Maurice O’Connell considers the forthcoming Irish National Dementia Strategy.

David Martin, MEP (UK-Scotland) discusses the situation for people with dementia in Scotland.

Helga Rohra talks about the European Working Group of People with Dementia.

Roberta Angelilli, MEP (Italy), speaks about how the EU addresses dementia.
Welcome
By Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe

Prioritising Dementia

European Working Group of People with Dementia (EWGPWD)
Helga Rohra, Chairperson of the EWGPWD, talks about her priorities and the challenges ahead. Alzheimer Europe looks at the work carried by the EWGPWD since its launch in October 2012.

The development of national strategies in Europe
A summary of the 2012 Dementia in Europe Yearbook which is dedicated to the development of national strategies with regard to diagnosis, treatment and research.

Alliance in action
Highlights from some of the ways in which members of the European Alzheimer Alliance are helping to raise awareness and understanding of dementia.

Ethical issues linked to restrictions of freedom of people with dementia
Alzheimer Europe provides an overview of the newly-published report “Ethical issues linked to restrictions of freedom of people with dementia” which provides a detailed discussion on some of the main ethical issues surrounding this topic.

Debating dementia in the European Parliament
A report on Alzheimer Europe’s 14th lunch debate in the European Parliament, where people with dementia shared their experiences of living with the disease.

Policy Watch

Dementia in the EU
Roberta Angelilli, MEP (Italy), and Rapporteur for the European Parliament report, “The prevention of age-related diseases of women” speaks with Alzheimer Europe.

Healthy ageing across the lifecycle
A look at the health priorities of the EU Cyprus Presidency (July-December 2012) by the EU Coordination Sector of the Ministry of Health, Cyprus.

Active and healthy ageing
Annette Dumas, EU Public Affairs Officer, Alzheimer Europe, provides an update on the European Innovation Partnership on Active and Healthy Ageing.

View from Scotland
David Martin, MEP (Scotland), reflects on the situation for people with dementia and their carers in Scotland and on the progress of the Scottish Dementia Strategy.

A national dementia strategy in Ireland
Maurice O’Connell, CEO of The Alzheimer Society of Ireland, speaks with Alzheimer Europe about the forthcoming National Dementia Strategy in Ireland and his hopes for people with dementia and their carers.
Improving the quality of life for people with dementia and their families in France
Marie-Odile Desana, President of France Alzheimer, looks at the campaign and work carried out in order to prepare the White Paper on Alzheimer’s disease in France.

Unjustified breaches of fundamental rights shall not be legalised
The need to reform current coercive measures to protect constitutional human rights of people with memory diseases is considered by Sirpa Pietikäinen, MEP (Finland).

Dementia in the news

World Alzheimer’s Day
Alzheimer Europe takes a look at how national Alzheimer associations around Europe marked the 2012 World Alzheimer’s Day.

Spotlight on Slovakia
In 2013 the Slovak Alzheimer’s Society celebrates 15 years’ work. Alzbeta Vesela, Secretary, looks back at the work carried out.

Dementia in the arts
Alex Teligadas, Communications Officer, Alzheimer Europe, reports on “Dimentia”, a new Cypriot musical which hopes to raise awareness of Alzheimer’s disease.

The perception of Alzheimer’s disease in France
Marie-Odile Desana, President of France Alzheimer, highlights the major findings of a survey that looked into French people’s perceptions and awareness of Alzheimer’s disease.

Alzheimer Europe’s 22nd Conference in Austria

Changing perceptions, practice and policy
Highlights from the Alzheimer Europe’s 22nd conference where more than 500 delegates from 43 countries came together in Vienna, Austria.

Involving people with dementia
Alzheimer Europe reports on presentations by Eleanor Edmond, Eva Quack, Andrea Capstick and Angela Clayton-Turner on how to involve people with dementia at all levels.

Agnes and Nancy
Agnes Houston and Nancy McAdam discuss their decision to participate in “Agnes and Nancy – A short film about two friendly campaigners.”
Over 500 delegates from 43 countries came together at our annual conference in Austria to discuss how “Changing perceptions, practice and policy” could help people with dementia and their carers. Our report on this successful conference includes highlights from a wonderfully inspiring presentation about living with dementia by Agnes Houston and Nancy McAdam.

At the end of 2012 Alzheimer Europe was able to realise a long-held aim when it launched the European Working Group of People with Dementia (EWGPWD). I am excited by the potential of this group and that it has already carried out a considerable amount of work. Helga Rohra, Chairperson of the EWGPWD, provides insight into the challenges and hopes ahead.

Members of the European Alzheimer’s Alliance continue to raise awareness of dementia. I am grateful to Sirpa Pietikäinen, MEP (Finland) and Alliance member, for hosting the lunch debate in the European Parliament in December where people with dementia presented their experience of living with the disease. She also talks in this issue about the need to reform coercive measures to protect the constitutional human rights of people with memory diseases in Finland.

Dementia and other neurodegenerative diseases remain on the European agenda. Roberta Angelilli, MEP (Italy), discusses the European Parliament report “the prevention of age-related diseases of women” of which she is Rapporteur. A reflection of the health priorities during the EU Cyprus Presidency by the Ministry of Health highlights the importance of addressing neurodegenerative diseases. In this issue of the magazine, Alzheimer Europe takes a look at the progress of the “European Partnership on Active and Healthy Ageing”. David Martin, MEP (Scotland), talks of the need for joint European research and action for dementia and highlights the achievements and remaining challenges of the Scottish Dementia Strategy.

I am encouraged that we are also able to report on various developments at national level. In France a White Paper on Alzheimer’s disease was presented to the Government and a new report highlights the French people’s perceptions and awareness of the disease. Marie Odile-Desana, President of France Alzheimer, discusses both these initiatives. A national dementia strategy is due to be launched in Ireland in 2013 and Maurice O’Connell, CEO of The Alzheimer Society of Ireland, considers the impact this may have. Alzbeta Vesela, Secretary of the Slovak Alzheimer’s Society, looks back at 15 years’ work by the society. Alzheimer Europe looks at how Cyprus has raised awareness of Alzheimer’s disease through a musical and also reports on the many and diverse ways in which national associations marked World Alzheimer’s Day.

Lastly, Alzheimer Europe summarises its new publications: the “2012 Dementia in Europe Yearbook” which focuses on the current status and development of national dementia strategies around Europe, particularly with reference to diagnosis, treatment and research and the report on “the ethical issues linked to restrictions of freedom of people with dementia”. I am extremely proud of both of these publications and I hope they will enable people to look at how common issues surrounding dementia can be addressed.

Heike von Lützau-Hohlbein,
Chairperson of Alzheimer Europe
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A report on Alzheimer Europe’s 14th lunch debate in the European Parliament, where people with dementia shared their experiences of living with the disease.
One of the first tasks of the newly-formed European Working Group of People with Dementia (EWGPWD) was to appoint a Chairperson. Helga Rohra was selected for this role and here Alzheimer Europe speaks with her about her priorities and the challenges in the year ahead.

Alzheimer Europe (AE): Many congratulations on your appointment, Helga. What do you hope to achieve during your term as Chairperson and what is your first priority?

Helga Rohra (HR): Firstly I want to thank Alzheimer Europe for giving people with dementia a platform. This multi-cultural working group for people with dementia is the first of its kind in the world. I would also like to thank the Scottish Dementia Working Group (SDWG) as it has proven to be a pioneer in the field of involving people with dementia. The SDWG has led to the development of the EWGPWD.

My voice is not just of Helga, but one of all those people who represent the people with dementia in their own country in the EU. The first priority is that we are able to raise awareness in Europe about what dementia means and help people to understand that there are many forms of dementia (not only Alzheimer’s disease) and that there are many phases of dementia. Dementia is a disease, not the end. We need realistic plans for the different phases and the different needs of people with dementia.

This is why it is important to promote early diagnosis but with diagnosis we need adequate support and to be included in society. It is important that people realise that there are people who get dementia at an early age and that they face particular challenges in society, whatever country they may live in. We need to show the world that we do have abilities and that inclusion in society is important. It is important to remember that all people are human and want similar things. Dementia unites us all.

AE: What are the challenges ahead for the EWGPWD?

HR: The EWGPWD faces similar challenges to the EU. We have the same differences you find in any business meeting: People with different backgrounds, different languages and different capabilities. We must focus on the existing capabilities of our group. It is a challenge for the EWGPWD to cope with the symptoms of the disease and still carry out good work. We need to show people that we really are working and not just sitting around complaining. Our group works just like a business. After our first meeting we decided to hold a 7.45 breakfast meeting the very next day. This enabled us to set the agenda for our next meeting in Brussels and further discuss Alzheimer Europe’s lunch debate which will be held in the European Parliament in December.

AE: What message would you like to convey?

HR: Until now the message was to “give people with dementia a voice” but now the message is “follow our voice”. We are now the ones who say what we need. I believe in the phrase “nothing about us without us”.

“Dementia is a disease, not the end.”
Helga Rohra
AE: You were very active in Alzheimer Europe’s 22nd annual conference in Vienna. What was, for you, the highlight of the conference?

HR: Compared to previous years, the number of people with dementia at this conference who were actively included as speakers and/or chairing sessions was much higher and this was a very huge step ahead. More steps need to be taken, but this involvement was significant. A highlight for me was also how open-minded participants were to come and talk with us. At the conference people were not reluctant at all to speak to us and it was clear we were seen on the same level. The society of this conference consisted of some 500 people, all of whom will take our message back with them.

AE: How do you see the work which the EWGPWD carries out helping people with dementia and their carers?

HR: By exchanging our experiences and ideas we can help to take the best ideas from one place and put them in another. For example, as new members such as Slovenia and Croatia join Alzheimer Europe, we want to share our message with them. We can show them that we can be strong by working together.

We teach people that the focus should be on the existing capabilities and politicians should develop programmes to include us. Dementia is an EU challenge. We are looking forward to Alzheimer Europe’s next lunch debate in the European Parliament in December. The EWGPWD is strongly involved in this event and we will speak up and politicians will have a different perception of what dementia means which will hopefully lead them to take action. Inclusion of people with dementia is more important than caring for us!

“We need to show the world that we do have abilities and that inclusion in society is important.”
Helga Rohra

Helga Rohra was born in Romania and lives in Germany. Until 2006 she worked as an interpreter and speaks English, French, German, Hungarian, Romanian and Latin.
Since receiving a diagnosis of dementia she has been an active advocate for the rights of people with dementia.

Alzheimer Europe looks at the work carried out by the EWGPWD since its launch in October 2012.

The EWGPWD has proved to be a highly active group since its launch. Members have participated in Alzheimer Europe’s 22nd Conference in Vienna, been guest speakers at the European Parliament, held meetings with various MEPs, advocated the work of the group on a national level and the group has already held two meetings!

The first EWGPWD meeting was held on 3 October in Vienna and the second on 3 December in Brussels. At the first meeting, Jean Georges, Executive Director of Alzheimer Europe stated the aims of the EWGPWD (as listed in Alzheimer Europe’s statutes): to advise the organisation and to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. During the EWGPWD meetings the group has:

- Elected the Executive Board: Chairperson: Helga Rohra (Germany) and three Vice Chairpersons: Jean-Pierre Frogn (Belgium), Jan
Frederick Meijer (Netherlands) and Agnes Houston (United Kingdom – Scotland).

- Identified topics which require further discussion: these include early diagnosis, delays in obtaining a diagnosis, loss and gain of talents and skills, the need for a chain of care and treatment, coping, understanding each person with dementia, raising awareness, stereotypes and “the new dementia” and the need for understanding from others.

- Explored ways in which members of the group can be involved in the work of Alzheimer Europe and helped members prepare for their participation in various events. For example, as Chairperson, Helga Rohra has represented the EWGPWD in several ways (by presenting at plenary during Alzheimer Europe’s 22nd conference in Vienna on 6 October, by participating in Alzheimer Europe’s Board meeting in Brussels on 4 December and by giving an interview – see above). Three members (Helga Rohra, Nina Baláčková and Daphne Wallace) of the EWGPWD made presentations about living with dementia at a lunch debate in the European Parliament on 4 December 2012 and several members met with their respective MEPs to discuss issues for people with dementia and their carers. In 2013, it is hoped that members from the group will participate in Alzheimer Europe’s 23rd annual conference, which will be held in Malta in October 2013. Further, members (Daphne Wallace and Helga Rohra) appointed by the Group will participate in two of Alzheimer Europe’s new projects (“Good incontinence care” and “The ethical issues linked to the perception and portrayal of dementia in society”).

- Exchanged ideas on how to best disseminate information about the EWGPWD: members reported on the responses at national level to the launch of the EWGPWD and considered how to raise awareness of the group in future. The group discussed ways to present itself via Alzheimer Europe’s newsletter, website and Dementia in Europe magazine (all of which carry information about the group). In addition, members of the EWGPWD are developing a leaflet and also a brochure on the work of the EWGPWD.

Much has been achieved in a few months. The EWGPWD is proving to be engaged, focused and highly motivated. This will not only help Alzheimer Europe in its quest to involve people with dementia but also result in people with dementia and their carers having a voice on the European platform.
THE DEVELOPMENT OF NATIONAL STRATEGIES IN EUROPE

This article highlights some of the findings from Alzheimer Europe's 2012 Dementia in Europe Yearbook, which is dedicated to the development of national dementia strategies with regard to three main topics: diagnosis, treatment and research.

The 2012 Dementia in Europe Yearbook is the first of two Yearbooks which focus on the development of national dementia strategies around Europe. Comparisons can be drawn from the 32 countries covered on the different approaches used to address the same issues. This report considers the issues of diagnosis, treatment and research within the context of national dementia plans. The next report will address more care-related issues and will be published at the end of 2013.

Background

The rate at which national dementia strategies have been launched is unprecedented. At the time of writing, several countries reported on a national strategy being in place [DK, FI, FR, IE, NL, NO, SE and four in the UK (E, NI, S and W)]. Whilst two countries (FR and NL) report that they are now on their third strategy, most of the other current (and first-time) strategies have been launched during the last two years. Other countries (IE, IT, LU, MT and CH) appear to be ready to launch a national plan imminently whereas the majority of remaining countries are in the process of developing a national dementia strategy. It is encouraging that those countries which lack the political support for a national plan (e.g. HR and TR) would appear to be in the minority, although a note of caution can be drawn from Portugal which reports on a waning of initial political interest for a national plan because of the economic crisis.

It is clear from the Yearbook that national Alzheimer associations have already acted in key roles during the development of national strategies. Their work has ranged from helping policy makers and the general public to understand the importance of addressing dementia, through to ensuring that the voices of people with dementia and carers are not only heard and reflected in the strategy documents themselves, but also acted upon.

The Yearbook includes examples of pivotal events which helped to prioritise dementia, such as the public reaction and ensuing debate on dementia which followed the airing of a TV documentary about the poor living conditions for people with dementia (IE) and the presentation of petitions to politicians, which reflected the enormous public support campaigns have had (GR and CH).

Ensuring that a strategy becomes a reality requires real commitment. The third French plan, launched in 2008, has enjoyed strong governmental and financial support. Indeed, EUR 1.6 bn was allocated to the third French plan in order to facilitate successful implementation. Similarly, with extra allocated funding and a personal commitment given in 2012 by Prime Minister
The English Dementia Strategy (2009-2014) has received a significant boost to its ongoing implementation process.

To ensure that people with dementia and their carers truly benefit from the plans, there need to be clear, measurable targets in place which are subject to rigorous monitoring. Whilst some countries, such as Scotland, report on such targets and procedural checks, other countries, such as Finland, require that responsibilities be identified clearly to enable effective monitoring.

Diagnosis

Receiving an accurate, timely diagnosis is essential if people with dementia and their carers are to benefit fully from the range of support and treatment available. Indeed, several countries [IT, MT, NO, PL, SL and UK (E, NI, S and W)] have specifically highlighted the need for a “timely diagnosis” in their draft/final plan. A diagnosis of dementia is a complex process and can only be achieved if the person giving the diagnosis has the time, knowledge and skill to recognise the symptoms and sensitively impart information.

Often, the first point of contact for a person experiencing memory problems is a General Practitioner (GP). In many countries, [AT, HR, CZ, DE, DK, GR, IE, LU, MT, NL, NO, PL, PT, SE, SL, CH, TR and UK (NI & S)] GPs are authorised to give a diagnosis of dementia (notwithstanding the fact that many also state the GP should refer the patient to a specialist once a diagnosis has been made). Even if GPs do not make a diagnosis, it is vital that they are able to recognise the signs of dementia to help the person obtain an official diagnosis so that relevant support can be accessed.

The findings on GP consultation times together with findings on GP dementia-specific training seem to be at direct odds with making a timely diagnosis. The report indicates that the average consultation time of a GP is approximately ten minutes. Whilst this time could be extended, only two countries (FR and UK) reported on specific incentives being offered to make a timely diagnosis - such as being able to charge a higher rate for a longer appointment.

GPs’ professional education was lacking in terms of dementia-specific training in many countries (AT, BG, HR, CZ, DK, FR, GR, IE, IT, JE, MT, NL, PL, RO, SL, SE, CH, TR and UK) and any dementia training that was administered was short and included within other courses, such as neurology. Whilst there is a possibility (sometimes obligation) for GPs to continue their training after qualifying, the deficiency in dementia-specific training was not necessarily addressed, as continued professional education allows GPs to select which course they follow.

Considerable variations are reported on the availability of, and adherence to, national obligatory guidelines on dementia diagnosis and tools (eg. clock test, Mini Mental State Examination (MMSE) etc.). Such guidelines can assist practitioners regarding best techniques as well as ensure uniformity of data. Some countries (HR, DK, DE HU, NO, NO, PT, RO and UK) reported having guidelines and/or recommendations for diagnosis of dementia which should be applied and many countries cited various guidelines which may be applied: neither situation guarantees that guidelines are applied appropriately or consistently.
Nearly all countries reported that all four Alzheimer drugs (rivastigmine, donepezil, galantamine and memantine) are available. Three countries (BG, HU and NL) reported having only three Alzheimer drugs available although interestingly each omitted a different drug: (BG - memantine, HU - galantamine and NL - donepezil).

Even though Alzheimer drugs were widely available, they were not always accessible to people with dementia. This is because some countries reported that not all four were necessarily reimbursable (BG, CY, EE, IT, LT, NO and PL). Whilst some may be partially reimbursable, Jersey and Scotland were the only countries to operate a system of free prescriptions ensuring 100% drug reimbursement.

In some countries [AT, BE, HR, CZ, DK, FI, HU, LU, NL, PT, RO, SK, SL, ES, SE, TR and UK (except S)], a person with dementia will only be eligible for reimbursement if the treatment (at least in the first instance) is prescribed by a specialist or supported by a specialist’s letter. This applies even if a country allows GPs to diagnose dementia.

Another issue is that of eligibility. There may be criteria that a person with dementia must fulfil before being eligible to be prescribed a specific drug. For patients to receive Alzheimer drug treatments, some countries (DK, FI, DE, IE, MT, PT, SE, TR) do not restrict MMSE readings to upper and lower levels, whereas others (BE, CZ, FR, IT, LT, LU, NL, NO, PL, SL, ES and CH) require that a patient’s reading falls between certain parameters. In the latter countries, treatment with acetylcholinesterase inhibitors (rivastigmine, donepezil and galantamine) ranged from an upper MMSE limit of 26 (IT, LU, NL, PL and SL) to a lower MMSE limit of 10 (IT, LU, NL, PL, RO, SL and CH), although an exception was in the case of treatment with donepezil, in which case the upper and lower limits were 20-0 respectively (LT). For treatment with memantine, the upper limit ranged from 18 (IT) to 14 (NL and PL) and the lower limit was either unspecified or ranged from 6 (CZ) to 3 (NL and CH). Such variations can result in discriminatory treatment.

Research

Research that is being conducted into Alzheimer’s disease and other forms of dementia ranges from being largely on a regional and/or personal level (AT and MT) to national level (DE, DK, FR, NL, SE and UK). Whilst several national dementia plans include measures to address research (DK, FI, FR, IE, MT, NL, NO, PL and UK), it was hard to establish how much funding is being allocated to support such measures, although there were a couple of examples of substantial funding being allocated (FR-EUR 30m and UK-GBP 66m).

Some countries plan to create “national research centres” (CZ) and some have already done so (DK, DE, NL, SE and UK). However, they were not necessarily dedicated to Alzheimer’s disease and other forms of dementia. Similarly, it was difficult to ascertain how much funding is allocated to Alzheimer’s disease research on a national scale, as the allocation was often included within a much wider budgetary framework, applying to more diseases than just dementia.

Basic research into the disease was widely reported, but there appeared a lack of social research. Even when social research was con-
Alzheimer Europe would like to thank the following experts for writing, updating and/or checking the various national reports. Without their help, the 2012 Dementia in Europe Yearbook would not have been possible:

**Austria** - Antonia Croy and Roswitha Bartsch; **Bulgaria** - Irina Vasileva Ilieva and Lora Ivanova; **Croatia** - Ninoslav Mimica; **Cyprus** - Noni Diakou; **Czech Republic** - Iva Holmerová and Daniela Bruthansova; **Denmark** - Anne Arndal; **Finland** - Heidi Häräma, Henna Nikumaa and Eila Okkonen; **France** - Judith Molland and Fanny Gaspard; **Germany** - Sabine Jansen and Hans-Jürgen Freter; **Greece** - Magda Tsolaki; **Ireland** - Maurice O’Connell and Gráinne McGettrick; **Italy** - Luisa Bartorelli; **Jersey** - Kim Averty; **Luxembourg** - Carine Federspiel; **Malta** - Charles Scerri; **Netherlands** - Marco Blom and Julie Meerveld; **Norway** - Anne-Kjersti Toft and May-Hilde Garden; **Poland** - Miroslawa Wojciechowska, Alicja Sadowska and Katarzyna Broczek; **Portugal** - Maria Rosário Zincke dos Reis, Celso Pontes, Alexandre de Mendonça and António Leuschner; **Romania** - Gabriela Cirstescu and Maria Moglan; **Slovenia** - Stefanija Lukič-Zlobec and Gorazd Bernard Stokin; **Sweden** - Kristina Westerlund; **Switzerland** - Mari Anne Wolfensberger; **Turkey** - Baṣar Bilgiç; **United Kingdom (England & Wales)** - Laura Cook; **United Kingdom (Northern Ireland)** - Laura Cook and Elizabeth Byrne McCullough; **United Kingdom (Scotland)** - Jim Pearson and Maureen Thom

There appeared a lack of social research being carried out. Conducted, the results were not exploited further (DK) and therefore potentially valuable information is going to waste.

Many countries (AT, BE, CZ, DK, FI, FR, DE, GR, HU, IE, IT, LV, LT, LU, MT, NL, NO, PL, PT, RO, SK, SL, ES, SE, CH and UK) reported on being involved to varying degrees with European research projects and in particular, in the European Joint Programming on Neurodegenerative Diseases and/or ALCOVE projects. This shows a willingness to engage in common research interests. However, compliance with international requirements was highlighted as a potential barrier to participation (CZ) and solutions may be found by countries joining forces in making research applications within the international sphere.

The report reveals a wide range of development of national plans and overall it is truly encouraging to find so many European countries actively pursuing the creation and subsequent implementation of a national dementia plan. However, much work is still needed to ensure plans are put in place, implemented and monitored effectively if they are to be successful in improving the quality of life of people with dementia and their carers.
ALLIANCE IN ACTION

There are 65 Members of the European Parliament who have joined the European Alzheimer Alliance. In this article, we highlight some of the ways in which Alliance members have helped to raise awareness of dementia.

Heinz K. Becker, MEP (EPP, Austria) attended Alzheimer Europe’s annual conference in Vienna on 6 October. This was an opportunity for him to meet Alzheimer Austria representatives and Alzheimer Europe’s Board members.

Françoise Grossetête, MEP (EPP, France) issued a press release on 20 September to mark World Alzheimer’s Day. In this press release she presents what the European Union is doing to address the challenges of an ageing population and the public health scourge posed by dementia across Europe. She explains in particular that the European Union focuses on creating synergies, learning from national experiences which are all too often scattered and isolated and stimulating public-private partnerships. In the field of research, she highlights that over EUR 8.5 bn of the EUR 80 bn allocated to the next Research Framework Programme (2014/2020) will be set aside for research in Alzheimer’s disease and other forms of dementia.

In addition, she feels that World Alzheimer’s Day must be a vehicle to acknowledge the work done by Alzheimer associations and volunteers “on the ground” to raise awareness about the disease. She expressed her support and encouragement to them all.

The local press (LYONcapitale.fr) published an article on F. Grossetête’s involvement as Chair of the European Alzheimer’s Alliance. The article adds that F. Grossetête warned that ‘if no treatment is found, the number of Alzheimer’s disease cases will treble by 2050; from 36 million today to 115 million’.

Marisa Matias, MEP (GUE-NGL, Portugal) accepted Alzheimer Portugal’s invitation to visit the organisation’s day care centre in Lisbon in October 2012. She saw the work done by the association for 15 of the people who visit the centre on a regular basis. She had the opportunity to meet the staff, day care users and their carers. She found the visit very inspiring and motivating and really got involved with the people with dementia and their activities.

This year, for the second time, Alzheimer Portugal organised national Memory Walks to mark World Alzheimer’s Day. Alongside hundreds of
Marisa Matias joined the Memory Walk of Coimbra. Through her participation, she clearly helped raise awareness about the disease and the importance of a healthy lifestyle to prevent dementia. On this occasion, leaflets informing people about the first signs of dementia, the differences between dementia and normal ageing and the importance of early diagnosis were handed out to the participants and the public during the walk.

Angelika Werthmann, MEP (ALDE, Austria) had hoped to participate in the Roundtable on National Plans during Alzheimer Europe’s annual conference in Vienna in October 2012. Unfortunately she was forced to cancel but sent a statement to be read out to the audience. In particular, she called for dementia to be a national priority in Austria and in Europe. She also raised the issue of the number of carers that will be needed in the future to care for older people and those with dementia. She urged policymakers and all stakeholders to come together, share best practices and support each other.

In September 2012, Angelika Werthmann put a series of questions on dementia to the European Commission on the regional variations in dementia prevalence in Europe, on how the Commission will deal with the increase in the number of people with dementia in Europe, the impact this will have on the healthcare systems and on the Commission’s plans to address the changes that will be seen in the workforce/people with dementia ratio in the future.

Alzheimer Europe warmly thanks Frieda for her unfailing support to dementia during her two mandates in the European Parliament and wishes her all the best for the future.

Marina Yannakoudakis (ECR, UK), a long-standing and supportive member of the Alliance, has accepted to take over as Vice-Chair of the Alliance.

On 4 December, Alzheimer Europe organised meetings between people with dementia (from Belgium – Jean-Pierre Frognet, Finland – Raoul Grönhqvist, Ireland – Dermod Slevin, Slovenia – Bojan Spanja and UK – Daphne Wallace) and their respective Members of the European Parliament. All these MEPs are members of the European Alzheimer’s Alliance.
In Memoriam

It is with great sadness that we report that Ornella Porro Possenti unexpectedly passed away on 14 October 2012.

Ornella was one of the founding members of Alzheimer Milano and Federazione Alzheimer Italia. She was also a great supporter of Alzheimer Europe and of our activities. We will remember her kindness, dedication and great sense of humour, as recently as our Annual Conference in Vienna which she attended as one of the representatives of Federazione Alzheimer Italia. She will be greatly missed!

We extend heartfelt condolences to her sister, Gabriella Salvini Porro, as our thoughts are with her in these difficult times.
The new report, “The ethical issues linked to restrictions of freedom of people with dementia” by Alzheimer Europe focuses on four main areas: the restriction to choose one’s residence or place of stay, the freedom to live in the least restrictive environment, the restriction of freedom to act according to individual attitudes, values and lifestyle preferences and the restriction of the freedom to play an active role in society.

After an explanation of the key concepts, each of the four topics are presented with background information, an examination of the ethical issues involved and a set of recommendations. The recommendations are not intended to be definitive, but rather to resemble principles and to be applied on a case by case basis, alongside the principles of proportionality and subsidiarity.

The restriction to choose one’s place of residence or stay

People with dementia may find that they have to give up some of their independence, learn to adapt to community life and may even be prevented from living in their own home if they are legally obliged to stay in a particular place (e.g. care home), whether on a temporary or permanent basis. This raises the ethical issues of autonomy, non maleficence, justice, dignity and the fundamental human right to freedom. Recommendations on freedom to choose one’s place of residence or stay include the provision of an alternative response to that of involuntary detention, additional legal safeguards and rights of appeal, better training of professionals in relation to capacity of people with dementia and that continual assessment procedures be put in place.

Freedom to live in the least restrictive environment

Various methods may be used to restrict the liberty of people with dementia which are not covered by legislation and for which there may not be consent. These include methods such as physical restraint, chemical restraint and various psychological, environmental and electronic measures or devices. The working group makes 43 recommendations divided into four categories: 1. government, policy makers and service providers, 2. care establishments, 3. healthcare professionals and 4. informal carers.

They call for changes in legal safeguards and policy as well as the development of guidelines for ethical reflection and conduct. There is also a set of general recommendations which start from the premise that “people with dementia should not be submitted to the use of restraint” and that it should only be tolerated in extreme situations where the physical and mental integrity of the person with dementia is in serious and imminent danger. Such situations were considered by the group as being rare and to be avoided by careful planning and reflection.
The restriction of freedom to act according to individual attitudes, values and lifestyle preferences

The respect for one’s individuality and right to self-expression is at the heart of the discussions in this section of the report. Within the context of a residential care setting, people with dementia may find that their individual preferences, habits and wishes are not taken into consideration. The group discussed various scenarios, including some practices within care settings and also the issues surrounding sexuality and relationships. Assistive technology was considered only briefly as it was the main topic of the 2011 report. Recommendations are provided for care establishments and include respecting residents’ rights, cultural diversity, freedoms, needs and wishes. Recommendations for residents with dementia include the provision of support and opportunities to participate in social life and in decision-making related to issues which affect their lives. There is a separate section on sexuality and relationships ranging from a call for people to explore their own attitudes and beliefs about the sexuality of older people and people with dementia to specific recommendations for the care establishments.

The restriction of freedom to play an active role in society

The last area to be reflected upon is the role which people with dementia can play in relation to voting, making decisions with legal implications (such as marrying and making a will) and driving. The group discussed people’s capacities and desires to vote, as well as obstacles which prevent people with dementia from voting. The recommendations centre around helping to ensure that people with dementia are encouraged and enabled to vote, with specific suggestions on how to help people with dementia in care homes to vote.

It is common that the law requires a certain level of capacity by decision makers and this section of the report considers such requirements, in particular for making a will. The discussion challenges the assumption that people with dementia automatically lose their capacity to make decisions with legal implications and offers useful recommendations when drafting wills for people with dementia.

In modern life many people drive cars. The restriction of this has been linked to the disruption of social roles, a perceived threat to one’s personal identity, a loss of self-esteem, independence and spontaneity and a dependence on others. It is a highly sensitive issue. The group considers whether people with dementia are a risk, the issue of stopping driving, how assessments can be carried out and the balance to be struck between confidentiality and safety. Recommendations cover a widening of the assessment criteria for driving capacity, the role of the GP in assessment and his/her duty to inform the authorities, the availability of refresher courses and the provision of support to reduce the risk of social isolation and reduced mobility resulting from driving restrictions.

Throughout the report, the ethical issues surrounding the restriction of a person’s freedom are sensitively raised and thoroughly and respectfully considered.
DEBATING DEMENTIA
IN THE EUROPEAN PARLIAMENT

Alzheimer Europe organised its 14th lunch debate in the European Parliament on 4 December 2012. It was the first time that people with dementia led the debate as they shared their experiences of living with dementia.

Sirpa Pietikäinen, MEP (Finland) hosted Alzheimer Europe’s 14th lunch debate in the European Parliament on behalf of Heinz Becker, MEP (Austria). It was entitled “Living with dementia: Learning from the experiences of people with dementia.” Ms Pietikäinen emphasised the importance that this debate would have in highlighting the rights and needs of people with memory disabling diseases. She called on policy makers to remember these voices when planning policy and decision-making systems. The presentations by Helga Rohra, Nina Baláčková and Daphne Wallace highlighted different experiences of living with dementia. The event was supported by an audience of 60 people consisting of representatives of the European Parliament, European Commission, European Working Group for People with Dementia, national Alzheimer associations and the pharmaceutical industries.

Helga Rohra

Helga Rohra reminded the audience that the only way of hearing the authentic voice of dementia was by listening to the experts - the people who live with the disease. Ms Rohra was diagnosed in 2006 in Germany with dementia with Lewy bodies and has since been an advocate for the rights of people with dementia. In 2012 she became the first Chairperson of the European Working Group of People with Dementia (EWGPWD).

The EWGPWD consists of people with dementia who actively campaign and advise on issues surrounding dementia. She said that the capabilities of people with dementia differ, depending on the personal characteristics and age of the person as well as the type and stage of dementia. Indeed, members of the group reflect exactly this as they come from different European countries and range from people in their 40s to 70s, with different types of dementia and at different stages of the disease. She challenged the perception that people often have of dementia as that of an elderly person at the late stage of Alzheimer’s disease. She said, therefore, that programmes are required which are tailored to specific needs.

Ms Rohra explained that the EWGPWD had been formed in 2012 with the support of Alzheimer Europe. The main aim of the group is to be listened to and integrated into society. Although the EWGPWD started work in 2012, Ms Rohra illustrated how Alzheimer Europe has given people with dementia the opportunity to participate and be heard for over 10 years at conferences, in working groups and in articles in newsletters and magazines.
Further, the Chairperson of the EWGPWD is an ex-officio member of the Board of Alzheimer Europe with full rights. Ms Rohra was particularly delighted that so many people with dementia had been involved in Alzheimer Europe’s 2012 conference in Vienna.

Ms Rohra concluded that the foundation of the EWGPWD is an important step as well as an historic moment in the development of the Alzheimer’s movement. It illustrates how, even in dementia, we can overcome borders and become united and strong. Ms Rohra said that the more a person progresses with dementia, the stronger they become and emphasised that “a person with dementia is as valuable as a person without”. However, Ms Rohra said that people with dementia can only be strong if they are offered the right programmes by politicians and that such programmes can only be developed if people with dementia have been listened to.

Nina Baláčková

Nina Baláčková is 54 and from the Czech Republic and was diagnosed with Alzheimer’s disease in 2007. She was aware of the disease because her mother had passed away with it. However, when she herself had symptoms six years ago doctors could not believe it possible that she had Alzheimer’s disease as they understood it to be a disease associated with older people. Ms Baláčková highlighted that this was worse for her younger friend, Hannah, who, because of a lack of understanding about the disease, had to wait three years and endure a stay in a psychiatric unit before a diagnosis was made.

After diagnosis, Ms Baláčková found out more about the disease through the Czech Alzheimer’s Society. She was given support and attended memory training sessions which, through much work, enabled her to recite 44 American Presidents! However, it also resulted in several doctors deciding that the diagnosis must be flawed as they did not believe it possible for a person with Alzheimer’s disease to do this. On talking with friends from other countries, Ms Baláčková found that such misunderstandings were not unique to the Czech Republic.

Many people think that the only symptom of dementia is that a person forgets, but Ms Baláčková explained that there are other symptoms too. In her case, she has also lost her sense of smell and taste. She finds that she is often tired and sometimes angry as her life is shorter and she is only too aware that time is more valuable. Ms Baláčková also highlighted the issue of care for younger people with the disease. In the Czech Republic, places in care homes are allocated for people over the age of 60 or 65. Where should she go, she asked? For now, she says she “will fight Mr. Alzheimer and win!” Calling for action to address the lack of understanding and knowledge about dementia, Ms Baláčková closed her presentation by reminding the audience that “the past is history, tomorrow is mystery and today is a gift and it is for everyone.”

Daphne Wallace

Daphne Wallace is 72 and a retired psychiatrist. At the end of 2004 she was surprised to find herself to be exhausted and stressed after carrying out some locum work. Having worked with
people with dementia, she recognised some of the symptoms and after speaking with her colleagues she went to her GP who referred her to a neurologist. The outcome revealed that she had a form of vascular dementia. She believes she received a relatively quick diagnosis, but this was only because of her own personal connections.

She emphasised the importance of understanding the particular disease a person has. This is because each disease interacts with each person's brain and personality in a unique way. Dr Wallace explained that the losses she has experienced are not always obvious to others. One change she has noticed is a delay in the message from what she can see to the reaction from her brain. She illustrated this by saying that although she can see a glass with wine in, the message does not reach her brain in time and may result in her knocking it over. She also finds that she is unable to remember faces as well as she used to and that her ability in maths is not what it once was. She notices this loss when she tries to adjust the quantities in recipes from four to two people. She now has to write down a sum if she wants to adjust these quantities.

Dr Wallace also said that she used to be able to navigate quite easily but now relies on a satellite navigation system.

Unfortunately Dr Wallace did not have any professional support after diagnosis and she found the adjustment hard. Although she now has a visiting psychiatrist, initially she did not see anyone for three and a half years after the diagnosis and this left her feeling professionally abandoned.

Dr Wallace also spoke of people who have dementia as having a responsibility to speak out for those who cannot. She said that we all have human rights, including people with the advanced stage of dementia, yet their voice cannot be heard. She said that society underestimates the capabilities of people who have dementia and reminded everyone that they are still human, still present, with rights to dignity and proper care.

**Discussion**

Ms Pietikäinen concurred and noted that although we have constitutional rights in the EU with an understanding that all of us are equally important, in reality we have not recognised equal rights for people with memory problems.

Jean Georges, Executive Director of Alzheimer Europe reiterated Helga Rohra’s comment that this event was indeed historic for Alzheimer Europe, as it was the first time we have had an event in the European Parliament where we have had people with dementia from ten different organisations and where three of those gave presentations. He asked the people with dementia what would be the one thing they would ask of their MEP if they had the opportunity. Helga Rohra asked that a campaign be made to show that dementia is more than Alzheimer’s disease and that it affects people of different ages and has different symptoms. She also asked that post-diagnostic support be provided so that people were not left with just a tablet. Nina Baláčková said she would like people to understand more about the lives of people with dementia. Daphne Wallace said she would ask that the issue of stigma be addressed as it arises from ignorance and it makes the lives of people with dementia more difficult than necessary. Dr Wallace said that people need to understand that having dementia is not entirely negative.
Iva Holmerova, Chairperson, Czech Alzheimer Society said that it was essential that people realise it can happen to anyone, including ourselves and that we will have to cope with it. She asked what kind of support was most useful on a personal level. Nina Baláčková said that she found the memory training very important to her as well as being socially included. Daphne Wallace said she wanted the right kind of support, which respected her rights and beliefs as an individual.

Jean-Pierre Frognet, Vice-chairperson of the EWGPWD, explained that he has lived with Alzheimer’s disease for almost five years. He said that he has accepted the disease and told his mother that, unlike having an accident resulting in broken bones, dementia is a disease that doesn’t hurt. Mr. Frognet said he would like doctors to tell people the truth.

Henry Simmons, Chief Executive, Alzheimer Scotland, asked how people were affected when they read of another “potential cure” in the media and asked what advice they would give to researchers and journalists about how to handle research news. Jan Frederick Meijer, Vice-chairperson of the EWGPWD, said that they do give a kind of hope. He explained that he is taking part in several investigations himself but does not have so much hope now.

Helga Rohra said that whilst medicine has a role to play, there are many other non-pharmacological programmes which can help people with dementia. Daphne Wallace said that the media coverage tends to raise people’s hopes but on closer inspection it may be something which is not so significant today. Whilst a search for treatment and/or care is carried out, people need appropriate support and care now. People need to be able to express the talents they have or even do not know they possess! Jean-Pierre Frognet spoke of the need for people with dementia to meet. There is a special care facility in Belgium which does not rely on the administering of medication in order to calm people with dementia. Instead, the staff try to establish the root cause of any anxiety and or challenging behaviour and address it. Knowing this gave great comfort to Mr Frognet, who said should he need to be put into care, he would want to be in a place like that.

Sirpa Pietikäinen thanked everyone for their contributions and in particular thanked the people with dementia who had provided a special moment in the Parliament by sharing their lives with everyone.

Closing, Ms Lützau-Hohlbein, Chairperson of Alzheimer Europe, said that it had been made clear during the debate how important it was to include people with dementia. She said that she was proud of the national associations’ work in this regard. She explained that whilst she understood dementia from the perspective of a carer, that she could only imagine how people with dementia really feel and was therefore extremely grateful to Helga, Nina and Daphne for sharing their personal experiences of dementia.

“It is essential that people realise it can happen to anyone, including ourselves and that we will have to cope with it.”

Iva Holmerova
A snapshot of Alzheimer Europe’s 14th lunch debate in the European Parliament

* European Economic and Social Committee
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The need to reform current coercive measures to protect constitutional human rights of people with memory diseases is considered by Sirpa Pietikäinen, MEP (Finland).
Alzheimer Europe (AE): As you know, neurodegenerative diseases like dementia affect more women than men: in Europe, over seven million people have dementia, close to five million being women and over two million being men. With the ageing of the population, these figures will dramatically increase in the future. What do you think should be done to raise awareness about dementia in Europe?

Roberta Angelilli (RA): Population ageing is one of the main challenges facing Europe: the age group over 65 accounts for more than 87 million people in the EU27, of which 50.6 million are women.

Despite increased longevity, older women tend to have a significantly higher incidence of debilitating diseases, including neurodegenerative diseases, and experience the development of progressive disability more than men of the same age.

Age is indeed a risk factor for the development of neurodegenerative diseases such as Alzheimer’s disease (the most common type of dementia).

Dementia is more common in the over-65s: it affects about 1 person in 20 over 65, 1 in 5 over 80, and 1 in 3 over 90. Over 7.3 million people in Europe suffer from dementia; recent studies (e.g. Alzheimers Europes’ EuroCoDe project) suggest that the prevalence of dementia is higher in women than in men, particularly in the over 85 age group.

Unfortunately stigma and lack of awareness about neurodegenerative diseases such as dementia lead to delayed diagnosis and a poor treatment outcome.

Information and prevention, accompanied by research, are key elements for a strategy which should involve all policy-makers, in particular national and European institutions, industry associations, media and local authorities. The aim should be the dissemination of strategies in terms of prevention in order to promote behaviour which is conducive to healthy and active ageing and good health for all.

The societal cost of dementia is high. Therefore, measures to improve prevention and early detection of the diseases need to be accompanied by an improvement in the sustainability and efficiency of social and health care systems.

The EU and the Member States should adopt a holistic and gender-sensitive approach to Alzheimer’s disease and other forms of dementia in order to improve the quality of life and dignity of patients and their families.

AE: When talking about age-related disease, one often thinks of diseases affecting elderly people. However, neurodegenerative diseases like dementia also affect young people. How would you see EU health policy embrace this challenge?

RA: Alzheimer’s disease and other forms of dementia may also develop in young people. The emotional impact of developing a dementia at a younger age is significant and has a dramatic effect on life expectations as well as on families. Dementia is indeed devastating, not only for the patients themselves but also for their relatives and carers, due to the strong emotional, physical and financial impact of this disease.

Younger people with dementia have specific and different needs. So, access to diagnostic services, research and care, support and accommodation should be improved for young people with dementia.
Younger people with dementia have specific and different needs.

Robert Angelilli

with the aim of maintaining a high quality of life. While respecting the principle of subsidiarity the European Union can continue all its efforts to promote a preventive health policy in relation to its interaction with cardiovascular illnesses, mental health, physical activity, education in the field of health and new technologies.

Prevention starts during youth, according to a general approach to a lifelong health: There are well-known preventative factors such as a healthy diet (i.e. the consumption of specific vitamins and anti-oxidants), promoting physical and cognitive activity and controlling cardiovascular risk factors such as diabetes, high cholesterol, high blood sugar, hypertension, overweight and obesity, alcohol abuse and smoking (both active and passive). Specific awareness campaigns targeting young people should be implemented at both European and national levels.

Although Alzheimer’s disease continues to appear on policy agendas in the Member States, it is necessary to close the disparities between, and even within, Member States. Further, it is necessary to address shortcomings both in terms of staff training and qualifications and the lack of equipment needed for diagnosis and research. Unfortunately the diagnosis of Alzheimer’s disease often takes place years after the onset of the disease, thus delaying any possible treatment to slow down the disease.

In this sense the new EU Research programme, Horizon 2020, and the Health for Growth programme may lead to important achievements.

But it is important to underline the need for a gender-related approach to health both in understanding the determinants of health and in optimising the effectiveness of healthcare systems. Women and men are subject to specific illnesses and health risks which must be suitably taken into account with regard to medical research and health services.

It is essential to strengthen significantly cooperation and coordination of innovative and multidisciplinary gender related clinical research efforts into the causes, prevention and treatment of neurodegenerative diseases.

This includes organising specific training courses for general practitioners and mental health professionals - including doctors, psychologists, and nurses - on the prevention and treatment of neurodegenerative diseases, paying specific attention to the additional challenges faced by older women.

One point to be underlined is the fact that most of the research effort in the field of neurodegenerative diseases is carried out by Member States, with a relatively low level of transnational coordination.

Different forms of dementia are being studied from multiple perspectives and in different areas of research. This may contribute to a further fragmentation of research activities and a limited sharing of knowledge and best practices among Member States.

A European response would help to overcome these issues and would better address the complexity of the challenge and the interdependency of its components. This could be done by conducting large-scale epidemiological and clinical studies in transnational collaboration, and by pooling the critical mass of skills, knowledge and financial resources.

AE: Age-related diseases can often be prevented with a healthy lifestyle and reversed through treatment. So far, no clear preventative measures have been identified to avoid dementia and no cure exists. In your opinion, how could Horizon 2020 and the next Health Framework Programme support the prevention and cure of unpreventable and disabling age-related diseases like dementia in women?

RA: A key answer to the big challenge of population ageing can certainly be found in science and research.

“Younger people with dementia have specific and different needs.”

Robert Angelilli
“HEALTHY AGEING ACROSS THE LIFECYCLE”

The EU Coordination Sector of the Ministry of Health, Cyprus, looks back at the health priorities of the Cyprus Presidency of the Council of the European Union which was held from July to December, 2012.

The fight against neurodegenerative diseases in general is recognised amongst the most crucial challenges that the ageing population of Europe is facing and will continue facing during the coming years.

Addressing these diseases is an enormous challenge and the Council of the European Union acknowledges the importance of cooperation between the Member States on actions for prevention, health promotion and cognitive stimulation throughout the lifecycle.

Having recognised the work already carried out in this area, the Cyprus Presidency of the Council of the European Union wishes to encourage the protection and promotion of health for a “Better Health for All”.

Therefore, it has set its main health priorities as follows:

- Organ donation and transplantation,
- Healthy ageing across the lifecycle,
- Cross-border health threats in the EU and its neighbouring countries with focus on Communicable Diseases,
- Innovative approaches in healthcare.

Within these four main priorities, “Healthy ageing across the lifecycle” is particularly significant for the future of European public health, with a strong influence on neurodegenerative diseases including dementias, such as Alzheimer’s.

Keeping in mind that neurodegenerative diseases are mostly prevalent among people over the age of 65 and that the genetic as well as environmental factors are the main causes of this disease, healthy and active ageing practices could be an effective method for the prevention and early diagnosis of such illnesses.

In this respect, a two-day High Level Conference on “Healthy Ageing Across the Lifecycle”, co-funded by the Cyprus Presidency and the European Commission (Community Action Programme on Health 2008-2013), was held in Nicosia, Cyprus on 5-6 September 2012. Experts from the EU Member States, European Commission, World Health Organisation, Academic Institutions, NGO’s and other EU organisations, as well as representatives of the European Parliament participated in this conference.

The Conference speakers emphasised that healthy ageing is a continuous process across the lifecycle that needs to be enhanced and promoted through disease prevention, early diagnosis and health promotion programmes, at every stage of life.

During the conference, the importance of adopting multidisciplinary actions in health promotion and disease prevention by public authorities and stakeholders at all levels was highlighted. These stakeholders include health professionals, patients, social partners, society, the media, business and other economic social groups.

Continued on page 27
Changing perceptions, practice and policy
Highlights from the Alzheimer Europe’s 22nd conference where more than 500 delegates from 43 countries came together in Vienna, Austria.

Involving people with dementia
Alzheimer Europe reports on presentations by Eleanor Edmond, Eva Quack, Andrea Capstick and Angela Clayton-Turner on how to involve people with dementia at all levels.

Agnes and Nancy
Agnes Houston and Nancy McAdam discuss their decision to participate in “Agnes and Nancy – A short film about two friendly campaigners.”
Alzheimer Europe's 22nd annual conference took place in Vienna, Austria on 4-6 October 2012. Alzheimer Europe takes a look at some of the highlights.

“Changing perceptions, practice and policy” was the theme of Alzheimer Europe’s 2012 conference. It was held in Vienna and organised jointly with Alzheimer Austria. Over the course of two days some 500 delegates from 43 countries had the opportunity to choose from a varied and intensive programme which included 120 speakers in plenary and parallel sessions, special symposia and workshops.

The spectrum of topics included national dementia strategies, diagnosis, psychosocial interventions, assistive technologies, legal and ethical issues in dementia, prevention and treatment of dementia, socio-economic cost of dementia, caregiver burden, end-of-life care, long-term care, dementia friendly communities, care services and care support. The challenge was choosing which to go to!

Participants represented a wide range of backgrounds within the field of dementia and included people with dementia and their carers, policy makers, healthcare professionals, researchers, chairpersons from national Alzheimer associations and volunteers.

Welcome

Antonia Croy, Chairperson of Alzheimer Austria, together with Heike von Lützau-Hohlbtein, Chairperson of Alzheimer Europe, opened the conference by welcoming everyone and expressing their delight that so many people from so many countries had been able to support the conference, giving it a truly international feel. Both were thrilled that more than 15 people with dementia from 12 countries were attending and that several would be taking an active part in the presentations. Ms Croy said that she had witnessed a change in policy and a progression in both diagnosis and medical treatment since her own mother developed Alzheimer’s disease 30 years ago. Her hope for this conference was that new discussions would be initiated, which would bring even greater changes, resulting in action to improve the lives of people with dementia and their carers. Ms von Lützau-Hohlbtein reflected how Alzheimer Europe had been able to influence policy-makers as a result of the support received by the European Alzheimer’s Alliance, which currently enjoys a membership of some 60 Members of the European Parliament.

A strong message of support was provided by Rudolf Hundstorfer, the Austrian Federal Minister for Labour, Social Affairs and Consumer Protection, who spoke at the opening session. He explained the far-reaching care system Austria enjoys and said that Austria is a “world champion” with respect to funding for care. Over the last 20 years a “seven-step system for care programme” has ensured that people can receive subsidies based on diagnosis alone. Notwithstanding this, Mr Hundstorfer recognised the need to specifically address dementia and, much to the delight of the audience, announced that the Austrian government would launch a national dementia plan within five years. He recognised the important contribution made by Alzheimer Austria and personally assured Ms Croy that the association would have a significant role in the development of the plan.

Changing policy

National plans were the focus of the very lively first plenary session, “Changing policy – na-
ctional strategies and European collaboration on dementia”. This enlightening round-table discussion included Prof. Alistair Burns, National Clinical Director for Dementia in England, Ms Teresa di Fiandra, Chief Psychologist of the National Health Service in Italy, Ms Caitriona Creely, International Liaison Officer, Irish Health Board and Mr Michael Hübel, Head of Unit for Health Determinants, DG Health and Consumers, European Commission.

Prof. Burns emphasised that having a strategy is an excellent way to focus on an issue. However, he listed three requirements which are necessary to make a strategy effective: (i) action to raise awareness of the issues which surround dementia, (ii) action in the form of a written plan and (iii) a procedure in place to monitor and assess action taken. Prof. Burns stressed that to make dementia a priority it was necessary to first give a context to dementia by telling the story behind it and seeing how facts relate to each other within that. He gave an example from the UK, where people over 55 fear dementia more than anything else. This, he said, needs to be considered in light of the fact that in the next election many people will be over 50. Initiatives will flow from these facts and, as long as they are based on good ideas, money will follow. He also highlighted that if you get the right approach for dementia you will often get it right for other things such as hospital care.

Ms di Fiandra added that a national strategy is a more cost-effective way to tackle a problem as it signifies an agreed approach by people in different contexts, enabling efforts to be optimised. She said that unless you combine the effort of all actors in the field you will never reach a point of a common strategy that will address all the needs of people with dementia. This point has been achieved in Italy, where a draft national plan is ready. However, she illustrated how implementation is a particular challenge: Italy has a regional government structure so discussions remain on-going as to how to apply the national plan locally. She believes that there should be agreement and an approved strategy by the end of 2012.

Outlining the place dementia has in the European programmes for active ageing and public health, Mr Hübel spoke of the importance of encapsulating both the social and health aspects when having discussions around ageing populations. The approach taken within the ambitious aims of the Joint Programming on Neurodegeneration (JPND) was explained by Ms Creely who said that although initially research into neurodegeneration is considered within broad terms, it is then important to focus on dementia apart from other diseases, disentangling it from issues such as active and healthy ageing. She also spoke of development of the strategic research agenda which, in the absence of a cure for dementia, includes a number of initiatives linked to prevention. Practical examples of prevention ensued and Prof. Burns explained that he himself uses a mobile phone application whereby each day he receives a reminder to eat fish, drink wine and go for a walk!

Each member of the panel was asked what they hope for in five years’ time. Mr Hübel said he hoped that the healthy ageing building blocks and instruments were in place to sup-
port Member States and that health, social and research agendas had moved forward towards a healthy ageing programme. Ms di Fiandra spoke of the need for a network based on cooperation and coordination in the field of dementia and the need for bodies at international level, such as the WHO and the EU, to work together. Ms Creely hoped that, on a national level, dementia would be a priority in Ireland and at EU level she hoped that the JPND would continue to grow. Prof. Burns perhaps reflected the wish of all delegates in that he hoped for every country to be able to say they have the best dementia care, so that people with dementia and their carers are able to say that things have improved.

Changing practice – medical aspects

Delegates learned of changes in diagnostic criteria. Under the 1984 NINCDS-ADRDA criteria, Alzheimer’s disease was difficult to diagnose as the clinical diagnosis was only “probable” until confirmation after death. However, Prof. Bruno Dubois, Head of the Dementia Research Centre (IMMA) and Director of INSERM Research Unit (ICM), explained that because of medical advances, discussions started in 2007 on whether dementia should be classified by a clinical definition, by a stage of severity, by the identification of the first symptom of the disease or by biological definition. These discussions have been enhanced by a number of events, including the possibility of integrating biomarkers of Alzheimer’s disease pathology into a diagnostic framework for earlier clinical diagnosis. Prof. Dubois explained that we now know there is a specific region of the brain (hippocampus) which is damaged and this damage follows a specific pattern which helps to identify the disease. Another development is that we are now able to identify Alzheimer’s disease lesions in vivo in the brain via PET examinations. Prof. Dubois said that these are not markers of a particular stage, but markers of the disease itself and are present at earlier stages of the disease. This information enabled researchers to propose new criteria (known as IWG/Dubois and NIA/AA) based on making a diagnosis in a much more positive way as a clinical biological entity.

Within the context of a world in which there is an unprecedented number of people living to an advanced old age, Prof. Eric Larson, Vice-President for Research, Group Health, presented the prospects for prevention of Alzheimer’s disease and other forms of dementia. He reflected that for many years we had searched for a “magic bullet” but that it had not manifested itself. Prof. Larson highlighted evidence from three epidemiologic studies, which indicated that the onset of dementia might be delayed through better education, more favourable socio-economic conditions and better control of cardiovascular risk. He concluded that whilst it is impossible to completely prevent dementia, we could ensure that people live longer and could be healthier for longer. To do this, Prof. Larson emphasised the huge role that social policies will play in years to come.

Prof. Achim Schneeberger, Chief Medical Officer at AFFiRiS AG addressed recent well-publicised drug trials (bapineuzumab Phase III studies, solanezumab phase III and AFFITOPE ADs programme) which had been described as disappointing. However, in Prof. Schneeberger’s opinion, none of these trials disproved the
Amyloid hypothesis; they revealed some significant findings which were promising and it is therefore necessary to reset the targets at earlier stages. He also highlighted the results from the large ADNI initiative and explained how these studies have made a significant contribution to our understanding of Alzheimer’s disease. For the first time, studies on prevention trials can be assessed which are based on populations with the inherited form of Alzheimer’s disease, i.e. who will definitely develop Alzheimer’s disease.

New insights for imaging for diagnosis of Alzheimer’s disease were presented by Giovanni Frisoni, Deputy Scientific Director of the Scientific Institute for Research and Care. He explained the changes that take place in the brain as dementia advances: the levels of amyloid increase, then functional changes take place and finally there is tissue loss and atrophy. These changes have been determined by observations of people at different stages of memory impairment: asymptomatic, MCI and dementia. There are markers for each stage and, in an attempt to establish the most accurate individual marker, an analysis had been carried out on 130 studies for predictive value of dementia from MCI. However, this revealed the need for a standard operational procedure which can be applied worldwide as there was lack of consistency in how the marker was read.

**Changing practice – social and care aspects**

More and more, stakeholders from across Europe are coming together in various projects with the aim of providing a better quality of life for people with dementia and their carers.

A project which aims to create better conditions of life for older adults through the use of communication technology was presented by Kerstin Zimmermann, Scientific Policy Officer, Austrian Federal Ministry of Transport, who described the Ambient Assisted Living Joint Programme (AAJJP). Launched in 2008, the six-year project includes 20 EU Member States and has a budget of EUR 600 M. Currently there are only 12 projects (out of 100) running which have people with dementia involved.

Armelle Leperre-Desplanques, Head of the Department of Pilot Programmes on Clinical Impact at the French National Authority for Health presented “ALCOVE”, which is a European Joint Action dedicated to Alzheimer’s disease and related dementia. The particular aims of this project are to improve (i) data on dementia prevalence, (ii) access to the earliest possible diagnosis, (iii) care for those living with dementia and (iv) the rights of people with dementia. The results are due to be published at the beginning of 2013 and presented in Paris in March 2013. Dr. Leperre-Desplanques highlighted one of the findings which had been the identification of 82 different databases in Europe with different types of data on dementia. ALCOVE will make suggestions on how data could be collected in a harmonised way to improve the situation.

The importance and need for greater funding into psychosocial research was raised by Bob Woods, Professor of Clinical Psychology of Older People at Bangor, Wales and Director of NEURODEM, Cymru, Wales. He spoke of European collaboration, in particular the JPND programme, and of the INTERDEM group. This is a pan-European network of researchers...
on timely detection and psychosocial interventions on dementia and currently has members from 20 European countries, with all members actively engaged in psychosocial research.

He explained that psychosocial research covers a wide range of topics from the experience of living with/adjusting to/coping with dementia for both the person with dementia and carer. It also concerns how care services are organised, how training and education is given, as well as a wide range of specific intervention approaches. Prof. Woods lamented that dementia research is the "poor relation" of medical and health research. He illustrated this inequality with figures from the UK: for every person with cancer, GBP 291 is spent on research compared to just GBP 61 on people with dementia. He explained that most funding goes into basic research (81.2%) and that this results in psychosocial research being the "poor relation" of dementia research. Prof. Woods highlighted research carried out by Olazarán (2010) et al. which showed that there was evidence that interventions would improve carers' lives and reduce admission to homes.

Marilène Filbet, Associate Professor in Palliative Medicine and Director of the Palliative Care Centre at the University Hospital in Lyon, spoke of the need for specialised palliative care for people with dementia, highlighting the specific symptoms (such as gradual loss of autonomy and control, psychiatric symptoms, behaviour issues, aspiration, fever and pain) that people with dementia have. Prof. Filbet also listed the suffering the carers face (such as prolonged grief, nursing home transfer, distress over decision-making and guilt). She explained that the use of palliative care programmes is increasing in European countries, but these services are very often dedicated to cancer patients.

**Changing perceptions**

Helga Rohra, Chairperson of the newly-formed European Working Group for People with Dementia, enlightened delegates about the benefits of involving people with dementia. She emphasised that, with or without dementia, she is still Helga - a person who has many existing capabilities and who can make a contribution. And she proved her point! She talked of the importance of the involvement of people with dementia at all levels. Her involvement with other people with dementia had given her a feeling of solidarity, strength and humour. She also mentioned the importance of support after diagnosis to ensure you do not feel alone with this disease and of a new type of patient that likes to be talked to. She also reflected on her participation in working groups and this conference and the associated feeling of being valuable. Ms Rohra concluded that people with dementia are a part of society and in this way people's perceptions can start to change, which will lead to a change in policy in dementia.

Prof. Cees Hertogh, VU University Medical Center, Netherlands, provided a fascinating insight into the ethical considerations surrounding the use of technology for people with dementia. He argued that the fundamental ethical question surrounding the use of technologies is not whether we want/accept technology or not, but how we allow technology to shape our lives and the lives of people with dementia. There is great debate over the balance between the ethical purposes of technology, its role in the caregiving process and its effects on individual free-
dom, privacy and dignity. Informed consent plays a significant role in achieving this balance but Prof. Hertogh illustrated how technology is not dependent on our consent. He used the analogy of the telephone: the original purpose of facilitating business conversation was overtaken by phones revolutionising the way in which we communicate. He said that smart phones have weaved themselves into the fabric of everyday lives until they become a part of life. They are interactive, invisible and establish a network with people - one in which we are dependent on our technology but in which technology is hardly dependent on our consent. He concluded that we cannot influence the development of technology, but there is a need for the earlier involvement of ethics and a development of ethics in this area. Technology should be considered within the context of inclusionary care.

Dianne Gove, Information Officer, Alzheimer Europe, presented Alzheimer Europe’s ethical recommendations on dementia research which were developed by a multi-disciplinary working group within the European Dementia Ethics Network (EDEN). These focused on involving people with dementia, informed consent, ensuring and promoting wellbeing, risk, benefit, burden and paternalism, medical research, end-of-life care, brain donation and publication and dissemination of results.

She emphasised the need to involve people with dementia in all aspects of research, to avoid paternalistic attitudes towards their participation, to recognise possible non-medical benefits of such participation as well as the huge contribution to society made by people with dementia and other groups of partici-

p pants through their involvement in dementia research.

Perceptions of capacity were discussed by Dr Helga Müller-Ebner, Regional Head of Guardianship with the Austrian organisation “VertretungsNetz”. At one end of the spectrum, patients who are capable of doing so have the right to make their own medical decisions, must consent to all forms of medical treatment, must be informed of their rights and are entitled to an explanation and information regarding treatment. However, people who have a mental illness may lose such rights and delegates heard of the structures in place to protect the potential vulnerability of this group.

Aside from the intensive conference programme, delegates were also able to relax and enjoy local hospitality during an unforgettable gala dinner at the “Piaristenkeller”, a 300-year-old monastery cellar with two imperial museums and a historic restaurant. This event proved to be extremely popular and well-received.

Antonia Croy and Heike von Lützau-Hohlbein closed the conference, giving particular thanks to all the people with dementia who had shared their experiences. They also thanked all speakers for helping us to understand how changing policy, practice and perceptions will help people with dementia and their carers to be better supported, cared for and to enjoy a better quality of life.

Prof. Hertogh argued that the fundamental ethical question surrounding the use of technologies is not whether we want/accept technology or not, but how we allow technology to shape our lives and the lives of people with dementia.
A snapshot of Alzheimer Europe’s 22nd Annual Conference in Austria
I. Brian and Rozel Snell (Jersey)  
II. Delegates from Ireland  
III. Henry Simmons (Scotland) and Jean Georges (Alzheimer Europe)  
IV. Andreas Winker, Bettina Schuster and Achim Schneeberger (Austria)  
V. Delegates from Luxembourg  
VI. Jean-Pierre Frognet and Marie-Anne Schreder (Belgium) with Mihela and Bojan Spanja (Slovenia)  
VII. Austrian organising committee  
VIII. Gwladys Guillory (Alzheimer Europe) and Sabine Jansen (Germany)
A key topic in both plenary and parallel sessions was how to involve people with dementia at all levels. Alzheimer Europe highlights some of the parallel presentations dedicated to this topic.

The conference included several inspiring presentations which illustrated both how people with dementia can make a valuable contribution and the benefits of involving people with dementia.

A reluctance to involve people with dementia in decision-making was discussed by Eleanor Edmond, Legal Policy Officer, Alzheimer Society of Ireland. To overcome this, Ms Edmond advocated taking a rights-based approach and highlighted the concept of “reasonable accommodation”. She explained that the basis of this can be found in various legal instruments (including documents at UN, EU and national level) which gives rise to an obligation to help people with dementia to be included by removing some of the obstacles they face (obstacles such as the perception of disability, the lack of opportunity to participate and the lack of involvement).

Challenging the notions of rationality on which European decision-making processes are based, Ms Edmond asked the audience to reflect on how they may have made their decision to marry or buy their last pair of shoes and whether they had employed rationality in making their choices! She therefore questioned the reluctance to involve people based on perceived ability to be rational.

Ms Edmond highlighted the importance of ensuring environmental factors were conducive to facilitating inclusion and used the conference venue as a case in point. Whilst recognising the huge contribution of Alzheimer Europe to ensure that people dementia were heard, participants with dementia had experienced some difficulties due to the venue (such as mirrored ceilings, pillars and walls, obstacles on the way to the room allocated for people with dementia). Agnes Houston, Chairperson of the Scottish Dementia Working Group (SDWG), added that whilst there are challenges, there are also solutions and the next conference will be even better for people with dementia because the European Working Group for People with Dementia (EW-GPWD) will help to get it right. Jean Georges, Executive Director of Alzheimer Europe, concurred and said in future he would try to ensure that the organisers “walked their walk” by working together to overcome such obstacles.

One of the characteristics of dementia is that cognitive ability can decline over time and this can be an obstacle in involving people with dementia. However, the presentation by Eva Quack from the Catholic University of Applied Sciences, Mainz, Germany, illustrated how practical and cognitive activation can help to maintain the abilities of people with dementia. She shared details of a six-month study which consisted of practical and cognitive activation by relatives on a person with dementia for one hour, six days every week. Each intervention was based on an individual, tailor-made plan. In addition, once a week cognitive activation took place by an external professional and the relatives received continuous training and counselling. Results showed that the practical and cognitive abilities remained the same.
over the six-month period, whereas in the control group they had deteriorated, leading to “early indications that the life routines can positively influence symptoms of a dementia patient.”

People with dementia have much insight to offer students of dementia yet are not always given the opportunity to do so. Andrea Capstick, Bradford Dementia Group, University of Bradford, UK, explained that in 2007 a UK survey found that dementia-related involvement in practitioner education was almost entirely by family carers, not people with dementia. Partly in response to this, Bradford University set up the Bay Tree Project, which had the aim of involving people with more severe dementia, those in long-term care, or with reduced verbal communication, in educating practitioner-students in Dementia Studies. By visiting people with dementia, filming the visit and carrying out interviews, students were able to learn from people with dementia.

A particularly moving account was that of one resident who appeared to not be engaged during a visit. However, this was rectified when the researcher realised that this particular resident used to have goats and arranged to visit them. The resident visibly changed as she not only remembered all the goats’ names, but also what sort of goats they were! It was clear that this resident was more engaged and empowered as a direct result of this trip. The results of the project will be published soon, but initial indications are positive in that people with dementia became involved in the process, students took an interest in the “characters” in the film and that their observation skills improved.

The perception that involving lay people (people with dementia and/or carers) in research can be burdensome and not worthwhile was challenged by carer Angela Clayton-Turner, who talked of her work as a Research Network volunteer for the Alzheimer’s Society (UK). She provided examples of how trials had become more robust due to lay people’s involvement in research, ensuring that the right criteria be employed. She cited Prof Rob Howard, Institute of Psychiatry, King’s College, London, who said of the network: “Our monitors became participating members of the research group and influenced the choice of instruments that we finally adopted in the study. They helped us to think of extra things we should look at and measure.” The role of the network members has developed as other organisations request their help. She reminded the audience that researchers can forget what they are working for if they don’t connect with people with dementia.

From these few examples shared during the conference, it was clear that the involvement of people with dementia can be both possible and beneficial, with positive outcomes for them and their wider communities.

Alzheimer Europe has been committed to involving people with dementia in its work since it was launched in 1996. Examples of this involvement can be found at Alzheimer Europe’s conferences (which provide a platform for people with dementia to share their experiences), in project work (nearly all working groups have included a person with dementia), in the magazine and on the website (which feature regular contributions by people with dementia) and, most recently, in the work of the European Working Group of People with Dementia (EWGPWD). This was set up in 2012 to provide a forum for people with dementia to advise Alzheimer Europe and the group’s Chair sits on the Board of Alzheimer Europe.
AGNES AND NANCY

One of the most popular presentations during Alzheimer Europe’s conference in Vienna was that of the workshop “Agnes and Nancy – A short film about two friendly campaigners”. Alzheimer Europe speaks with Agnes Houston and Nancy McAdam, both of whom live with dementia, about the reasons why they participated in the film, the Scottish Dementia Working Group (SDWG) and how they cope with various aspects of dementia.

**Alzheimer Europe (AE): How was the idea of making the film “Agnes and Nancy” conceived and what is it about?**

Agnes: “Agnes and Nancy” forms part of an educational resource entitled “No Limits: Reimaging Life with Dementia” which is aimed for people whose role it is to educate others about people with dementia. Director Anne Milne, who conceived the idea of making this 23 minute film, likes to put people at the centre of her work and to tell stories which slowly reveal something about that person, in creative, humorous and visual ways. The film is about my visiting Nancy at her remote home and joining in her day’s activities (from wood-cutting and exercising to making mojitos!). The visit is part of our journey with dementia and we discuss how we met, our experience of dementia, our fears and our wishes.

**AE: Why did you participate in this project?**

Agnes: I felt like everything was a crisis after diagnosis. I wanted to heal my spirit. Can you imagine grieving the loss of ability on a regular basis and no-one understands? I wanted to find a bit of normality and an ability to cope with laughter. I couldn’t find answers in text books or from nurses or doctors. I could only find answers from someone who was living with dementia. I only agreed to be filmed if I could be taken to Nancy’s. I wanted to see for myself how Nancy was living.

Nancy: I signed up to the project because the art-aspect of the project and the opportunity to design banners really appealed to me. Also, the project involved residential time with others with a diagnosis. This everyone felt was amazing and provided a deep connection which has lasted to the present.
AE: Agnes, at the beginning of the film you talked about the need to get rid of the clutter and to come to terms with the loss of the "very productive and academic Agnes" in order to find a new persona. To what extent did making this film help you on this journey?

Agnes: Although my life couldn’t be further away from the life Nancy enjoys in the Black Isles, being with Nancy resulted in my bringing back hope. I immediately transformed into that third person I spoke of at the beginning of the film. I’m reinventing the new Agnes and am helped by some of the strategies that Nancy taught me. After being with Nancy I often find myself laughing! Our journey will go on, but wow, what a journey! There are some magical and special moments.

AE: You both spoke of the support and acceptance you feel by being part of the SDWG. What is this group and how has it helped you?

Agnes: The Scottish Dementia Working Group (SDWG) is a campaigning group run for and by people with dementia. Currently there are around 140 members and it is supported by Alzheimer Scotland. Whatever background the members have, the group offers solidarity, healing, friendship and a deep humanity that people in need cling to. When we come together we can communicate at a deeper level.

Nancy: When you go to the dementia working group you meet other people with dementia. You don’t feel a fool, there is nothing you can say that’s going to be wrong.

AE: Nancy, Agnes says that when she met you she was “drawn to you like a magnet because of your laughter, humour and insight”. However, in the film you explained that it took you some three years to pick yourself up after receiving the diagnosis of vascular dementia eight years ago. What was the process by which you achieved this?

Nancy: After finding out that I had suffered four or five mini-strokes, diagnosis followed and I cried. I was very emotional. Before diagnosis...
I had started to grow vegetables, planting carrots and broccoli. I realised that there was much work to be done. I had digging to do. My personality means I just got on with it. You’re not dead, so you have to go on living.

AE: Both of you came across as having been highly independent. Has dementia impacted on that?

Agnes: I feel sometimes that you don’t want people to see you are vulnerable. I put a lot of work into looking in control, into doing day-to-day living. For people to see that vulnerability means that we’ve lost the persona we want people to see - which is a person with dementia and how well we are doing.

Nancy: I'm probably the same and I like to be in control and like to be independent. It's something I need to accept and find ways to ask for help and be less independent.

AE: You highlighted that people often speak of pre-diagnosis, diagnosis and post diagnostic support but are less likely to discuss the end-stage of the disease and/or a good death. For you, what would be a good death?

Agnes: I've just done a statement, or “death wish” as I call it! I want a celebration of life.

Nancy: A good death would be with my family about me. I said in my death plan that I want a Céidh. I want people smoking and drinking.

AE: The film was warmly received by delegates at the Alzheimer Europe conference in Vienna. What have you found to be the reactions to the film?

Agnes: I feel that it shows that a diagnosis of dementia can have positive aspects, showing how we are living positively with dementia, that humour is a great way to deal with the issues as well and that friendships can be made and maintained.

Nancy: We have been overwhelmed with the positive reaction to the film. I feel that the positive talk Agnes and I had over my “death plan” showed that difficult discussions do not need to be morbid and depressing.

AE: Thank you both for your inspirational presentation at the conference and for this interview.

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**No Limits Resource Pack**

“No limits: Reimagining life with dementia is an educational resource which is aimed for any individual or group with an interest in and/or whose role it is to educate others about people with dementia. It is designed to “inspire, refresh, provoke, assure, pique your curiosity, inform, initiate conversations and … make you think!” The resource consists of a short documentary film called Agnes & Nancy by Anne Milne, a set of postcards depicting “protest banners” designed by Shaeron-Caton Rose and based on original work created by people with dementia and a series of thought-provoking questions to facilitate discussion about the film and postcards. The following topics are covered:

- Active citizenship, diversity, and well being
- Seeing dementia as a journey
- Nurturing friendships and peer support between people with dementia
- End-of-life and advance planning
- Our connections with place and nature

For further information please see [www.nolimitsdementia.com](http://www.nolimitsdementia.com)
OVER 500 DELEGATES FROM 43 COUNTRIES ATTENDED ALZHEIMER EUROPE’S 22ND CONFERENCE IN VIENNA

ALZHEIMER EUROPE RECEIVED FEEDBACK FROM 107 DELEGATES INDICATING THAT:

- Over 80% of delegates found all plenary sessions to be good/very good
- Over 85% of delegates found the quality of the parallel sessions to be good/very good
- Over 95% of delegates found the conference material and programme book to be good/very good
- Over 96% of delegates found the friendliness of the staff at the conference to be good/very good and
- Over 98% of delegates would recommend future Alzheimer Europe conferences to their colleagues

Countries represented at Alzheimer Europe’s conference

EUROPE:
Austria, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Italy, Jersey, Luxembourg, Malta, Macedonia, Monaco, Netherlands, Norway, Poland, Portugal, Romania, Russia, Slovakia, Slovenia, Spain, Sweden, Switzerland and UK (England, Wales Northern Ireland and Scotland)

WORLD:
Australia, Chile, Hong Kong, India, Israel, Mexico, Saudi Arabia, Taiwan and USA
OUR MEMBERS ARE HELPING PEOPLE WITH DEMENTIA AND THEIR CARERS IN 29 COUNTRIES

- **AUSTRIA – VIENNA**
  Alzheimer Austria

- **UNITED KINGDOM – LONDON**
  Alzheimer’s Society

- **UNITED KINGDOM – EDINBURGH**
  Alzheimer Scotland

- **TURKEY – ISTANBUL**
  Alzheimer Vakfı

- **SWITZERLAND – YVERDON-LES-BAINS**
  Association Alzheimer Suisse

- **SWEDEN – STOCKHOLM**
  Demensförbundet

- **SWEDEN – LUND**
  Alzheimerföreningen i Sverige

- **SPAIN – MADRID**
  Fundación Alzheimer España

- **SPAIN – PAMPLONA**
  C.E.A.F.A.

- **SLOVAKIA – BRATISLAVA**
  Slovak Alzheimer Society

- **SLOVENIA – ŠENTJUR**
  Association “Forget-me-not”

- **ROMANIA – BUCHAREST**
  Societatea a Alzheimer

- **PORTUGAL – LISBON**
  APFADA

- **POLAND – WARSAW**
  Polish Alzheimer’s Association

- **NETHERLANDS – BUNNIK**
  Alzheimer Nederland

- **NORWAY – OSLO**
  Nasjonalforeningen Demensforbundet

- **MALTA – MSIDA**
  Malta Dementia Society

- **CYPRUS – LARNACA**
  Pancyprian Alzheimer Association

- **CZECH REPUBLIC – PRAGUE**
  Czech Alzheimer Society

- **DENMARK – HELLERUP**
  Alzheimerforeningen

- **ESTONIA – TARTU**
  Estonia Association of Alzheimer’s Disease

- **FRANCE – PARIS**
  Association France Alzheimer

- **GERMANY – BERLIN**
  Deutsche Alzheimer Gesellschaft e.V.

- **GREECE – THESSALONIKI**
  Greek Association of Alzheimer’s Disease and Related Disorders

- **IRELAND – DUBLIN**
  Alzheimer Society of Ireland

- **ITALY – ROME**
  Alzheimer Uniti Onlus

- **ITALY – MILAN**
  Federazione Alzheimer Italia

- **JERSEY – ST HELIER**
  Jersey Alzheimer’s Association

- **LUXEMBOURG – LUXEMBOURG**
  Association Luxembourg Alzheimer
The conference structure included a number of parallel sessions, with one of them entirely focusing on “Wellbeing in Later Life – Innovative therapeutic Approaches in Elderly Care – Neurodegenerative Diseases”. During this session the importance of Stem Cell Therapy was stressed, and the significance of the treatment for neurodegenerative diseases, including Alzheimer’s, was highlighted. This may prove to be a significant step towards the fight against dementias.

In conclusion, when considering neurodegenerative diseases and their negative effects on the health of elderly, the essential need for collaborative measures for prevention, at national and European levels is recognised.

Recognising the particular specificities and challenges arising from these neurodegenerative diseases, the rights of patients need to be respected at the time of diagnosis and the care support they may receive needs to be adequately considered. Equal access to healthcare services is of paramount importance for this specific population. It is only once this is in place that we can ensure that people with dementia will receive an early diagnosis, appropriate treatment and high quality care.
The six priorities aim to improve the quality of life of European senior citizens between now and 2015.

Annette Dumas, EU Public Affairs Officer, Alzheimer Europe, reports on the progress of the European Innovation Partnership on Active and Healthy Ageing since the launch of the Strategic Implementation Plan.

On 6 November, in Brussels, the European Commission organised the first Conference of Partners of the European Innovation Partnership on Active and Healthy Ageing (EIP AHA). This officially launched the Action Plans prepared by the Partnership’s six Action Groups.

The conference was opened by Neelie Kroes, Commissioner for the Digital Agenda, along with Máire Geoghegan Quinn, Commissioner for Research, Innovation and Science, Kathleen Lynch, Irish Minister of State, Department of Health and Department of Justice and María Pilar Farjas Abadía, Spanish Secretary General of Health and Consumers, Ministry of Health, Social Services and Equality.

The six Action Groups Plans

The Action Plans stem from the six priorities identified by the Partnership Steering Group in its Strategic Implementation Plan of November 2011. They aim to improve the quality of life of European senior citizens between now and 2015 by implementing and scaling up innovation for active, independent and healthy ageing. Presented by the leaders of the six Action Groups, the Plans are dedicated to the following areas:

- Prescription and adherence to treatment: The aim is to improve the quality of life and health outcomes of older people living with chronic conditions and prevent decline through a holistic approach, including enhanced self-care, personalised care, better adequacy of treatment, increased adherence to safe and effective care plans,

- Personalised health management, starting with a falls prevention initiative: this action will seek to find innovative solutions for personal health management through validated programmes and good practices for early diagnosis and preventive measures (including health promotion). These will encompass innovation in organisation, business models and tools and services for early diagnosis and prevention of diseases, centred on identified users’ specific needs,

- Prevention and early diagnosis of frailty and functional decline, both physical and cognitive, in older people: The aim is to develop and implement sustainable multimodal interventions for the prevention and comprehensive management of functional/cognitive decline and frailty,

- Replicating and tutoring integrated care for chronic diseases, including remote monitoring at regional levels: This action aims to reduce avoidable/unnecessary hospitalisation of older people with chronic conditions, through the effective implementation of integrated care programmes and chronic disease management models that should ultimately contribute to the improved efficiency of health systems,

- Development of interoperable independent living solutions, including guidelines for business models: The aim is to enhance the deployment and take-up of interoperable independent living solutions based on open standards, including guidelines for business models,

- Innovation for age-friendly buildings, cities and environments: The goal is to implement innovative age-friendly policies and practices at the regional and local level (for example by communities, local governments and health
Background

The “European Innovation Partnership on Active and Healthy Ageing” is a pilot initiative launched and facilitated by the European Commission to tackle the challenges of an ageing European population. By pooling resources, projects and initiatives that are scattered across Europe, the Partnership will seek to change how health and social care for older people are delivered across Europe. This implies coordinating and scaling-up actions, as well as sharing best practice.

The Partnership will seek to improve the health and quality of life of older people, enabling them to live active and independent lives, to contribute to the sustainability and efficiency of health and social care systems, and to foster competitiveness and growth of businesses.

The Partnership also aims to increase the healthy life years of EU citizens by two years on average by 2020. This will be a triple win: a better quality of life, more sustainable systems for health and social care, and innovation, jobs and economic growth.

In 2011, the Partnership Steering Group identified six areas in its Strategic Implementation Plan where action could be taken. In 2012, all stakeholders were invited to submit commitments to these specific actions. 261 consortia, from all over the EU, committed to one out of six action points. They represent nearly 1,000 regions and municipalities and over 3,000 stakeholders. The consortia joined one or more of the six Action Groups, made up of universities and research groups, public authorities, health providers, industry and non-governmental organisations representing citizens, older people, patients and others interested in the field.

services); promote integrated and evidence-informed policies and practices through a campaign for a covenant for demographic change supported by the operation of a multi-level/multi-sectorial network of stakeholders; develop, foster, promote and evaluate age-friendly physical/environmental innovation and practice, including the use of ICT.

Each Action Group has identified clear goals to reach within a given timescale.

To monitor the outcome of the Partnership, the European Commission has proposed indicators gathered under three headings: quality of life, sustainability of the healthcare services and innovation and growth.

The presentations were followed by information from the European Commission on horizontal issues such as regulatory framework conditions and funding opportunities offered by different EU funding schemes (Structural Funds, AAL, Cohesion Funds, FP7).

To illustrate the purpose of the Partnership, Candidate Reference Sites from different regions presented some concrete examples highlighting the important role of regions in the Partnership. One example came from the Regional Council of Bas-Rhin (France): It showed how seven public/private projects provided an answer to the combined lack of old people’s homes in the region and the old people’s desire to remain in a familiar environment for as long as possible. There was also an exhibition of real-life examples of innovation in the field of active and healthy ageing.

The next steps

The Action Groups can now start implementing the Plans. The European Commission and the Joint Research Centre are developing a monitoring framework to report on the progress and impact of the Action Plans on European people, society and economy. The monitoring will cover two areas: the process (involvement of stakeholders) and the outcome (objectives and deliverables).

“The European Commission and the Joint Research Centre are developing a monitoring framework.”

Annette Dumas
The nature of Alzheimer’s disease and other dementias clearly single them out for joint European research and action.

David Martin, MEP (Scotland), speaks with Alzheimer Europe about the situation for people with dementia and their carers in Scotland.

Alzheimer Europe (AE): Mr Martin, what are the key challenges that people with dementia and their carers face in Scotland?

David Martin (DM): In August last year I was honoured to speak at the 8th World Congress on Active Ageing held here in Glasgow during the European Year of Active and Healthy Ageing and Solidarity between Generations. The theme of this ‘European Year’ was to incentivise stakeholders at all levels to set goals and take action that will enable the society cope with demographic ageing as well as to raise awareness of the contribution that older people make to society.

With the increase in life expectancy across all European Member States, the incidence of dementia has, and will continue to increase dramatically. The nature of Alzheimer’s disease and other dementias clearly single them out for joint European research and action. In Scotland, as in many other Member States, the fear and stigma attached to dementia and access to effective post diagnostic support, inhibits people seeking a diagnosis. There is also no effective coordinated approach, which brings together and coordinate the full range of health and social care interventions. There are a small number of drugs used to treat dementia, none are cures. The main form of treatment for the symptoms of dementia is human interventions. Therapeutic, high quality and coordinated personalised community support can help people with dementia live well for longer at home and avoid unnecessary crisis interventions. Alzheimer Scotland recently published Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support. This report sets out a model for delivering coordinated and integrated community support, which is currently being considered as part of the national dialogue which will inform Scotland’s next dementia strategy.

AE: Governments across Europe are starting to pay more attention to the demographic changes in our societies and the resulting increase in the number of people with dementia in the future: Scotland is no exception with the Scottish Dementia Strategy being launched in 2010. What has been achieved by this action and what challenges remain?

DM: Like other European countries, Scotland is facing an ageing population and an increase in the numbers of people with dementia. Based on current prevalence rates there are 86,000 people with dementia in Scotland and this number is set to double within 25 years, impacting not only on people with dementia, but on their partners, families and friends who care for them. Dementia became a national priority in 2007 and the
Scottish Government in partnership with Alzheimer Scotland, health and social care providers, scrutiny bodies and other stakeholders developed and published the first National Dementia Strategy for Scotland in 2010. This strategy builds on Scotland’s Charter of Rights for People with Dementia and their carers putting human and other legal rights at its very centre. The strategy sets out two priority areas for improvement: post diagnostic support and acute hospital care and eight supporting actions. The strategy has made good progress in addressing these two key priorities.

Based on a model of post diagnostic support developed by Alzheimer Scotland, the Scottish Government has made a commitment to guarantee a minimum of one year post diagnostic support for every person diagnosed with dementia. This is designed to help people with a diagnosis and those who care for them to understand the illness and manage symptoms, provide support to stay connected to the community with access to peer support, help with future decision-making and begin to develop a personalised care plan for future care.

Promoting Excellence: a new national training framework sets out the knowledge, skills and behaviours expected from staff coming into contact with people with dementia, underlining a common understanding of what constitutes a good quality of care based on human rights. New standards of care for dementia have been developed and a new national implementation and monitoring group has been established to ensure that the new standards are effective at bringing about improvement in acute hospital care. An inspection programme into the care of older people in acute general hospitals is being rolled out and will be informed by the Dementia Standards.

The work to improve the experience of people with dementia in acute hospital care is also supported by a network of Dementia Champions who have been trained to better understand, recognise and respond to the particular needs of people with dementia and to lead front line improvements in dementia care in the hospital units they work. This is further supported by Alzheimer Scotland’s Dementia Nurse Consultants in each of Scotland’s National Health Service (NHS) Boards to ensure that Boards are responding to the implementation of the Dementia Standards and Promoting Excellence.

Three Dementia Demonstrator Sites are currently working on how Scotland’s Health and Social Care system can make best use of existing investment in dementia care and are exploring how to redesign the system to provide better outcomes for people with dementia and their carers. The findings from the demonstrator sites will help inform Scotland’s next dementia strategy.

Overall the strategy is making very good progress and Scotland has some of the most progressive dementia policies in Europe and beyond. However, it is also recognised that a great deal of work remains to be done. Scotland’s next dementia strategy will be published in June 2013 and should not only identify the new priorities for the next three years but also ensure that work continues to build on the achievements so far and to continue to deliver on the improvements set out in the current strategy.

AE: Contrary to national strategies in other European countries, the aims of the three-year Scottish Dementia Strategy focus on relatively only a few issues. Why is this and how can policy makers continue to improve the lives...
of people with dementia and their carers in Scotland once the current Strategy ends in 2013?

DM: The decision to focus on a small number of key objectives is based on ensuring that Scotland’s National Dementia Strategy is deliverable. It is tempting, when setting out to tackle a complex issue such as dementia, to try and do too much all at once. Strategies, of all types, often fail for that reason. Scotland has taken a sensible approach by focussing on two key priority areas for improvement and the supporting actions. Progress in these areas is regularly reviewed by a monitoring and implementation group. This approach ensures that the key objectives of the strategy are delivered.

Scotland is currently reviewing the progress of the current national dementia strategy through a series of dialogue events across Scotland. This dialogue process provides all stakeholders with an opportunity to reflect on the progress of the current strategy, and help shape the direction and priorities of the next strategy which is due to be published in June 2013.

AE: A last question on the need for a European response to the growing numbers of people with dementia. Would you support the development of a European Action Plan in this field and, if so, what should the priorities for such a collaboration be?

DM: Yes, of course. Billions have been invested into science and technology via the EU’s Seventh Framework programme and this continues to see outstanding results. Here in the UK we don’t hear enough about the benefits of these united European initiatives. Neurodegenerative diseases are one of the ‘grand challenges’ facing European society. ‘Grand challenges’ are beyond the capacity of any individual country to resolve, and of course must be undertaken with a coordinated approach to research. All Member States are facing tough economic choices and some are in crisis. Cutting the budgets of initiatives to promote healthy and active ageing would be such a mistake. It is in all of our interests to ensure our population ages well and remains independent for as long as possible. This will have positive repercussions on the sustainability of the health and care services in Scotland and Europe.

David Martin is Scotland’s longest serving European MP and is also Chairman of the European Parliament ‘Working Group on Innovation, Access to Medicines and Poverty-Related Diseases’ that has been established to put the needs of poor patients in developing countries before the profits of the big drug companies.
A NATIONAL DEMENTIA STRATEGY
IN IRELAND

In 2013, Maurice O’Connell will be stepping down as CEO of The Alzheimer Society of Ireland after 14 years. He speaks with Alzheimer Europe about the forthcoming National Dementia Strategy in Ireland and his hopes for people with dementia and their carers.

Alzheimer Europe (AE): Why did the Irish Government decide to commit to a National Dementia Strategy?

Maurice O’Connell (MOC): Our campaign was strengthened by two events in 2005/6. We hosted the Alzheimer Europe conference where a number of people with dementia spoke and shared their hopes and aspirations at plenary sessions in 2005. It was the point where consciousness changed in Ireland and I suspect in many other countries present where the direct influence of the person with dementia became ever more central to our work. In 2006 the Paris Declaration was very much part of the Alzheimer Europe conference making dementia a health priority and challenge for the European Union. Many of the member countries strengthened their resolve to make dementia a public health priority in each of their countries. These two events as well as our own growing political and public advocacy work at local and national level were significant influencers in the continuing journey to our achieving a commitment to developing a national strategy.

2011 represented a pivotal moment for the 44,000 people living with dementia and 50,000 carers when the new Fine Gael - Labour Government prioritised dementia as a health issue. The Programme for Government 2011-2016 states that:

“We will develop a national Alzheimer’s and other dementias strategy by 2013 to increase awareness, ensure early diagnosis and intervention and development of enhanced community-based services. This strategy will be implemented over five years.”

The current economic climate and wider challenges mean that the impact of dementia is being felt in areas more broadly than health or social care alone. At present, dementia has a baseline cost of approx. EUR 1.6 bn and, with the number of people diagnosed with dementia due to double every 20 years, this is a significant societal and financial issue. In this context, and for the 44,000 people living with dementia and their more than 50,000 carers, a National Dementia Strategy is a key priority.

A transformative approach to dementia has been modelled elsewhere – in Scotland, England, France, Norway and the US, national “challenges on dementia” touching on every government department and area of work have been launched with full political support and significant funding. At a time when the Irish exchequer cannot, understandably, commit to the significant funding required to deliver in this area, we can commit to the necessary political leadership in support of a transformative approach that can deliver for the country.
“We believe a key consideration in the development of the National Strategy is the meaningful inclusion of people directly impacted by dementia.”

Maurice O’Connell

AE: When will the Strategy be published?

MOC: The Programme for Government gave a commitment to develop a National Strategy on Dementia by 2013 which will increase awareness, ensure early diagnosis and intervention, and enhance community based services for people living with this condition. The first stage of the process, which was to assemble the research and evidence upon which the policy will be developed, was recently completed. The findings of the review were published and presented to the Minister for Health James Reilly T.D. The report is available at www.doh.ie.

The Department of Health has recently completed a consultation where a number of patient groups, advocacy groups such as ourselves and the wider public were invited to make submissions on the National Dementia Strategy. Following on from this consultation process, a Working Group will now be established, at the beginning of this year, to develop the strategy. We will be keeping the pressure on to ensure this deadline is kept.

AE: What services are currently in place in Ireland for families with dementia?

MOC: As to be expected with a significantly high ageing demographic in our population, we have noticed a vast increase and demand for dementia services and we continue to develop supports for people in the community through day care and training to meet this growing demand.

Our primary challenge is to ensure that funding sources are maintained and that dementia specific policies are designed and implemented against the backdrop of the proposed abolition of the Health Services Executive (HSE) and move towards developing a universal, single tier system.

In relation to the provision of services the Health Service Executive provides a range of services for people with dementia including Primary Care Services, Home Support Services, Day Care, Respite, Housing with Care and Continuing Care Services. These services are delivered through the HSE’s network of local offices, via Public Health Nursing, Day Care Centres and Public and Private Residential Care Facilities and where appropriate, Psychiatry of Old Age teams. The HSE also funds non-governmental agencies to provide a range of services under section 38 of the Health Act (2004). In addition a limited number of memory clinics and specialist services are available.

It is not possible to state exactly what the volume of community services is, as data relating to service provision is not collated in a way that identifies dementia-specific services. It is estimated that 63% of all long-stay residents have dementia (Cahill, O’Shea and Pierce 2012 Creating Excellence in Dementia Care, TCD; Dublin).

The families and carers of people with dementia can access a number of services through their primary care team or HSE funded services such as those provided by The Alzheimer Society of Ireland. Respite services are the most common request and this is provided in a number of ways i.e. through the provision of a Home Care Package to support respite in a person’s own home, or through day respite within dementia specific or generic day care centres. Respite is also provided in residential homes. In addition carer support groups have been established across the country, details of which can be obtained from local Primary Care Teams.
AE: What role do you see The Alzheimer Society playing in the implementation of the strategy?

MOC: We believe a key consideration in the development of the National Strategy is the meaningful inclusion of people directly impacted by dementia. Based on feedback we have already received from people with dementia, patient groups, volunteers and the families they work with, we suggest that the National Strategy focus on the five key areas of: diagnosis and early intervention, enhanced community services, awareness and education, service provision for those under 65 years and research and evidence-based policy.

Crucially, when focusing on the implementation of a National Strategy, it is not only financial resources that are key. A strategy grounded in the community, with partnership and capacity development at its heart and “owned” by the wider sector as a whole, would give the country a roadmap to begin improving the lives of all people living with dementia. In effect, we want to create “dementia friendly communities” throughout our villages, towns and cities. By making our communities “dementia friendly” we can support people to continue to be active in their local communities and lead a good quality of life.

AE: What do you see as the main priorities and challenges of the strategy, particularly in relation to dementia?

MOC: Seven key priority areas have been identified where opportunities exist to intervene to transform people’s lives through a series of direct, concrete, efficient and cost effective “solutions through action” covering the spectrum of the dementia journey including:

- Getting a diagnosis, disclosure and early intervention supports and services,
- Living well in the community: information, supports and services,
- Care in the acute hospital setting,
- Life in residential care,
- Dementia palliative care and end-of-life care,
- People with younger-onset dementia,
- Addressing stigma and maintaining stakeholder awareness and education,
- The strategy will include all those affected by dementia including those under 65.

AE: What do you see as a necessary improvement of services for people with dementia in Ireland?

MOC: At this time of major change in our society and in particular with a new emerging health services landscape, we can be transformative in relation to how we respond to dementia. We need to see leadership emerging from within the health and political spheres; we need a new narrative to understand dementia in local communities and we need to see a genuine commitment of resources to this highly marginalised, excluded and invisible group in our society.

“The need to see leadership emerging from within the health and political spheres; we need a new narrative to understand dementia in local communities and we need to see a genuine commitment of resources to this highly marginalised, excluded and invisible group in our society.”
Maurice O’Connell
The respondents very often expressed their grief after the loss of a loved one, the guilt they felt when committing a person with dementia to an institution, their isolation and physical burn-out and the financial difficulties they had to face daily.

Marie-Odile Desana

In September 2012, at the 14th meeting of the Alzheimer Plan Steering Committee, France Alzheimer presented its White Paper on Alzheimer’s disease to the French Government. Marie-Odile Desana, President of France Alzheimer, talks about the campaign and preparatory work to draft the White Paper.

France Alzheimer’s 10 proposals

The presidential election in May 2012 provided France Alzheimer with the opportunity to alert the candidates and raise their awareness about the economic and social challenges of Alzheimer’s disease and related disorders. The association asked the candidates to position themselves on “10 proposals put forward by France Alzheimer to improve the quality of life of people with dementia and their families”.

The 10 proposals centred around three themes: the Alzheimer Plan 2008-2012, carer support and the loss of autonomy reform:

1. Launch of a 4th Alzheimer Plan,
2. Financially sustain the existing support and respite services,
3. Develop specialised units for people with Alzheimer’s disease,
4. Widen the scope of both therapeutic and non-therapeutic support,
5. Recognise the role of family carers,
6. Financially sustain the training of informal carers,
7. Decrease the out-of-pocket costs for those in a nursing home,
8. Set up a personalised and quality care pathway for all,
9. Initiate talks for a reform to finance the loss of autonomy,
10. Mobilise the necessary resources to finance the loss of autonomy.

All presidential candidates responded to the 10 proposals. This demonstrates their awareness about the real challenges of Alzheimer’s disease in France and also shows that France Alzheimer is recognised as a dedicated and legitimate partner.

The moving testimonies of the families

France Alzheimer’s members were informed about this awareness campaign. They were asked to express their support by sending testimonies about their daily difficulties and suffering and by stating their expectations and needs.
By the end of June 2012, several thousand people had responded: they asked the new President to take the necessary measures that will improve the support of people with dementia and their families.

Responses included very moving testimonies about daily life with dementia and how difficult it is to confront the disease. The respondents very often expressed their grief after the loss of a loved one, the guilt they felt when committing a person with dementia to an institution, their isolation and physical burn-out and the financial difficulties they had to face daily.

Here are two extracts:

“My wife has Alzheimer’s disease since 2003. Until now, I could manage, but it became very difficult. She went into a nursing home. Cost: EUR 1,750 a month. Our combined pensions amount to EUR 1,600 a month. How can we manage?”

“My wife has had the disease for 10 years... I have discovered that the disease was a heavy cross to bear, both for my wife at the beginning of the disease and myself as the disease progressed. She is now in long-term residential care. I feel guilty despite being aware that it has become ‘impossible’ to continue living under the same roof.”

The White Paper

Following this campaign, France Alzheimer published a White Paper entitled “Alzheimer’s disease and related diseases – Urgency for a real public health policy”. This Paper compiles France Alzheimer’s 10 proposals, around 100 testimonies as well as the commitments made by François Hollande when he was a presidential candidate. With this Paper, France Alzheimer wants to highlight that stable and sustained financial support provided by the State and the implementation of a meaningful public health policy for Alzheimer’s disease and related diseases will improve the daily quality of life of the persons concerned.

The White paper was officially presented to Marisol Touraine, Social Affairs and Health Minister, Michèle Delaunay, Deputy Minister for the Elderly and Autonomy and Geneviève Fioraso, Minister for Higher Education and Research, during the 14th meeting of the Alzheimer Plan Steering Committee, in September 2012.

The President of the French Republic participated in the close of the meeting. In his speech, he announced that the Alzheimer Plan 2008-2012 would be continued and evaluated to improve the outcomes. He also said that the Plan will be extended to neurodegenerative diseases.
UNJUSTIFIED BREACHES OF FUNDAMENTAL RIGHTS SHALL NOT BE LEGALISED

Sirpa Pietikäinen, MEP (Finland), talks about the need to reform current coercive measures to protect constitutional human rights of people with memory diseases.

Austerity measures all over Europe greatly affect the lives of people with memory-disabling diseases. As the care of older people is mostly seen as a burden, it is often on the front line of budget cuts - or “rationalisation of activities”.

Whereas the rights-based approach towards the lives of older people has never been strong enough, the fundamental rights of most disadvantaged people need defending more than ever. The voice of those unable to speak for themselves can never be too loud.

One of the latest examples of forgetting fundamental rights comes from my own home country, Finland. The Ministry of Social Affairs and Health is preparing a law permitting the use of coercive measures in the care of people with memory diseases and people with disabilities. Ironically, the official purpose and title of the revision is to strengthen the rights of people to decide on their own lives.

The main argument for legalising coercive measures is the following: as the existing practice is uncontrolled and probably widely used, it is better to restrict its use and, at the same time, legalise it. This approach has good intentions: i.e. to restrict and limit every day violations of those fundamental rights which go unnoticed due to common (and tolerated) practices. However, you should never legalise unjustified breaches of constitutional human rights. Memory disabled people are not second-class citizens whose rights can be restricted just because we are used to doing so and are unable to understand or communicate with them.

It is sad but true that the use of coercive measures form part of everyday care of people with memory diseases - doors are locked and in the worst cases, patients are restrained in their beds either with straps or with medication. Possibilities to go outdoors are often minimal. I often use a comparison to “imprisonment” when talking about the rights of people with memory diseases - the right to breathe fresh air is better enforced in prisons than in old-age homes.

With this same principle, we could legalise many other kinds of discrimination in our societies. What is most striking is the fact that the proposed legalisation of coercive measures with regard to the care of older people and people with intellectual and developmental disabilities would breach fundamental rights - especially those of disadvantaged people, unable to defend their own rights.

Arguments for the use of coercive measures also reflect the idea of safety of patients and carers. It is true that the outside world may be a dangerously cold place in the wintertime for a person with memory disease, or that a carer may get punched by a frustrated patient. However, legalising the use of coercive measures with regard to the care of people with memory
diseases is not really about the safety of the patients and their carers. It is more about a lack of human resources and this is something that needs to be tackled by other measures. The problem is that we do not understand the needs of people with memory diseases. Accordingly, we react to behaviour that makes complete sense from the perspective of memory disabled people with our own rationale and interpretation. How would you react if you were restricted in some way from using the toilet?

Where can one draw the line between the safety and the freedom of the patient? The Alzheimer Europe working group on ethical issues took a closer look at the concept of “reasonable accommodation” which was defined in the UN Conventions on the Rights of People with Disabilities as “the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms”.

What would the fundamental rights of people with memory diseases be in practice? I have been drafting a practical list of rights that need to be secured for older people, including people with memory diseases. The list is non-exhaustive and thus I invite you all to help me completing it.

- The right to make choices.
- The right to decide on one’s place of living.
- The right to eat sufficient and tasty food in peace.
- The right to assistance to maintain one’s physical condition.
- The right to participate in outdoor activities.
- The right to a mind-refreshing activity at least once a week.
- The right to live by one’s own habits and preferences.

I mentioned other alternative measures which could ensure the security of patients with memory disease and their carers. One of the most useful is education. Obviously, we need more trained professionals to work with people with memory diseases - I call them “memory nurses”. Also, general practitioners and nurses need more information and training on how to treat people with memory diseases.

We need more people to understand the frustration, anxiety, fear and aggressiveness that people with memory disease experience every day. Instead of restraint and psychotropic medicines, these people need comfort and security. These people need to be understood. They need to be respected and their self-respect needs to be supported.

“Instead of restraint and psychotropic medicines, these people need comfort and security.”

Sirpa Pietikäinen
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DEMENTIA IN THE NEWS


World Alzheimer's Day
Alzheimer Europe takes a look at how national Alzheimer associations around Europe marked the 2012 World Alzheimer's Day.

Spotlight on Slovakia
In 2013 the Slovak Alzheimer's Society celebrates 15 years' work. Alzbeta Vesela, Secretary, looks back at the work carried out.

Dementia in the arts
Alex Teligadas, Communications Officer, Alzheimer Europe, reports on “Dimentia”, a new Cypriot musical which hopes to raise awareness of Alzheimer's disease.

The perception of Alzheimer's disease in France
Marie-Odile Desana, President of France Alzheimer, highlights the major findings of a survey that looked into French people's perception and awareness of Alzheimer's disease.

Marie-Odile Desana highlights findings on French people's perception and awareness of Alzheimer's disease.

Alzbeta Vesela reflects on 15 years' work by the Slovak Alzheimer Society.
Activities to mark World Alzheimer’s Day are held each year on or around September 21st. Alzheimer Europe takes a look at events which were hosted by national Alzheimer associations around Europe. All had the same aim: to raise awareness and understanding of dementia and, as a result, improve the lives of those living with dementia and their carers.

**Belgium:** Belgium’s Ligue Alzheimer and the Vlaamse Alzheimer Liga co-hosted a special Alzheimer Café Day in Brussels to commemorate World Alzheimer’s Day. During the event, LINAL (the Belgian national Alzheimer League) announced the creation of a new national group called Dementia Alliance Belgium (DAB). This group will bring together all the Belgian associations and authorities that are active in the dementia cause. DAB intends to consolidate all of its members’ resources in order to develop a national dementia plan for Belgium.

**Bulgaria:** The Alzheimer Bulgaria Association and the Aleksandrovска University Hospital (AUH) held a joint press conference which focused on the necessity of developing a national strategy for Alzheimer’s disease. The results of the first Bulgarian research project on the prevalence of dementia were also published which showed that there are 100,000 people diagnosed with dementia in Bulgaria and that Bulgaria lags in public awareness of dementia. A performance of traditional Bulgarian dances and songs by the care home residents was given after the conference.

**Denmark:** The Danish Alzheimer Association and the Alzheimer Research Fund marked World Alzheimer’s Day with a scientific conference on the role of exercise in the development and treatment of Alzheimer’s disease. Meanwhile, volunteers from the association ran fundraising and awareness campaigns all over the country, under this year’s “Break the Isolation” theme. They distributed information packs and sold “Remember Cakes” and presented one to the Danish Prime Minister.

**France:** France Alzheimer launched a dedicated World Alzheimer’s Day website with the theme “We are all involved”. The association also organised a Memory Walk which was followed by a photo exhibition entitled “Alzheimer’s disease without filters”. Through the eyes of the families, the exhibition showed that despite the disease, people with dementia and their carers can live a life filled with emotion and joy.

**Finland:** Numerous activities were organised by the 42 member associations of Muisti liitto, the Alzheimer Society of Finland, under the main theme, “Memory is a valuable thing.” Activities included public seminars, memory marches and memory cafés, averaging two events per week for each association.
Germany: A joint press release was issued by three German associations: the Alzheimer Association, the Brain League (Hirnliga) and the Association for Geriatric Psychiatry and Psychotherapy (DGGPP). 1.4 million people live with dementia in Germany and this will increase to 3 million by 2050. The related cost will also increase rapidly. The messages that dementia affects all citizens of the community, that it is possible to positively influence the course of the disease through early diagnosis and timely interventions and that tests for early diagnosis and treatment should be covered by insurance were also stated.

Ireland: The Alzheimer Society of Ireland held a record 29 events nationwide with attendance figures much increased on previous years. These included an awareness evening in Dublin and information events in various day care centres. Many centres also held parties to celebrate World Alzheimer’s Day with staff, clients, family and friends.

Luxembourg: The Luxembourg Alzheimer Association held its 11th Memory Walk to commemorate World Alzheimer’s Day. The walk ended in the city centre, where volunteers provided information about dementia, served food and drink and even provided musical entertainment.

Greece: Alzheimer Hellas gave a press conference with Alzheimer’s Disease International (ADI) where a report on dementia in Greece was presented. After the press conference, Prof Tsolaki, President of the Panhellenic Alzheimer’s Federation, met with Greek President Karolos Papoulias who declared that he fully supports people fighting with dementia and their carers.
Monaco: The Monaco Alzheimer association (AMPA) organised its third Memory Walk to raise awareness and reduce stigma about dementia. On the same day, the local Princess Grace Hospital announced that 30 beds would soon be made available exclusively to people with dementia.

Netherlands: Alzheimer Nederland celebrated World Alzheimer’s Day with over 55 activities across the country’s 52 regional branches. Each branch planned and carried out their own activities, which included Memory Walks, boat trips, a charity golf tournament, symposia and special Alzheimer Café evenings. All in all, the activities attracted some 6,000 people nationwide.

Norway: The Norwegian Health Association held a national fundraising drive for dementia during which the 500 local chapters of the association collected more than EUR 600,000 for research, information and local initiatives. The local chapters arranged open meetings and gatherings, all focusing on dementia. The two Oslo chapters held lectures for secondary school students and also screened a new film, “Pyramiden”, which focuses on younger relatives of people with dementia. The Regional Dementia Awards were also presented to relatives who work for better dementia services in their region, to dedicated health personnel and to a nursing home that offers services beyond the ordinary for those with dementia and their relatives.

Poland: The Polish Alzheimer’s Association and the Alzheimer Coalition organised a debate entitled “People with Alzheimer’s disease are still waiting for the European standards of care in Poland”. The Coalition presented the description of the current state of medical support for patients in Poland, as well as the foundations and goals of the Polish Alzheimer’s Plan.

Portugal: Alzheimer Portugal held a full week of events across the country. There was a series of “cinema and conference” events where four films with dementia themes were shown, followed by interactive discussions between the audience and a panel of expert speakers. Also, the association held its first Alzheimer Café and ended the week’s activities with the second annual Memory Walk which took place in five cities.
**Slovenia:** The Slovenian Alzheimer Association organised a press conference, a concert and a variety of activities to raise awareness of dementia. It presented a new brochure for children and teens entitled “Grandma is becoming a little strange - she always forgets things”. Volunteers were on hand to explain the importance of educating young people about dementia.

**UK Scotland:** Alzheimer Scotland - along with NHS Education for Scotland, NHS Health Scotland and the Scottish Social Services Council - held the first ever award ceremony for “Scotland’s Dementia Awards” on World Alzheimer’s Day. These awards celebrate the work of both professionals and community groups who are committed helping people with dementia and their families.

**UK England:** The UK Department of Health, supported by the Alzheimer’s Society, launched a three-month national dementia campaign entitled “A Day to Remember.” It will raise awareness of the condition and the initial signs and symptoms of Alzheimer’s disease. It will also encourage people to have that first “difficult conversation” with a friend or family member when they spot the signs and symptoms of dementia and encourage them to visit their GP.

**Spain:** The Confederation Spanish Associations of Families of People with Alzheimer’s and other Dementias (CEAFA) held a press conference with the aim of informing the public and lobbying the government on the importance of developing a national dementia plan. The Fundación Alzheimer España (FAE) organised a musical theatre evening, “I forgot you, Alzheimer”, the proceeds from which were given to the association. It also launched a smartphone application which has practical advice for daily living with a person with Alzheimer’s disease.

**Switzerland:** On World Alzheimer’s Day, the various chapters of the Swiss society held award ceremonies to recognise exceptional people in their local communities. The winners were cited as role models for how we can all get involved to make life better for people with dementia. They received the “Focus” glass sculpture along with a cash prize.

**Spain CEAFA - Press conference**

**Switzerland - Dementia awards**

**Spain FAE - Musical theatre**

**UK (Scotland) - Dementia awards**

**Switzerland - Dementia awards**
In 2013, the Slovak Alzheimer’s Society (SAS) celebrates 15 years’ work. Alzbeta Vesela, Secretary of SAS, looks back at how the Society was established and highlights some of the work carried out.

Today, the Slovak Alzheimer’s Society (SAS), is a stable and well-established non-profit organisation in Slovakia. Since its launch in 1998, its membership has grown to about 450 people and includes people with dementia, family caregivers, volunteers, doctors, scientists and professionals working in the field of research, prevention, diagnosis and treatment of Alzheimer’s disease. Since then, the Society has implemented dozens of projects to promote the rights and to improve the quality of life for people with Alzheimer’s disease and their families.

15 years of Slovak Alzheimer’s Society means:

- 15 years of raising awareness and education about Alzheimer’s disease,
- 15 years of helping people with dementia and their families,
- 15 years of participation in Alzheimer’s disease research,
- 15 years of educating professionals working in health and social institutions,
- 15 years of publishing and distributing information brochures,
- 15 years of prevention activities for seniors,
- 15 years of cooperation with organisations that have similar aims.

The early years

Professor Michal Novak played a significant role in the creation of the Slovak Alzheimer’s Society. He also initiated the establishment of the MEMORY Foundation, which is now successfully led by its operating president - opera singer Miroslav Dvorsky. The Foundation cooperates with SAS and provides financial support for its work. We wanted to establish an organisation that would be meaningful to people with dementia and their families and happily, we can look back at the work of SAS and say that we have achieved this.

The beginnings of the Slovak Alzheimer Society can be traced back to 1996 when the Institute of Neuroimmunology of the Slovak Academy of Sciences was founded. This enabled a group of young scientists - led by experienced and recognised experts – to work toward finding a cure for the insidious disease named Alzheimer’s disease. The Institute has been, and continues to be, an invaluable partner for SAS.

Over the years, the activities of the MEMORY Foundation increased as more and more people, who needed help with this disease, came to us. We decided that it was necessary to establish a civic association that brought together patients, caregivers and professionals in the field of research, treatment and care. The first meetings of family members and caregivers of people with Alzheimer's disease at home provided a natural basis for the creation of the Slovak Alzheimer’s Society. At the time, there was no information on dementia in Slovakia. It was our great desire to help people who are affected by Alzheimer's disease.
The impact of the association on carers has been deeply felt. As one lady explained: “You can't imagine what you are doing! We are a childless couple. I’m taking care of my husband 24 hours per day. No one cares about us and suddenly we received an invitation to a meeting. I could speak about my problems, about what I live through every day.” This comment was received on 21 September (World Alzheimer’s Day) in 1998 and contributed to the start of regular support group meetings taking place for family members. During this short time we contacted approximately 180 people. We listened to their problems and responded to their needs by creating a specialised institution, which could provide professional help. We searched for a place to operate from and an empty place was found in a former kindergarten in Bratislava.

In 2002 the MEMORY Foundation established the MEMORY Centre – a non-profit association that was the first of its kind. It is a specialised institution for people with Alzheimer’s disease and memory disorders, offering preventative and diagnostic advice. The centre also provides education facilities, including accredited training courses.

2013

Today, the Slovak Alzheimer’s Society represents about 60,000 people affected by dementia in Slovakia and creates a space where people and their carers can meet professionals. It also advocates promoting the rights and meeting the needs of people with dementia and those who care for them.

In 2013, we will also remember:

- 15th anniversary of participation in World Alzheimer’s Day,
- 10 years of membership in Alzheimer Europe,
- 6th anniversary of participation in Brain Awareness Week,
- 6 years of membership in Alzheimer Disease International,
- 5th anniversary of organising an international conference about Alzheimer’s disease,
- 4th anniversary of building contact points in Slovakia,
- 3rd anniversary of engaging volunteers in favour of people with Alzheimer’s disease.
A new Cypriot musical theatre show is helping to raise awareness of Alzheimer’s disease. Alex Teligadas, Communications Officer, Alzheimer Europe, attended the premiere as a guest of the Cyprus Alzheimer’s Association.

Last October, I attended the premiere of “Dimentia”, a new musical that tells the story of a man diagnosed with Alzheimer’s disease. I spoke to members of the cast, the production team and the family that conceived of the musical and brought it to stage. In addition, I met many of the volunteers that make up the Cyprus Alzheimer’s Association. I am very grateful to them all for their warm welcome.

“Dimentia” is a Greek-language musical featuring songs in both Greek and English. The show’s name aims to reflect the many dimensions of dementia and the numerous challenges that people must overcome after being diagnosed. The show tells the story of Ulysses, a successful musician who develops Alzheimer’s disease and must deal with the physical and psychological consequences of the diagnosis. His own emotions and the evolving symptoms cause considerable turmoil in his relations with both his family and friends. Their reactions to Ulysses’ advancing dementia and the family’s dark secret are in turn poignant and humorous, interspersed with songs about life, hope and betrayal. Their conflicts seem irreconcilable until - at Ulysses’ funeral - they discover that they are strong enough to deal with their differences: “Farewell, live fully in the present moment, our lives are like a tempest which passes away. Farewell, you are taken away by oblivion.”

Ulysses is played by Alex Panayi, a professional singer and musician who also conceived of the original idea and wrote all the music. His portrayal of a man gradually succumbing to dementia is based on his mother Klery, who was diagnosed with Alzheimer’s disease thirteen years ago. As the show progresses, Alex enacts many of the symptoms and behaviours that Klery has displayed over the years. These include memory loss, misplacing objects, restless wandering and aggression - but also the gentle, repetitive hand gestures that evoke Klery’s earlier life as a professional pianist. In one particularly moving scene, Ulysses laments “I’ve become an immigrant in my own body”. During rehearsals, all the cast members spent some time with Klery; observation is commonly used by actors to prepare for a role. In this case, Alex - who usually accompanied them - noticed that some of the younger cast members were clearly uncomfortable around his mother: “They had obviously never been so close to someone with Alzheimer’s”. The preparation proved helpful: during the performance, I saw displays of fear, uncertainty and avoidance as Ulysses’ relatives and friends slowly came to grips with his condition.

The show was co-produced by Alex Panayi and Katerina Christofidou. They are co-owners of Silver Spotlight, a Cypriot production company, and “Dimentia” is their fifth original musical. “We always want to provide a fresh look on things”, said Katerina. “In “Dimentia”, we wanted to show how Alzheimer’s disease can also afflict younger...
people, not just our grandparents.” “Dimentia” was directed by Giorgos Rodosthenous with a book by Stergios Mavrikis. The production was made possible by UNESCO, the Cypriot Ministries of Education and Culture and the A.G. Leventis Foundation. The Nicosia performances were under the auspices of the Ministry of Health.

In turn, the co-producers donated part of the proceeds to the Cyprus Alzheimer’s Association. The association, created in 1996, now has volunteer teams in all the main cities. They’re very active in raising public dementia awareness, but also in cooperating with government officials at the Ministry of Health. Chairperson Noni Diakou said: “It’s very important to have the ministry involved in all of our activities. I am pleased to say that the association is well known and respected within the ministry.”

Noni strongly believes in using art to raise dementia awareness: last year she led a campaign inspired by the work of Nicholas Panayi entitled “Mother Memory”. This year, his set for “Dimentia” consists of three illuminated cubes that create different settings as they are moved around the stage. These were partly inspired by “Mother Memory”, where similar cubes were used to symbolise the connection of thoughts in the brain.

Dr Androula Agroti, Cypriot Minister of Health, attended the musical and congratulated the Cyprus Alzheimer’s Association for its long-term voluntary service. Dr Agroti said that the Ministry welcomes creative and worthwhile works of art that raise awareness of health issues and also address human dignity. The Minister cited “Dimentia” for its accurate portrayal of the advancing symptoms of dementia. She also noted that the production could be a valuable training tool for raising awareness of Alzheimer’s disease and other forms of dementia.

Dr Yannis Kalakoutsas, President of the Multidisciplinary Committee for Alzheimer issues of the Ministry of Health, was impressed by the many facets of dementia portrayed in the musical. He was particularly struck by the poignant scene where Ulysses expresses his end-of-life care and legacy wishes. Dr Kalakoutsas remarked on the need to closely examine the Cypriot legal system and seek improvements in relation to dementia.

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The Cyprus Alzheimer’s Association and Silver Spotlight are now seeking new partners to help bring “Dimentia” to a wider audience.
THE PERCEPTION OF ALZHEIMER’S DISEASE IN FRANCE

Marie-Odile Desana, President of France Alzheimer, highlights the major findings of a survey that looked into French people's perceptions and awareness of Alzheimer’s disease.

Today Alzheimer’s disease and related disorders affect more than 850,000 people in France and some 250,000 new cases are diagnosed each year. Projections for the future are bleak: in 2020, over 1.2 million people will have the disease; in 2040, over 2 million. Dementia has now become a real public health challenge.

To mark World Alzheimer’s Day 2012, ViaVoice – an opinion poll institute – carried out a survey on behalf of Groupe Pasteur Mutualité and France Alzheimer. The survey looked at the public perception and level of knowledge the French have about the disease.

Alzheimer’s disease, a major concern for the majority of French people

The results show that 86% of French people rate themselves as “worried” by Alzheimer’s disease and 58% even declare being “very worried”. This level of worry is higher in the population most concerned by the disease: women (91%) and people over 65 (90%).

Eight out of ten young people between 18 and 24 say that Alzheimer’s disease is a worry to them. This can be explained by the increasing number of people who have dementia in their close environment.

French people need more information about the disease

The majority of people (59%) consider themselves sufficiently informed about the disease. This can be attributed to the many information campaigns carried out during the year by France Alzheimer.

41% of people say they are not sufficiently informed about the symptoms, causes, evolution and diagnosis of the disease, the social and financial support available to them. It is thus vital to increase information, communication and awareness about the disease towards the general public and policy makers.

There is a slight difference between women who rate themselves as sufficiently informed (59%) versus men (55%). This difference is even larger between the population aged 65 and over (64%) and the younger population aged 18-24 (49%).

Slight divides are seen between the different socio-professional groups: 66% of the middle class and 56% of white collar workers reveal they are sufficiently informed about the disease, whereas 75% of farmers and 52% of craftsmen believe they do not have enough information.

Doctors and the media are the main information sources

Those who feel they are not sufficiently informed wish to be informed either by their General Practitioners (62%), the media (50%) or a specialist (32%). Only 16% wish to be informed first by a family association. The population who feels sufficiently informed claims to have accessed the information via the media (68%), their General Practitioner (24%), by a specialist (13%) and by a family association (11%).

In conclusion, the main information sources about Alzheimer's disease are the media and General Practitioners. The role of family associations is scarcely recognised, in spite of their public actions to improve the daily lives of the people with dementia and their close relatives.
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

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23rd Alzheimer Europe Conference
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