Dementia in Europe
The Alzheimer Europe Magazine

Heike von Lützau-Hohlbein
Alzheimer Europe appoints new Chairperson

Nessa Childers, MEP (Ireland)
hosted a lunch debate on dementia in the European Parliament

Alzheimer Associations throughout Europe celebrate World Alzheimer’s Day
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Welcome
By Heike von Lützau-Hohlbein, Chairperson of Alzheimer Europe.

Prioritising dementia

Facing dementia together
An overview of Alzheimer Europe’s 20th Annual Conference “Facing dementia together” which took place in Luxembourg in October 2010.

The organisation of Alzheimer associations
Alzheimer Europe reports on how the associations are structured and financed.

The ethical use of assistive technology in dementia care
Project workgroup leader, Dianne Gove, summarises Alzheimer Europe’s report on the ethical issues linked to the use of assistive technology by and for people with dementia.

Debating dementia
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Taking up the challenge
Newly-elected Chairperson of Alzheimer Europe, Heike von Lützau-Hohlbein, speaks about her hopes for the future of the organisation.

Guardianship measures
Dianne Gove, Information Officer at Alzheimer Europe, describes the recent work carried out by Alzheimer Europe on legislation relating to guardianship and proxy decision making.

Policy Watch

EU Presidency Watch: Belgium
Alzheimer Europe reports on the Belgian EU Presidency Conference “Improving the quality of life of people with dementia: A challenge for European society”.

Developing a European initiative on Alzheimer’s disease
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A look at the Council of Europe’s symposium on the decision making process regarding medical treatment in end-of-life situations.

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The future of Health in Europe
Annette Dumas reports on the 13th European Health Forum Gastein.

The View From the Czech Republic
Milan Cabrnoch, MEP (Czech Republic) talks about the situation for people with dementia and their carers in the Czech Republic.

Dementia in the News

 Members News
A snapshot of national Alzheimer Associations in Europe celebrating World Alzheimer’s Day last September.

Spotlight on France
A look back at the work of France Alzheimer over the last 25 years.

Putting a face to commitment
Alzheimer Europe reports on the news about the people who work for the organisation and/or its members.

Living with dementia
Helga Rohra, who lives in Germany, writes about how her life has changed since her diagnosis of dementia.
“Facing dementia together”: That was the motto of our 20th Annual conference held in Luxembourg and it reflected how Alzheimer Europe strives to help people with dementia and their carers. Examples of how effort can become more effective when people work together can be found in this issue, which has information written by people with dementia, carers, policy makers, health care professionals and Alzheimer associations.

The conference highlighted the fact that, in recent years, significant developments have occurred at both European and national level. Having been a carer for both my mother and mother-in-law, both of whom had dementia, I am keen that these developments reflect and directly help people with dementia and their carers by providing appropriate support and care.

The European Parliament adopted its own initiative report on the Commission’s Communication on a European initiative on Alzheimer’s disease, the Belgian EU Presidency dedicated a conference to dementia and the Council of Europe organised a symposium on the end of life. All of these developments are reported on in this issue of the magazine.

Alzheimer Europe is fortunate to receive the support of the European Alzheimer’s Alliance which, in addition to other activities, hosts lunch debates on dementia in the European Parliament. Nessa Childers, MEP (Ireland), hosted a debate on the Joint Programming of research in neurodegenerative diseases. These debates are essential in raising awareness of the disease and facilitating open and frank discussions.

Alzheimer Europe published two major pieces of work at the end of 2010: a report on the ethical issues linked to the use of assistive technology and the 2010 Dementia in Europe Yearbook which focused on legislation relating to guardianship and proxy decision making. Initial feedback on both has been highly positive. Dianne Gove, Information Officer at Alzheimer Europe, provides an overview of these publications.

The Paris Declaration (2006), which lists Alzheimer Europe’s political priorities, calls for national dementia plans to be implemented at national level. The momentum at which countries recognise the need for such strategies is steadily increasing. This edition brings an update of the progress of dementia strategies in Denmark, England, Finland and Portugal.

Milan Cabrnoch, MEP (Czech Republic) and member of the European Alzheimer’s Alliance, explains how the situation for people with dementia and their carers is in the article “The View from the Czech Republic”.

I hope you enjoy seeing the photographs of some of the work which national Alzheimer associations carried out to mark World Alzheimer’s Day. Each year I am amazed by the growing commitment and creativity shown by associations to raise awareness and provide information about dementia on this day. It is important to me that people with dementia and their carers are central to all the work which Alzheimer Europe carries out. It is their needs, expectations and wishes which drive our work and I am grateful to Helga Rohra, who lives with dementia, for sharing her thoughts on the impact of the diagnosis with us in the article “Living with dementia.”

I look forward to working with you in my new role as Chair of Alzheimer Europe and sincerely hope that you find this edition of the magazine useful and informative.

Heike von Lützau-Hohlbein, Chair, Alzheimer Europe
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FACING DEMENTIA TOGETHER

In September 2010, over 300 delegates from 34 countries participated in Alzheimer Europe’s 20th Annual Conference, which was held in Luxembourg and organised around the motto “Facing dementia together”. Participants explored the various partnerships and collaborations which can be promoted to result in a better quality of life for people with dementia and their carers.

Alzheimer Europe’s 20th Annual conference took place in Luxembourg, under the patronage of Her Royal Highness the Grand Duchess. Participants were from a variety of backgrounds and included people with dementia, their carers, representatives of national Alzheimer associations, healthcare professionals and national and European policy makers. Under the motto “Facing dementia together” the aim of the conference was to explore ways in which the relationships between people with dementia, their carers, professional carers, doctors and researchers, as well as the relationship between the dementia community as a whole and policy makers could be enhanced to improve the quality of life of people with dementia and their carers.

At the opening ceremony, Maurice O’Connell, out-going Chairperson of Alzheimer Europe and Liane Kadusch Roth from the Association Luxembourg Alzheimer (ALA), welcomed participants. Mr O’Connell reflected on his time with Alzheimer Europe, paying tribute to his predecessor, Jeannot Krecké, for steering the organisation “from the pioneering stage of development to a professional organisation”. Mr O’Connell felt that at the time he became Chairperson Alzheimer Europe was “poised for new beginnings” and that the last six years had been significant in terms of recognition of Alzheimer’s disease at both European and national political level. He cited the Paris Declaration, (which contains Alzheimer Europe’s political objectives), the support of Alzheimer associations, the work of the European Alzheimer’s Alliance, European bodies and sponsors, as being key components in achieving such visibility.

Mars di Bartolomeo spoke of how his own perception that a person with dementia was “out, game over” had been challenged when someone close to him had dementia.

Marie-Josée Jacobs, Minister for Family and Integration in Luxembourg and Mars di Bartolomeo Minister for Health and Social Security in Luxembourg spoke of the importance of working
together to address dementia. Ms Jacobs directed our attention to the stigma and isolation experienced by both people with dementia and their carers. She insisted that tailored solutions be adapted to their specific needs as the disease progresses. Mr di Bartolomeo was convinced that our work enables us to better understand our parents, grandparents touched by dementia and perhaps even ourselves later in life should we find we have dementia. He also spoke of how his own perception that a person with dementia was “out, game over” had been challenged when someone close to him was diagnosed with dementia. Instead of this negative outlook, Mr di Bartolomeo found that having dementia was not the end and that the person was very much present, but with different needs, fears, joys and sorrows.

The European Union’s role in addressing the dementia challenge was presented by Dr. Rys and Mr Montserrat from DG Health and Consumer Policy. The European Commission’s Communication on a European initiative on Alzheimer’s disease of 2009 aims to support national efforts in the field of prevention, coordination of research, sharing of best practise in the area of care, ethical and legal aspects. An EU-funded Joint Action (ALCOVE) involving several Member States will be the instrument to implement this Commission Communication. The Ageing and Healthy Ageing Partnership and 2012 being designated as the European Year for Active and Healthy Ageing will be the other two vehicles to develop concrete actions at European and national level. Alzheimer Europe has been identified as a key partner in supporting all these initiatives.

Mr Montserrat explained the significance of the Pharmacog project in that it is the first time that a partnership has been created between the European Commission and the pharmaceutical industry. This project offers a new perspective and unique opportunity to accelerate the drug discovery process into the field of Alzheimer’s disease.

To address the challenge Alzheimer’s disease and other dementias present, Mr Montserrat said that whilst the Commission has a public health approach (joint action), a research approach (joint programming), a pharmacological approach and a social protection approach it is necessary to ensure that the approaches are used in a coordinated way by working together. He also highlighted that whilst the Commission is convinced that Alzheimer’s disease and other dementias are a European health priority, it is now necessary for Alzheimer Europe and its members to campaign to make sure that dementia is recognised as such within the 4th health programme and the 8th Research Framework Programme. Mr Montserrat concluded, “Alzheimer Europe and those here today have proved you can be an exceptional lobby and can be exceptionally efficient in helping the

“I think a common effort between the European Commission, Alzheimer Europe and national organisations should be a guarantee of success.”
Antoni Montserrat
European institutions to adopt what is necessary to have as a European priority. I think a common effort between the European Commission, Alzheimer Europe and national organisations should be a guarantee of the success.”

It is the person with dementia and their carer who face dementia together at a very personal level. James McKillop, who has dementia, and his wife, Maureen, shared with honesty and humour their experience before, during and also after diagnosis. They illustrated beautifully the contrasting perceptions of the person with dementia and carer which included feelings of frustration, confusion, irritation, worry, devastation and guilt. Maureen talked of her fear that her “home and family were crumbling around [her] and couldn’t do anything.” James spoke of his family’s withdrawal from him as his temper increased which resulted in James finding he “detested” home life. However, they also demonstrated the importance of obtaining a diagnosis. After diagnosis (which took three years) the couple finally received much-needed support and information about the disease. The impact this support had was significant. Maureen said, “Looking back I could never envisaged such a happy outcome. I feel we are stronger and more able to cope with whatever comes our way. I feel I have become a more compassionate and tolerant person. Whereas once I could not stand James I have now found I am so proud of him.” James concluded that, “despite the limitations imposed by dementia I have a happy fulfilling life (…) I am enjoying my life with dementia. Life is worth living again, it is like a second honeymoon.”

Philippe Amouyel, Chair of the Joint Programming in Neurodegenerative Diseases research, spoke of how EU Member States have elected to come together to address dementia research at supranational level. He highlighted the fact that in the US between 85 and 90% of research grants are involved in competitive federal funding whereas in Europe transnational collaboration is only between 10 and 15%. Mr Amouyel said that the question Joint Programming asks is “how can we better assign money for research?” and is answered by the harmonisation of approaches throughout countries, the pooling of grants and the provision of a clear accountability of decisions made. The field of neurodegenerative diseases is the first area in which Joint Programming is being employed and Alzheimer’s disease has been selected as a pilot. Currently, 23 countries have voluntarily come together to try to reverse the high level of research fragmentation and low investment levels. Mr Amouyel said that urgent topics are being proposed including biomarkers, intervention technique and new avenues for drug discovery.

Jeannot Krecké, Minister of the Economy (Luxembourg), co-founder of ALA, and ex-Chairperson of Alzheimer Europe, spoke of how countries can help people with dementia at a national level. Speaking of the imbalance between the international debt crisis on the one hand and the need to provide more money for the ageing population on the other, Mr Krecké also pointed out that the ageing population creates growing employment in the services sector. Therefore the ageing population is not only to be associated with cost but should be considered as an economic sector which is an investment for governments.

Mr Krecké said that the ageing population is not to only be associated with cost but should also be considered as an economical sector which is an investment for governments.
He also raised the issue of competitiveness, which is often associated with financial costs. He highlighted that competitiveness can also be seen in the context of a good quality of life by providing high quality services. Mr Krecké said he hoped that Luxembourg would play its part in investing in cutting down costs of Alzheimer's disease by new diagnostic methods and new treatments.

Other relationships which can enhance the quality of life for people with dementia were discussed during the parallel sessions which offered a wide range of topics from which to choose such as innovative care services, nursing home care, non-pharmacological approaches to the management of dementia, successful campaigning, organisation and financing of care, the international dimension of dementia and also national dementia strategies currently in Europe (which proved to be of particular interest to participants).

2010 marked Alzheimer Europe's 20th anniversary and the Executive Director of Alzheimer Europe, Jean Georges, emphasised some of the key achievements of the organisation, highlighting the Lawnet projects and the Paris Declaration. Mr Georges remarked on how much Alzheimer Europe had grown from just seven national associations in 1990 to now consisting of 31 national organisations from 28 EU countries. This, he said, makes Alzheimer Europe able to represent people with dementia better across Europe.

The newly-appointed Chairperson of Alzheimer Europe, Heike von Lützau-Hohlbein and Carine Federspiel, the vice-president of the Luxembourg Alzheimer association (ALA), thanked everyone who had organised the conference. Ms Federspiel asked for more visibility and transparency from policy makers to make sure that work commences on action plans. She also called for the financial stability of people with dementia to be guaranteed.

Ms von Lützau-Hohlbein reflected on how wide the conference subjects had been, covering many topics around dementia. She said that we have fought for more than 20 years to break the taboo of dementia and “fought the dragon” to help achieve an earlier diagnosis. This, Ms von Lützau-Hohlbein said, had in turn enabled people with dementia to take part in the dementia debate. Her hope for the future is that we no longer have discussions about how to involve people with dementia but that people will automatically be a part of our work and conferences, as we face dementia together.

The conference received the support of the European Commission, which enabled Alzheimer Europe to offer (for the second year) some complimentary tickets for people with dementia to participate. The event was organised by Alzheimer Europe and Association Luxembourg Alzheimer (ALA) in collaboration with the Integrative Research Unit: Social and Individual Development, University of Luxembourg and the Association Luxembourgeoise de Gérontologie and Gériatrie.
A snapshot of Alzheimer Europe’s 20th Annual Conference in Luxembourg

Sabine Jansen (Germany) and Jan Kileen (Scotland)

Charles Scerri (Malta) and Gwladys Guillory (Alzheimer Europe)

Liane Kadusch Roth (Luxembourg) and Heike von Lutzau-Hohlbein (Germany)

Mr and Mrs Laine (Finland)

Grazia Tomasini and Dianne Gove (both Alzheimer Europe)

Denis Mancini (Luxembourg)

Jean Georges (Alzheimer Europe) and Antoni Montserrat (European Commission)

Maija Juva (Norway) and Sigurd Sparr (Norway)

Patrick Maugard (France) and Marie Odile Desana (France)

Maria do Rosário Zíncke dos Reis (Portugal), António Oliveira Costa (Portugal) and Charles Scerri (Malta)

Jeannot Krecké (Luxembourg) and Alicja Sadowska (Poland)
HOW NATIONAL ALZHEIMER ASSOCIATIONS ARE ORGANISED

As the work of national Alzheimer’s associations has grown, they have had to respond by becoming more professional. Alzheimer Europe carried out a survey among its members and in this article, we report on how the associations are structured and financed.

Initially set up with the three broad aims of providing information on Alzheimer’s disease, supporting carers of people with dementia and raising awareness of the disease, the role of Alzheimer associations across Europe has grown and diversified considerably over the last few years.

**Structure of National Alzheimer Associations**

Nearly all national associations now have regional branches, filling the void at a local level for support and care. Some of the more established national associations have expanded considerably having a high number of regional branches [FR 106, DE 116, NO 130, ES 285 and UK (England) 232]. It is encouraging that some of the more recently formed Central and Eastern European Alzheimer associations have similarly managed to reach out locally too [CZ 65, PL 29].

**Representing individual members**

It is difficult to say how many individuals are members of Alzheimer Europe’s member organisations as the definition of member varies between countries. Some organisations are themselves umbrella organisations with regional associations as members, whereas other organisations have individual members. This is the structure that the vast majority of Alzheimer Europe members have adopted. Only four countries reported having a regional membership structure (FI, DE, IT and ES). However, from table 1, it can be estimated that the associations which replied to the survey represent some 291,421 individual members throughout Europe, with the Netherlands having the greatest number of individual members (126,253).

This representation throughout Europe appears low when comparing it to the current prevalence figures for people with dementia in Europe [7.3 m (EuroCoDe) and 19 m carers] and illustrates that there may be many people with dementia or carers who are not receiving information and/or support to help them. At the same time, Alzheimer associations provide services, support and information to interested individuals regardless of whether people are members of the organisation and no organisation has made membership of their organisation a prerequisite for access to services.

<table>
<thead>
<tr>
<th>Country</th>
<th>Individual members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria*</td>
<td>700</td>
</tr>
<tr>
<td>Belgium (Ligue)</td>
<td>1,000</td>
</tr>
<tr>
<td>Belgium (Liga)</td>
<td>1,400</td>
</tr>
<tr>
<td>Bulgaria</td>
<td>286</td>
</tr>
<tr>
<td>Croatia</td>
<td>650</td>
</tr>
<tr>
<td>Cyprus</td>
<td>300</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>65</td>
</tr>
<tr>
<td>Finland</td>
<td>300</td>
</tr>
<tr>
<td>France</td>
<td>16,000</td>
</tr>
<tr>
<td>Greece</td>
<td>2,200</td>
</tr>
<tr>
<td>Ireland</td>
<td>725</td>
</tr>
<tr>
<td>Italy</td>
<td>4,000</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>550</td>
</tr>
<tr>
<td>Malta</td>
<td>180</td>
</tr>
<tr>
<td>Netherlands</td>
<td>126,253</td>
</tr>
<tr>
<td>Norway</td>
<td>4,100</td>
</tr>
<tr>
<td>Poland</td>
<td>1,200</td>
</tr>
<tr>
<td>Portugal</td>
<td>6,786</td>
</tr>
<tr>
<td>Slovenia</td>
<td>69</td>
</tr>
<tr>
<td>Spain</td>
<td>82,938</td>
</tr>
<tr>
<td>Sweden</td>
<td>5,000</td>
</tr>
<tr>
<td>Switzerland</td>
<td>7,800</td>
</tr>
<tr>
<td>Turkey</td>
<td>300</td>
</tr>
<tr>
<td>UK England</td>
<td>25,000</td>
</tr>
<tr>
<td>UK Scotland **</td>
<td>3,619</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>291,421</td>
</tr>
</tbody>
</table>

* In Vienna, not possible to give figure for federation
** Plus 32 groups

“In many countries the work could just not be done if it were not for the dedicated volunteers who give up their time.”
Staff and volunteers

Initially many national associations started with the vision and drive of one or two people. From these humble beginnings, Alzheimer associations have grown in size and they have been able to count on an increasing number of volunteers and staff members. With the exception of Austria, Croatia, Malta and Slovenia, national associations employ staff both at national and regional level, with Spain employing 3,210 staff (table 2). In addition, nearly all 26 participating countries said they can count on volunteers to support them in their work. Indeed, in many countries the work could just not be done if it were not for the dedicated volunteers who give up their time. At regional level the number of volunteers ranged from 4 (TR) to 5,000 (UK England). The work volunteers carry out is extensive often helping out with the helpline, administrative work, fund-raising and events. In some countries volunteers also help with provision of day care (BE, HR, CY, EL, PL, ES, CH and UK England and Scotland). Further, volunteers help to run Alzheimer Cafés (BE and NL), give cover for holidays (CH) and sit on various committees (UK Scotland).

Governance

All national associations who participated in the survey have a Board of Directors with an average of 8 people on each Board, ranging from 3 people on the Board in Bulgaria to 27 in Scotland. Other than in the UK (Scotland) where two members of the Board have dementia, no other national associations had people with dementia on their Boards. Nearly all Boards included carers (save for BG) and many include medical personnel.

Income and Expenditure

The income of national associations has grown alongside the range of work they carry out. Income ranged from EUR 150 (BG) to EUR 59 m (UK England) and the sources of income for each association also varied considerably. For some, a high proportion of their income was derived from membership fees (AT), donations (NL, NO), government funding (IE) and/or corporations (FI). Some associations also received income from services provided and sales (publications and merchandise).

Table 3 shows the expenditure, or financial contribution made by Alzheimer Europe member associations. This contribution is, quite simply, staggering. Nearly EUR 102 m is spent by national Alzheimer associations in trying to improve the lives of people with dementia and their carers.

With the ageing population, the projected number of cases of Alzheimer’s disease in Europe is that it will double by 2040. The work which the associations around Europe carry out will be even more in demand and more challenging. Policy makers must give full recognition to the role played by the associations and ensure that their essential activities continue to be supported and funded without exception.
### TABLE 4: SERVICES OFFERED BY NATIONAL ALZHEIMER ASSOCIATIONS IN EUROPE

Owing to a mistake made by the publisher, which occurred when making up and processing the data in the above chart, an inaccurate version was published in the previous edition. The present version has been duly corrected and completed. We would like to thank you for your understanding.
In December 2010, Alzheimer Europe published its report on the ethical issues linked to the use of assistive technology (AT) by and for people with dementia. Dianne Gove, Alzheimer Europe’s Information Officer who led the workgroup for this project, summarises the main elements of the report.

In December 2010, Alzheimer Europe published its report on the ethical issues linked to the use of assistive technology (AT) by and for people with dementia. The report is the result of the first 18 months’ work of the first working group set up in the context of the European Dementia Ethics Network (EDEN). It was part of the 2010 Work Plan of Alzheimer Europe, which received funding from the European Union, in the framework of the Health Programme. The idea for EDEN originated from Michael Schmieder from the Sonnweid Centre in Switzerland and the project was initially set up with funding from the German Federal Ministry of Health.

Disability can be reduced or overcome in a number of ways such as by changing attitudes, providing therapeutic interventions, developing coping skills and adapting the environment or practices. It can also be overcome or at least reduced in many cases through the use of AT.

Many people associate the use of AT with the deprivation of liberty, the loss of dignity and privacy, coercion and/or the stigmatisation of people with dementia. Such concerns must be addressed as the use of assistive technology, especially with potentially vulnerable groups, does raise a number of ethical concerns, particularly for certain forms of AT such as tracking, surveillance and monitoring devices.

However, this is only one side of the coin. AT is not limited to tracking, surveillance and monitoring devices, nor is its use for such purposes...
necessarily negative or abusive. On the contrary, such devices can promote the user’s autonomy, help ensure safety, enable greater freedom and provide privacy. Moreover, there are other forms of AT such as smart devices which may enable people with dementia to live independently in their own homes for longer or to accomplish tasks alone (even those who are in residential care) and this in turn may promote their autonomy and self-esteem.

AT can also be used for recreational and leisure purposes. This is by no means trivial as many people with dementia gradually withdraw from social contact, become socially isolated and may become depressed. Lack of social interaction may have serious consequences on how they are considered by others and ultimately on their perceived personhood, which can affect the way they are treated by others. Inactivity may also lead to a premature loss of remaining capacities.

If people with dementia are to benefit from AT, measures must be taken to ensure that it is used ethically. Devices are not ethical or unethical. It is the way they are used which makes them so. In this report on the ethical use of AT, we describe a wide range of ethical principles and explain how they might relate to the use of AT for or by people with dementia, presenting a balanced view of the ethical use of different types of AT, highlighting both potential benefits and possible dangers.

Making ethical decisions is not an easy task. Certain ethical principles may seem to be in direct opposition to each other. For example, a device which provides safety may also restrict a person’s liberty. Some devices (e.g. for leisure activities) may intrude on the privacy of other people. Some devices may be greatly appreciated by those using them but relatives may feel that they are demeaning. In some cases, devices may be highly effective but disproportionate to need or primarily of benefit to other people (i.e. not the person with dementia). We therefore provide an ethical framework and suggest various tools to help people organise all the issues that they need to consider. We also emphasise throughout the report that any AT measure must be first and foremost for the benefit of the person with dementia but that when making decisions the perspectives of all involved must be considered as they also have rights and needs, and their cooperation may be vital.

An important part of the publication is the section which contains guidelines on the ethical use of AT. These are divided into the various stages of the use of AT starting at the point at which the use of AT is being considered and the need for it assessed, through to its organisation (including the issue of consent), implementation, use and constant assessment. A separate set of recommendations, linked to the ongoing development and commercial distribution of AT, are made to researchers, AT developers and commercial distributors in which the need to actively involve people with dementia and carers is emphasised.

AT has a huge potential for people with dementia provided that it is used in an ethical manner, part of which involves ensuring that the views of people with dementia are respected and that it is adapted to each person’s needs and unique situation. One major obstacle to the more widespread use of AT is that in practice all too often dementia is not considered a disability despite the fact that all Member States of the European Union as well as Iceland, Norway and Turkey have signed the United Nations Convention on the Rights of Persons with Disabilities which has also been ratified by 16 Member States as well as Turkey.

“One major obstacle to the more widespread use of AT is that in practice all too often dementia is not considered a disability”
DEBATING DEMENTIA IN THE EUROPEAN PARLIAMENT

In this article we report on the lunch debate in the European Parliament which was dedicated to the Joint Programming of research in Neurodegenerative diseases and hosted by Nessa Childers, MEP (Ireland).

Alzheimer Europe organised its 8th lunch debate in the European Parliament on 7 December 2010. It was hosted by Nessa Childers, MEP (Ireland), and entitled “The Joint Programming of research in Neurodegenerative Diseases (JPND). What progress so far?” Answering this were Pieter Jelle Visser, an observer of the JPND Management Board and Elmar Nimmesgern of the European Commission, Research and Innovation Directorate General, Medical Research Unit.

Opening the debate, Ms Childers gave a brief introduction regarding action on Alzheimer’s disease at European level, highlighting how neurodegenerative diseases require specific action. She said that EU initiatives in Alzheimer’s disease should eventually help secure earlier diagnosis, enabling appropriate treatment and support to be given, but also hoped that we could work towards finding a cure for Alzheimer’s disease. Recognising that it is not possible to give predictions on how long this process may take, she believed that the JPND should accelerate the process.

Pieter Jelle Visser explained how the JPND works and said that it was instigated to help address the fact that in Europe research on Alzheimer’s disease is fragmented and budgets are not as effectively used as they might be. 85% of research budgets in Europe are spent nationally and this fact increases the risk of fragmentation, duplication and also often results in a lack of a critical mass. Diagram 1 (on page 19) illustrates the differences between the level of research spending in different areas and the levels of fragmentation and coordination. Currently, research spending and coordination on dementia is low and the level of fragmentation high and he compared this to the research into nuclear fusion where fragmentation is low and funding together with collaboration levels are high. It is hoped, he said, that by increasing the collaboration between Member States on key research topics, such as Alzheimer’s disease, Joint Programming can result in great benefits such as harmonising national strategic research approaches, achieving a synergistic use of shrinking research budgets, reinforcing the potential for scientific collaboration in Europe by grouping calls for grants, offering greater accountability to stakeholders in pooling research efforts addressing common social issues in Europe and a simplification of European procedures governing scientific collaboration and its administration.

Joint Programming is a completely new collaborative approach to European health research. Neurodegenerative diseases became the first area to be targeted by Joint Programming as they are a
recognised “major societal challenge” in Europe (Mr Visser highlighted the fact that there are over 6 million Europeans with Alzheimer’s disease and attached to this is a societal cost of EUR 72 billion). The JPND, which commenced in 2009, now has 23 countries participating. It is a long-term project (10 years) and the mission of the JPND is to develop a shared vision and a strategic research agenda (by mapping ongoing research and running workshops), by identifying “best suited instruments” and funding mechanisms and to build up an “à la carte” programme whereby Member States participate on a voluntary basis. For example, a programme on diagnosis may have 10 of the participating 23 countries collaborating.

This year, said Mr Visser, the Commission’s Framework Programme (FP7) funding of EUR 2 million was approved for a 3 year project (JUMPAHEAD) in support of the implementation of JPND. Work has now commenced to develop a Strategic Research Agenda (SRA) to address the medical and societal impacts of neurodegenerative diseases.

Mr Visser also gave an overview of the management structure, workflow of the JPND and research priorities. The latter included priorities in three research fields (basic, clinical and health care) and six themes (pathophysiology, diagnosis, prevention, therapy, care and infrastructure). Currently, he said, there is a pilot call on cerebrospinal fluid biomarkers for neurodegeneration being made and this should result in the pilot project commencing in 2012. Further programmes should then start in 2013. He concluded his presentation by offering his own feedback of the JPND over the last two years. Mr Visser said that it is encouraging that many countries have come on board and that such a positive approach was being adopted for selecting the research topics. However, he acknowledged that there are challenges such as:

- A need to improve the communication between various EU options for funding neurodegeneration research;
- A need to avoid “reinventing the wheel” regarding the implementation of JPND;
- The fact that funding may not meet the requirements of such an ambitious project;
- The rate of progress being relatively slow (one project per year), but this may speed up after the start-up phase.

Frieda Brepoels, MEP (Belgium) asked for clarification on the issue of neurodegenerative diseases being a broad field and asked what impact this may have. Mr Visser said that it was important to focus on a number of diseases at first and then to prioritise.

Marco Blom, Alzheimer Nederland, asked if patient organisations would be involved in the development of the Research Agenda and Mr Visser confirmed that Alzheimer Europe is considered as one of the stakeholders and as such would be able to comment.

Elmar Nimmesgern then clarified the role which the Commission plays in terms of the JPND. He emphasised that the process of Member States collaborating and developing a common vision and strategic research agenda (SRA) is an interactive one. However, he reminded the audience, that it takes time to develop and subsequently implement the SRA (which will be available in 2011). This, in turn, means that the Commission cannot yet fully realise its role of facilitator (as asked to do by the Council) but rather than wait, the Commission has published a call under the health theme of the research programme with a focus on neurodegenerative diseases. This call is in the middle of an evaluation process, which
should result in EUR 60 million being invested. This amount is in addition to the EUR 180 million funding allocated to neurodegenerative research under the Framework Programme (FP) 7 so far and marks a significant increase from the funding for neurodegenerative diseases under the FP6, in which EUR 136 million were allocated over the entire programme. The Council also invites the Commission to look into possible forms of consultation and cooperation at international level and this, Mr Nimmesgern believes, is important for the medium to long-term success of the project. Currently, the Commission is actively supporting the Joint Programming by having organised a workshop, developing the SRA, preparing a report for the European Parliament (due in 2011) and supporting the mapping of ongoing research. Evidence of concrete progress was given by highlighting the discussions which have occurred about early priorities for joint action which expanded to include several countries.

Addressing the issue of the broad field of diseases which neurodegenerative disease cover, Mr Nimmesgern recommended not to focus solely on one disease and he concluded his presentation by explaining that the Commission supports neurodegenerative research in various areas.

Jean Georges, Executive Director of Alzheimer Europe, highlighted the differences between the two approaches for funding at EU level, with one communicating with the European Parliament and Commission rules applying and the other a more inter-governmental approach in which the role of the Commission is limited. Mr Nimmesgern concurred that there are indeed two very different approaches but said that among Member States there is a variance of views regarding collaboration so both were useful. He recognised that if the funding was given at national level then it would be appropriate that the control is also at national level.

Mr Georges commented how happy he is that such collaboration is occurring, especially as Alzheimer Europe has been asking for this, but also sought reassurance as to what will happen after 2012. Pieter Jelle Visser said that if a project requires EUR 20 million from Member States that it has to be acknowledged asking each Member for a contribution of EUR 1.5 million is a lot. Mr Nimmesgern again emphasised the need to take a medium to long-term perspective saying that as Member States learn to work together and share a common vision that a better understanding results which will eventually ensure that new money becomes available. However, in the near-term it is how we use the existing money which matters and that better allocation and use of money is needed. He said, “I’m rather optimistic that we can build on our experience and can take it a step further.”

Nessa Childers said that some countries are subject to austerity programmes and she was concerned that existing research programmes may no longer be protected. She stressed that in the area of research, politics should not matter, saying “I hope that this part of the EU will continue to work.”

The recently-elected Chairperson of Alzheimer Europe, Heike von Lützau-Hohlenbein shared her personal history of being a carer for family members with Alzheimer’s disease. She reinforced how important research can be to the quality of life of people with dementia in that it can lead to earlier diagnosis and better treatment. She stated that Alzheimer Europe is delighted by the European Initiative and the JPND. She then launched Alzheimer Europe’s 2010 Dementia in Europe book (which focuses on legal capacity and proxy decision
making for people with dementia) together with the Alzheimer Europe Report on the ethical issues linked to the use of assistive technology. Ms von Lützau-Hohlbein thanked in particular, Dianne Gove, Information Officer of Alzheimer Europe, for her contribution to the books and thanked both the European Commission and German Health Ministry for their support. Lastly she thanked the speakers for giving all the participants at the lunch debate a much deeper insight into how the European action is working, the sponsors for their support and Nessa Childers together with her assistant for hosting and organising the event.

Nessa Childers remarked on the depth of information in the Alzheimer Report on assistive technology, calling it a “magnificent piece of work”. She said she herself remembered some good and bad memories of trying to take care of her own mother and that the book “covers areas I would not even have thought of”. Ms Childers said that in the area of ethics it is not really possible to solve the dilemmas which arise, but it is important to ask the right questions. Ms Childers closed the meeting by thanking Alzheimer Europe and said that she looked forward to collaborating with it in the future.
In this article, newly-elected Alzheimer Europe Chairperson, Heike von Lützau-Hohlbein, talks of her vision for the organisation.

I was delighted to be elected as the new Chairperson of Alzheimer Europe. I am grateful to the previous Chairperson’s leadership and relish the challenge to oversee the implementation of Alzheimer Europe’s next five-year Strategic Plan.

As a former carer of both my mother and mother-in-law (both of whom had dementia), I hope to make a real contribution to the organisation. Because of my experience and emotional involvement, I always try to imagine myself in the place of the person with dementia.

Currently there is much discussion about the negative connotations which dementia has and the need to de-stigmatise it. I agree. On the other hand, I do not believe it is helpful to either trivialise it or ignore the experience of the very people who live with the disease first-hand, day in, day out. Rather it is necessary to validate their experience. Dementia is often an extremely difficult disease to live with and it can be overwhelming. However, the impact this disease has can be reduced if the needs of people with dementia and their carers are met. We can help. I see us making a real difference by focusing on the following areas:

- Diagnosis. We need to ensure that an early and accurate diagnosis is given. European countries vary from a 10 month wait for a diagnosis of dementia (Germany) to 32 months (UK). Practical information needs to be given at the time of diagnosis and available support needs to be made accessible.
- Good care and best practice models. Pilot projects which have been identified to enhance good care and best practices need to be replicated to reach a wider audience. Too often, there are many pilot projects which do not reach the implementation stage. By establishing processes of implementation and dissemination we can overcome this shortfall.
- National dementia plans. The measure of the success of a national dementia plan needs to directly relate to the impact the plan has on people with dementia and their carers.
- Budget control. A tight control of budgets in the area of dementia care is required. At the Alzheimer Europe 20th Annual Conference, Luxembourgish Minister for the Economy, Jeannot Krecké, spoke of how dementia care is fast becoming an important sector of our economies, offering opportunities for investment. This is indeed true. Increasingly, businesses have greater opportunity to make money in the dementia care sector and the opportunity for job creation also increases.
- Paris Declaration. Alzheimer Europe’s political priorities as listed in the Paris Declaration (2006) need to be fully realised. At the Belgian European Presidency Conference current European initiatives in the field of dementia were highlighted (including the identification of best practices, national plans and collaboration on ethical issues surrounding the disease). I am pleased as each and every one of them had been identified by Alzheimer Europe in the Paris Declaration. But more work remains to achieve recognition of other priorities listed in the Declaration.

Alzheimer Europe has made tremendous headway over recent years and I look forward to continuing this work to ensure that our visions are transferred into a reality.
RECENT DEVELOPMENTS IN LEGISLATION RELATING TO GUARDIANSHIP MEASURES

In this article Dianne Gove, Information Officer at Alzheimer Europe, describes the recent work carried out by Alzheimer Europe on legislation relating to guardianship and proxy decision making.

In 2000, Alzheimer Europe collected information on the legal provisions relating to the rights and protection of people with dementia in fifteen Member States of the European Union and produced a summary of the findings for each country. This was carried out in collaboration with legal experts from each country and necessitated the translation into English of several laws and extracts from laws. Each report was divided into three sections: 1. restrictions of liberty (covering involuntary internment, driving, the unlawful deprivation of freedom and coercive measures), 2. guardianship measures (including various forms of guardianship and continuing powers of attorney) as well as different types of capacity (e.g. the capacity to marry, make a will, make a contract or vote as well as civil liability and criminal responsibility of people with dementia) and 3. healthcare decision making (covering informed consent, substitute decision making in relation to healthcare, access to information, the right to be informed of the diagnosis, confidentiality and end-of-life decision making). Now, ten years later, many of these reports are out-of-date. Moreover, new countries have joined the European Union which means that for many countries we have no information about their legal provisions for people with dementia.

The fact that the reports are out of date in terms of the legal provisions of relevance to people with dementia is actually a good sign as looking at the amendment that have occurred and the new laws that have been passed, it is clear that there is a greater awareness not only of the need to protect people with dementia but also to respect their rights. However, people need to be informed about the rights and protection to which they are entitled if it is to be of any use to them but as legislation rarely refers directly to people with dementia, it is not always easy to know which laws are of relevance or applicable to people with dementia. This is why the assistance of legal experts is vital and so greatly appreciated. In 2010, with their help, Alzheimer Europe updated the information on legal provisions on the topic proxy decision making and various forms of capacity and published the findings in the 2010 Dementia in Europe Yearbook. This update covered 25 Member States of the European Union as well as Iceland, Switzerland, Norway and Turkey. Brief details of some of the recent amendments and laws are described below.

Due to changes in the guardianship law in Austria, effective from 1 July 2007 (Sachwalter-Abänderungsgesetz BGBl 2006/92), guardianship is restricted to cases in which the appointment of a guardian is unavoidable. The changes also included the introduction of two alternatives to guardianship which made this possible. The first is the agent’s authority granted to next of kin which allows for the next of kin to handle the person’s current income and cover his/her care needs. This can even extend to consenting to medical treatment provided that it would not have a lasting or serious impact on the person’s health and that the person lacks the insight and judgement to make the decision him/herself. Next of kin cannot be appointed if the person
concerned objects or already has a guardian or durable power of attorney for legal representation. The person can even object after having lost capacity, insight or judgement with the effect that the agent’s authority would be terminated or not become effective.

A durable power of attorney (DPA), on the other hand, can be granted to anyone the person trusts. The DPA can be combined with an advance directive and may, if drawn up before a lawyer, public notary or court, cover consent to serious medical treatment with a long lasting effect or the refusal of vital treatment. For both of these alternatives to legal guardianship, the chosen representatives are registered in the Central Austrian Registry of Representation (ÖZVV).

In the same year, the Finnish Act on Continuing Powers of Attorney (648/2007) also came into force. As is also the case with the Austrian DPA, a medical certificate must also be provided before the continuing power of attorney can become effective, which provides a measure of protection against abuse of the system.

With specific reference to legal guardianship, a law was passed in Italy (Law n°6/2004) which introduced a new set of rules known as the “amministrazione di sostegno”. According to Marina Presti (2010), the new system is very similar to the German system of guardianship and balances the opposing needs for protection and independence, granting people as much freedom as possible, whilst at the same time ensuring that they are provided with the necessary protection that is fair and proportionate to their needs. Currently, the only law applicable to guardianship is this new law even though it has not actually repealed the previous rules on judicial disability (which involves the loss of fundamental basic rights acquired with adulthood) and judicial disqualification (relating to incompetence to carry out business).

In France, the Law of 5 March 2007 led to the introduction of the mandate for future protection (mandat de protection future). This permits adults or emancipated minors who are not under tutorship to appoint one or several persons to represent them, should they become incapable of taking care of their own interests (e.g. due to medically ascertained incapacity). This provides them with an opportunity to choose the person they would like to look after their interests, to define the extent of the mandate and to set down provisions for the management of their assets. This helps ensure that their wishes are respected in the future.

The above-mentioned changes in legislation reflect a growing awareness of the importance of guardianship measures being adapted to each individual’s needs.

“The changes in legislation reflect a growing awareness of the importance of guardianship measures being adapted to each individual’s needs.”

Acknowledgements
Alzheimer Europe would like to thank the following experts for writing, updating and/or checking the reports on guardianship measures and issues related to incapacity contained in the 2010 Dementia in Europe Yearbook. Without their help, this publication would not have been possible.

• Irene Müller (VertretungsNetz – Recht), Austria
• Philip Bentley, Belgium
• Lora Ivanova, Bulgaria
• Iva Holmerová, Czech Republic
• Daniela Bruthansova, Czech Republic
• Dorthe Buss, Denmark
• Eve Lääts, Estonia
• Anna Makk-Petäjä-Leinonen, Finland
• Federico Palermi (Fondation Médéric Alzheimer), France
• Harold Kasprzak (Fondation Médéric Alzheimer/etaglaire au Pôle Études), France
• Bénédicte Toussaint, France
• Bärbel Schönhof, Germany
• Magda Tsolaki, Greece

• Vassiliki Slapera, Greece
• Stefánia Kapronczay (Hungarian Civil Liberties Union), Hungary
• Eleanor Edmond, Ireland
• Marina Presti, Italy
• Association Luxembourg Alzheimer, Luxembourg
• Charles Scerri, Malta
• Kees Blankman, the Netherlands
• Berit A. Holmimö, Norway
• Mirosława Wojciechowska, Poland
• Paula Guimarães, Portugal
• Maria Rosário Zincke dos Reis, Portugal (also for report on Malta)
• Letitia Dobranicï, Romania
• Sten-Sture Lidén, Sweden
• Marianne Wolfensberger, Switzerland
• Murat R. Özsunay (Özsunay Avukatlık Bürosu/Law Office, Istanbul and Frankfurt), Turkey
• Luke Warren, United Kingdom – England
• Jan Killeen, United Kingdom – Scotland
• Hilary Patrick, United Kingdom – Scotland
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As a sign of her interest in improving the quality of life of people with dementia, Laurette Onkelinx, Deputy Prime Minister and Minister for Social Affairs and Public Health of Belgium, gave an inspiring welcome address. She highlighted socio-economic implications of dementia now and in the future, emphasised the need to develop home care and to be aware of the legal implications concerning the protections and rights of people with dementia and ended with a call to participants to express their views during the conference and her desire to take away clear recommendations which she would then present at the next meeting of the Council of Ministers.

Magda Aelvoet, Belgian Minister of State and Coordinator of the high-level conference set the scene of the whole meeting by explaining the key objectives. The overall aim of the conference, which was organised by the Belgian Presidency in collaboration with the King Baudouin Foundation, was described as being to facilitate exchange between Member States, experts and associations in order to identify promising initiatives and good practices and to transform the results of the conference into conclusions to be presented by the Belgian Presidency to the Council of Ministers.

Next, Joanna Darmanin, speaking on behalf of Commissioner John Dalli, outlined some of the priority areas such as prevalence, early detection of dementia, research, ethics and rights and thanked Alzheimer Europe for providing a key platform for patients and carers and stated that it was a key partner of the European Commission.

James and Maureen McKillop ended the first plenary session with a moving account of their experience of having dementia and being a carer. James insisted on the fact that people with dementia had an important role to play in making their views and experience known to policy makers but also that people with dementia could be very active and creative. This he proved in his contributions throughout the conference and in his performance with Maureen of “I remember it well” from the film “GiGi”, which was both humorous and poignant.

The rest of the day was mainly dedicated to three main themes: 1. creating dementia-friendly societies, 2. the image that the general public has of dementia and how dementia is portrayed and 3. providing support to carers.

On the topic of dementia-friendly societies, different approaches to ensuring the integration of people with dementia in society were discussed and it was agreed that creativity is needed and that effective measures do not always involve high costs.

For the second theme, speakers presented the work they had carried out on framing and reframing dementia, on the image campaign carried out by the Alzheimer Society in Finland, part of which included changing the name of the
Society and the term used to refer to people with dementia, and on a photographic awareness campaign carried out in Germany. The emphasis was on showing a more positive image of dementia. The risk of brushing under the carpet the real lived experience of many people with dementia and carers was raised but these initiatives were welcomed and recognised as a step towards providing a more balanced portrayal of dementia.

The third theme concentrated on supporting and promoting the mental health of informal carers, providing tailor-made assistance to carers and the importance of psychosocial counselling and information for carers.

The first day ended with an excellent film documentary by Klara Van Es entitled “Lost down memory lane” which followed a group of people with dementia in a supervised group living home. The film gave some insight into the daily lives of the residents, some of whom expressed their fears about the future and in particular of moving into a nursing home.

On the second day, participants had the opportunity to attend one of three working groups, either on ethical aspects and rights, increasing the quality of life of the person with dementia and the carer or image and public awareness of dementia. The aim of these workshops was to stimulate discussion about these issues and to improve or adapt the recommendations which had been written in advance. Several amendments were made which the “rapporteurs” then reported back during the final plenary session, in which three speakers were asked to comment.

Myrra Vernooij-Dassen, Chair of INTERDEM (European Research Group in INTERventions in DEMentia Care) expressed her view that research into psychosocial interventions should be recognised as research. She explained that some findings were already available such as the effectiveness of person-centred, autonomous and intensive approaches and the need for multi-component approaches, for evidence-based interventions and for quality indicators – issues which INTERDEM had addressed in the context of Alzheimer Europe’s recent EuroCoDe project.

Next, Jean Georges, Executive Director of Alzheimer Europe, encouraged carers, families and friends to initiate or facilitate social inclusion and shared his personal experience of how his own attempt was met with extremely positive attitudes from the general public. He stated that for Alzheimer Europe, this conference marked the end of a process in that some of the aims of the Paris Declaration had been achieved, including making dementia a European priority but that for Alzheimer Associations to continue their important work at national level financial support was essential.

The third speaker was Mario Galea Hon, Parliamentary Secretary for the Elderly and Community Care, Government of Malta. He explained how the Paris conference had given Malta the impetus needed to make important changes and to become more aware of issues of relevance to people with dementia and their carers. He spoke at length about the numerous measures that had been taken in Malta and felt that whilst there is still a certain stigma attached to dementia in Malta, it is becoming less. He concluded by stressing the importance of working with people with dementia rather than for them.

In her closing speech, Laurette Onkelinx, Deputy Prime Minister and Minister for Social Affairs and Public Health of Belgium, highlighted a number of key issues to address such as developing new strategies and an integrated approach which goes beyond the health structure, finding strong, dynamic and innovative strategies, officially recognising carers, ensuring a good collaboration between all involved in dementia care and adopting a multi-sectorial approach which necessitates consultation with organisations.

“The Paris conference had given Malta the impetus needed to make important changes and to become more aware of issues of relevance to people with dementia and their carers.”
Mario Galea, MP (Malta)
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DEVELOPING A EUROPEAN INITIATIVE ON ALZHEIMER’S DISEASE

Annette Dumas, Alzheimer Europe’s EU Public Affairs Officer, provides an update on the progress of the European initiative on Alzheimer’s disease and other dementias.


In June 2010, the European Parliament decided to produce an own-initiative report in response to the Commission’s Communication. The Rapporteur was Marisa Matias (GUE/NGL, Portugal). The Shadow Rapporteurs were Elena Oana Antonescu (EPP, Romania), Nessa Childers (S&D, Ireland), Frédérique Ries (ALDE, Belgium) and Marina Yannakoudakis (ECR, UK).

Since then, the Environment and Health Committee (ENVI) organised, on 28 October 2010, an expert workshop on “Alzheimer’s disease and other dementias” in the European Parliament to prepare M. Matias’ report. Nick Fahy, Health Information Unit, DG SANCO, said the Commission could support the Member States through actions under the Health Framework Programme (including the financing of specific joint actions) and funding opportunities under the Innovation Union action. Jean Georges (Alzheimer Europe), mentioned the high financial costs related to Alzheimer’s disease, the impact of the disease on carers, the need to increase the availability of respite care and raise awareness among the public about the availability of such services when available. Jean Georges also called for national plans and a coordinated European programme in the field of patient rights and ethical issues. Dr Giovanni Frisoni, Italy’s National Centre for Research and Care of Alzheimer’s disease, spoke of the different advances on the pathophysiology of Alzheimer’s disease, the different studies funded over the world and the need for an ambitious programme for EU research to compete at global level. Dr. Anna Caputo, International Psychoanalytical Association, spoke about the emotional impacts the loss of memory has on both the people with dementia and their family. Dr. Lars-Olof Wahlund, Karolinska Institute, talked about treatment of people with dementia, including non-pharmacological treatment, and about the impact of the disease on the health of the care-givers.

The questions from Members of the European Parliament that followed the workshop evolved mainly around the coordination and funding of research, prevention through dietary changes and the link between smoking and Alzheimer’s disease. The workshop, that was then followed by an exchange of views between the ENVI members, was presided by Dagmar Roth-Behrendt (S&D, Germany, Vice Chair of the European Alzheimer’s Alliance).

188 amendments were proposed to improve M. Matias’ report. The vote in the ENVI Committee took place on 30 November. The text voted on is most comprehensive: it focuses on the prevention, access to early diagnosis and treatment of dementia, increased and coordinated research at EU level, social impact of dementia as well as legal and ethical issues. The report was adopted by 48 votes in favour, none against and one abstention.

At its plenary session of 19 January 2011, the European Parliament adopted M. Matias’ report by 646 votes in favour, 6 against and 6 abstentions. In 2013, European Commission will produce a report to evaluate how the Member States have progressed on the Commission’s Communication.
DECISION MAKING IN END-OF-LIFE SITUATIONS

Prof. Pablo Simón Lorda, Lecturer on Bioethics of the Department of Citizenship and Ethics, Andalusian School of Public Health, Granada, made a presentation entitled “Advance directives in Europe: situation and challenges” at the Council of Europe’s symposium on end-of-life care which took place in Strasbourg from 30 November to 1 December. In this article he summarises the main points of his presentation.

The situation of Advance Directives (ADs) in Europe is characterised by its disparity between the different countries of the region and even between the European institutions. Probably it is the Council of Europe who has the longer tradition defending the need to include ADs in the regulations of the States as well in the clinical practice.

In fact, article 9 of the Oviedo Convention (1997), refers to “previously expressed wishes” and this was a milestone that led the way for the subsequent development of an Advance Directives regulation in many European countries – for example, this was the case of Spain.

In 1999, the Parliamentary Assembly of the Council passed the “Recommendation 1418: Protection of the human rights and dignity of the terminally ill and the dying”. This Recommendation encouraged the State Members “to ensure that a currently incapacitated terminally ill or dying person’s advance directive or living will refusing specific medical treatments is observed”.

More recently, on 9 December 2009, the Council of Europe’s Committee of Ministers adopted the Recommendation (2009)11 on “continuing powers of attorney and advance directives for incapacity”. This document represents an important step forward in the promotion of patients’ self-determination regarding medical treatments to be implemented in the event that the individual becomes incapacitated.

The Recommendation (2009)11 consists of a preamble and seventeen principles. Most of the 17 principles of this Recommendation (9/17) concern continuing powers of attorneys and only (4/17) deal with Advance Directives.

Principle 14 of this Recommendation establishes that Advance Directives may apply to health, welfare and other personal matters, to economic and financial matters, and to the choice of a guardian, should one be appointed.

Principle 15 indicates that States should decide to what extent these documents should have a binding effect. This is a very important point and a lack of consensus exists between the different European countries.

In my opinion, it is difficult to accept a non-binding approach, at least in relation to the refusal of treatments.”
when the clinical situation of the patient is the same described in the AD and the decisions and desires expressed by the patient in the document are clear and unambiguous. Even in this condition, if we do not give any binding effect to the ADs and we allow doctors to decide whether or not to follow a patient’s desire, we could be said to be dishonest to the citizens. We are telling to people, “OK, we want to respect your autonomy so you have the legal right to decide in advance, so fill in your AD!”; but the true thing we should be telling them is “OK, you can write what you want in your AD, it is your right, but you have to know that, in the end, the doctors will decide your best interest because they do know what to do in such situations”. A good example should be Jehovah Witnesses (JW). At least in Spain, many of the citizens that have filled in an AD are JW. They do it because they feel that their wishes will be truly respected if they become incapacitated. In Spain, ADs are legally binding if the clinical situation and the decision which has to be made is clearly expressed in the AD.

Sometimes doctors, lawyers and even specialists in bioethics say that we can not be confident with ADs, because people “can change their opinion in the last moment”, “you can not be sure about the possibility that, in the last seconds before becoming incompetent, a patient should have changed his desires and preferences about to be or not to be treated”. Fine, but then we have to apply this argument to any kind of “expressed wishes”, to any kind of “will”, including, obviously, the financial or economic wills. In my opinion, these arguments hide, again, a classical paternalistic approach.

In any event, Principle 15 states that if ADs do not have binding effect, then they should be treated as statements of wishes. The regulations should also address the issue of situations that arise in the event of a substantial change in circumstances that can limit the valid use of these documents.

Principle 16 of the Recommendation states that Advance Directives should be made or recorded in writing and that regulations should include other provisions and mechanisms to ensure validity and effectiveness of these documents. This is important: desires and preferences expressed verbally are not “Advance Directives”. Advance Directives are written documents. Another different question is the value that regulations give to these verbal expressions in the surrogate decision-making process.

Finally, Principle 17 indicates that Advance Directives shall be revocable at any time and without any formalities.

The effect that this Recommendation will have in the legal regulation of Advance Directives in Europe is yet to be seen. Nowadays the situation is that legal regulation in European countries is quite diverse, from strict and broad regulation in some countries to no regulation in others. In 2008, a report prepared by Prof. Roberto Andorno, from the Institute of Biomedical Ethics of the University of Zurich was clear about this. This Report was presented to the 35th meeting of the Steering Committee on Bioethics (CDBI) of the Council (2-5 December 2008). The title of this Report was “The previously expressed wishes relating to health care: common principles and differing rules in national legal systems”. It was the result of an “Exploratory Workshop on Advance Directives” organised by the Institute of Biomedical Ethics of the University of Zurich with the support of the European Science Foundation (ESF), held on the 18-22 June 2008. In my opinion, it is difficult to accept a non-binding approach, at least in relation to the refusal of treatments.”
We do need to do more research about this topic if we want to understand better how European doctors and patients are using ADs and to know what we can do to ameliorate it. In fact, only if the approach of “Advance Care Planning” is used as the main guide, we will be able to increase the use of ADs by patients and clinicians. The evidence is telling us that speaking with patients and their proxies is the best way to increase the use of ADs, and that passive informative material, such as posters, leaflets, information in websites or videos, in isolation does not significantly increase AD completion rates. Interactive communication is the most important tool for this task. This is the approach of Advance Care Planning.

1 More information on Advance Directives all over the World can be found at www.advancedirectives.eu. Accessed December 5th 2010.

Alzheimer Europe summarises the Council of Europe’s symposium on the decision making process regarding medical treatment in end-of-life situations.

“The capacity should not be considered as an all or none phenomenon as it may be partial, fluctuating and vary depending on the situation, the time and the nature of the decision to be made.”

Dianne Gove

The symposium on end-of-life decision making related to medical treatment, which was organised by the Steering Committee on Bioethics (CDBI) and held at the Council of Europe in Strasbourg, brought together doctors specialising in palliative care, lawyers, ethicists, theologians and a few patient organisations and covered a wide range of ethical, medical, legal and social issues.

One of the topics covered was the withdrawal of treatment, examined from the angle of the patient, the family and the doctor. However, the debate on euthanasia and assisted suicide was not the subject of the meeting. A distinction was made between patients who are conscious and those who are unconscious as well as between those who have the capacity to decide for themselves and those who lack the capacity to do so.

It was acknowledged that a growing number of people are dying in hospital rather than in the comfort of their own homes, that death is becoming medicalised and that the role of doctors in assisting people during the process of dying should be recognised in addition to that of saving lives. Prof. Dr. Jochen Vollmann (Psychiatrist and Specialist of Ethical Medicine at the University of Bochum) pointed out that natural death seldom occurs, that medical/intended death is frequent and that it was therefore impossible to avoid the ethical issues involved. This also led to a discussion about the need for semantic clarification of terms used (i.e. developing common words for a common approach to the decision making process linked to dying).

Death was described as a process rather than a moment which may in certain cases be linked to over-treatment, under-treatment or negligence. Prof. Eugenijus Gefenas (from Lithuania, Vice Chair of the CDBI) showed the results of an anonymous study in six countries which revealed considerable differences in the percentages of non-treatment decisions and those related to the
alleviation of pain. He also revealed that decisions not to initiate treatment are generally more common for elderly patients.

The place of death and the provision of palliative care were discussed. Prof. Stein Kaasa (Professor in Palliative Care from the Trondheim University Hospital) highlighted the disproportionately high number of people in palliative care centres having cancer and the need to expand the provision of palliative care to other conditions and in other domains.

Ms Isabelle Erny (Coordinator of the Symposium) drew attention to articles in the Convention on Biomedicine of relevance to end-of-life care such as the right to live, protection against torture, inhumane treatment and degrading treatment, the right to family and private life and the necessity to take into consideration previously expressed wishes. She added that whilst the text emphasised the need to take wishes into account, it was not, in principle, against legislation to make advance directives legally binding.

Later in the meeting, Prof. Emmanuel Agius (Dean in the Faculty of Theology at the University of Malta) presented different approaches to decision making in cases where the patient is unable to decide for him/herself. He argued in favour of a collaborative, consensus building approach which he considered preferable to substitute judgement and best interests approaches.

Dianne Gove, Information Officer at Alzheimer Europe was invited to talk on behalf of Alzheimer Europe about its position paper on the use of advance directives by people with dementia. Recognising the different groups of people with dementia who might need end-of-life care, Ms Gove emphasised that not all will have end stage dementia. She also explained that capacity should not be considered as an all or none phenomenon as it may be partial, fluctuating and vary depending on the situation, the time and the nature of the decision to be made. Alzheimer Europe’s opinion is that it is important that people with dementia are given the opportunity to exercise their right to self-determination and that advance statements and directives are an effective means of preserving the autonomy of people with dementia and reflecting their human dignity. Participants were urged to consider the writing of advance directives in the context of advance care planning in general. For people with dementia, this can be seen as a global approach to future health care and welfare involving reflection, discussion and communication of treatment and care preferences throughout the course of the disease and also at the end of life. However, for people to be in the position to make such decisions, they need to be considering such issues when they have sufficient capacity to do so which is why early diagnosis is important.

Finally, Ms Gove reflected on possible factors which might influence people in their choices regarding life-sustaining and life-saving treatment such as their perception of the message from society that some lives are less worthy of being saved or prolonged than others. In the case of dementia, this might be linked to messages about insufficient funds to cover healthcare, by negative stereotypes, discrimination, loss of status and in the last stages even loss of personhood. Alzheimer Europe recognises its role in increasing awareness of dementia as a disease, ensuring an accurate and balanced portrayal of it, reducing the stigma attached to it, protecting the dignity of people with dementia of all ages and presenting a positive image of people with dementia.
The Danish National plan for dementia is now a reality.

Representatives from the ministries involved and the regional and local authorities have, after consultation with various interested parties, developed a national dementia plan. It is mostly a recapitulation of what has been achieved in the dementia field over the last 10 years, in the medical field as well as in psycho-social care.

The plan “National Handlingsplan for demensindsatsen” makes 14 recommendations, the first three of which are centred around the question of timely diagnosis of dementia in all parts of the country as well as the quality of the diagnosis. The Danish Alzheimer Association has been pointing to problems securing the right diagnosis for some time.

There are recommendations for all the regions in Denmark (responsible for the hospital sector) to follow guidelines (to be made by the Danish Health Board) for a cross-sectional diagnostic procedure. Measures to improve communication between hospital, general practice and local authorities are also recommended. The aim is to avoid a loss of important information when a person with dementia moves from care in one sector to another. However, neither the regions nor the local authorities have been allocated more money to fund this. It has to be taken from the day to day budget.

On the other hand, we are pleased that a new (although temporary) allowance of DKK 8.8 million (around EUR 1.2 million) has been secured to fund the National Centre for Knowledge on Dementia over the next three years. The centre plays an important role in the implementation of good quality diagnosis and of care, as well as being a driving force in research and education.

Eight recommendations focus on the care for people with dementia and their informal caregivers. Much of the new knowledge on how to implement activities to make everyday life better for people with dementia is obtained through temporary projects paid for by the government. This is problematic as the activity is started with “project” money and it can only continue on a permanent basis if the local authorities have money to continue the activity. Therefore, these activities will often have to stop with the result that what was learned from them is lost.

The National plan recommends establishing a way of sharing experience of “good practice in dementia care”, which we naturally welcome. However, how this is to be implemented is not quite clear. We also welcome the focus on new assistive technology in the coming years.

It is suggested that work should be done to inform people with dementia that they can carry out advanced care planning, providing guidelines
for future caregivers. This is not very often done in Denmark at the moment.

Ongoing endeavours to minimise the use of restraint in the care of people with dementia should continue. The Danish Alzheimer Association had for some time been discussing the question of restraint in connection with treatment of a medical or surgical illness. Adhering to the present very strict rules can lead to situations of neglect. We are thus very happy that the group behind the report recommends looking into the possibility to create more “workable” rules.

Only one of the fourteen recommendations addresses the education of nurses, and of staff in general involved in caring for people with dementia. It is suggested to intensify in-service training for qualified staff. This is a responsibility for regional and local authorities. But, again, no extra money is coming forth from the government, as far as we can see.

The report does not address the problem of a growing number of people with dementia and a falling number of younger people to look after them. However, it does suggest to make better and a more systematic use of patient-organisations and volunteers to create better daycare and relief facilities for people with dementia and there carers.

The last recommendation is to conduct a country-wide awareness campaign, as was last held in 2007 and 2008.

In conclusion, the National plan focuses more or less on the same problems as in other European Dementia plans: timely diagnosis, self-determination for the person with dementia, unbroken “care chain”, better possibilities for the relief of informal carers, balanced view on assistive technology, destigmatisation.

The plan is, unfortunately, not very well funded. About EUR 750,000 is allocated to be used each year over the next four years. This is on top of the money for the National Centre for Knowledge on Dementia.

UK (England): Professor Alistair Burns, Director for the English dementia strategy, speaks with Alzheimer Europe about the key priorities ahead and the involvement of carers and people with dementia in the implementation of the strategy.

Alzheimer Europe (AE): Professor Burns, you were appointed as the Director for the English dementia strategy in January this year. What have your key priorities been and what will be the key challenges ahead?

Alistair Burns (AB): The priorities for dementia care in England have been well described in our recent Outcomes Focused Implementation Plan. For the next year we have four particular priorities, not to the exclusion of other things, but areas where we think we can make a significant difference quickly to the lives of people with dementia and their carers.

• First, encouraging early diagnosis and intervention with support in Primary Care as we know
that two thirds of people with dementia never receive a diagnosis.

- Second, care of people with dementia in the general hospital. We know that care can be improved greatly for people with dementia in this setting and not only that, there is evidence that length of stay in the general hospital for people with dementia can be reduced by improving care.

- Third, care of people with dementia in nursing and residential Homes. A high proportion of people with dementia are in care and, in some Nursing Homes, the majority of residents suffer from dementia. We know that training and education have a key role to play in the care of people with dementia in homes where many of the care staff do not have professional qualifications.

- Fourth, reduction in the use of antipsychotic drugs for people with dementia. In the UK there are an estimated 180,000 people with dementia being prescribed an antipsychotic drugs and estimates have been given that there is an excess of some 1,800 deaths per year as a result of their prescription. It is our priority to reduce the level of prescribing by two thirds within two years of a baseline audit (i.e. by November 2011).

Central to each of these areas is continued support and care for the carers of people with dementia – that is so important and it underpins everything else.

We have a number of developments in services for people with dementia in England which support these initiatives. First, the NICE Quality Standards were published in June 2010 and detail 10 standards which, if adhered to, would become the marker of a good service for a person with dementia. These cover the whole pathway of a person with dementia right from early diagnosis through care at home, care in the hospital, admission to Nursing or Residential Homes and end of life care. It underscores the importance of education and training and increased awareness of the challenges of people with dementia and the need to support their carers.

AE: People with dementia and carers were actively involved in the development of the English dementia strategy. How do you see their continued involvement during the implementation of the strategy?

AB: People with dementia and their carers were intimately involved in the creation of the National Dementia Strategy. This is important because it is people with dementia and their carers who are uniquely placed to know and understand the major problems faced in everyday life and what the solutions are. A strategy will only be sustainable in the long-term if it is in accord with the needs of people with dementia and their carers.

The issues facing people with dementia and their carers remain stark and in the climate of challenging financial times, it is important that we focus on the need to align and join up Health and Social Care services. In the UK, £8.2 billion is spent on the care of people with dementia and there is no doubt that considerable efficiencies can be made in terms of economies of scale and avoidance of duplication of effort with the prospect of reinvestment in services for people with dementia.

AE: France, Norway, the Netherlands and Scotland also have established dementia or Alzheimer plans and other countries are in the process of developing their own strategies. Is there a role for greater European collaboration on this issue and do you envisage to exchange experiences and best practices with your colleagues from other countries?

AB: There are undoubtedly synergies which can accrue from working across various centres and I think people in different countries have much to learn from others in terms of the priorities and challenges around dementia care.
Finland: The Minister of Health and Social Services in Finland, Paula Risikko, talks with Alzheimer Europe about the announcement that Finland will develop a national dementia strategy.

Paula Risikko (PR): As the Minister of Health and Social Services I deal with a wide spectrum of public health issues. I’m very motivated to tackle those issues that pose a serious challenge for our social and health care system.

In the next few decades, the Finnish population will be ageing fast. Our aim is to promote healthy ageing keeping in mind the life course perspective. This is where the national strategy concerning memory disorders and diseases comes into the picture: brain health promotion, preventive actions and early interventions are of utmost importance.

We have to give a clear message for our municipalities: invest in brain health promotion and prevention as well as early recognition and appropriate interventions and thus, potentially reduce the need for social and health services, especially the need for 24-hour care.

We have a lot of good knowledge and good practices in the treatment of progressive memory diseases by the Panel of experts set up by the Finnish Alzheimer’s Disease Research Society. This kind of knowledge has to be exploited and implemented.

I’d like to stress the fact that Finland is not preparing just a “dementia” strategy but a memory strategy or programme. The scope must be wider including brain health promotion and prevention keeping in mind the life course perspective.

AE: Minister, you recently announced that Finland should start the development of a national dementia strategy. What motivated you to give such a priority to dementia?

PR: The Working Group will work until the end of November 2011. During its work an implementation as well as an evaluation plan will be prepared. I’m looking forward to the propositions of the Working Group!

AE: What will be the next steps for the development of the strategy and when should the new strategy be put in place?

PR: The national programme to combat memory disorders will be coordinated with the care and quality recommendations and the objectives of social and health policy.

AE: What are the key areas and issues that should be addressed in the Finnish strategy?

PR: I find it important that the programme draws special attention to the promotion of brain health as well as to the entire care chain for persons with memory disorders, its quality and functionality. Staff competence and leadership are factors that secure a continuous and effective care chain.

“I’d like to stress the fact that Finland is not preparing just a “dementia” strategy but a memory strategy or programme. The scope must be wider including brain health promotion and prevention, keeping in mind the life course perspective.”

Paula Risikko
Portugal: Dementia has finally been placed firmly on the political agenda in Portugal, where the government has approved two Resolutions concerning dementia. António Oliveira Costa, Executive Director of Alzheimer Portugal, talks about these recent developments.

The need for political recognition of dementia as a national priority has been advocated, for a long time, by Alzheimer Portugal. Early diagnosis, training for formal and informal carers, support for people with dementia and their carers or differentiated care units are some of the demands from the Portuguese Association and, within the framework of Alzheimer Europe, these calls have become part of the agenda being presented to decision makers as a global public policy addressing dementia.

The work with MPs and the media, and the effort to raise more public awareness and support for this cause have proved to be effective.

Last September, the Portuguese Parliament approved two Resolution Projects, from PSD and CDS/PP recommending the Government policy priority on developing a national plan of action for Alzheimer’s disease and other dementias.

These Resolutions invite the government to “recognize Alzheimer’s disease as a social and public health priority and to produce a nationwide study with an exhaustive survey of the reality” of this disease in Portugal. In addition, the government calls for an increased effort on training for professionals caring for people with dementia.

Although these Resolutions are only an invitation to the government they mean that for the Parliament dementia is now a priority and they are a significant sign that dementia and the need for a National Plan are now on the agendas of both the political decision makers and the media.

For the second year now, at Alzheimer Portugal’s annual conference, there was a panel with MPs, representing all the political parties in the Parliament. At the conference “Alzheimer’s Disease – Towards an integrated policy?”, organised last December by Alzheimer Portugal and Calouste Gulbenkian Foundation, the Socialist Party MP Luísa Salgueiro said that “next year the standards for the Alzheimer’s patients units, will be adopted in the National Network for Continuous Care (RNCCI) framework.” Nevertheless, this solution, although not contradicted, raises doubts for some of the other Members. The MP of the Left Block, João Semedo, who defends the need for specific approach, even said it was a measure of “major concern” because “in a network for so vast and different pathologies, there is a risk of care being provided in a undifferentiated way”.

Mr Semedo’s view was shared by the Social Democrat MP Maria José Nogueira Pinto, who
stressed that the “versatility” of the network, as well as the fact that it was “too broad”, raised doubts about whether it “will be able to integrate these patients.”

Questioned on what can be done in a context characterised by a great economic restraint, Maria José Nogueira Pinto emphasized that we should aspire for specific measures without making large expenditure. First, consider this disease as a “national priority”, something that was formally recognised with the approval of the two resolutions. In 2011 she said, “you can work on the training, information, awareness and support for families. Then, in two years, we could develop the process further.”

Knowing the reality is also a priority for all MPs, Teresa Caeiro, the Christian Democrat MP, who prioritised the need to carry out an epidemiological study, stressed: “We are now in 2011 and we still don’t know how many people have Alzheimer’s disease, where they are, how many live alone, how many are institutionalised and what the costs (both in terms of money and time) are to families.”

The Communist Party MP, Paula Santos, also expressed her concern about the impact of reduced funds for health. She elected as one of the “sensitive issues” in the context of Alzheimer’s disease the area of “precarious employment” which affects many of the informal caregivers of people with Alzheimer’s disease. For Maria Jose Nogueira Pinto and Teresa Caeiro, this is also a distressing situation, because for families to fulfill their role, there must be out-patient solutions, which means that there must be “Home Care Support” and “Day Care Centers”.

According to Alzheimer’s Portugal’s Chairperson, Maria do Rosário Zincke dos Reis, “we are certainly closer to achieving an integrated policy in which it is essential to recognise the role of all players: social, political and economic stakeholders and general public as well. Our commitment to go on working as we have been doing – with willingness and determination – is fundamental to reach our main goal: improving quality of life for people with dementia towards a society that integrates them and respect their values and their rights.”

“We are now in 2011 and we still don’t know how many people have Alzheimer’s disease, where they are, how many live alone, how many are institutionalized and what the costs (both in terms of money and time) are to families.”

Teresa Caeiro MP
THE FUTURE OF HEALTH IN EUROPE

Annette Dumas, EU Public Affairs Officer of Alzheimer Europe reports on the 13th European Health Forum Gastein which took place in Bad Hofgastein, Austria, from 6 to 9 October 2010 under the theme: “Health in Europe – Ready for the Future?”

The European Health Forum Gastein is an annual European health policy conference that provides a platform for discussions between a wide range of stakeholders active in public health and healthcare. Within a context of globalisation and an ageing society, the participants discussed how to tackle the future health challenges while ensuring the common good.

Alois Stöger, Minister of Health, Austria, explained that healthcare systems must be seen as a driver for the creation of new jobs, and adapt to the different situations. Cooperation between all actors in the health sector can unlock the new challenges of an ageing population.

Dr. Gunther Leiner, President of the European Health Forum, sets the scene: the European population is getting older. This has strong intertwined and challenging market, social and economic policy impacts. This is more acute during an economic crisis when there is a danger that healthcare services are rationed and cost-saving measures put in place.

Dr. Gunther Leiner, President of the European Health Forum, sets the scene: the European population is getting older. This has strong intertwined and challenging market, social and economic policy impacts. This is more acute during an economic crisis when there is a danger that healthcare services are rationed and cost-saving measures put in place.

Dirk Cuypers, President of the Federal Public Service for Health in Belgium, stressed that solidarity and innovation are key concepts for the delivery of high quality healthcare systems (management of chronic diseases, sufficient provision of healthcare services and innovation in prevention, screening and development of medicines).

Miklos Szócska, Minister of State for Health in Hungary, mentioned the need for a more strategic approach to reflect the Member States different situations.

The Healthy Ageing Forum explored what individuals, communities, society and employers could do to keep the population healthy, active and productive and how the politicians and health systems responded to the challenges of demographic change.

Bernd Marin, European Centre for Social Welfare Policy and Research in Austria, gave his view on the key challenges of an ageing population. People get older but do not work longer. This new paradigm has huge societal consequences.

Care calls for better integration of healthcare/long-term care, choice, improved access to care for dependent elderly people. Concerns exist about labour shortages in the healthcare sector.

Karl Kuhn, Demography Network of Germany, advocated moving from a deficiency model to an efficiency model, thus shifting the image of a less attractive and less participative elderly population to a now dynamic, attractive, participative and contributive population.

Dr. Shu-Ti Chiou, representing the Health Minister of Taiwan, shared the country’s strategies to address the demographic challenge and
health and said that active ageing became a national priority in Taiwan 2009 with a National Plan on Healthy Ageing (2009-2012).

Dorian Block, New York Academy of Medicines, presented the New York Age-Friendly City project with new initiatives covering community and civic participation, housing, public spaces and transportation, health and social services.

Mike Martin, Joint Improvement Team, Scotland, presented the "Reshaping Care of Older People Programme" in Scotland, a project that will optimise the elderly’s independence and wellbeing at home or in a homely setting.

The Healthy Ageing Forum gave Alzheimer Europe the opportunity to present dementia as one of the challenges of an ageing population. While most of the discussions evolved around promoting good health to age actively, Alzheimer Europe showed that ageing could also be marred by complicated diseases, such as Alzheimer’s disease, that have a strong impact on the economic and social systems. Age itself is a risk factor: the risk to suffer from a form of dementia doubles every 5 years over the age of 65.

Alzheimer’s disease is the first cause of dependency in Europe and involves informal carers. In addition to the 7.3 million people affected by dementia, some 19 million informal carers are directly affected by the disease.

Health literacy, as a tool to help citizens age in good health, avoid or postpone the onset of diseases, and reduce healthcare costs was another topic to be discussed over two days.

Health literacy as a means to engage citizens to age in good health and prevent debilitating diseases was discussed in the Healthy Ageing Forum.

To Commissioner Dalli, DG Health and Consumer Policy, society must adapt to the challenges: intergenerational solidarity in health and citizens’ life potentials must be promoted.

The answer to tackle the demographic challenges in difficult time lies in innovation that will unlock the demographic challenges, help prevent, diagnose and treat diseases. New medicines and personalised medicines are part of a clear patient-centred approach, along with new technologies such as e-health and Health Technology Assessment.

Commissioner Dalli presented the Innovation Partnership on Active and Healthy ageing. The overarching goal of the partnership is to increase by two years the active and healthy lives of the EU citizens and propose concrete and innovative solutions to meet the patients’ needs and the demographic challenges, while allowing the EU to remain competitive in a globalised environment.

Antonyia Parvanova, MEP (Bulgaria) mentioned the challenges of the EU healthcare workforce and called for a plan to identify the training needs and adequate planning to adapt to the situation. She also mentioned long-term care and the provision of tailored services, employment strategies will have to include the ageing dimension, the living environment, immigration policies and suicide in elderly people.

Integrating health and social policies, innovation and creativity will provide a comprehensive answer to the challenges of an ageing population coupled with difficult economic times. Coordination and partnerships between all stakeholders must be further explored.

Innovation and creativity are the buzz words to remember when shaping the policy agenda. The challenges of an ageing population are high. Alzheimer Europe and its members at national level have a lot of grass-root expertise to bring to the EU level and are key partners in implementing all recommendations that will enhance the life of the people with dementia and their carers at national level. It is by working together to share best practices, coming forward with innovative and creative ideas, addressing the hurdles in a timely manner that we will make real progress.
The proliferation of counterfeit medicines poses a real and growing threat to patients around the world.

Over a two month period in 2008 customs from the EU Member States seized more than 34 million* illegal medicines.

* Brussels, 16 December 2008 IP/08/1980 Customs: Millions of illegal medicines stopped by “MEDI-FAKE” action

Safety • Deterrence • Partnership
THE VIEW FROM THE CZECH REPUBLIC

Milan Cabrnoch, MEP, and member of the European Alzheimer’s Alliance, talks with Alzheimer Europe about the challenges faced by people with dementia in the Czech Republic.

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

Milan Cabrnoch (MC): I think that the biggest problem was that there was no concept for long-term care in the Czech Republic and also inadequate support of carers (both professional as well as informal). Now, the situation is changing. The expert panel launched by the Ministry of Labour and Social Affairs in 2009, is preparing a concept for long-term care in the Czech Republic to ensure better connections between health care and social care systems. In the expert panel, officials cooperate with medical personnel, carers and other stakeholders.

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. Are there similar discussions in your country on a governmental or parliamentary level?

MC: On 6 October 2010 the Minister of Labour and Social Affairs submitted a proposal for the elaboration of the strategy for social and health care for Alzheimer’s disease. The government has supported the proposal. The Ministry of Labour and Social Affairs in cooperation with the Ministries of Health, Justice and Finance will now prepare a long-term care plan which will also focus on the needs of the people with dementia.

AE: Do you believe that the Czech Republic will follow the example set by France, Norway, the Netherlands, Scotland and England and create a National Alzheimer’s Plan?

MC: Yes, one of the outcomes of the cooperation among the above-mentioned ministries should be a National Alzheimer’s Plan. The Czech Alzheimer Society will be involved, because they have already prepared a strategy for the support of people with dementia and informal carers.

AE: What do you believe the three policy priorities should be for Czech policy makers to improve the lives of people with dementia and their carers in their country?

MC: Basic priorities for the Czech policy makers should be to support the education of doctors and other health professionals and also to support informal carers, not only via education but also by “shared care”, etc.

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 European collaboration be?

MC: I would support a European Action Plan. I think that broader cooperation is always fruitful. In this case, cooperation in the field of science and research might be very useful as well as sharing best practices and ways of supporting informal carers.
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We believe that partnerships between governments, public institutions and the research-based pharmaceutical industry are essential to meet public demand for medical excellence, while revitalizing Europe’s spirit of innovation and competitive position in the global marketplace.

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Members News
A snapshot of national European Alzheimer Associations celebrating World Alzheimer’s Day last September.

Spotlight on France
A look back at the work of France Alzheimer over the last 25 years.

Putting a face to commitment
Alzheimer Europe reports on the news about the people who work for the organisation and/or its members.

Living with dementia
Helga Rohra, who lives in Germany, writes about how her life has changed since her diagnosis of dementia.
WORLD ALZHEIMER’S DAY 2010

On 21 September each year, people with dementia, their carers and Alzheimer associations from nearly 80 countries come together to raise awareness about the realities and effects of dementia on individuals, families and societies. Below are snapshots of World Alzheimer’s Day activities from the various European Alzheimer Associations.
This year, France Alzheimer has celebrated its 25th anniversary. Back in 1985, the date of its creation, very little was known about dementia and no reliable data on the number of people affected were available. The organisation was created by families of people with dementia and health and social professionals with the mission to support the families of people with dementia, inform the public about the disease and influence the political agenda. From the early beginnings, the organisation also contributed to research and trained volunteers as well as health professionals. The organisation’s mission has certainly not changed since and its activity has tremendously increased over the years.

More than ever, France Alzheimer has a role to play on the French map. Today, in France, it is estimated that close to 1 million people suffer from dementia. 225,000 new cases are diagnosed every year and the diagnosis rate is estimated at only 50%. A “younger” population is also concerned: 35,000 French people below 65 are affected by Alzheimer’s disease. 70% of the people with dementia live at home. The cost of dementia is close to EUR 10 billion a year, 50% of this amount falling on the person with dementia’s shoulders. In addition, the number of people with dementia is expected to increase in the future due to the increase in life expectancy...

All these figures make it even more essential for France Alzheimer and its 106 regional branches across the French territory to be active on all fronts. After intense lobbying, France Alzheimer’s major impact on policy development has been the decision by the policy makers to make Alzheimer’s disease a national priority in 2007. This label recognised the importance and challenges of Alzheimer’s disease and is a unique opportunity to raise awareness both among the general public and the policy makers.

In particular, France Alzheimer was a member of Prof. Joël Ménard’s team who drafted the French third Alzheimer Plan (2008/2012). The organisation was instrumental in identifying the Plan’s priorities (research, early diagnosis, support to people with dementia and their carers) and in drafting the 44 measures of this Plan. In 2009, France Alzheimer became deeply involved in the implementation of Measure 2 of the Plan: the organisation is now the main provider of training to family carers. The organisation also participates in the regular Plan meetings organised by President N. Sarkozy who closely oversees the implementation of this Alzheimer Plan.

Every year, France Alzheimer offers research grants to projects directed to fundamental, clinical, social and psychological research. The research agenda is proposed on a scientific basis by the Science and Medicine expert committee and the Human and Social Science expert Committee. Since the allocation of its first grant in 1988, France Alzheimer has dedicated over EUR 7 million to research, and over EUR 1 million in 2009. The research funds come from the citizens’ donations to France Alzheimer.

In 1988, France Alzheimer initiated the first therapeutic holiday camps. These are holiday breaks for people with dementia and their carers. These camps are manned by volunteers and health professionals trained by France Alzheimer.
and last between 3 days to 2 weeks. Participation to a holiday camp is linked to the individual’s own financial resources. Support may be given via the France Alzheimer Social Fund.

France Alzheimer publishes/recommends a series of publications or audio-visual material to the public ranging from books and leaflets to DVDs.

Every year, France Alzheimer takes advantage of World Alzheimer’s Day to raise awareness about Alzheimer’s disease among the public by organising meetings and exhibitions. This year, the organisation made this day a special event with many activities planned across the country. This year’s theme was "France Alzheimer: 25 years of daily commitment... What about tomorrow?" To counterbalance the fact that Alzheimer’s disease is still a disease with no foreseeable curative treatment, France Alzheimer wished to highlight the major steps taken over the past, understand the current state of play and comprehend the future challenges. Over the past 25 years, France Alzheimer has noted major progress in regarding the person with Alzheimer’s disease as a person, improving the care pathway, boosting scientific research and providing support to family carers.

France Alzheimer set up a website (www.25ansdengagement.org) entirely dedicated to the organisation’s Anniversary. The website provides a historical background and explains how the disease has been understood and addressed during France Alzheimer’s 25 years of existence.

To further reach the public and raise awareness, the organisation has made five informative films that can be seen on the Anniversary website: France Alzheimer has changed their life; Why do they become volunteers? Life carries on in spite of the diagnosis; Alzheimer’s disease: let’s change our views on the disease and Research: what for? Each France Alzheimer regional branch has received a copy of the films and has been invited to show them at conferences and information meetings. France Alzheimer also shared these films with thousands of internet users during September 2010.

For the first time, between 18 and 21 September, France Alzheimer volunteers walked the streets to raise funding. 30 France Alzheimer associations and headquarters were involved. This was a superb opportunity to raise money and meet the general public.

The communication agency Saatchi & Saatchi also participated. The agency provided two visuals that could be seen in popular papers and magazines such as Paris Match, Le Monde, Témoignage Chrétien, Le Parisien, Femme Actuelle and Pleine Vie.

This year, France Alzheimer was a partner of the Alzheimer Train project initiated by SNCF (French Railways) and France Télévisions. The Alzheimer Train, which travelled across France, stopped in major stations and invited the public to attend the conferences organised on the train and visit the exhibitions.

“The disease is a national priority in France and it must become, now, more than ever, a priority at European level and worldwide.” Marie Odile Desana President of Alzheimer France

A note from President of Alzheimer France, Marie Odile Desana

For 25 years, France Alzheimer has been fighting alongside the people with dementia and their families who have to deal daily with the physical, moral and financial impact of Alzheimer’s disease. France Alzheimer’s commitment to accompany the person with the disease and their families, support research, raise public awareness, involve the policy makers will carry on in 2011. This year, there will be discussions on reforming dependence and adding a 5th pillar of the French Social Security system. But Alzheimer’s disease has no frontier. The disease is a national priority in France and it must become, now, more than ever, a priority at European level and worldwide. I wholeheartedly welcome the increasing support given by the various actors at EU level to the issues relating to Alzheimer’s disease.
Alzheimer Europe brings news of its newly-elected Board, the recognition of Peter Ashley for his services to dementia as well as reports on the passing of Jim Jackson, the much respected former Chief Executive of Alzheimer Scotland.

Alzheimer Europe welcomes its new Board

The representatives of 22 Alzheimer Europe member organisations voted in the new Board at the Alzheimer Europe Annual General Meeting held in Luxembourg on 30 September 2010.

The new Board thanked Pekka Laine, Neil Hunt and Marc Schaefer for their work on the previous Board. Maurice O’Connell was thanked for his six years’ service as Chairperson of Alzheimer Europe and special recognition was given to Pekka Laine for his significant contribution to the organisation over the last 10 years. Mr Laine served as a Board member and, for several of those years, as Honorary Treasurer.

2010-2012 Board Members
- Heike von Lützau-Hohlbein, Germany (Chairperson)
- Iva Holmerová, Czech Republic (Vice-Chairperson)
- Maria do Rosário Zincke dos Reis, Portugal (Honorary Treasurer)
- Sigurd Sparr, Norway (Honorary Secretary)
- Alicja Sadowska, Poland
- Charles Scerri, Malta
- Henry Simmons, UK (Scotland)
- Liane Kadusch-Roth, Luxembourg
- Maurice O’Connell, Ireland
- Patrick Maugard, France
- Sabine Henry, Belgium
- Sirpa Pietikäinen, Finland

Board: Back row, left to right: Maria do Rosário Zincke dos Reis (Portugal), Liane Kadusch-Roth (Luxembourg), Patrick Maugard (France), Sigurd Sparr (Norway), Iva Holmerová (Czech Republic), Charles Scerri (Malta), Maurice O’Connell (Ireland). Front row, left to right: Alicja Sadowska (Poland), Sabine Henry (Belgium) and Heike von Lützau-Hohlbein (Germany). Not shown: Henry Simmons (UK, Scotland) and Sirpa Pietikäinen (Finland).
Honorary Degree awarded to Peter Ashley in recognition of services to dementia

In November 2010, the University of Worcester, UK, presented ex-businessman, Peter Ashley with an Honorary Masters Degree in recognition of Mr Ashley’s services in the field of dementia. Peter Ashley, an Alzheimer’s Society ambassador, was diagnosed with Lewy body dementia in 2001 and has since worked tirelessly to inform and raise awareness of the disease, taking on many different roles and speaking at a number of Alzheimer Europe conferences.

Professor Dawn Brooker, Director of the University of Worcester’s Association for Dementia Studies, said: “Peter is a truly remarkable man and has pioneered the movement in Europe for people living with dementia to speak out on their own behalf.” Peter said: “It is a privilege to be closely associated with the University of Worcester. The formation, with others, of the Association for Dementia Studies, headed by Professor Dawn Brooker, is recognising the special needs of some 700,000 to 800,000 people having dementia in 2010, not to mention those of their carers. This major initiative, so very near my heart, can only be applauded.”

Chairperson of Alzheimer Europe thanks Jean Georges for his work with the organisation

On 2 October 2010, as part of the Alzheimer Europe’s 20th anniversary celebrations, outgoing Alzheimer Europe Chairperson, Maurice O’Connell and newly-appointed Chairperson, Heike von Lützau-Hohlbein presented Jean Georges with a gift to acknowledge his service and unstinting commitment to the organisation. Mr Georges has worked with Alzheimer Europe as Executive Director since 1996.

In Memoriam

It is with great sadness that we report that Jim Jackson OBE, former Chief Executive of Alzheimer Scotland, passed away on 12 January 2011. Mr Jackson was the first Chief Executive of Alzheimer Scotland (1994-2008) and following his retirement he became a volunteer research adviser for the organisation. He was also very active at Alzheimer Europe conferences and projects, being a passionate supporter in the European and International dementia movement.

Henry Simmons, Chief Executive of Alzheimer Scotland said, “It is impossible to sum up in just a few words the contribution made by Jim Jackson to improving and developing dementia care.”

Henry Simmons

“It is impossible to sum up in just a few words the contribution made by Jim Jackson to improving and developing dementia care.”

Henry Simmons
“A letter to you - my friends and to all of you who have been touched by dementia” by Helga Rohra

Almost 4 years have passed since I got that diagnosis: “You have got a quite seldom form of dementia. It is called Lewy-Body dementia”.

Today I realise that life with such a diagnosis is a challenge. It is a daily challenge for myself and all those around me.

Imagine…
- I was a person in a highly demanding profession. A translator, who spoke 5 foreign languages. Someone who was very active in her early 50 ties.
- I took care of my son and my 2 cats.
- I was very involved in social activities. I dedicated my time to helping refugees, especially youngsters seeking asylum in Germany and handicapped people.
- I enjoyed life.
- I was respected and admired. My neighbours knew I could always give an answer. I was a very open-minded person. My life was okay.

And all of a sudden everything changed... Everything became different.
I forgot my vocabulary, even in my mother tongue. I got lost.
My visual hallucination became my best friend. My fatigue permanently present.
My son is my assistant. My cats are my best companions. Social activities are a burden.

Dementia is something others are afraid of. They know just a bit about Alzheimer’s disease. They avoid me. They feel embarrassed. What can they talk about with someone like me? They think I do not understand. They have in their mind a certain picture of people affected by dementia. The press is, in part, to be blamed.

It was a long way. A journey to my new self.

I know that a dementia is more or less a clinical diagnosis. The way I deal with this “handicap” is to fight. I started a special programme. New way of diet, of daily physical exercise, mental training.

I am actively speaking up on behalf of all of us affected by dementia. We are in the very beginning. Medicine/tablets are important, but even more important is the way you deal with your handicap. Believe it or not you can make the best of it.

Life is beautiful even with dementia!

I attend German and European conferences. I tell them to forget what books say about cognitive impairment and to instead please realise the still existing abilities people with dementia have and promote them! I tell doctors, carers, authors to talk to us, to listen to us, to involve us in their decisions about new programmes for people with dementia. We know best what we need, what burden our family carries day by day.

I speak up for us all: Involve us, believe in us.

Living with dementia is a new life. It is a challenge for you all and also the chance to face dementia together.

Best, Helga Rohra from Munich/Germany
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

You can make a difference. Join the European Alzheimer’s Alliance today.
21st Alzheimer Europe Conference
European Solidarity without borders
Warsaw / 6-8 October 2011
Mark the dates!

www.alzheimer-europe.org/conferences