ALZHEIMER EUROPE NEWSLETTER

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WELCOME
At the end of March, Europe celebrated the 60th anniversary of the signing of the Treaties of Rome - the birth of the EU. The Lancet journal published an excellent editorial to mark the occasion, looking at the EU’s achievements in the area of public health as well as some areas for improvement. It is a timely reminder, under the shadow of Brexit and with increasing support for extremist parties across Europe, of the importance of continued collaboration and investment in health. On the subject of Brexit, there is uncertainty about the future of the European Medicines’ Agency, which will have to relocate from its current home in London. It is likely that a decision on the new location will be taken by the EU’s heads of state in June, so together with other civil society organisations, we have sent a letter to the Commission and the Council, drawing attention to some important aspects to be considered, with particular emphasis on facilitating the involvement of patients and consumers and on facilitating safe and easy travel for external experts.

On the conference front, we have just closed the call for abstracts for the 27th Alzheimer Europe Conference (27AEC) and I am delighted to report that we have close to 400 abstracts, which I am sure will make for another exciting and diverse event. The call for the German sessions remains open until 26 April.

Finally, also on the subject of Annual Conferences, I would like to congratulate our friends at ADI on another successful conference, this year in Kyoto, Japan. I was unable to attend, but AE Board member Stefanie Becker represented us at the Elected Board and Council meetings and EWGPWD Vice Chair Chris Roberts was a speaker. We look forward to hearing more about his experience in next month’s issue!

Jean Georges
Executive Director
ALZHEIMER EUROPE

6 April: Alzheimer Europe publishes new Dementia in Europe magazine

On 6 April, Alzheimer Europe (AE) published the 24th edition of its “Dementia in Europe” magazine. In issue 24 of the magazine, Hon Dr Justyne Caruana, MP, Parliamentary Secretary for Rights of Persons with Disability and Active Ageing, discusses how Malta is addressing dementia during the current Maltese EU Council Presidency, Herta Adam of the European Commission talks about addressing dementia at the European level and Professor Michal Novak of the Czech Republic talks about the European Dementia Monitor and the reactions of the MEPs who attended. We present our new Board and Chairperson, two new member associations from Albania and Hungary, our 2016 Yearbook on legal capacity in dementia and our discussion paper on ethical issues linked to the changing definitions/use of the term Alzheimer’s disease.

In our own news, you can take a look at our recent lunch debate at the European Parliament in Brussels, discussing the results of the European Dementia Monitor and the reactions of the MEPs who attended. We present our new Board and Chairperson, two new member associations from Albania and Hungary, our 2016 Yearbook on legal capacity in dementia and our discussion paper on ethical issues linked to the changing definitions/use of the term Alzheimer’s disease.

We are also pleased to showcase three new EU projects in which we are involved: AMYPAD (Amyloid imaging to prevent Alzheimer’s disease), MOPEAD (Models of Patient Engagement for Alzheimer’s disease) and ROADMAP (Real world outcomes across the Alzheimer’s disease spectrum for better care: multi-modal data access platform).

In the society section, we congratulate the European Working Group of People with Dementia (EWGPWD) on receiving the “Mano Amiga” - a prestigious international award. Also in this section, one of the group’s members, Chris Roberts shares his experiences of living with dementia in Wales and discusses Welsh dementia policy. The Alzheimer Society of Ireland tells us about its recent “Dementia care begins at home” campaign and Federazione Alzheimer Italia describes progress thus far in its dementia-friendly community project. In a new spot in this section, we take a look “behind the headlines” with Dr Tom Russ of Edinburgh University, who discusses media reports linking air pollution and dementia.

Last but not least, there is a special “spotlight” section of the magazine dedicated to the 26th Alzheimer Europe Conference (26AEC) in Copenhagen, from 31 October to 2 November 2016. You can buy the magazine here.

About the Dementia in Europe magazine

“Dementia in Europe” magazine appears in print twice per year with a circulation that varies between 2,600 and 3,500. It is distributed to all the Members of the European Parliament (MEPs) and many high-level decision makers in the European Commission, among others. Past issues can be freely downloaded.

For further information

Please contact Communications Officer Kate Boor Ellis on Katherine.Ellis@alzheimer-europe.org or Policy Officer Vanessa Challinor on Vanessa.Challinor@alzheimer-europe.org.

6 April: Alzheimer Europe presents European Dementia Monitor

Eurodiaconia AE was invited to present the results of the upcoming publication “The European Dementia Monitor” at a meeting of the informal coalition of Civil Society Organisations (CSO’s) working on long term care (LTC) and informal care (IC) hosted by Eurodiaconia. The Dementia Monitor is intended as a tool to allow policy makers to identify both gaps and best practices, in order to improve care and support of people with dementia and their carers all over Europe and to give national associations a means to lobby for change within Member States by comparing their country to others.

The ageing population and increasing numbers of people living with dementia is one of the greatest social and economic challenges facing Europe today. Being able to benchmark and use comparative figures is essential to create the need for more awareness on a political level.

Also present at the meeting was Daniel Molinuevo (Eurofound) who presented the draft version of a report on private provision in care homes – “The role of the private providers in nursing and residential care services”. Eurofound wanted to gather the input of other CSOs for the report. In particular, about the EU policy context section and the concluding remarks about the European Semester and the deinstitutionalisation debate at the EU level.

Policy Officer Vanessa Challinor represented Alzheimer Europe.

22 April: AE Chairperson presents our ethics work at a meeting in the Czech Republic

On 22 April, there was a meeting held in Prachatice, a town in the South Bohemian Region of the Czech Republic, organised by the Hospice Providers’ Association. At this meeting, AE Chairperson Iva Holmerova (pictured) presented some of our work on ethical issues.
25 April: Czech version of online Diagnosis of dementia carers’ survey launched, three countries reach target

At the end of March, we announced the launch of our online Diagnosis of dementia carers’ survey. The survey had been launched in four out of the five participating countries at that time - Finland, Italy, the Netherlands and Scotland. We are pleased to announce that the fifth and final participating country, the Czech Republic, launched the survey in Czech language during April.

The carers’ survey is a project we are working on together with five of our national member organisations and academic lead, the University of Bangor, Wales (UK). It has received financial support from the pharmaceutical company Roche.

Feedback is being sought from 1,000 informal carers (e.g. family members or friends) in total (200 per country) via the online survey. Paper copies are also being used when necessary.

If you are caring for a relative or friend with dementia, live in one of the following countries and wish to participate in the survey, the links are:

- **Czech Republic** [https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-czech](https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-czech)
- **Italy** [https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-survey-italy](https://bangor.onlinesurveys.ac.uk/alzheimer-europe-carers-survey-italy)

The Finnish, Dutch and Scottish surveys are now closed, as the target number of respondents have already been surpassed. Congratulations to our member organisations in those countries for their hard work achieving these targets!

26 April: AE signs joint letter to Commission and European Council setting out patient organisations’ criteria for relocation of EMA

Alzheimer Europe (AE), along with 14 other civil society patient organisations has sent a letter to Mr Michel Barnier, Chief Brexit Negotiator at the European Commission, Mr Vytenis Andriukaitis, Health & Food Safety Commissioner, and Mr Donald Tusk, European Council President, to draw attention to important aspects to be considered when deciding the new location of the European Medicines Agency (EMA).

European Commission President Jean-Claude Juncker and European Council President Donald Tusk will discuss general principles for the relocation of the European Medicines Agency (and the European Banking Authority) with EU heads of states and governments at the Brexit summit on Saturday 29 April, to agree on a calendar for the decisions regarding the agencies’ relocation.

The full letter can be read here: [https://goo.gl/VBDxUa](https://goo.gl/VBDxUa)

You can read more about Brexit and the uncertain fate of the EMA in our EU developments section: [https://goo.gl/pPO5gX](https://goo.gl/pPO5gX)

30 April: Alzheimer Europe closes call for abstracts for 27AEC, except for German sessions

The call for abstracts for the 27th Alzheimer Europe Conference (27AEC) is now closed for all sessions except for those in German. The call for abstracts for the german sessions will remain open until 26 April.

We are delighted to have received close to 400 abstracts. These will be reviewed by the Programme Committee during the month of May.


31 March: ACTIFcare presents its results to the advisory and consumers board

On 31 March 2017, after a preparatory meeting, members of the ACTIFcare project (Access to Timely Formal Care) presented the results of the study to the advisory and consumers’ board, of which Alzheimer Europe is a member.

The results, which are still undergoing further analysis, will eventually shed light on reasons for the use or non-use of services and support for/by people with dementia as well as the costs and consequences of formal care services utilisation for people with unmet needs in Europe.

As part of this study, which covered eight different countries, members of the European Working Group of People with Dementia (EWGPWD) contributed towards and some took part in a Delphi study, which will contribute towards the development of best practice recommendations aimed at overcoming barriers and enhancing access to and/or the use of community care services.

Director for Projects Dianne Gove represented Alzheimer Europe at this meeting, which was held in Brescia, Italy.

31 March-1 April: PACE project organises international conference on palliative care

On 31 March and 1 April, the PACE project (Palliative Care for Older People in long-term care facilities in Europe) held an international conference on “End-of-life care for older people in long-term care facilities”. The conference took place in the Nowodworski Hall of the Jagiellonian University Medical College in Krakow, Poland.
The 200 or so delegates, both from Poland and abroad, were welcomed by Professor Beata Tobisz-Adamczyk, the representative of the Provost of the Jagiellonian University for education and international cooperation at the Medical College, who expressed her hope that the conference would contribute to a better understanding of palliative medicine.

During the conference, the main aims of the PACE project were presented and preliminary results for the project were also presented. PACE aims principally to assess the quality of care at end of life for residents in care facilities in six countries in Europe, as well as the development of an efficient model of education and development for the staff in the facilities.

The quality of care for people with dementia was included on the conference agenda, and was discussed particularly in the context of Finland, by Professor Harriet Finne-Soveri of the National Institute of Health and Welfare, Finland.

The conference was complemented by workshops in the field of end-of-life care, during which, the « PACE Steps to Success » programme was presented, with particular attention being paid to efficient communication with the resident, identification of individual needs, assessment of pain and depression, and recognition of the symptoms of dying and coping with the loss of loved ones.

The conference was organised by the team of the Chair of Epidemiology and Preventive Medicine as well as the Chair of Internal Medicine and Gerontology, Jagiellonian University Medical College, with the support of the Medical Centre for Postgraduate Education of the Jagiellonian University. The event was held under the auspices of the Provost of the Jagiellonian University, Professor Wojciech Nowak as well as the Prorector of the Jagiellonian University for Medical College, Professor Tomasz Grodzicki.

The conference was also held under the auspices of the European Association of Palliative Care, the Council of Medical Doctors in Geriatrics in Poland and the Polish Association for Gerontology.

The event hashtag was #CareEOL where you can find many of the tweets at and about the event.

More information about the PACE project can be found on the project website: http://eupace.eu/
You can also follow PACE on Twitter: https://twitter.com/fp7PACE

The PACE project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement no 603111.

8 April: AMYPAD researchers present the project at “Memory day” in Amsterdam

On 8 April, the Alzheimer Centrum at the VUmc in Amsterdam opened its doors to the public for the second edition of what is called Geheugendag (Memory day). The vision behind Geheugendag is to allow the general public to interact with researchers at the Alzheimer Centrum and to inform themselves about the latest developments in the field of Alzheimer’s disease (AD) and dementia research, as well as current research projects of the centre itself.

In addition to a guided tour of the facilities, visitors were able to attend two talks on AD and current research, meet researchers and share experiences, and obtain information regarding the projects running at the hospital.

As part of these activities, two researchers, Lyduine Collij and Isadora Lopes Alves prepared and presented a poster to introduce and explain the AMYPAD project (Amyloid imaging to prevent Alzheimer’s disease). The poster highlighted the importance of assessing the β-amyloid status at the early stages of AD for secondary prevention, the advantages of PET imaging and its relationship to other radiation sources, as well as the setting in which AMYPAD will take place and how participants could join the project.

The researchers reported that the poster was very well received and many visitors understood and appreciated the relevance of the project and some even asked how to join. The researchers believe this was an important experience to understand the motivation behind participating in the AMYPAD study, which will hopefully help not only recruitment but also the way in which AMYPAD gives back to the community during and after the project.

18 April: AMYPAD project launches its website

AMYPAD is proud to announce the official launch of its website http://www.amypad.eu/. The AMYPAD website is devoted to targeting different audiences including the scientific community, policymakers, carers,
people with Alzheimer’s disease/dementia and the general population. On the website, you can find information about the project’s objectives, its progress and achievements. Visitors also have the opportunity to subscribe to the quarterly newsletter.

The AMYPAD project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115952. The Joint Undertaking receives support from the European Union’s Horizon2020 research and innovation programme and EFPIA.

### 23 April: INDUCT project 7 is researching the (cost-)effectiveness of exergaming for people living with dementia and their (informal) caregivers

Research has shown that exercise positively influences physical fitness, daily functioning, general health and well-being in people living with dementia. However, people with dementia often experience several barriers to engage in physical activity, such as problems with orientation (wandering, getting lost), and a decrease of initiative, interest, and motivation. This makes it harder to be active independently outside their house.

Exergaming (exercise & gaming) is an innovative, fun and relatively safe way of exercising in a virtual reality or gaming environment. For instance, bicycling on a home trainer while seeing a route through a village on a big screen. The faster the person cycles, the faster the movie plays, making it feel as if you’re actually cycling through the village. As part of the Interdisciplinary Network Using Current Technology in Dementia (INDUCT) project, Early Stage Researcher Joeke van der Molen-van Santen (pictured) investigates the (cost-)effectiveness of exergaming in day care centers for people living with dementia and their (informal) caregivers. Furthermore, the motivation for and the satisfaction with exergaming are studied, as well as how exergaming can be successfully implemented in dementia day care centers. Joeke is based at the Department of Psychiatry of the VU University Medical Center (VUmc) in Amsterdam, carrying out the research under the supervision of project leader Dr Franka Meiland, Prof. Dr Rose-Marie Drosis, and Prof. Dr Annemieke van Straten (Faculty of Behavior and Movement Sciences).

Currently, a factsheet describing guidelines for the successful implementation of exergaming for people living with dementia, is being written, based on the pilot and literature. This factsheet will be updated with findings obtained throughout the project. Simultaneously, a systematic literature review is carried out to provide an overview of research done in the area of exergaming in dementia. Additionally, a randomised controlled trial (RCT) will be conducted to compare exergaming to regular day care activities on physical (primary outcome), cognitive, emotional and social functioning, and quality of life of people with dementia; and on positive experiences, quality of life and burden of informal caregivers (secondary outcomes). Although the recruitment of day care centres for this study is still ongoing, data-collection for the RCT has already started in the ones which have currently agreed to participate.

Would you like to know more? Send an email to: j.vandermolen@vumc.nl

### 27 April: IMI project IMPRiND will investigate mechanisms of AD and Parkinson’s

Recent evidence suggests the progressive loss of brain cells seen in Alzheimer’s disease (AD) and Parkinson’s disease may be due to brain cells taking up and releasing specific aggregated proteins (misfolded proteins, which clump together). Newly-launched Innovative Medicines Initiative (IMI) project IMPRiND will investigate whether mechanisms of the spreading of such aggregated proteins between cells could enable novel therapeutic approaches in AD and Parkinson’s.

“We are seeking to understand how aggregated proteins are handled once inside brain cells and how they are passed from cell to cell. To this end, we will work collaboratively to develop standardised tools and assays to establish disease-relevant mechanisms that could enable future therapies against disease progression in this area of unmet need,” said project coordinator George Tofaris of the University of Oxford. IMPRiND has a total budget of EUR 11.4 million, of which EUR 4.7 million comes from the EU’s Horizon 2020 programme, EUR 6.4 million comes in the form of in-kind contributions from EFPIA companies and EUR 0.3 million comes from the Swiss Federation.


### Alzheimer Europe Networking

On 3 April, Dianne attended the ROADMAP Ethics Advisory Board telephone meeting.

On 3 and 4 April (The Hague, Netherlands), Gwladys and Marco Blom from Alzheimer Nederland visited potential venues and accommodation for 29AEC.

On 4 and 5 April (Rotterdam, Netherlands), Gwladys and Marco Blom from Alzheimer Nederland visited potential venues and accommodation for 29AEC.
On 6 April (Brussels, Belgium) Vanessa presented the European Dementia Monitor to the LTC-IC coalition at Eurodiaconia. On 6 April (Luxembourg, Luxembourg) Gwladys met with Lufthansa airlines to discuss a partnership for the 27AEC as official carrier of the event.
On 6 April, Dianne attended the ROADMAP ethics work package telephone meeting.
On 10 April, Dianne and Ana attended the MinD telephone conference.
On 11 April, Dianne and Ana attended the INDUCT telephone conference.
On 11 April (Luxembourg, Luxembourg), Jean met with a representative of DG SANTE of the European Commission to discuss the upcoming meeting of government experts on dementia in Malta
On 20 April (Luxembourg, Luxembourg), Jean met with a representative of Biogen to discuss areas for collaboration in 2017.
On 24-25 April (Berlin, Germany), Dianne, Chris and Cindy attended the AETIONOMY/PRECISESADs Joint Ethics Meeting.
On 25 and 26 April (Kyoto, Japan), Stefanie Becker represented Alzheimer Europe at the Alzheimer’s Disease International (ADI) Elected Board and Council meetings.
On 26 April (Luxembourg, Luxembourg), Gwladys attended an event with HC&L SolutionS, meeting with various event suppliers.
On 27 April Dianne, Ana and Kate participated in the SMART4MD General Assembly meeting by telephone conference.
On 27-28 April (Bucharest, Romania), Jean attended the meeting of the European Alzheimer’s Disease Consortium (EADC).

Members of the European Alzheimer’s Alliance

Currently, the total number of MEPs in the Alliance stands at 127, representing 27 Member States of the European Union and six out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer’s Alliance:

**Austria:** Heinz K. Becker (EPP); Karin Kadenbach (S&D); Barbara Kappel (NI); Paul Rübig (EPP). **Belgium:** Mark Desmesmaeker (ECR); Frédérique Ries (ALDE); Bart Staes (Greens/EFA); Marc Tarabella (S&D); Kathleen van Brempt (S&D); Hilde Vautmans (ALDE). **Bulgaria:** Andrey Kovatchev (EPP). **Croatia:** Biljana Borzan (S&D); Tonino Picula (S&D); Ruža Tomašić (ECR). **Cyprus:** Costas Mavrides (S&D); Eleni Theocharous (EPP). **Czech Republic:** Olga Sehnalová (S&D); Pavel Svoboda (EPP); Tomáš Zdechovský (EPP). **Denmark:** Ole Christensen (S&D); Jens Rohde (ALDE); Christel Schaldemose (S&D). **Estonia:** Urmas Paet (ALDE); Finland:** Liisa Jaakonsaari (S&D); Anneli Jäätteenmäki (ALDE); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France:** Dominique Bilde (ENF); Nathalie Griesbeck (ALDE); François Grossetête (EPP); Philippe Juvin (EPP); Elisabeth Morin-Chartier (EPP); Gilles Pargneaux (S&D). **Germany:** Angelika Niebler (EPP); Udo Voigt (NI). **Greece:** Kostas Chrysogono (GUE/NGL); Manolis Kefalogiannis (EPP); Kostadinka Kuneva (GUE/NGL); Kyrkos Miltiadis (S&D); Dimitrios Papadimoulos (GUE/NGL); Sofia Sakorafa (GUE/NGL); Maria Spyraiki (EPP); Eleftherios Synadinos (NI); Elissavet Vozemberg (S&D). **Hungary:** Ádám Kósá (EPP). **Ireland:** Lynn Boylan (GUE/NGL); Matt Carthy (GUE/NGL); Nessa Childers (S&D). **Iceland:** Birgitta Jónsdóttir (GREEN/EFA). **Italy:** Brando Benfié (S&D); Elena Gentile (S&D); Stefano Maullu (EPP); Pier Antonio Panzeri (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Georges Bach (EPP); Frank Engel (EPP); Charles Goerens (ALDE); Viviane Reding (EPP). **Malta:** Therese Comodini Cachia (EPP); Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands:** Esther de Lange (EPP); Jeroen Lenaers (EPP); Lambert van Nistelrooij (EPP). **Poland:** Elżbieta Łukacijewska (EPP); Krystyna Lybacka (S&D); Jan Olbrycht (EPP); Marek Plura (EPP); Bogdan Wenta (EPP). **Portugal:** Carlos Coelho (EPP); Marisa Matias (GUE/NGL); Sofia Ribeiro (EPP). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP); Daciana Octavita Sarbu (S&D); Claudiu Ciprian Tanasescu (S&D); Renate Weber (EPP). **Slovakia:** Miroslav Mikolásik (EPP); Ivan Stefanec (EPP); Anna Záborská (EPP); Jana Žitnanská (ECR). **Slovenia:** Franc Bogovič (EPP); Tanja Fajon (S&D); Alojz Peterle (EPP); Igor Šoltes (Greens/EFA); Patricija Šulin (EPP); Romo Tomc (EPP); Ivo Vajgl (ALDE); Milan Zver (EPP). **Spain:** Izaakun Bilbao Barandica (ALDE); Soledad Beczán Ruiz (S&D); Luis de Grandes Pascual (EPP); Rosa Estarás Ferragut (EPP); Juan Carlos Girauta Vidal (ALDE); Sergio Gutiérrez Prieto (S&D); Juan Fernando López Aguilar (S&D); Pablo Zalba Bidegain (EPP). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (EFD); CeciliaWikström (ALDE). **United Kingdom:** Martina Anderson (GUE/NGL); Richard Ashworth (ECR); Anneliese Dodds (S&D); Ian Duncan (ECR); Theresa Griffin (S&D); Ian Hudginton (Greens/EFA); Jean Lambert (Greens/EFA); Linda McAvan (S&D); Claude Moraes (S&D); Alyn Smith (Greens/EFA); Catherine Stihler (S&D); Keith Taylor (Greens/EFA); Derek Vaughan (S&D); Julie Ward (S&D); Glenis Willmott (S&D).
EUROPEAN ALZHEIMER’S ALLIANCE

26 April: MEP Olga Sehnalová, member of the EAA - action on dementia

MEP Olga Sehnalová (Czech Republic) has been a member of the European Alzheimer’s Alliance (EAA) since 2014. She recently attended Alzheimer Europe’s European Parliament lunch debate in December 2016 "Comparing and benchmarking national responses to the dementia challenge"

In light of this, Alzheimer Europe (AE) asked Ms Sehnalová: From a policy maker’s perspective, why do you think it is important to bring the challenge of Alzheimer’s disease to the front and centre of the European Parliament and what could be done to meet this public health challenge?

“For policymakers it is an obligation to react to challenges of our societies. As a starting point, these challenges have to undergo a broad and open debate at all levels from local to European based, on facts, expertise and context. In this regard, the European Parliament can play an important role in prioritising the agenda and bringing it to the focus of the other EU institutions. This fully applies to the public health challenge of Alzheimer’s disease with its many aspects which will only grow over time and which has to be addressed in a holistic way.”

https://goo.gl/dzgMiw

EU DEVELOPMENTS

24 March: European Solidarity Corps health stakeholder meeting

On 24 March, the European Commission hosted a meeting on the European Solidarity Corps (ESC) in Brussels. Representatives from DG SANTE, including Martin Seychell, Deputy Director General of Health gathered stakeholders for informal discussions to highlight the potential for health action and opportunities to be involved in the ESC.

The ESC, which was launched on 7 December 2016, will create opportunities for young people to support communities and people in need. These opportunities will include volunteering and solidarity-related jobs, traineeships and apprenticeships, both in the young people’s home countries and abroad.

The meeting focused on discussing the development of the ESC and the possible implications for the current health programme and how patient organisations such as Alzheimer Europe could benefit. Policy Officer Vanessa Challinor attended this meeting.

25 March: The EU turns 60, the Lancet journal looks at its track record on health

On 25 March, Europe celebrated the 60th anniversary of the signing of the Treaties of Rome - two treaties that gave birth to the European Economic Community (EEC) and to the European Atomic Energy Community (EURATOM) –

To highlight this anniversary the Lancet journal published an editorial “What has Europe ever done for health?” looking at the achievements of the European Union (EU) in the area of public health over the past 60 years, as well as pointing out some areas for improvement.

The editorial, looks at the many public health-related successes of the EU, with particular emphasis on its firm stance on tobacco, despite intensive industry lobbying. It also highlights the importance of the newly-created European Reference Networks (ERNs), connecting 900 medical teams across Europe, tackling complex or rare diseases and conditions; and the development of European guidelines that help promote evidence-based management of a wide range of conditions.

“Most European countries have made impressive progress in population health in the past two decades, showing how Europe offers a natural learning community enabling each country to benchmark itself against others”.

The editorial also stresses the importance, of the European Medicines Agency (EMA), which provides a single pathway for new drug approval; of the European Commission’s Directorate General for Health and Food Safety Consumer Protection (DG SANTE), which protects and promotes the wellbeing of its citizens through public health, food safety, and consumer protection; and of the European Court of Justice, which “has consistently upheld public health principles”.

The Lancet also highlights some gaps to be filled, including: better engagement with younger generations, intersectoral collaboration, and investment in primary health care, which it says are key to addressing “the double challenge of epidemiological and demographic transitions and the multimorbidity of chronic mental and physical ill-health.”

Under the shadow of the UK “Brexit” vote last year, and with rising support for extremist anti-EU parties across Europe, union and solidarity in the 28 EU member states seems to be at risk. “The dawn of the next 60 years in Europe heralds an opportunity to tackle all these challenges. EU collaboration and investment in health can build a visibly cohesive European community based on founding values of solidarity, freedom, sustainability, and wellbeing—which remain even more relevant today than 60 years ago” it concludes.

http://thelancet.com/journals/lancet/article/PIIS0140-6736(17)30812-7/fulltext?dgcid=twitter_social_lancet
8 April: CPME endorses Declaration of Taipei on ethical considerations regarding health databases and biobanks

On 8 April, the Standing Committee of European Doctors (CPME) endorsed the WMA Declaration of Taipei on ethical considerations regarding health databases and biobanks, adopted by the General Assembly of the World Medical Association (WMA) in October 2016.

CPME President Dr Jacques de Haller said: “The re-use of health data in the context of medical research is at the centre of EU discussions. If medical research using Big Data has the potential to increase knowledge for the benefit of society, it is equally important to guarantee patients’ autonomy and their rights to self-determination. The WMA Declaration of Taipei provides ethical guidelines, which are needed to guarantee an ethical and transparent re-use of health data”.


26 April: Countries jockey to host the European Medicines Agency after Brexit

The uncertain fate of the European Medicines Agency (EMA), follows Britain’s vote last June to leave the European Union (EU) and the triggering of Article 50 by British Prime Minister Theresa May on 28 March 2017. The EMA, which has been located in London since 1995 when it was first established, employs nearly 900 people and plays host to 36,000 national regulators and scientists each year from across Europe who come to London to approve the safety and efficacy of drugs for the EU’s population.

In two decades, the agency has authorised about 1,000 products for use across the 28-nation EU, plus Iceland, Liechtenstein and Norway.

It is likely a decision on the new location will be taken by the EU’s heads of state, at a meeting of the European Council on 22-23 June.

The European Federation of Pharmaceutical and Industries and Associations (EFPIA) issued a statement on Monday, signed by 19 top executives at member companies including Pfizer, Novartis, Sanofi and Roche, stating “The Council’s deliberations on the Agency’s future location need to be conducted on the basis of very essential criteria and put for decision as early on as possible, preferably at its meeting in June this year,”

An EMA spokesperson said the agency has made a list of things the new location should have. It includes good transport links, a large enough building, and hotel capacity nearby. "For our staff we need sufficient housing, access to international/European schools, employment opportunities for spouses/partners in a safe location".

No fewer than 21 EU member states have expressed their interest in hosting the EMA, including The Netherlands, Italy, Denmark, Sweden, Spain, France, Ireland and Poland.

26 April: European Commission releases comprehensive Work-Life Balance Package

The European Commission (EC) has released the European Pillar of Social Rights, in the form of a recommendation listing twenty key principles for driving the future of the European Union’s (EU) social policy agenda.

One of these principles focuses on “Work-Life balance for working parents and carers”, an ambitious and comprehensive proposal.

For the first time the new Directive includes a carer’s leave of five days per year in case of sickness of a direct relative. All of these family related leave arrangements will be compensated at least at the level of sick pay. The proposal will also give parents of children up to 12 years old and carers the right to request flexible working arrangements, like reduced or flexible working hours or flexibility on the place of work.

"Balancing work and family life is a daily challenge for women and men all over Europe," said Věra Jourová, EU Commissioner for Justice, Consumers and Gender Equality. “It is our duty to deliver the right framework so that people can make their own choice. Our new proposal aims to strengthen the rights and improve the conditions for working parents and carers to reconcile work and family responsibilities. It will give more flexibility and better protection to mothers, fathers and carers, whether they wish to take time off caring for their children, benefit from flexible working arrangements or wish to go back to work.”

The work-life balance package is expected to be the first in a long line of pillar packages, to address all the social and employment challenges faced by EU countries, not least the need to include people with disabilities in all aspects of life, the need to develop adequate childcare and long-term care services, reinforcing gender equality, and promoting access to basic financial services.


26 April: Disappointing result of the European Parliament Internal Market Committee (IMCO) Committee vote on the Accessibility Act

The European Commission’s (EC) proposed European Accessibility Act is about bringing more accessible products and services to disabled and elderly European citizens. The draft directive set out accessibility requirements for services in Europe including ATMs, ticketing and check-in machines, PCs and operating systems, phones and TV equipment, consumer banking services, e-books, transport and e-commerce products and services. The act also includes accessibility for built environments such as banks, schools train stations etc.
The European Disability Forum (EDF), together with its members (including Alzheimer Europe) and partners, have been strongly campaigning for ambitious legislation on the accessibility of products and services in Europe.

In a final vote in the Internal Market Committee (IMCO) on the European Parliament report on the Accessibility Act by MEP Morten Løkkegaard, the report was only adopted by a narrow majority of IMCO MEPs: 19 votes in favour and 17 abstentions - Almost all amendments on issues that the disability movement had proposed were rejected by the IMCO Committee.

EDF stated “Achieving a wide-reaching and ambitious legal text that will make a real difference in the lives of 80 million Europeans with disabilities, 150 million older people and all other citizens is now at risk”

The report also fails to see the full potential of the Act as an instrument for the European Union (EU) and its Member States to implement the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). The EU itself and almost all its Member States, except Ireland have ratified the CRPD and have the obligation to apply its principles in practice, including accessibility.

This report only represents the view of the IMCO Committee on the Accessibility Act. The European Parliament as a whole has yet to vote on it in its plenary session in June. The negotiations among the European Parliament, the Council and the European Commission on the Accessibility Act have not started yet.


MEMBERS’ NEWS

21 March: Alzheimer Hellas tells us about the Greek play “Caregiver’s voice”, in Thessaloniki

Three professional actors and a caregiver have presented in a theatrical performance, the stories of the caregivers, which have been produced during the therapeutic intervention “Listen to my story” in the Department for Caregivers of Alzheimer Hellas in Thessaloniki. Based on the therapeutic benefits of art, the intervention “Listen to my story” has been designed in order to help families of people with dementia to express their feelings, to find new meanings in their experiences and to better acclimatise to dementia. During each session, literature or poetry stimulate caregivers to talk about their thoughts and emotions. Through each one’s eyes, poems and texts are analysed and shared with the group. The aim of these caregivers’ narratives is to give answers to their questions about dementia. Besides vocalising their thoughts, the members of the group write their own stories, using expressive and spontaneous writing techniques.

As an evolution of this intervention, there has been an attempt to merge all the stories of the caregivers into a single story and then dramatise them with the help of professional actors. A preliminary step of this work in progress was presented in the conference “Caring for the caregivers” in Thessaloniki on from 18 to 20 March 2016 and the complete theatre performance, “Caregiver’s voice” was held in March 2017.

At the end of the performance, the spectators shared their feelings and thoughts in common with the caregivers’ stories. The caregivers who had written the stories expressed their gratitude for being part of this experience, and reported that it was very helpful in order to express deep feelings and to find new meanings in their experiences. Gratitude is one of our feelings too, as psychologists and facilitators of the intervention, as well as great happiness. That’s why we hope that “Listen to my story” will continue its route and even more personal stories will be written by caregivers, in order for us to understand their world!

26-28 March: Alzheimer Slovenia reports on 2nd AD-GAMING project meeting

From 26 to 28 March 2017, representatives of the AD-Gaming project partners attended a 2nd meeting in Thessaloniki, Greece. We reviewed early results of conducted co-creative sessions of serious games in each country, and concluded that participants showed great engagement with selected games and some mild improvement in eight cognitive areas: memory, language, orientation, attention, perception and gnosia, recognition, calculus and praxia. We summarised basic findings and elaborated a plan for further work.

In the following months, we will create contents for a methodological guide for health professionals in order to help them to perform workshops of serious games for individuals with dementia and individuals with mild cognitive impairment (MCI). Regardless of the outcomes, special emphasis will also be given to developing training materials for both caregivers and professionals.

The final step of the project will be the implementation of all these contents in the e-platform.

27-30 March: Alzheimer Society of Ireland attends ADI Alzheimer University in Washington

The Alzheimer Society of Ireland was awarded two bursaries by Alzheimer’s Disease International (ADI), to attend its Alzheimer University in Washington DC from 27 to 30 March. This training focused on strategic planning for advocacy, highlighting how to identify
policy issues, build consensus on priorities and create lasting political leadership on dementia. The participants also had an opportunity to attend the opening ceremony and a morning session of the Alzheimer’s Association annual Advocacy Forum, providing valuable insight into how advocacy work on dementia is prioritised and structured in the US. The Alzheimer University was also an excellent opportunity to build relationships with key stakeholders from ADI, the Alzheimer’s Association and other associations from around the world. The Alzheimer Society of Ireland would like to thank ADI for supporting and facilitating its staff to participate in this training.

31 March: Jersey receives international recognition for its Splashchat initiative

In its March newsletter, the Jersey Alzheimer’s Association was delighted to announce that “Splashchat”, its award-winning local health initiative, was selected to feature at the 32nd Alzheimer’s Disease International Conference taking place in Japan this month. A joint venture between the Occupational Therapy Service, the Memory Clinic, AquaSplash and Jersey Alzheimer’s Association (JAA), it was the overall winner of the Health Department’s quality improvement awards in 2016.

The project gives carers and people living with dementia the chance to meet on a weekly basis for a swim and a chat and was chosen by ADI conference organisers as one of the best examples of community engagement and good practice out of hundreds of schemes from across the world.

JAA Manager Mark Blamey will write a report about the ADI conference for the next edition of our newsletter.

31- March 1 April: Alzheimer Croatia co-organises 1st Regional Conference on Alzheimer’s Dementia

On 31 March and 1 April 2017, the 1st Regional Conference on Alzheimer’s Dementia was held in City of Požega in Eastern Croatia, under the auspices of The Ministry of Demographics, Family, Youth and Social Policy of the Republic of Croatia and Požega-Slavonia Count. The event was co-organised by Alzheimer Croatia.

The conference discussed answers to the questions asked at the clinic and social welfare centres, and problems that family and professional caregivers of people with dementia encounter.

The value of this conference was ensured by a good selection of topics and practices prevailing in the region. The Conference in Požega was also an opportunity for the presentation of the EU programme Demenca aCROsSLO, in which Alzheimer Croatia plays a prominent role in the development of educational programmes and recommendations for the design of the environment for people with dementia.

The conference began with the adoption of the Global Dementia Charter and ended with a Round Table “Assistance to Alzheimer’s Dementia and Their Families”.

Great organisation and attendance indicates that such conferences are needed in other regions of Croatia, Alzheimer Croatia stressed.

11 April: Alzheimer Uniti Rome raises funds together with Eataly

For the Italians, the culture of food is very important - not so much the food itself but the convivial encounter around the meal. With this in mind, Alzheimer Uniti in Rome invited its members to an Easter dinner, hosted and generously supported by the worldwide group Eataly, who reserved one of their restaurants for a whole evening for the association. And not to say that the food itself is of no importance! In fact, they served a traditional Easter dish of tasty lamb with delicious vegetables. But the most important aspect was the cheerfulness of the evening that included people with dementia and their families, caregivers, and health care workers. Eataly offered to repeat the evening for World Alzheimer’s Day in September and the event has been booked. For the Easter event, Eataly had created a big poster (pictured) which, together with the meal itself, created a buzz towards public awareness, as we continue to fight stigma.

14 April: Alzheimer Slovenia campaign poster awarded second place at prestigious advertising festival

Spominčica – Alzheimer Slovenia launched a successful campaign in 2016: Svinčnik (Pencil), created by well-known Slovenian advertising agency Pristop and Europlakat. In November 2016 a poster appeared in more than 280 places all over Slovenia for a week. As another means of increasing awareness of dementia, it was published in 27 Slovenian newspapers.

During the 26th Slovenian Advertising Festival (SOF) - “the” event of the Slovenian marketing-communications industry – which took place at Hotel Kempinski Palace, Portorož on 6 and 7 February 2017, the poster received second, silver prize in the category H Print Advertising and Posters. “This a great success for Spominčica and dementia”, said Spominčica President, Stefanija Lukic Zlobec.

A translation of the slogan on the poster: “When you have a dementia, you are always haunted by the shadow of a doubt.”

https://sof.si/katalog/svincek-2/
24 April: Czech Alzheimer Society receives excellent evaluation of its Memory Days project from Ministry of Health

The Ministry of Health in the Czech Republic has evaluated the last year of the Memory Days project, conducted by the Czech Alzheimer Society. The Society has sent us this report:

Almost 8,500 Czechs have had their memory tested between June 2008 and the end of 2016. More than 3,100 of them have been referred to a specialist (a geriatrician, a neurologist, a psychiatrist), thanks to our project.

The aim of the Memory Days project is timely diagnosis of Alzheimer’s disease and other forms of dementia. Although we have no valid data about the diagnosis rate in the Czech Republic, we believe that the rate of diagnosed people with dementia is around 30%.

During 2016, almost 1,200 people had their memory tested thanks to the project, with 36% of them showing signs of “objective” cognitive disorder. This rate has been more or less the same throughout the project, with the best rate we have observed yet being in 2010, when an extraordinary 48% of those tested were referred to a specialist.

2016 has been the first year in which there has been public support for the project and during April 2017, we received an evaluation of our project from the Ministry of Health, which financially supported the project last year. The evaluation is: “1 - project fulfilled in an excellent way, the effect fully achieved”. This evaluation not only makes us proud of our good work, but is also essential for further support for the year 2017, meaning that memory tests continue to be conducted at 30 “contact places” of the Czech Alzheimer Society in 2017!

25 April: The Alzheimer Society of Finland reports on its election pledge campaign for memory-friendly communities

Finnish people cast their votes in the municipal elections in April 2017, and the Alzheimer Society of Finland (Muistiliitto) organised an election pledge this spring. With the campaign site www.muisti17.fi and local campaigning by its 44 member associations, we got nearly 1,200 candidates in 183 different municipalities and from all major parties represented in these elections.

The election pledge aimed at raising awareness among candidates and voters about the needs of people with memory-related diseases and their families. The Finnish system of health and social services is currently under a massive reconstruction and many of the responsibilities of current municipalities will be transferred to larger regions in near future. Therefore, in the pledge, we stressed the importance of memory-friendly local services such as public transportation and cultural activities.

The 1,192 candidates that signed the pledge promised to contact their local memory association when they make decisions that influence the care or services for people with memory diseases. Some of the candidates left encouraging personalised messages to the campaign site, such as this one: “My goal is a memory friendly Raahe. I am part of the building force. I will listen to the voice of the people with memory diseases and their families in my municipality. In matters regarding age politics, I will contact my local memory association. Memory diseases are serious and burdensome both personally and for the close family. Especially, I look upon the volunteers who awaken the rest of us to remember healthy habits that can prevent or hinder memory diseases. Big thanks!”

26 April: Foundation Compassion Alzheimer Bulgaria reports on its recent activities

In 2016 Foundation Compassion Alzheimer Bulgaria (FCAB) implemented several initiatives aimed at improving quality of life of people with Dementia and raising awareness for the need of services:

- The team of the Foundation exchanged experience and good practices with an Italian organisation in the field of services for people with Dementia (we visited their Residential home Rifugio Re Carlo Alberto for people with Dementia in the town of San Giovanni, Italy). We were impressed by the variety and the quality of services provided there and will use the experience for lobbying in Bulgaria for services for people with Dementia.
- Thanks to project funded by the Municipality of Varna for five months, since June 2016, Foundation Compassion Alzheimer Bulgaria provided the service “Center for information and consultations for people with Alzheimer’s, dementia and other memory disorders” in Varna. The project aimed at improving the quality of life of people with Alzheimer’s and dementia, as well as family members who care for them by providing information and consultations. The service included psychological counselling and the multidisciplinary team (psychotherapist, animator, art-therapist, lawyer) used a variety of activities - individual and group sessions, excursions, walks, classes in drawing and music.
- In September 2016, in the city of Varna, on the occasion of World Alzheimer’s Day, the Foundation participated in a conference with representatives from Varna Municipality and NGOs and we hope that, in the near future, there will be services for people with Alzheimer’s, supported by the authorities and public funds.
- FCAB joined the campaign “Move for Dementia – Living well with Dementia in the Community” of the German organisations “Aktion Demenz” and “Enger” and organised a basketball game (pictured) on the occasion of
the World Alzheimer’s Day. The campaign was marked in several European countries and will continue in 2017 as well.

26 April: UK Alzheimer’s Society holds Symposium at ADI conference in Japan

The “Building a Dementia Friendly World” Symposium held on 26 April preceded the annual ADI 2017 conference, this year held in Kyoto, Japan. The Symposium was co-hosted by Alzheimer’s Society (UK) and WHO Kobe Centre working in partnership with Alzheimer’s Disease International (ADI). It was an opportunity to showcase exemplary work from initiatives around the world working to create dementia-friendly communities. Dementia-friendly initiatives from the Netherlands, Australia, Indonesia, Costa Rica and Japan demonstrated how they have taken the principles of dementia-friendliness and applied them within their cultures and local communities.

The symposium attended by over 350 people from at least 33 countries was also streamed online to viewers unable to attend ADI 2017 in Kyoto.

Participants were encouraged to focus on what dementia-friendly means to them and how they believe we can achieve a dementia-friendly world. The symposium provided an opportunity to collaborate, debate and network with others to build a dementia-friendly world. Proceedings will also inform the development of a dementia-friendly framework, currently in development by the World Health Organisation (WHO) with an aim to promote and support dementia-friendly initiatives around the world.

Further information on how to get involved in the development of the WHO framework will be available soon.

www.youtube.com/watch?v=kvzeHKQSXDY

27 April: Larissa Association of Alzheimer’s Disease reports on its “Multimodal Laboratories”

The Larissa Association of Alzheimer’s Disease and Related Disorders (EENAA) follows people in the journey of life. Some of them feel strong, some feel weak, and some are desperate. The EENAA team teaches understanding regarding human life and circumstances. Through interactive engagement, volunteers guide people to find and keep their inner strength, share experiences, mobilise themselves, and inspire those around them, aiming at a sound mind in a sound body. Since 2004, EENAA has been organizing a number of thematic sessions, informative seminars and open festival activities.

Its “Multimodal Laboratory” was initiated in 2007 and formulated based on volunteers’ experiences, people’s needs and group dynamics. In particular, the Larissa Association runs regular multimodal weekly meetings to challenge cognitive performance, memory enhancement, reciprocity and receptiveness. The beginning is a story that gives birth to a painting, or a picture that gives birth to a story. Recollection and narration of memorised proverbs, poems and stories is a major part of EENAA’s multimodal approach. Taking advantage of seasonal or random cues, participants concentrate activities around a theme, aiming at first to their primary sensory input: hearing and vision. As participants work in pairs or groups, they:

- practice and improve language skills
- become adept in hand tasks
- socialise
- feel confident
- become more extrovert.

Physical mobilisation is also encouraged as the day unfolds. Simple gestures and movements are followed by steps and dance. For some of the participants, lack of balance and stability are major issues that interrupt their daily routine. Therefore, it is necessary to set realistic goals and modify routine according to individual potential, rather than set a goal and work towards it: Visualising a runner and imitating him is more fun and feasible than setting a pace or the power of an exercise. “In flight” exercise or pulling a handkerchief is more efficient than a regular stretching routine. As more real life elements-targets are incorporated, the more cooperative and successful exercises prove.

Overall, EENAA’s approach includes proximal and distal stimuli to initiate verbal and creative communication, and further exploits activities to transpose the mental and physical effort to memory recollection, consolidation and creation, and predominantly to maintain individuality and soundness. It is a common belief that age and neurodegenerative disorders come with weakness, and that assistance is needed in every step. Indeed, caregiving may help in coping with daily life, though without affecting individuality.

The work groups are open to everybody: those in older age, concerned or not about their cognitive abilities, as well as people with mild cognitive impairment (MCI), suspected Alzheimer’s and other types of dementia. Everyone has their own rhythm and character; is accepted and respected. Even people who are not mobile are invited to set personal goals and monitor their progress accordingly. Self satisfaction from the completion of a simple task is gratifying for both instructors and participants, who look forward to the next session and are eager to advertise their progress to family and other people.

Pictured: Caregivers writing their stories during the intervention

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**POLICY WATCH**

**21 March: The Norwegian Government announces a National Brain Strategy**

On 21 March, the Government of Norway held a high level meeting on brain health, for which it invited Norwegian brain researchers, user organisations, and patients affected by brain diseases. Altogether 10 out of 46 member organisations of the Norwegian Brain Council were represented.

A status report on the situation of brain health in Norway from the Directorate of Health, published in February 2017, revealed severe shortcomings in the care of brain health patients. The Minister of Health and Care services emphasised that through better coordination of services, many people would experience improved quality of life.

As a consequence, the Norwegian Prime Minister, Erna Solberg and the Minister of Health and Care Services, Bent Høie announced that the Norwegian Government will initiate work on a National Brain Strategy.

The focus of the plan will be to address the requirements needed for more extensive brain research, improved treatment and rehabilitation of people with brain diseases as well as increased brain health for the general public, as part of a preventive approach.

During the course of the meeting, the invitees shared their points of view on the new National Brain Strategy and provided valuable input on the approach.

The National Brain Strategy will be launched after the establishment of a mandate to the Directorate of Health, which is currently in process.


**23 March: Irish All-Party Group on Dementia hosts round table on home care**

There is wide-spread recognition of the need for a fair and equitable network of home care across Ireland. The All-Party Oireachtas Group on Dementia therefore welcomed the announcement in January 2017 that Minister of State for Mental Health and Older People, Helen McEntee TD* will be launching a consultation process with a view to establishing a new statutory home care scheme.

The All-Party Group hosted a round table event for key stakeholders on 23 March, to advance the discussion on how Ireland can develop a scheme for home care that is equitable, well-resourced and well-regulated.

**10 April: Social care workers quitting at a rate of 900 per day in England**

More than 900 adult social care workers a day quit their jobs in England last year, announced the BBC, analysing data from the charity Skills for Care. 60% of these left working in the adult social care sector altogether. Much of this is put down to the pressures of low pay and zero hours contracts, and lack of access to adequate training.

43% of homecare workers in England reportedly asked for further dementia training, but in 54% of those cases the request was turned down. Only 2% of people affected by dementia felt that homecare workers had enough dementia training.

Service providers warn that growing staff shortages mean vulnerable people are receiving poorer levels of care.

In a letter to Prime Minister Theresa May, Mike Padgham, Chairman of the UK Homecare Association, said:

"My biggest fear is that we will soon run out of capacity to provide care to those who cannot fund themselves. I agree wholeheartedly with Age UK’s warning that the social care system will begin to collapse this year, but I would go further and say that the system has already begun to collapse.”

**11 April: New support measures for people with dementia announced in France**

On 11 April, the French Minister of Social Affairs and Health Marisol Touraine (pictured) announced the implementation of new support measures for people with neurodegenerative diseases (NDs) such as Alzheimer’s dementia. Access to GP practice consultations for information and treatment of neurodegenerative diseases will be available at a cost of EUR 60 per consultation. GPs will also be able to make three home visits per patient per year, at a cost of EUR 70 per visit.

These measures, which will come into effect on 1 November 2017, are to recognise and increase the role of GPs in the prevention and care of NDs, particularly dementia and to improve the care pathway for patients.

Ms Touraine also announced the opening of 20 additional cognitive-behavioural units in France, half of which are planned in 2017.

**21 April: Croatian Alzheimer’s Alliance is formed**

Our friends at Alzheimer Croatia have informed us that the country has recently formed a Croatian Alzheimer’s Alliance, and has kindly sent us this report about...
this new and exciting initiative to help support people with dementia in Croatia:

The Croatian Society for Alzheimer’s Disease and Old Age Psychiatry of Croatian Medical Association and Alzheimer Croatia gave themselves a task, following the guidelines of the World Health Organization, to develop a national strategy / plan to combat Alzheimer’s disease (AD).

For this purpose, the Croatian Alzheimer Alliance (CAA), or in Croatian language Hrvatska Alzheimer Alijansa / HAA, was established with the desire to bring together as many people, professional societies and associations to join their forces to lobby for the implementation of the national strategy to fight against Alzheimer’s disease (AD).

In parallel, a draft text of the proposal entitled “Croatian strategy for the fight against Alzheimer’s disease 2015 – 2020” was prepared and for the first time has been presented and discussed in public in Brela, during the Croatian Congress on Alzheimer’s Disease (CROCAD-14), with International Participation. The text of the draft strategy, together with the adopted additions from the preceding discussion, was presented at the 6th Croatian Psychiatric Congress in Zagreb. Then, the text of the strategy was sent to all members of the CAA for review and comments.

At the end of the year 2014, an expert meeting of the Croatian Society for Alzheimer’s Disease and Old Age Psychiatry, CroMA, discussed the text of the final version of national strategy for the fight against AD. When obtained, the final version of the strategy will be published in Croatian and English language, available on the Internet, for the purpose of encouraging others, but also for the possibility to make comparisons with others in the region, regarding the quality of life of people with dementia and their carers. Croatia, as part of the EU, should ensure it cares for the vulnerable population.

We are aware that it will take some time for Croatia to catch up with other European countries in the level of care for people with dementia, but without the initial concrete steps, such as an adoption of national strategy against AD, we cannot move forward.

25 April: Muistiliitto is fighting for self-determination legislation in Finland

In 2010, an unsuccessful attempt was made by the Alzheimer Society of Finland (Muistiliitto) to draw up a law on self-determination for people with memory-related diseases (dementia). Now, another attempt is being made and Finnish Social Affairs and Health Ministry officials are discussing this issue during the spring.

The aim of this reform is to strengthen self-determination and to reduce the use of restrictive measures. Additionally, it is intended to secure essential treatment and care in accordance with the constitution for everyone and to improve legal protection of customers and personnel. The focus is particularly on preventing situations where restrictive measures would have to be used.

The Ministry of Social Affairs and Health has continued drafting the legislation governing patient self-determination. The ongoing drafting affects an even larger group of people than before. In connection to the reform, the regulations of the law on Intellectual Disabilities regarding patient self-determination are to be transferred into general legislation. Necessary changes will also be made to the Mental Health Act and the Act on Welfare for Substance Abusers. At the same time, the interface is defined more clearly in relation to child welfare.

People with memory-related diseases are the single largest group affected by the reform. The regulations would also affect people who have, for example, experienced brain damage causing a significantly lowered decision-making ability. If a person’s decision-making ability has decreased, their own decision-making should always be primarily supported, says Muistiliitto.

The drafting of the patient self-determination legislation is based on extensive group work, several reports and statements requested on them and continued drafting of the legislation has begun on the civil servant level.

People with relevant expertise and constitutional law experts are involved in the drafting. It is important to hear the views of both people with memory-related diseases and their relatives, as well as employees during drafting. Drafting will be continued by an official working group that is starting work in April - May 2017.

The government proposal will also be circulated for comments before being submitted to Parliament. Various hearings and methods of consultation will also be arranged.

28 April: Deltaplan Dementie care programme launches website

Recently, the Dutch “Deltaplan Dementie” gave rise to a new programme called “Dementia Care for each other”, which has now launched a website: www.dementiezorgvoorelkaar.nl

The programme was developed by Movisie, Nivel, Pharos, Trimbos Institute and Vilans and is funded by the Dutch Ministry of Health.

The Deltaplan for dementia is the Dutch national strategy to tackle and manage the growing problem of dementia. The eight year plan, deriving its name from the Dutch water works that protects a large area of land from the sea, intends to limit the consequences of the foreseen explosive rise in people with dementia. To be able to achieve these goals, funding is intended to come from both public (government and national research funds) and private sources.
BEHIND THE HEADLINES

5 April: Reports that Marmite prevents dementia are “laying it on a bit thick” says NHS Choices

Following recent media headlines about the yeast extract food paste Marmite and its ability to “help prevent dementia”, NHS Choices wrote the following report:

"A daily slice of Marmite on toast may help prevent you getting dementia," the Daily Mail reports, with little justification.

A small study did find that Marmite had an effect on electrical activity in the brain, but there is no evidence this would prevent dementia.

The study involved 28 people in their early 20s. Researchers looked to see whether eating Marmite affected the brain’s response to watching flickering images on a screen, measured by electroencephalogram (EEG) scans. This test is used as a measure of “brain cell excitability” in the visual cortex area.

Marmite contains vitamin B12 and glutamate which are thought necessary for the brain to produce GABA, which is thought to reduce brain cell excitability. Too little GABA may be a factor in epilepsy.

The study compared the effect of eating a teaspoon of Marmite each day for one month with eating peanut butter. Healthy volunteers were tested before and after the trial of Marmite or peanut butter. After a month, scans on the Marmite-eaters’ brains showed lower levels of excitability.

The researchers suggest that boosting GABA levels through diet might contribute to treating epilepsy. However, there’s no clinical evidence to support this indication, never mind the media speculation about dementia.

For those who fall into the "hate camp" when it comes to Marmite, other sources of vitamin B12 include meat and cheese.

Where did the story come from?

The study was carried out by researchers from the University of York and was funded by the Wellcome Trust and the Leverhulme Trust.

The Leverhulme Trust was set up by the founder of Lever Brothers (William Hesketh Lever) now Unilever, which manufactures Marmite. However, the trust says it does not seek to influence the topic or study design of research when it provides grants.

The study was published in the peer-reviewed Journal of Psychopharmacology.

Predictably, the UK media loved this story. The Daily Telegraph and Daily Mirror referred to Marmite "giving a boost" to the brain. Sky News said it "keeps the brain healthy" and The Sun said it "may prevent dementia."

The Daily Mirror’s report is the most balanced and was the only one to point out the link between funding and Unilever. It concludes that: "an analysis by the Daily Mirror of the nine-page study [ie reading it] found zero references to dementia or Alzheimer’s disease”.

Several media outlets reported that the study was done in men only; however the study makes clear that more than half of the participants were women.

What kind of research was this?

This was a randomised controlled trial, which is a good way to see the effect of an intervention. Researchers wanted to see if the yeast extract reduced the brain’s response to visual stimuli.

What did the research involve?

Researchers measured brain response to visual stimuli (flickering images on a screen) using EEGs, in 28 volunteers. They were randomly allocated to take a teaspoon of either Marmite or peanut butter a day, in addition to their usual diet. After a month they were tested again, and the results compared between the two groups.

The volunteers (10 men and 18 women) were all in their 20s. None had epilepsy (in case flickering images triggered a seizure), smoked, had nut allergies or used controlled substances.

The experiment used flickering images with a "control" task, in which volunteers had to estimate the difference in contrast between two wave forms. This allowed researchers to check the groups were concentrating on the screen equally.

Researchers used several variations of the task, including a "mask" variation which should reduce the effect on an area of the brain called the visual cortex.
Volunteers were asked to take a teaspoon of their allocated spread each day and record that they had done so. Statistical models were used to look for differences between the EEGs for those who'd eaten Marmite and those who'd eaten peanut butter.

The researchers also tested both spreads for levels of glutamate and B vitamins. A sub-group of Marmite-eaters was tested again two months later.

**What were the basic results?**

Researchers say that on average the people who ate Marmite had reduced levels of "evoked response" – activity in response to images – compared to their baseline results. The average response didn't change for those eating peanut butter.

Only evoked responses were changed – response to background levels of activity when viewing a blank screen were not affected. The volunteers' performance on the attention test was no different between the two groups, suggesting that Marmite-eaters and peanut butter eaters had concentrated on the screen to the same degree.

In the group of Marmite-eaters retested after two months, response levels were still lower than at baseline, but not as low as immediately after the month-long trial.

In the chemical analysis of the spreads, Marmite had three times as much vitamin B6, almost twice as much glutamate and 116 times as much vitamin B12 than the peanut butter.

**How did the researchers interpret the results?**

The researchers said their results were "consistent with an increase in the availability of GABA in visual areas of the brain."

They said that previous research has shown that people with epilepsy showed increased visual responses when tested using the same visual stimuli as used in this experiment. "This raises the possibility that dietary interventions geared towards increasing GABA concentration might reduce excitability to normal levels, and potentially alleviate some symptoms of the disorder," they say.

They suggest it could reduce the number of seizures and be particularly useful for people who can't take anti-epilepsy drugs, or whose medicines haven't controlled their seizures.

They conclude that additional studies would be required to determine which substance in Marmite might be responsible for the results.

**Conclusion**

This is an early investigative research study, and while some of the findings are interesting, it's a long way from showing that yeast extract spreads can help with conditions like epilepsy or other neurological disorders.

The study's strength is that it was carried out as a randomised controlled trial. However, its small size means we need to see the results replicated in larger studies to be sure they are not down to chance. We also need to see longer-term studies into the actual clinical effects of the changes measured. At this point, we don't know what effect – if any – the changes in brain response have on the people involved.

The study has no implications for people with dementia, or at risk of dementia. The lead researcher told NHS Choices: "We're a bit puzzled as to where the idea [that dementia is involved] has come from. Our study didn't test any patients and we don't have any reason to expect that Marmite would have any effect on dementia at this time."

It's also important to be aware that the suggested effects on epilepsy have not been tested on people with epilepsy. No-one with epilepsy should be tempted to stop taking their medicines in favour of Marmite.


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**SCIENCE WATCH**

2 March: Scientists investigate the relationship of Alzheimer disease-related stigma and social media tweets on Twitter

Scientists from Oregon State University have developed a new software to better analyse large sources of information. The research team used the software to investigate Alzheimer’s disease (AD) stigma on the social media site Twitter. The report of their findings was published on 2 March, in the Journals of Gerontology: Psychological Sciences.

The main finding of the analysis of AD stigma was that a substantial proportion of the AD-related posts on Twitter contained ridicule and perpetuated AD stigma. In conclusion, the research team said that their findings add to a growing body of work, which documents problematic levels of public stigma related to dementia in the US.

The research group has documented their methodology and provided resources for other scientists to replicate analyses. As a positive outlook they wrote that “the raised awareness of the power and potential impact of social media to shape
21 March: Study reveals a new gene associated with Tau pathology

In a study published in The Journal of Molecular Psychiatry on 21 March, US researchers at Brigham and Women's Hospital and Rush University Medical Center identified a new gene that is associated with Tau accumulation in the brain. This accumulation occurs in Alzheimer’s disease and certain forms of dementia.

Scientists analysed autopsy samples from 909 individuals participating in studies of ageing. They discovered a high association of the PTPRD gene with Tau pathologies. In addition, the authors confirmed their findings in another independent study that included 369 brains.

27 March: Overexpression of ephexin5 is linked to AD impairment

In a study published in The Journal of Clinical Investigation on 27 March, US researchers from The Johns Hopkins School of Medicine reported that a protein called ephexin5 may have a role in Alzheimer’s disease (AD).

Accumulation of the amyloid-β (Aβ) protein is considered to play a key role towards the development of AD. Previous findings on AD brains underlined an overexpression of ephexin5. This protein regulating brain cell connections appeared to limit the growth of nerve cell connections in brain development.

In the published study, researchers worked on AD mouse models who produce Aβ in abundance. They revealed high levels of ephexin5 in brain cells of people with AD and in AD mouse models. In fact, Aβ may promote an increase of ephexin5 levels, leading to synapse degeneration and cognitive impairment.

Additionally, by using genetic tools, scientists developed mouse models whose brain cells could not produce ephexin5. They discovered that removing ephexin5 prevented learning and memory impairment in the mouse models.

As ephexin5 appeared not to be found in healthy adults, the researcher team is currently investigating how brain cells naturally regulate ephexin5.

1 April: AXON Neuroscience announces positive Phase 1 results for its tau vaccine

The Slovak biotechnology company AXON Neuroscience, which develops tau-immunotherapies for Alzheimer’s disease (AD) and Frontotemporal Dementias (FTD), has announced results from its Phase I trial for the vaccine AADvac1. AADvac1 is an active immunotherapy directed against tau protein, the main constituent of neurofibrillary tangles.

The Phase I study was conducted in Austria to assess the safety and tolerability of AADvac1 in AD treatment. This trial showed that the vaccine can elicit the production of antibodies, which could recognise pathological tau protein and slow down the progression of the disease.

On 1 April, at the 13th International Conference on Alzheimer’s & Parkinson’s Diseases (AD/PD2017) in Vienna, AXON Neuroscience presented data of its AADvac1 follow up Phase I study. This 18-month follow-up study indicated similar positive data in two other forms of dementia - corticobasal degeneration and progressive supranuclear palsy.

AXON Neuroscience announced a new Phase I trial to test the vaccine in another form of dementia (a subgroup of FTD) planned to start in the second quarter of 2017.

1 April: Scientists reveal new link between cardiac diseases and brain dysfunction

In a study published in The Journal of JAMA Neurology on 1 April, researchers from National University Health System, Singapore have identified a strong association between markers of cardiac...
5 April: Recent study reveals disappointing results from Phase 3 immunoglobulin trial for AD

In a study published in the Journal Neurology on 5 April, US researchers working for the Alzheimer’s Disease Cooperative Study reported that intravenous immunoglobulin (IVIg) was an ineffective treatment for mild to moderate Alzheimer’s disease (AD).

The randomised and double-blind Phase 3 study was conducted in US and Canada to assess the efficacy and safety of 2 doses of IVIg administered every 2 weeks for 18 months in 390 participants with mild to moderate AD. Although researchers found that IVIg was well-tolerated, no beneficial effects were observed at 18 months in participants with mild to moderate AD. In fact, cognitive functions were not improved for the two doses tested. The cognitive performance was measured through specific tools, including a memory test or a test to access instrumental and basic activities of daily living.

10 April: Risk of pneumonia might be associated with benzodiazepine use in Alzheimer’s disease

On 10 April, researchers from the University of Eastern Finland (UEF) in Kuopio published findings from analyses on a large cohort study in the Canadian Medical Association Journal. In their article they describe the assessment of a link between benzodiazepine use and pneumonia in patients with Alzheimer’s disease (AD).

Precedent studies have suggested that dementia is a contributing risk factor for pneumonia. The fact that pneumonia, a lung infection which can be caused by either bacteria or viruses, can lead to death heightens the relevance of further investigation. It is even more important because people with dementia are at a higher risk of death related to pneumonia.

The research team used data (2005-2011) from 49,484 participants with Alzheimer’s disease. The data were obtained from the Medication use and Alzheimer disease (MEDALZ) cohort. It incorporates national registry data on prescriptions, reimbursement, hospital discharges and causes of death. 5232 of these participants were taking benzodiazepines and 3269 were taking Z-drugs. Both of these treatments are used to treat insomnia. The information they used included: hospital discharges, prescriptions as well as the causes of death. Their results led them to the conclusion that benzodiazepine use of patients with AD was associated with a 30% higher risk to develop pneumonia.

The research team therefore highlighted that the “benefits and risks of the use of benzodiazepines should be carefully considered for patients with AD and include risk of pneumonia”. Due to the nature of the study, which was observational, a cause and effect relation cannot be drawn. However, the fact that benzodiazepine is a sedative might increase the risk of salvia or food aspiration into the lungs.

11 April: Vascular disease risk factors in midlife linked to higher beta-amyloid levels

New research published on 11 April in the journal JAMA, provides further insights into the build up of beta-amyloid in the brain. Scientists from Maryland, US have investigated the association between beta-amyloid deposition and vascular risk factors in 322 older adults without dementia. The participants had taken part in the “Atherosclerosis Risk in Communities” (ARIC)-PET Amyloid Imaging Study for almost 25 years.

The accumulation of beta-amyloid to plaques is one of the main causes of cell death in Alzheimer’s disease (AD). So far, it has been unclear whether vascular disease risk factors are directly associated with the build up of beta-amyloid in the brain. The most common controllable risk factors of vascular diseases are smoking, high blood pressure, high cholesterol, diabetes and obesity.

The scientists compared the levels of beta-amyloid of participants with and without risk factors for vascular diseases. With the help of these analyses, they detected that participants having two or more vascular risk factors in midlife had higher levels of beta-amyloid deposition. They also indicated that there was no association for late-life vascular risk factors.

13 April: Biogen licenses AD experimental drug

On 13 April, the biotechnology firm Biogen announced the rights acquisition of an experimental drug for Alzheimer’s disease (AD) and progressive supranuclear palsy (PSP) from Bristol-Myers Squibb. Biogen will pay USD 300 million upfront and an additional USD 410 million as milestone payments and potential royalties. The deal is expected to be closed in the second quarter of 2017.
The AD candidate drug BMS-986168 is an antibody targeting the tau protein, which is a protein abnormally hyperphosphorylated and which presents in excess in AD brains. The company plans to initiate Phase 2 studies for BMS-986168 in both AD and PSP.


19 April: Depression and cancer drugs could slow neurodegenerative diseases

Results published on 19 April in the Journal Brain suggest that an antidepressant and an anti-cancer drug prevent neurodegeneration. Both drugs could reduce brain shrinkage linked to some neurodegenerative diseases such as Alzheimer’s disease (AD).

In the published study, researchers from the Medical Research Council’s Toxicology Unit in Leicester, UK, along with Cambridge University suggest that a licensed antidepressant called trazodone could restore protein production and rescue memory deficit in early tests done in dementia mouse models. In fact, this drug blocks an important pathway, which is overactivated in brains of people with AD and related disorders.

Trazodone has already been shown to be safe for humans. Scientists want to do further studies to know if the drug could slow down the disease in people at an early stage. They plan to start clinical trials with trazodone on people with dementia and expect data within two to three years.

In addition, an anti-cancer drug, dibenzoylmethane, was also found to have the same protective effect on the brain.

https://academic.oup.com/brain/article/3737867/Repurposed-drugs-targeting-eIF2-P-mediated/searchresult=1

24 April: USP9 gene may contribute to gender differences in AD

In a recent study published in The Journal of Molecular Neurobiology, scientists from the Luxembourg Centre for Systems Biomedicine (LCSB) of the University of Luxembourg identified a new gene that may contribute to gender differences in Alzheimer’s disease (AD).

AD is the most frequent neurodegenerative disease causing loss of neurons in the brain, affecting more than 35 million people worldwide, including 6,000 people in Luxembourg. AD is diagnosed most often in people over 65 years and the risk of developing the disease at an advanced age is much higher in women than in men but the exact causes of this difference are still unknown.

The study, led by Dr Enrico Glaab, head of the research group Biomedical Data Science at LCSB, investigated why women are at greater AD risk than men. The team analysed public data on samples from AD and normal brains of around 650 deceased people. Researchers identified a gene called USP9 that is much more active in the brains of healthy women than in men with AD. This gene has an indirect influence on the tau protein, which is found in higher levels in the AD brain. In addition, they noticed that blocking the USP9 gene significantly reduced the tau activity.


LIVING WITH DEMENTIA

31 March: Idalina Aguiar, member of the EWGPWD, writes “A busy month…with a smile”

On 25 March I participated, for the first time, in the Madeira Memory Cafe (I had one previous experience in Oeiras Memory Cafe). This time, the theme was the well-being of the caregivers of people with dementia. I recognise that this is a very important theme and an important part of my life now. To feel well, I need a healthy family and caregivers. For sure I will be present at the next Memory Café with the theme of laughter as therapy.

On the last day of March, I was present at the Social Economy and Solidarity Fair, organised by a sector of Madeira’s Government, with my colleagues from the Delegation of Madeira of Alzheimer Portugal. It was a way to show our work and the services of the Delegation. We produced some Easter Baskets (I love to do arts and crafts) and filled them with chocolates to display at the Fair.

More news in my life - as I am always trying to be independent and autonomous, - is that I am now engaged in occupational therapy sessions. I started this month and the objective is to train the basic and instrumental activities of daily living. It was a busy month, with gardening, card games, writing, reading and dancing, but it was always with a smile: the smile is the spirit of music!

About Idalina Aguiar

Idalina participates in several activities in Delegation of Madeira of Alzheimer Portugal. This Delegation promotes the following services: Cognitive stimulation, psychological counselling for caregivers and people with dementia or with memory problems,
training to formal and informal caregivers, support groups for caregivers, group activities for people with dementia, music therapy, occupational therapy, gardening, technical aids for people with dementia, Memory Cafes, awareness sessions for the community, fund-raising activities. Idalina is supported by her daughter Nelida, to whom we are grateful for her help in translating Idalina’s words to English.

25 April: Karin Gustafsson, member of the EWGPWD, writes about her diagnosis in 2014

When I was diagnosed with mild Alzheimer’s in the fall of 2014, I was completely determined that there were other factors that affected me. I was convinced that my Alzheimer’s diagnosis was incorrect. I felt that my changed behaviour was due to the fact that my mother, at the age of 94, had moved to a retirement home and that together with my two sisters, I was trying to deal with matters related to her home and belongings. It was an emotional time that affected me a lot, especially as my mother died of pneumonia quite soon after moving to the retirement home.

During this period of grief, I was in denial there could be something wrong with my intellect. I underwent tests and I was shocked when all the results indicated that I had mild Alzheimer’s disease. It was a diagnosis that I found very hard to accept. I had an image of myself as an intellectual, and for me it was unthinkable that I would have this disease, because I lived a healthy life - for 30 years I ran three times a week and practiced yoga regularly, deliberately chose ecological living and healthy foods. Since I had a lot of interest in health issues for many years, I ate organic. It was difficult for me to incorporate the disease into my self-image.

When I realised that my life would change in many ways, my husband and I gathered our three grown children and informed them of my diagnosis. The children were also shocked and we cried together.

At this time, I was a lecturer in Education at the University of Gothenburg, and also had a part-time job in the city of Gothenburg as a development director. At this point, I was employed by the City of Gothenburg at 50% and by the University of Gothenburg at 50%. Both my university work and my work with the City of Gothenburg were demanding positions: helping preschool teachers, participating in various research projects, and being responsible for development issues for preschool leaders and preschool teachers at an overall level in the municipality. My working week usually exceeded 40 hours and in my dissertation work, my commitment was yet higher.

I began to realise that my situation was untenable and that I was only able to change the current situation. I decided to stop both of my jobs during the summer of 2016.

EWGPWD

My husband Lars and I were invited to an Alzheimer’s café and were asked by Alzheimer Sweden if we could consider joining the European Working Group of People with Dementia (EWGPWD). Both Lars and I thought it would be interesting to get involved and to help influence change in this context. For my part, it has been a positive experience to meet other people with a similar diagnosis and our joint meetings have given us both much strength.

8 April: The first person to be diagnosed with Alzheimer’s disease passed away 111 years ago

Auguste Deter (May 1850 – 8 April 1906) passed away 111 years ago. She was the first person to be diagnosed with the now-called early onset of Alzheimer’s disease.

In the late 1890s, Auguste D. started to experience delusions, memory loss and other symptoms of dementia. On November 1901, she was examined by Dr Aloysius Alzheimer in the Institution for Mentally Ill and for Epileptics in Frankfurt, Germany. In 1902, Dr Alzheimer left the institution and started working in Munich, nevertheless he made frequent calls to Frankfurt to follow up on her condition. On 9 April 1906, Dr Alzheimer received a call that she had died the day before. He requested both her medical records and brain to be sent to him for examination.

During the examination of her brain he was the first to identify amyloid plaques and neurofibrillary tangles in the brain of such a young person. Later that year, Dr Alzheimer presented his results to the South-West German Society of Alienists. During his presentation, he described both the plaques and tangles, which have come to be considered the hallmarks of AD and in 1910, the German psychiatrist Emil Kraepelin and a former colleague of his were the first to name “Alzheimer’s disease” in the eighth edition of his book “Psychatrie”.

http://ad.foundation/auguste-deter/
NEW PUBLICATIONS AND RESOURCES


On 27 March, the Organisation for Economic Cooperation and Development (OECD) published a new Health Working Paper on “Measuring social protection for long-term care”. This paper is the result of a major piece of research, conducted by the OECD and supported by the European Commission.

The report provides the first quantitative estimates of the impact of social protection systems on the affordability of long-term care for people living in 14 OECD and European Union (EU) countries. Focusing on five scenarios with different long term care (LTC) needs and services, it quantifies the cost of care; the level of coverage provided by social protection systems; the out-of-pocket costs that people are left facing; and whether these costs are affordable.

Work in this area will continue for at least the next two years, during which time OECD is planning to develop a more advanced methodology and expand country coverage.


26 April: Dementia Innovation Readiness Index launched at ADI Conference

Alzheimer’s Disease International (ADI) and the Global Coalition on Aging have launched the first ever Dementia Innovation Readiness Index at the 32nd conference of Alzheimer’s Disease International in Kyoto Japan on 26 April, during a special pre-conference session.

The index provides a comprehensive evaluation of existing and possible approaches and processes that have an impact on the prevention, treatment of or care for dementia in the G7 countries - supporting advocacy of ADI and others for coordinated, continuous and committed action on dementia by governments and stakeholders globally.

The index highlights a growing need to address a lack of data on dementia care and treatment, including building a better picture of and comparisons between the diagnosis of dementia, and encouraging the standardisation of diagnostic tools.

Evaluation of the countries in the report is based on an assessment of 10 elements including strategy and funding, education and the workforce, prevention and diagnosis, and access to and quality of care. In every country, the Index calls for increased funding for dementia care appropriate to the growing impact of the disease, adding that people living with dementia should be provided with greater choice in the type and level of support they can receive.

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## AE CALENDAR

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<td>3 May</td>
<td>GA4GH telephone meeting</td>
<td>Dianne</td>
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<tr>
<td>3-4 May</td>
<td>Dementia Platform UK Conference 2017 (London, United Kingdom)</td>
<td>Cindy, Chris and Jean</td>
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<tr>
<td>8-9 May</td>
<td>PACE consortium meeting (Treviso, Italy)</td>
<td>Dianne and Ana</td>
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<td>9-10 May</td>
<td>SyDAD Annual Meeting (Bonn, Germany)</td>
<td>Cindy</td>
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<tr>
<td>10 May</td>
<td>Alzheimer’s Prevention European Registries Workshop (London, United Kingdom)</td>
<td>Jean</td>
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<td>10-19 May</td>
<td>Eurodiaconia Healthy Ageing and Long-Term Care (HALTC) network meeting (Vienna, Austria)</td>
<td>Vanessa</td>
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<td>12 May</td>
<td>ROADMAP f2f Research Questions workshop (Amsterdam, Netherlands)</td>
<td>Chris</td>
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<tr>
<td>12-14 May</td>
<td>EDF General Assembly (Madrid, Spain)</td>
<td>Vanessa</td>
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<tr>
<td>13-15 May</td>
<td>Dementia Platform UK Conference 2017 (London, United Kingdom)</td>
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<td>14-15 May</td>
<td>Joint meeting EWGPWD and MinD (Luxembourg, Luxembourg)</td>
<td>Ana, Dianne and Chris</td>
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<td>15-16 May</td>
<td>Meeting of the Government expert group on dementia (Malta)</td>
<td>Jean</td>
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<tr>
<td>15-17 May</td>
<td>EPAD General Assembly Meeting (Stockholm, Sweden)</td>
<td>Dianne, Cindy and Kate</td>
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<td>17 May</td>
<td>Covenant for Demographic Change GE (Brussels)</td>
<td>Dianne</td>
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<tr>
<td>19 May</td>
<td>PRIME Workshop of European Medicines Agency (EMA) (London, United Kingdom)</td>
<td>Jean</td>
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## CONFERENCES

<table>
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<tr>
<th>Date</th>
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<tbody>
<tr>
<td>16-29 June</td>
<td>Royal College of Psychiatrists’ International Conference, <a href="https://www.rcpsych.ac.uk/events/conferences/2017-06-13-06-29-2017/">https://www.rcpsych.ac.uk/events/conferences/2017-06-13-06-29-2017/</a></td>
<td>Edinburgh, Scotland</td>
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<td>24-27 June</td>
<td>3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a></td>
<td>Amsterdam, Netherlands</td>
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<tr>
<td>24-27 June</td>
<td>3rd Congress of the European Academy of Neurology (EAN), <a href="https://www.ean.org/amsterdam2017/">https://www.ean.org/amsterdam2017/</a></td>
<td>Sheffield, UK</td>
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<td>16-20 July</td>
<td>Alzheimer’s Association International Conference (AAC), <a href="https://www.alz.org/aac/">https://www.alz.org/aac/</a></td>
<td>London, UK</td>
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<td>17 September</td>
<td>Innovations and state of the art in dementia research, <a href="http://alzheimers-dementia.org/">http://alzheimers-dementia.org/</a></td>
<td>Rome, Italy</td>
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<tr>
<td>22-25 March 2018</td>
<td>12th World Congress on Controversies in Neurology (CONy), <a href="http://www.cony.org/">http://www.cony.org/</a></td>
<td>Warsaw, Poland</td>
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27th Alzheimer Europe Conference
Care today, cure tomorrow
Berlin, Germany
2–4 October 2017

www.alzheimer-europe.org/conferences  #27AEC