with dementia. She came home 'buzzing' about how it was like work again, how she was able to join discussions and have her opinions valued.

She quickly took the next step and joined the Scottish Dementia Working Group (SDWG), becoming involved in National campaigns such as 'Fair Dementia Care'. She regularly gave presentations to trainee nurses about living with dementia, she spoke at National Conferences, became involved in research and countless other activities.

“ Margaret always worked and took pride in doing every job as well as she could. She particularly enjoyed the feeling that her work was helping people. She had an ability to relate equally well to all members of staff from refuse collectors to the Chief Executive. She was confident, professional and extremely able. She was also very independent, and still is today!”

Margaret came alive again with renewed purpose - she was being listened to and having her contributions valued. Margaret hadn't lost those presentation skills, nor had she lost her confidence, whether it was talking to a lecture theatre full of nurses or a conference hall, she had that burning desire again to make a contribution, to make a difference. We're not for giving in!

Challenges

We were so ignorant when we got the diagnosis. Early Onset Alzheimer's, that means she's going to lose her memory, forget dates etc. Right? We didn't know



Margaret and Barry Northedge

that Margaret was going to lose her sight or that she would have trouble 'finding her words' or that she wouldn't be able to read books or watch films because she wouldn't be able to follow the storylines. We didn't know that the disease would make her hearing so sensitive that we could no longer go to concerts because the music is too loud, or that her eyes would become sensitive to sunlight. No one told us what to expect, but unfortunately, we are finding out.



Margaret knows that she can't do all the things that she used to. She gave up her driving licence which was a huge wrench, especially living in a rural area such as Highland, but she realised that she was no longer safe to drive. This was not only a loss of independence it also meant that she could no longer drive her beloved Mini. When she retired, she wanted a black Mini Cooper but not just any black mini. She wanted blacked-out windows and black alloy wheels and then she saw the green spots! So, she bought a brand new black mini, with blacked out windows and black alloys and green spots all over the roof, doors and wing mirrors, even the black alloys had tiny green spots in the centre. It was her 'dream' car, and now she couldn't drive it. For a while I became a semi-competent chauffeur with the Mini, bringing a smile to her face every time it came out of the garage but now it's gone, sold for something more practical.

Margaret used to teach IT and was a 'touch typist' but she can no longer use a computer

or her mobile phone because she can't see the words and keys. She used to have excellent handwriting but she can't sign her name or write a text. She used to love cooking (and I used to love the results!) but she can't follow a recipe, weigh or measure ingredients. There have been so many unexpected changes, so many skills lost.

You have a choice - mourn what you have lost and let life pass you by or focus on what you can do and continue to do that as well as you can for as long as you can. Margaret has always been very positive. We believe that this is a vital part of her character that has really helped. Life doesn't need to end - it may change a little (or even a lot), but there are still new things to learn and new challenges to rise to if you look for them.

Walking

Not long after the diagnosis we heard about a man who walked up the Old Man of Coniston, a hill in the Lake District. He asserted that the exercise helped to delay the symptoms of Alzheimer's. We're a long way from the Lake District, but we are in the Highlands which is better! We live on a lovely lane, a very steep uphill lane! And we have countless forest paths within five minutes of our doorstep, so we began to walk every day, come rain or shine. Sometimes when we are walking back home, bedraggled in pouring rain, or when

“When Margaret joined the Scottish Dementia Working Group, she came alive again with renewed purpose - she was being listened to and having her contributions valued. She hadn't lost those presentation skills, nor had she lost her confidence, whether it was talking to a lecture theatre full of nurses or a conference hall, she had that burning desire again to make a contribution, to make a difference. We're not for giving in!”

we stand at the top of our hill looking like snowmen, our neighbours do question our sanity, but we firmly believe that the aerobic exercise helps our circulation, improving the blood flow to our brains, slowing the progression of the disease. We may be wrong and if we are, we don't care. Being outside in our beautiful surroundings is good for our soul! We walk about 2,500 kms every year and, yes, our legs are getting shorter!!

Running

If you can walk then you can run, can't you? Margaret always hated running and PE at school, but that changed when she developed breast cancer (she is fully recovered now). She completed the 5k Race for Life and it nearly 'killed' her, but at the age of 60 she decided she could and would run more. Every year since then, Margaret has competed in 5k races and stepped up to running 10k races. She has now completed more than a dozen 10k races. She's not fast but she is determined and never walks which is some feat, especially as she can't see where she's going! I have to ride a bike either beside or just behind her trying to guide and keep her safe, not an easy task with a strong willed woman.





Margaret with her "dream car" which she got after retirement

“You have a choice - mourn what you have lost and let life pass you by or focus on what you can do and continue to do that as well as you can for as long as you can. Margaret has always been very positive. We believe that this is a vital part of her character that has really helped.”

Holidays

We love holidays, especially with our families. We live approximately 750 kms away from our children and grandchildren, so we try to take them on holiday as often as we can. We only get to see them a couple of times a year and miss so much of their growing up. Time together is precious and spending a week together is priceless so we have found a lovely hotel in Cyprus where Margaret knows her way around and where the staff know and treat us like extended family, our home from home in the sunshine where you'll find us each April and October!

Bucket list

And we plan, we plan new challenges to look forward to, our 'bucket list'. Last year Margaret decided she wanted to swim in the sea off the north coast of Scotland. Why she

wanted to swim in the coldest sea in Britain I'll never know, she doesn't particularly like swimming but there was the challenge! In September, when the sea was at its warmest (just above freezing!), we drove to the north coast, to a beautiful and almost deserted beach at Bettyhill. We swam and she loved it! She loved it so much that we have a return visit on the list for this year (why me?!). She wants to climb Ben Nevis, the highest mountain we have in Britain, conveniently just 100 kms away, and she has also set her sights on another smaller mountain on the way to our swim called Ben Klibreck. I have no doubt we'll be trying to climb both.

I may not particularly relish the thought of swimming in a cold sea (give me Cyprus anytime) and trying to support Margaret to climb those mountains will be challenging, but these are the things that keep us looking forward, things to look forward to, and we want to keep looking forward. What will you be doing next year?

Summation

Alzheimer's disease is progressive, it makes your world smaller and, unfortunately, there is currently nothing to prevent that, but we still need ambition, Margaret still feels that she can make a difference. She still needs to have opportunities to make a contribution, to share her experiences and to validate her self-worth. Life goes on but, she still can't draw those boxes or remember where Mr Brown lives.

My wife is an incredibly brave, resourceful woman. She has an inner strength that is helping her to cope with the most awful of diseases and she's not for giving up. Of course, we have tears and fears but we also have fun, laughter and the will to set ourselves challenges and targets for the future and we will try to meet them.

We need to recognise the incredible support from Flora who was, almost quite literally, a life saver. We have benefitted immensely from being part of the SDWG and truly appreciate the opportunities we have been able to access because of Wendy, Chris and Norrie, the Alzheimer Scotland Active Voice team, and we need to recognise the many true friendships that Margaret has found within the SDWG. When other friends turned away, we found new and true ones.

A dementia truism that trips off the tongue is "see the person not the disease". Do you see Margaret?



All ABOARD! Dutch project takes a personalised medicine approach to “Stop Alzheimer’s before it starts”

The ABOARD project is now at its halfway point, with the “ABOARD Midterm Meeting” having taken place on 20 November 2023. Here, we introduce the project and project leader Wiesje van der Flier from Alzheimer Center Amsterdam shares what has been achieved so far. We also hear from some of the project’s early stage researchers, about what motivates them and how they are contributing to this research.



Wiesje van der Flier

“Stopping Alzheimer’s before it starts” - This is the slogan of a nationwide collaborative project in the Netherlands, led by Wiesje van der Flier from Alzheimer Center Amsterdam. ABOARD, short for “A personalised medicine approach for Alzheimer’s disease”, is a public-private project which aims to prepare for a future in which Alzheimer’s disease (AD) is stopped before dementia has started. This is being done by: improving timely and accurate diagnosis, developing individualised risk profiles, initiating nationwide data collection, with a focus on patient-reported outcomes, and a focus on prevention strategies by creating awareness around dementia and brain health. In addition, the readiness of the Dutch healthcare system

for disease-modifying treatment is being evaluated.

ABOARD takes as its starting point the fact that AD develops over a period of over twenty years. The project is therefore focussing on the stages before the onset of dementia, working towards prevention. In addition, AD is highly heterogeneous, both in its underlying biology and specific pathways involved, and in the needs and preferences of patients and their carers. The wishes and needs of patients should be the starting point of care and ABOARD is therefore developing (e-)tools to support patient-orchestrated care. Realising that one size does not fit all, ABOARD envisions a future with individualised prevention

encompassing tailored combinations of lifestyle- and disease-modifying interventions.

Over 30 partners representing the entire translational value chain are working together in the ABOARD project. Partners include the five Dutch Alzheimer Centres, Alzheimer Nederland and partners from academic and applied research, healthcare, private, semi-private and public organisations, all dedicated to achieve personalised medicine for AD. Jean Georges, Executive Director of Alzheimer Europe is on the Advisory Board of this exciting initiative.

The ABOARD project began in April 2021 and, with a duration of five years, is now at its halfway point and organised the “ABOARD Midterm Meeting” on 20 November 2023.

Wiesje van der Flier discusses what ABOARD has already achieved at its halfway point

What were the aims set out at the start of the project and are you on track to reach these goals at this halfway point?

Our overarching goal is to take all steps to prepare for a future where we can do more for patients with Alzheimer’s disease. The challenges which Alzheimer’s disease poses us for, in terms of diagnosis, prediction and prevention, are multi-faceted. Therefore, we need to take many steps, all at the same time. And this is what we are doing in the ABOARD project. Project results are diverse, but as a consortium, we realise that all these individual results are pieces of the larger puzzle we make together. As such, the ABOARD

meetings have evolved into network events, where people share results, ideas and inspiration. Are we on track? Yes. Are we doing enough? No, there is always more that could and should be done! Nonetheless, I think we can be quite proud of what has been achieved so far.

Can you share some of your personal highlights from the project so far?

There are a number of important results, already too many to list. But a few that are really close to my heart are the review papers that PhD student Jetske wrote about the psychosocial implications and considerations

around an early, and biomarker-based diagnosis. These papers provide a starting point to have a meaningful patient-doctor discussion about the pros and cons of a biomarker-based diagnosis. A second highlight is the launch of Breinzorg.nl (translation: braincare.nl); the online platform which was developed by the colleagues in Maastricht, to provide information on lifestyle in a memory clinic setting. Third, we launched aboard-cohort.nl, a national initiative to engage as many Dutch citizens as we can in Alzheimer’s research. Using the slogan “one hour for Alzheimer’s”, we ask people to participate by filling in questionnaires. In this way, we study the entire disease trajectory of Alzheimer’s disease. The first 5,000

participants have signed up, we are very proud! And I hope this is only the beginning, since we need many more participants to draw meaningful conclusions.

What are your hopes for the future of dementia research and how is the ABOARD project helping to move the field forward?

My hope is that we will actually take steps forward in the field of Alzheimer's disease

and that lifestyle interventions prove to be beneficial and find their way to clinic. I also hope that treatments will become available also in Europe, that actually bend the disease trajectory and that we will be able as society to implement this novel generation of treatments in an accessible and sustainable way. That is, knowing full well that these treatments will be beneficial to a small subgroup of patients only. ABOARD attempts to help move the field forward by

developing the diagnostics of the future and prediction models for outcomes that matter. And also, by actually having these discussions on the future of Alzheimer's healthcare, with different stakeholders and different views. Realising all the while that citizens should be at the steering wheel of the choices regarding their own health and disease. And developing e-tools to keep healthcare accessible and scalable.

Some of the project's early stage researchers tell us what motivates them and how they contribute to ABOARD

Tessel Frankfort, project manager

Why did you become involved in dementia research and what keeps you motivated to work in this field?

During my master's in management and policy analysis in health and life sciences, I became motivated to contribute to a more sustainable healthcare system. One of the major challenges we are facing is the ageing population and accompanying rise in number of people with dementia. Both reducing the burden for individuals having Alzheimer's disease and their caregivers, and contributing to a healthcare system that remains accessible and affordable drove me to work in the dementia field. For me as a young professional, it is a huge privilege to be involved in the middle of all the organisations and people that together make the ABOARD project.

What in particular attracted you to work on the ABOARD project and how is your research contributing to the success of the project?

ABOARD caught my attention by its mission and design. The mission is to prepare for a future with personalised medicine for Alzheimer's disease, by engaging parties and people from the entire knowledge chain: academia, healthcare institutions, knowledge institutions, industry and societal organisations. In my view, public-private collaborations are essential for the incorporation of results and innovations in actual practice. Moreover, for me as project manager, it makes the stakeholder management exciting and interesting! My job is to strengthen cohesion in the consortium, most importantly by organising the biannual consortium meetings. Moreover, I contribute to the communication activities



such as the ABOARD newsletter, the ABOARD webinar series, and currently we prepare for a series of round table discussions with dementia care professionals, in 2024.

Fleur Visser, PhD student

Why did you become involved in dementia research and what keeps you motivated to work in this field?

During my time as a medical student, I developed a fascination for the brain. Later, while working as a physician, I gained valuable experience in the neurology department of a hospital and in a nursing home where I encountered challenges in providing care to people with dementia. I realised that there still is a lot of room for improvement in dementia care, especially in taking a person-centred approach. The complexity of dementia and its interdisciplinary nature appeal to me and also motivates me to contribute as a dementia researcher.

What in particular attracted you to work on the ABOARD project and how is your research contributing to the success of the project?

I was attracted to ABOARD because of its unique collaboration between different organisations. The opportunity to work with other passionate and experienced people on this project excited me. For example, the Juniors On Board programme has resulted in a network of other PhD students across the Netherlands, which is really valuable for me. My research focuses on improving timely diagnosis. Together with my research team and other partners within ABOARD, I am investigating how well healthcare professionals currently recognise cognitive problems. We are also trying to gain insight into the complex process between recognising signs of dementia and starting the diagnostic



pathway. This information will help us to understand how we can improve the timing of dementia diagnosis.

Matthijs Keijzer, PhD student

Why did you become involved in dementia research and what keeps you motivated to work in this field?

I think this is an exciting time to work on Alzheimer's disease, especially with the field being on the brink of multiple breakthroughs. I am intrigued by the potential of digital tools, as they can give more insight into changes in the earliest stages without being measured at the clinic. This will hopefully pave the way for more early, proactive interventions and personalised treatments. Contributing to the development of these technologies together with individuals with dementia motivates me to work in this field!

What in particular attracted you to work on the ABOARD project and how is your research contributing to the success of the project?

The collaboration between industry and academia is what made me interested in ABOARD: having companies and universities work together can accelerate the development of clinically validated innovations. The multidisciplinary team of ABOARD helped me to include multiple facets of research, such as the addition of qualitative research methods, to a project that otherwise has quite a data-driven and artificial intelligence-based methodology. With the unique opportunity to do my PhD in both academia and a company, I hope to aid the development of digital biomarkers in ABOARD using knowledge from both worlds!


ABOARD in pictures


ABOARD Spring meeting, consortium with keynote Minister Conny Helder for Longterm Care and Sport and consortium lead Wiesje van der Flier frontrow middle, 13 april 2023, Zeist (PGGM office)



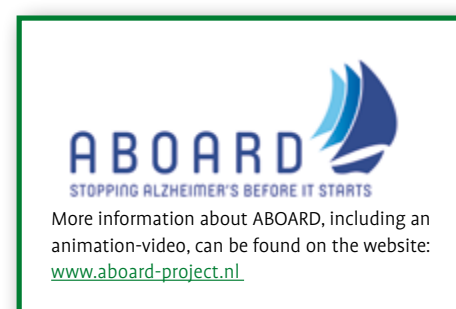
ABOARD Midterm meeting, plenary session for laymen's audience Charlotte Teunissen (lead WP diagnosis), 20 November 2023, Amstelveen (KPMG office)



ABOARD Midterm meeting, interactive break-out session WP Patient Orchestrated Care, 20 November 2023, Amstelveen (KPMG office)



Overnight retraite of Juniors On Board (JOB), the PhD students within the consortium. 30 May 2023, Amersfoort





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December 2023
EMA-COR-23-00044

“Waltzing Matilda”

The film “Waltzing Matilda” was directed by Czech screenwriter, renowned documentary and theatre director and author of several TV dramas, Petr Slavík. Alzheimer Europe spoke to Nataša Slavíková, film producer at Phoenix Production, who is both Petr Slavík’s wife and the film’s producer.

Synopsis

The film tells the story of bailiff Karel Jaroš, his mother, former choir singer Matilda, and Karel’s teenage son Pavel. The withdrawn, emotionally torn Karel does not get along with his extroverted and bohemian mother and only thanks to a strong sense of duty does he visit her regularly. Pavel, on the other hand, who comes across as an irresponsible flunky, despises his father’s profession and cannot forget that he abandoned his family as a child. The relationship of all three is disturbed, but an unexpected life situation brings them together. Matilda develops

Alzheimer’s disease, loses her apartment, and Karel has to take her in. However, he is unable to take care of her and in a deadlocked situation, it turns out that the only solution is for Pavel to take care of his sick grandmother. However, the illness progresses rapidly...

The tragicomic story inevitably ends with the question of whether and how our heroes will stand up to this test of life.

The film is directed by Czech screenwriter, renowned documentary and theatre director and author of several TV dramas, Petr Slavík. His wife and the film’s producer Nataša



Nataša Slavíková

Slavíková runs the company Phoenix Film, an artistic production platform, which has produced over 350 films and TV programmes. This is the first foray into feature-length movies for both the director and producer.

Interview with producer Nataša Slavíková

What made you decide to make this movie, “Waltzing Matilda” (“Tancuj, Matyldo”)? Is the subject of dementia particularly close to your heart?



The topic of Alzheimer’s dementia hit our family very closely because my mother had this diagnosis and because she desperately didn’t want to go to any institution (nursing home), we did everything we could to keep her at home, and we succeeded. During this home care, I realised how serious the disease is. As a filmmaker, I visited many caring families, filmed the film Diagnosing Alzheimer’s Disease and the documentary film Life with Alzheimer’s. So I have been intensely interested in the topic of dementia for 10 years.

The film tells the story of Karel Jaroš, his mother Matilda, and Karel’s teenage son Pavel, who form a rather dysfunctional family. How well do they manage to navigate their difficult relationships and how does the family evolve, throughout the dementia journey?

In this film, we tried to show that caring for a loved one with dementia is very demanding and that it can be beyond the limits of what can be managed. In my opinion, the movie’s

grandson Pavel was better able to take care of his grandmother in the sense of living with her, understanding and living comfortably, he was worse with medical care, for example he could not manage to give her medicine, he was careless in this care. Son Karel, when he was left to care for himself, although he tried, he would not have been able to handle the care himself. What was important was that they were able to find a way to each other, understand each other and recognise each other’s qualities while living together with their sick grandmother. Despite numerous difficulties, our film family was united by the grandmother’s illness.

“In this film, we tried to show that caring for a loved one with dementia is very demanding and that it can be beyond the limits of what can be managed.”



Matilda

What is the most important message in the movie?

I think, that when people can cooperate with, tolerate and trust each other, then it enriches them the most. And also that it is important to act according to your conscience, according to what your heart tells you to do.

Do you feel that the story and the experiences of the characters are quite representative of real people and their struggles with this condition?

I think so. We already have this feedback from both caregivers and doctors who have seen the film, as well as from the discussions we conduct with people after the screening of the film. I am grateful for this communication, it shows how it is important for people to talk about this problem. But the real situation can of course be much more complicated and worse.

Following your own family's experience of your mother having dementia, what did you find most difficult and what do you feel needs to be improved by policymakers in your home country, to help families in similar situations?

The answer to this question is not simple at all. For us, the most difficult thing was knowing that you don't know what's coming and how long it will last, and also knowing that you don't know how much you can manage. Politicians should devote

comprehensive attention to this issue and enable the involvement of various non-profit organisations as much as possible. A person is not able to handle this disease on his own or it is only a case of complete exceptions. It is also up to politicians what credit they give to caring people and cooperating organisations. Currently, at least in the Czech Republic, this credit is desperately low. These rare people who help are not adequately rewarded for their work and are in real danger of being left insecure when they need to care for themselves, and that is unfair. Here, there are great reserves on the part of the State and politicians to improve the valuation of these people, because it is the caregivers who save the state a lot of money with their work.

When did "Waltzing Matilda" premiere and where can people see the movie?

The film premiered on November 30 in the Czech Republic and it can currently be seen in cinemas in the Czech Republic. A version with subtitles is also available and screenings can be arranged (see contact details in the box).

“These rare people who help are not adequately rewarded for their work and are in real danger of being left insecure when they need to care for themselves, and that is unfair.”

Trailer: <https://vimeo.com/891799454/fe7b69c598>



Petr Slavík

If you have questions about the film, or would like to organise a screening (a version with English subtitles is available), please contact:

Vít Janeček, Nataša Slavíková

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natasa.slavikova@seznam.cz

☎ +420*603*164 232, +420*602*660 575

🌐 virusfilm.sk,
phoenix-production.com

New book written by people affected by dementia challenges preconceived ideas about the condition

“Challenging Assumptions Around Dementia” is a book about dementia, written by those affected by it. It seeks to challenge preconceived ideas that dementia is only for old people, only about memory and that a diagnosis of dementia means that life is over. The co-authors are six people living with dementia and six who support or have supported someone with the condition. Their work was brought together by research psychologist Dr Rosalie Ashworth. Alzheimer Europe spoke to Dr Ashworth and to two of the co-authors David Ross and Agnes Houston.



Rosalie Ashworth

Research psychologist Dr Rosalie Ashworth is the Lead for the NHS Scotland Neuroprogressive and Dementia Network

‘Patient and Public Involvement’ group known as “Partners in Research”. They work together on a range of activities including

book writing, developing research proposals, reviewing research materials and raising awareness. Dr Ashworth has also worked as a Research Fellow at the University of Edinburgh and the University of Stirling, with a special interest in coproduced research. Her focus is on getting those with lived experience to become more involved in informing research – and moving the focus of research from the illness to the people affected by it.

Dr Rosalie Ashworth, Editor, tells us about the book and why she wanted to publish it

How did “Challenging Assumptions Around Dementia” come about and why did you feel that it was important to publish this book?

Our book came about as a result of several conversations with our Partners in Research who felt that their experiences were not being well represented in other areas. They also felt that there was limited accessible information about dementia and what it means for those living with the condition. We wanted to make sure that we wrote a book that captured the different experiences people face living with different types of dementia, pushing against the misconceptions that all dementia is Alzheimer’s disease and that people living with the condition cannot have a good quality of life. Although several of our co-authors have had experience in sharing their story with dementia in some ways, they had also come up against a barrier of not being seen as a valid source of expertise particularly within academia. Therefore we wanted to show how working together could

form a piece of work that has relevance to both the public and scientific community.

Can you tell us a bit about your role in the book? How did you go about pulling the content together?

My main role within the book was to pull together the different stories that were being shared and organise them in a way that helped us to educate others about the condition. When we started the book we had expected our chapters to focus on the different types of dementia but in the end the amount of knowledge and expertise shared about living with dementia, meant that the types of dementia formed a single chapter and the rest of the book considered other areas of importance to those with lived experience. My other role within the book writing was to use my academic background to make sure that what we were communicating linked in to the scientific literature available. As a group we felt this was particularly important

for giving the book credibility among the scientific community and we hoped that it would provide a useful resource to healthcare professionals working in the area.

Who are the 12 co-authors and how important was it to have all their perspectives included?

The co-authors were all Partners in Research. For some of the co-authors this was the first activity that they got involved in, and others had experience either participating in or co-researching various research projects. There were also Partners in Research who expressed interest in the book but didn’t feel that they have capacity at that time to contribute. It can be very difficult to know how best to include as many people as possible in a supportive and flexible way it also highlights how important is to include a range of experiences so that those who could not contribute they could still see themselves in the book. In the end we have six people



Book launch, V&A Dundee, 1 September 2023

living with different types of dementia and six people who were either current or past carers for loved ones with dementia. The co-authors' contributions are not just important; they are absolutely vital to the book and its success. They opened up about difficult experiences with the hope that it would mean that other people do not have to go through the same challenges in the future. I am continually humbled by how willing people are to share their stories and be vulnerable for the sake of helping others.

Who is the book aimed at?

From the start we wanted the book to be open access in order to allow as many people as possible to find information if they wanted to. We know that for some people living with dementia it can be very difficult to look at this type of information and therefore we wanted to present it in a way that people could dip in and out as they choose. We also deliberately wanted to work with an academic publisher as we thought that this would make sure that the book was on the radar of academics and healthcare professionals. The co-authors felt that this was important for showing how valuable including people with lived experience as experts can be. Since launching the book we are delighted that it has been accessed over 8000 times online. We have also worked hard to make sure that hard copies of the book are available within the local communities including within hospitals and libraries.

David Ross, co-author, shares his thoughts about the book

Joining the group and writing the book was not only beneficial for everyone involved, but for everyone who reads it, they will be just that little bit more aware, which is a large step

in the right direction. The launching of "Challenging Assumptions Around Dementia" and the support it received is only the first step in a journey of indeterminable length that we must all try to reign in to make real progress. The book is out there, and it is now time to challenge some of the myths as well as look at the more aggressive modifiable risk factors associated with these conditions.

There is no elixir of long life, we cannot prevent the ageing process, but we can understand it and make it as smooth as possible. The seeds of dementia can be sown much earlier than people expect, sometimes decades in advance of showing symptoms. There are many institutions, groups and charities looking after the welfare of those already diagnosed, an essential part of our social care system when funding and services are diminishing. The 'unpaid carers' in our society are the unsung heroes who are themselves caring without due regard to their own mental and physical health. This unselfishness, unfortunately, may be leading them to also developing a neurological condition through stress and other related conditions, exacerbating the future load on our social services. Preventing and curing neurological illness must be a team effort, where all players are treated equally and given the respect they deserve for their efforts and commitment. I appreciate things can take time to change, unfortunately we are fast running out of time, it is now time to shake up the system and change how we approach research, before it becomes an impossible task.

Agnes Houston, co-author, shares her thoughts about the book

The book's co-authors want to encourage people to find what is meaningful to them

and to create a new life with the diagnosis of dementia. One of the twelve co-authors, Agnes Houston, former Vice-chair of the European Working Group of People with Dementia, told us why she wanted to be involved and what she hopes it will achieve:

Agnes said she hopes that every NHS professional will read the book. Her dementia affects her senses and, even after her diagnosis, professionals were telling her she couldn't possibly have dementia, forcing her to go through the process to have her diagnosis confirmed a second time: "I've never looked back. I decided – what do they know? It's my diagnosis. It's my life. I will live it the way I want to."

You can find the book (open access), here: <https://link.springer.com/book/10.1007/978-3-031-27223-3>



NEUROPROGRESSIVE AND DEMENTIA

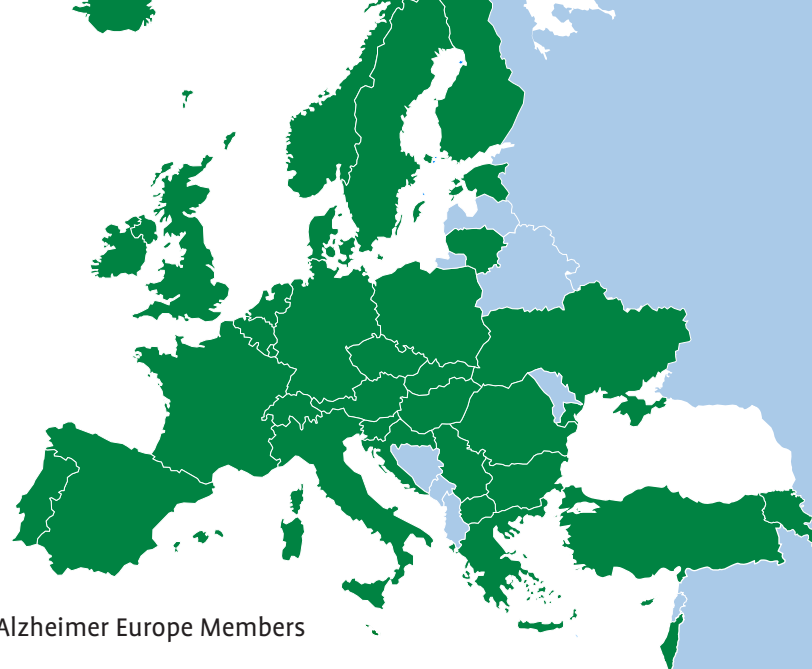
✉ tay.ppipartners@nhs.scot

🌐 <https://www.nhsresearchscotland.org.uk/research-areas/dementia-and-neurodegenerative-disease/get-involved>

✂ [@NRS_NDN](https://twitter.com/NRS_NDN)

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Our members are helping people with dementia and their carers in 36 countries



Alzheimer Europe Members



ARMENIA – YEREVAN
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Demenz Selbsthilfe Austria



IRELAND – DUBLIN
The Alzheimer Society of Ireland



SERBIA – BELGRADE
Serbian Society for Alzheimer Disease (SUAB)



BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Liga



ISRAEL – KEFAR SABA
EMDA – The Alzheimer's Association of Israel



SLOVAKIA – BRATISLAVA
Slovenská Alzheimerova spoločnosť



BULGARIA – SOFIA
Alzheimer Bulgaria



ITALY – MILAN
Federazione Alzheimer Italia



SLOVENIA – LJUBLJANA
Spominčica – Alzheimer Slovenija



CROATIA – ZAGREB
Alzheimer Croatia



ITALY – ROME
Alzheimer Uniti Onlus



SPAIN – MADRID
Fundación Alzheimer España



CYPRUS – NICOSIA
Cyprus Alzheimer's Association and Related Dementias, Forget-Me-Not



LITHUANIA – VILNIUS
Demenција Lietuvoje



SPAIN – PAMPLONA
Confederación Española de Alzheimer (CEAFA)



CZECH REPUBLIC – PRAGUE
Czech Alzheimer's Society



LUXEMBOURG – LUXEMBOURG
Association Luxembourg Alzheimer



SWEDEN – STOCKHOLM
Demensförbundet



DENMARK – COPENHAGEN
Alzheimerforeningen



MALTA – MSDA
Malta Dementia Society



SWITZERLAND – BERN
Alzheimer Schweiz Suisse Svizzera



ESTONIA – TALLINN
NGO Living with Dementia



NETHERLANDS – AMERSFOORT
Alzheimer Nederland



TURKEY – ISTANBUL
Türkiye Alzheimer Derneği



FINLAND – HELSINKI
Alzheimer Society of Finland (Muistiliitto)



NORTH MACEDONIA – SKOPJE
NGO Institute for Alzheimer's disease and Neuroscience (IAN)



UKRAINE – KYIV
Nezabutni – Charitable Foundation



FRANCE – PARIS
France Alzheimer



NORWAY – OSLO
Nasjonalforeningen for folkehelsen



UNITED KINGDOM – EDINBURGH
Alzheimer Scotland



GERMANY – BERLIN
Deutsche Alzheimer Gesellschaft e.V.



POLAND – WARSAW
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