Prof. Philippe Amouyel talks about the Joint Programming on Alzheimer’s disease.

Sirpa Pietikäinen highlights the situation of people with dementia in Finland.

Mattias Karlsson becomes Chairperson of a local Swedish Alzheimer association.

Françoise Grossetête, MEP (France)

MEPs speak about the role of the European Alzheimer’s Alliance.

Brian Crowley, MEP (Ireland)

Frieda Brepoels, MEP (Belgium)

Dagmar Roth-Behrendt, MEP (Germany)
MEMBERS OF THE EUROPEAN PARLIAMENT UNITE FOR THE DEMENTIA CAUSE

Alzheimer Europe gratefully acknowledges the support of the following MEPs, who have become a member of the European Alzheimer’s Alliance.

You can make a difference. Join the European Alzheimer’s Alliance today.
Prioritising dementia

Facing dementia together
The role which the European Alzheimer’s Alliance has, and will continue to play, is considered in four articles from the members of the Alliance’s Executive (MEPs Françoise Grossetête, Frieda Brepoels, Dagmar Roth-Behrendt and Brian Crowley).

Ethical dilemmas of assistive technology
The working group on assistive technology (AT) discusses the ethical implications of using AT at its meeting in Brussels in March.

Healthcare decision making in Europe for people with dementia
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Improving the drug development process in Europe
Alzheimer Europe takes a look at the new and exciting European project known as “PharmaCog” which hopes to improve the process of drug development.

Dementia in the News

Dementia in Society
A look at how dementia is reported and portrayed in literature and the arts.

Living with dementia
A care from Spain speaks with the Spanish Alzheimer Association, Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), about his experience of caring for his wife who had Alzheimer’s disease.

Spotlight on Greece
The Greek Association of Alzheimer’s disease and related disorders celebrates its 15th anniversary this year. Nina Kotras, Executive Director, speaks of the highlights and hopes she has for the Association.

Putting a face to commitment
Alzheimer Europe reports on the appointment of Thierry Jarlet (as Director General, France Alzheimer) and of Mattias Karlsson (as Chairman of the Dalarnas Iän Association, Sweden) as well as the departure of Neil Hunt (former Chief Executive of the Alzheimer’s Society, UK).
Alzheimer Europe is extremely grateful to receive support from the passionate and dedicated MEPs who make up the European Alzheimer’s Alliance. In this issue, the determination of the executive members of the Alliance to keep Alzheimer’s disease on the European agenda is clear. The Chairperson of the Alliance, Françoise Grossetête, highlights the recent activity taken to put dementia on the European agenda and the role which the Alliance has played in doing so. Frieda Brepoels explains how the Alliance has played such a crucial role in the last Parliamentary session, highlighting the need to call upon the recently appointed Commissioners Dalli, Andor and Geoghegan-Quinn to keep up the momentum. Dagmar Roth-Behrendt reminds us that Member States need to be serious in their efforts to address dementia and Brian Crowley explains how the Alliance can work in the future to ensure that the goals set out in Alzheimer Europe’s Paris Declaration are implemented in a timely fashion.

I am delighted at the European level of activity surrounding Alzheimer’s disease over the past year and that we are able to bring to you an interview with the Chair of the Management Board of the current European pilot Joint Programming Initiative, Professor Philippe Amouyel. With 24 countries already agreeing to participate in this Initiative, Professor Amouyel speaks of the emerging need for Member States to ensure that their budgets be spent on common objectives and in an integrated way.

We bring you up to date with two of Alzheimer Europe’s 2010 projects, including the partnership between the European Commission and European Federation of Pharmaceutical Industries and Associations (Pharmacog) and also the continued development of the Dementia Ethics Network project. We also give an overview of our 2009 Dementia in Europe Yearbook, in which we consider the differences and similarities found between Member States with regard to health care decision making (for consent, access to information and diagnosis, advance directives and end-of-life issues) for people with dementia.

Alzheimer Europe has long advocated the establishment of national dementia plans and it is wholly encouraging to be able to bring you reports on the ongoing discussions to do just this. In this regard, we hear from Charles Scerri, (Chair of the National Dementia Strategy Group in Malta), Teresa Caeiro (MP, Portugal), Antigoni Diakou, (President of the Pancyprian Alzheimer Association) and also Dr Christos Patsalides (Minister for Health in Cyprus).

Sirpa Pietikäinen, MEP, talks about the situation for people with dementia and their carers in Finland and we also hear how carers and people with dementia in Greece have benefitted from the work of the Greek Association of Alzheimer’s disease and related disorders in the anniversary article by Nina Kotras, Executive Director of the Association.

Finally, this issue carries a very honest and heart-wrenching account of how it can feel to be a carer of someone with dementia. Reading this article brought it home to me just how essential the work which Alzheimer associations carry out is, in particular, how crucial it can be that the support and the opportunity to have someone to talk to are available as the journey with dementia is taken.

Maurice O’Connell, Chairperson
PRIORITISING DEMENTIA

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Alzheimer Europe takes a look at the new and exciting European project known as “PharmaCog” which hopes to improve the process of drug development.
The European Alzheimer’s Alliance has the support of 44 MEPs who have given their commitment to support Alzheimer Europe and its members in making dementia a European public health priority and shaping the European health, social and research agenda. In this article, the MEPs (Françoise Grossetête (France), Frieda Brepoels (Belgium), Dagmar Roth-Behrendt (Germany) and Brian Crowley (Ireland), who make up the Executive of the Alliance speak about the work of the Alliance and their future hopes.

Françoise Grossetête, MEP (France) and Chairperson of the European Alzheimer’s Alliance, summarises the achievements and her future hopes for the Alliance.

We can reasonably be proud to see that the European Alzheimer’s Alliance efforts to put dementia on the European health, social and research agenda during the European Parliament (EP) previous mandate, combined with the impulse given during the French Presidency and the work of the European Alzheimer’s Associations, have significantly moved the European dementia agenda forward.

After the European Commission presented in July 2009 its Communication on Alzheimer’s disease and its proposal for a Council Recommendation on measures to combat neurodegenerative diseases through the joint programming of research activities, some Member States have reinforced their commitment: at the time of printing this magazine, they were pulling together a European Joint Action on dementia with hopefully funding from the Public Health Framework Programme and had engaged in the Joint Programming of the dementia research agenda.

Public health (prevention of dementia, early diagnosis), research (improve the understanding of dementia and coordinate research), social protection (exchange of good practices with regards to the diagnosis, treatment and financing of treatments for Alzheimer’s disease), the rights and autonomy of people with dementia as well as the stigma they experience will constitute the four dimensions of the Action Plan embedded in the Commission’s Communication.

The Joint Programming particularly aims to engage the Member States to work towards a common vision of how research, cooperation and coordination at European level can help us understand, detect, prevent and treat Alzheimer’s disease. Some 20 Member States have agreed to participate. They are currently developing a common research agenda and putting the management structure in place.

“It is undeniable that the more united we stand to fight Alzheimer’s disease, the more progress we will make.” Françoise Grossetête
I am delighted that Alzheimer’s disease is one of the EP’s successes: our current mandate starts with some 44 MEPs having renewed their commitment or joined the Alliance. In 2009, the EP Written Declaration on Alzheimer’s disease, which I initiated with four other Alliance members, was adopted by close to 60% of the Chamber and the EP Resolution on the Joint Programming of research to combat neurodegenerative diseases that I coordinated with seven of my colleagues was adopted by a large majority of the Chamber.

It is undeniable that the more united we stand to fight Alzheimer’s disease, the more progress we will make. The Alliance’s next priorities will be to ensure the momentum does not decrease and that the Member States’ Action Plan is followed by concrete deliverables.

As policy makers, we are all too aware that we need to answer the needs of the people who suffer from dementia and their carers. Above all, let’s not forget that the figure of 7.3 million of people with dementia is only an estimate, that the figure will dramatically rise in the near future alongside the ageing of the population and that it does not include the still undiagnosed cases.

True, we have achieved a lot but we have no room for complacency. Let’s continue our fight against dementia!

Brian Crowley, MEP (Ireland) and Vice-Chairperson of the European Alzheimer’s Alliance talks about the work which the Alliance has carried out at European and national levels as well as the future role the Alliance can play to help people with dementia and their carers.

The European Alzheimer’s Alliance provides a vital cross party forum, which invites and encourages greater communication among the political representatives of European Member States on the pressing issue of Alzheimer’s disease.

As a founding member of the European Alzheimer’s Alliance and Vice-chair since 2006, I see the Alliance as a multipurpose organisation. The Alliance acts to increase awareness of Alzheimer’s disease, and the wide variety of attendant issues, on both a Community wide and nationwide level. In this manner the Alliance encourages the allocation of sufficient resources to properly address the public health issue of dementia. Furthermore, the Alliance operates to ensure that through communication and open information exchange that the best support and care can be made available to those who suffer from dementia and their carers. In this way, the Alliance provides protection and a critical support structure both to those who live with dementia and their carers.

On a European level, the Alliance has worked tirelessly with Alzheimer Europe and national Associations to ensure that dementia is given the priority it deserves as a public health concern. This hard work has begun to pay off, as important progress is being made at Community level. In February 2009, following a successful information

“Looking forward, the Alliance has an essential role to play in bringing dementia into focus as a community-wide public health concern and in ensuring the momentum gathered at Community level is maintained.”

Brian Crowley
Frieda Brepoels, MEP (Belgium), 
Vice-Chair of the European Alzheimer’s Alliance, highlights the importance of the recent developments in combating Alzheimer’s disease at European and national level.

In my contribution to the election special of “Dementia in Europe” last year, I marked the adoption of the Written Declaration on Alzheimer’s disease and the Resolution on the Mental Health Pact as the main accomplishments of the European Parliament. At that time we were still looking very much forward to the initiative on Alzheimer’s disease announced by Commissioner Vassiliou, which defined the need for joint programming in research as a key challenge for European policymaking.

The European Alzheimer’s Alliance has definitely played a crucial role during the previous mandate in getting Alzheimer’s disease at the centre of the political agenda by raising the profile of dementia, and in particular Alzheimer’s disease, at European and national level. At national level we see that indeed an increasing number of authorities in the Member States are now putting dementia plans and strategies in place, which is a clear result of the awareness campaigns driven and supported by the Alliance.

On a national level, the work of the Alliance and Alzheimer Europe has inspired the development of National Dementia Action plans. There has been encouraging movement across the community in the adoption of national plans and with sustained effort by the Alliance further developments are inevitable.

Looking forward, the Alliance has an essential role to play in bringing dementia into focus as a community-wide public health concern and in ensuring the momentum gathered at Community level is maintained. We will work closely with the other European institutions to ensure that the goals set out in the Paris Declaration are implemented in a prudent and timely manner. We will support and encourage all Member States in the further development of National Health, Social and Research agendas on dementia.

Furthermore, we will call on the new European Commissioners for Health, Social Affairs and Research to closely examine the issue of dementia in light of their specific portfolios. So much progress has been made but there are still many challenges to be met. With an ageing population, it is vital we stay the course and meet these challenges head on.

“The Alliance should call upon the EU policy makers, and especially the recently appointed Commissioners Dalli, Andor and Geoghegan-Quinn, to keep the momentum and ensure that the Commission’s Communication issued last July actually delivers.” Frieda Brepoels
Furthermore, at European level, 2009 was a remarkable year since the Commission published its Communication on Alzheimer’s disease and its proposal for a Council Recommendation on measures to combat neurodegenerative diseases through the joint programming of research activities (July 2009). I immediately welcomed the four priorities put forward by the Commission, in particular the joint programming of research: I strongly believe in the added value that European cooperation can have in this regard. The largest share of public investment in research (up to 85%) still occurs without European coordination, which inevitably leads to fragmentation and costly overlaps. By pushing for a coordinated European approach, we can indeed strive for a smarter and more efficient use of existing means and thus speed up insights in causes of dementia and enhance treatment options.

Moreover, the European Parliament clearly voiced its support for the actions put forward by the Commission in the resolution on joint programming of research of November 12 2009. I would like to highlight the Parliament’s call to the Commission and Council to consider launching a “European Year of the Brain” in order to raise awareness of age-related neurodegenerative diseases and measures to prevent them. Given the fact that the European population is ageing, that currently already around 7.3 million citizens across the EU-27 are affected with a type of dementia and that many more are indirectly confronted with the disease, I consider this would be an excellent opportunity to pull our efforts together.

To capitalise on the success of its previous work, the Alliance should call upon the EU policy makers, and especially the recently appointed Commissioners Dalli, Andor and Geoghegan-Quinn, to keep the momentum and ensure that the Commission’s Communication issued last July actually delivers. Both the people with Alzheimer’s disease and their carers must be on their agenda. We should also remind the competent authorities in the Member States to keep dementia as a top priority on their health, social and research agenda and stimulate the Member States who are still lagging behind to follow suite.

Dagmar Roth-Behrendt, MEP (Germany) talks about her involvement with the European Alzheimer’s Alliance as Vice-Chairperson and the need for Member States to take action against dementia.

It is undeniable that awareness about the challenges of an ageing population and its correlated brain disorders has increased across the Member States over the past couple of years. The European Commission’s Communication on Alzheimer’s disease and the Council Recommendations on research into neurodegenerative diseases are now leading the way to concerted action at European level. Some Member States are joining forces to work on a dementia action plan and engaging in a joint programming of research activities in neurodegenerative diseases.

This is most laudable. Increased awareness and the growing number of carers of people with dementia have lead to a greater demand for
better diagnosis, prevention and treatment as well as innovative care schemes. The stakes and the expectations of both the Members of the European Parliament who supported Alzheimer Europe in making dementia a European public health priority and the population are high. The Member States will have to deliver on the intended goals of these two latest important European developments. I now want to see real commitment from the Member States in bringing changes.

It is important that all health related research programmes dedicate money to understanding the causes of dementia, and work towards a variety of treatments to – at least – halt the progress of the disease and increase the quality of life of both people with dementia and their carers.

Mentally confused people are a very specific and growing population with well-identified needs and caring for them requires timely and tailored solutions. It is thus time to re-think how the care of these people needs to be organised. I strongly believe they need an individual care plan to respond effectively to their condition. My plea is to keep these people in their own environment (evidence shows that the state of health of mentally confused people dramatically declines in hospital), with care tailored to the different brain disorders and their different stages. Not only is this a matter of dignity, it is a matter of urgency.

The Member States have to be serious. They must share best practices and effectively implement the findings and recommendations that will come up from the Joint Action Plan. It is not acceptable to see only a handful of Member States taking the elderly issue seriously. ALL Member States must act and it is the European Parliament’s role to make sure this is the case. The European Alzheimer’s Alliance will be vigilant and a whistle blower in this respect.

Patient organisations like Alzheimer Europe must also be whistle blowers. While they are the link between the policy makers and the families of people with dementia, the patient organisations also have a role in identifying the shortcomings of the care systems in Europe and mobilising the policy makers to bring about effective changes.

By working together and putting action to the words, I am confident that the current plight of the people with dementia and their carers will be alleviated in the future. But this needs a truly dedicated political approach if we seriously want to change the current situation and prepare our future.

Lunch-debates hosted by Alliance members
• Alzheimer’s disease, a major European public health challenge. Where are we 100 years on?
• The prevalence of dementia in Europe.
• Alzheimer’s disease, social support priorities.
• Is Alzheimer’s disease preventable? The risk and protective factors in Alzheimer’s disease.
• The socio-economic cost of Alzheimer’s disease.
• Towards a European Action Plan on Alzheimer’s disease.
• European Action on Alzheimer’s disease.
ETHICAL DILEMMAS OF ASSISTIVE TECHNOLOGY

Following on from the article “Dementia Ethics Network” in the last issue of the magazine, Dianne Gove, Information Officer, Alzheimer Europe, gives an update of the progress made by the working group on assistive technology.

On 8 March 2010, the working group on assistive technology (AT) met for the first time in Brussels, in the framework of the Dementia Ethics Network, to assess progress with the literature review and discuss various issues of relevance to this topic. Members of the group from different backgrounds presented their views on the use of assistive technology each from their own perspective (i.e. as a person with dementia, an informal carer or a professional care provider). This was followed by presentations which focused on the ethico-legal implications of the use of AT, possible conflict between ethics and the cultural, social and financial context and last but not least, how AT can positively contribute towards the respect of ethical principles such as autonomy, privacy and beneficence/beneficence.

The group concluded that it was not sufficient to simply highlight the ethical issues involved but that in addition the working group should develop an ethical framework for decision making including guidelines which could be used by individuals faced with ethical dilemmas but also by professional bodies and even governments interested in developing their own guidelines.

The next day, the results of this meeting were presented to some of the members of the Steering Committee (Michael Schmieder from whom the idea for the network stems, representatives from the German Federal Ministry of Health and the King Baudouin Foundation, experts in ethics and representatives from the Alzheimer Associations of the Czech Republic and Portugal) who were very enthusiastic about the work of the group. Updated information about ethical principles for the ethics section of Alzheimer Europe’s website was also approved and the discussion forum for ethical issues was presented. Work on the Dementia Ethics Network will continue and a publication, including guidelines, on the ethical use of AT will be ready by the end of the year.

Assistive technology must be demystified and presented in a positive way, highlighting the potential benefits it can bring and the way that it can, first and foremost, improve the quality of life people with dementia, but also contribute towards the wellbeing of carers.
Over the past 200 years European scientists have been at the forefront of medical progress. Today, that proud tradition is under pressure from policies that devalue the role of innovation.

Innovation takes many forms: from the ground-breaking treatments and cures that emerge from our laboratories, to new solutions for today’s and tomorrow’s major health challenges. An ageing population, access to the best treatments and the availability of credible health information are issues of concern for both policy makers and society as a whole.

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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HEALTHCARE DECISION MAKING IN EUROPE FOR PEOPLE WITH DEMENTIA

This article gives an overview of Alzheimer Europe’s 2009 Dementia in Europe Yearbook, which focused on the laws regarding health care decisions made at a national level throughout Europe.

Claude Moraes, MEP, explains in his foreword in the 2009 Dementia in Europe Yearbook that “the protection of people with dementia, one of the most vulnerable groups in our societies and the respect of their self-determination and their wishes is clearly an ethical challenge for which national laws have adopted different solutions”. These national ‘solutions’ have been catalogued in the 2009 Dementia in Europe Yearbook and were obtained by Dianne Gove, Information Officer at Alzheimer Europe in collaboration with national legal experts. The result is an inventory of the laws regarding healthcare decision making in 31 European countries.

The main symptom associated with dementia is that the mental capacity of the individual becomes progressively impaired and, as such, differentiates dementia from many other terminal diseases. The healthcare decision making process for a person with dementia, their carers and health care providers is therefore intrinsically linked to the issue of capacity. The 2009 Yearbook considers the legal protection afforded by European countries in four areas of healthcare decision making: (a) consent, (b) access to information and diagnosis, (c) advance directives and (d) end-of-life issues for people with dementia.

Consent

Consent has been increasingly debated and some countries, such as France, have had significant reforms over the last decade. In addition, instruments which incorporate the issue of consent at European level have impacted on a national level. An example of this is the Council of Europe’s Convention on Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (1998) which contains provisions for consent and the provision of information.

Although the ability to give informed consent diminishes as dementia progresses, a person with early stage dementia is able to consent. Therefore, the earlier a diagnosis of dementia can be made, the longer a person with dementia will be able to participate fully in decisions affecting his/her life. It is therefore important to understand, from a legal perspective, when, how and who can give consent to a person with dementia’s healthcare.

There are certain situations when it is not obligatory to obtain consent, for example, consent is not required if the physician considers there to be a “case of emergency” as in this situation consent is presumed.

However, in general terms, the inventory revealed that the provision of healthcare goes hand in hand with obtaining consent.

If a person is deemed unable to give oral or written consent themselves, then that person could be protected if an obligation were in place to obtain
Evidence was found of an increasing willingness to discuss advance directives. One way to obtain such consent is to identify someone other than the incapacitated person who can give consent on their behalf. Different definitions were given of who could take on this role, although it was common that it would be the incapacitated person’s legal representative or family.

It appears that consent given on behalf of an incapacitated person is established more easily in some areas. Understandably, if the consent required is for clinical trials or medical research, assuming that the person with dementia cannot give consent, then very specific criteria are often applied. EU directives also prescribe good practice for participation in clinical trials and research. The issue of confidentiality also arises as it becomes necessary to protect the privacy of the person participating.

Not all countries describe how consent may be withdrawn for participation in clinical trials, although it was often reported that consent could be withdrawn at any time. In France it seems possible that withdrawal can be implied but, in other countries, it was more often reported that withdrawal should be in writing.

Another way a person’s wishes could be communicated was highlighted in the Netherlands, where, in respect to withdrawal of consent, the “slightest resistance to the treatment or procedure” could amount to withdrawal of consent. It may also be possible to ascertain a person’s wishes if they have previously made them known, for example, in a living will. This instrument can be helpful for people with dementia, particularly if their wishes regarding future participation in research are noted. Other wishes contained in living wills are discussed below.

Many countries reported that a person may refuse a proposed treatment (AT, BE, BG, CR, CZ, FI, FR, GR, HU, IS, IT, LV, LT, LU, MT, NL, NO, PL, PT, SK, SI, ES, CH and UK), but the conditions for allowing this vary. Often a requirement that the refusal of a specified treatment be in writing is made and this may be included within an advance directive, although not all countries recognise such documents. The right to refuse treatment can be overruled if lack of treatment would endanger others. Court intervention may be sought if a doctor disagrees with such refusal (AT, BG, CY, CZ, FI, LT, NL and PT). Some countries require that additional requirements be fulfilled such as an acceptable alternative treatment should be offered in place of the original treatment (FI), that the consequences of refusal of such treatment be made known to the patient (IS, LV, SI) or that a second opinion be sought (FR).

The Yearbook also considers the issue of consenting to organ donation. Generally speaking a presumption that after death a person consents to donate their organs exists in several European countries (BE, FR, HU, LU, PT, SK and SI). However, this can be rebutted if it can be proved that in life the donor did not wish to do so and some countries demand that doctors endeavour to ascertain this. In addition, this presumption of consent is not the case in all European countries and it may even be considered illegal to remove organs without evidence of an organ donation card (MT).

Advance directives

Although in the late stages of dementia the ability to display the necessary level of capacity required to make an advance directive is most probably lacking, this is not the case in the early stages of the disease. Advance directives have been used to
record a person’s future preferences on topics such as: appointment of proxy decision makers for financial, administrative or care decisions, donation of organs, consent to clinical trials or research participation, the refusal of treatment (provided it is described precisely), life prolonging treatment and life support. An advance directive may also be used to provide information on the type of food or preferred clothing someone has. It is not possible to carry out requests made in an advance directive which are deemed to be illegal or that are not what was envisaged when the document was drafted.

Half of the countries which took part in the survey reported some kind of recognition (legal or otherwise) of advance directives or previously recorded wishes (AT, BE, CY, DK, EE, FI, FR, DE, GR, HU, IS, IT, IE, LU, NL, NO, ES, CH, TR and UK). On the other hand, just over a quarter of countries (mainly Eastern European) said that the whole concept of advance directives was not yet recognised in their country (BG, CZ, LT, MT, PL, PT and SK). Nevertheless, evidence was found of an increasing willingness to discuss advance directives. In 2009 the Hungarian Parliament voted for a new civil code which contains requirements for advance directives and although the president vetoed this code, there will be another vote in May 2010. Switzerland also has new guidelines which encompass directives and discussions have commenced in Malta as well as Ireland. The issue of advance directives will be further raised if and when countries sign European legislation such as the Convention on Biomedicine, which recognises the legal status of directives.

The existence of interest in advance directives at non-governmental level could be evidenced in some countries by organisations being established with the purpose of helping people draft their wishes even when advance directives are not legally binding (NO), and also by information being offered about advance directives by NGOs such as Alzheimer associations (CH).

Certain formalities need to be adhered to if a directive is to be valid. Of these there are two which may prohibit a person with dementia having a valid and revocable directive: capacity and time limits. To fulfil the requirement of capacity, should a person with dementia wish to make an advance directive, it should be done during the early stages of the disease. It is a common feature of directives that they may be revoked at any time, although ambiguity exists regarding whether it is possible for a person with dementia to revoke a directive as revocation may be evidenced by a range of measures from changes in behaviour to formal notification.

Validity also may become an issue for a person with dementia if it becomes impossible to renew the directive. This is because some European countries placed a time period on the validity of a directive of 2, 3 or 5 years (HU, FR and AT respectively). Conversely, some countries stipulated that there is no set time limit for the validity of an advance directive (CH, ES and FI).

Although a country may recognise the legal status of an advance directive, it does not necessarily follow that an obligation to comply is created. Mostly, it is the specific nature of each request which often determines whether it will be binding or not. Dementia is a terminal condition and this is an important factor for some countries when determining whether a particular instruction is binding or not. In Denmark, providing formalities are adhered to, directives which state that life supporting treatment is not desired if the person is facing unavoidable death will be considered as
PRioRITISING DEMENTIA

Around a third of countries reported on some kind of provisions for carers to be given leave to care.

legally binding. However, if the same request declining life supporting treatment is made but the reason is because of illness, advanced debilitation due to old age, accidents, heart failure or similar situations that cause such a severe invalidity that they would be permanently unable to take care of themselves physically and mentally, then the directive would be considered as advisory. There is a similar distinction in other countries which results in a directive being deemed as advisory or binding.

If the directive is not considered binding, it can still be taken into account and this is the case in many of those European countries who recognise, legally or not, the concept of a legal directive (AT, BE, DK, FI, FR, DE, HU, LU, NL, SI, ES, CH and UK) and in some countries directives are only considered on a case by case basis (BE).

Access to information and diagnosis

The issues which surround access to information must be considered alongside the issue of consent (above) as one is often reliant upon the other.

Whilst generally speaking people do have a right to information and doctors are obliged to inform them, the majority of countries also reported that at the same time, doctors do have a right (or responsibility) to decide to withhold information (AT, BE, CY, CZ, DK, FR, GR, HU, IS, IE, IT, LV, LT, LU, MT, NL, NO, PL, PT, SK, SI, ES, SE, CH, TK and UK). For example, in Austria a doctor may choose not to tell a patient a non-confirmed diagnosis and in many countries if doctors are concerned about the impact on the patient’s physical or mental health then they may also choose not to pass information on.

For people with dementia and their carers it is the disclosure of diagnosis which can present problems. Sometimes it may be assumed that people with dementia cannot understand their diagnosis, or that telling them may be detrimental to their health. This can result in a carer being told of a diagnosis, or given a medical file without the person with dementia having been informed and the issue of confidentiality then arises. The inventory found that whilst doctors were bound to secrecy, this right of confidentiality was reduced when dealing with people who have a mental incapacity. Also of paramount importance for people with dementia is that the information be conveyed in an appropriate and understandable way as they may have problems retaining information and communicating.

Naturally, there will come a time when it is necessary for carers to be included in any information given, and they may want the right to receive information. The right to designate another to receive information was not mentioned in many of the country reports. Where this was not an option, it was not always clear exactly who would be given access. Sometimes the access would be granted to anyone who had been appointed by the Court whereas sometimes it would be determined by a prescribed list (by relationship type). In addition, there was ambiguity as to whether the right to medical files would extend to healthcare outside that of an institution. With many people with dementia receiving care at home it seems unclear whether their medical files would be accessible.

End-of-life care

As dementia is a terminal illness, special consideration was given in the Yearbook to the healthcare given at the end of life.

Alzheimer Europe has advocated that palliative care is the best option for people with end-stage
dementia in their report “The use of advance directives by people with dementia”. Only half of the countries expressly reported on (varying) degrees of palliative care rights or guidelines (BE, BG, CY, DK, FI, FR, HU, IT, LT, LU, MT, NL, NO, PL, PT, SK, ES, CH, and UK) and even where a right to palliative care exists, it didn’t follow that palliative care was received. For example, in Bulgaria, there is a right to palliative care and yet it is infrequently realised, largely because there are no laws governing the organisations, hospice or activities of palliative care and therefore no control of this right. Another case in point is Poland, where there are over 500 facilities which offer palliative care, yet they are often reserved for cancer patients which results in it being uncommon for people with dementia to have access to this care. However, it seems that the area of palliative care is one which is being developed. In Malta, the Malta hospice movement (which is the only provider of palliative care) has ongoing discussions with the Department of Health to introduce palliative care into medical practice.

The end stage of dementia requires constant care and for carers who are also in paid employment this is a real challenge. Around a third of countries reported on some kind of provisions for carers to be given leave to care (BE, DK, FI, NL, NO, PL, PT, CH and UK). Poland is one of the few Eastern European countries which recognises a special leave entitlement for carers. Commonly, countries granted special leave to care of the terminally ill (although in Portugal it was to take care of those in need of urgent and unavoidable care). There is quite a wide range in the time allowed off between countries, which can be up to 12 weeks a year in the Netherlands. Often, rather than a right per se to time off, it was more that if the employer agrees then the state may facilitate (either by ensuring the job is kept open or that the time off is reimbursed). Some states wish to make the special leave protected on a statutory basis with the employer being obligated to grant the leave.

The Yearbook also contains information on euthanasia. Even in those countries which recognise euthanasia, there is a requirement that the person has capacity to ask for this. People with dementia will not be able to give consent to euthanasia in the late stages of the disease because they will probably lack the required capacity to do so. Reports in the Yearbook distinguish between passive and active euthanasia and debate is ongoing as to whether euthanasia can be requested specifically in cases of dementia.

Overall the Yearbook offers greater insight into each national legal situation for people with dementia. Whilst many variations are evident between the Member States in terms of their legal provisions and approaches to healthcare decision making, it is hoped that the 2009 Yearbook, as Claude Moraes (MEP) said, “will prove highly useful to policy makers on a European and national level. The exchange of good and best practices in this field will hopefully lead to a greater recognition of the need to respect the dignity and autonomy of people with dementia and to involve them as much as it is possible in all decisions affecting their lives.”

“The exchange of good and best practices in this field will hopefully lead to a greater recognition of the need to respect the dignity and autonomy of people with dementia and to involve them as much as it is possible in all decisions affecting their lives.”

Claude Moraes MEP
IMPROVING THE DRUG DEVELOPMENT PROCESS IN EUROPE

PharmaCog is a European project funded by the Innovative Medicines Initiative, a new and unique partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations.

PharmaCog, short for “Prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development”, a cross party project, co-ordinated by GlaxoSmithKline R&D and the Université de la Méditerranée, Marseille, France, started its activities on 1 January 2010 thanks to significant funding (EUR 20.2 million) from the Innovative Medicines Initiative. Its launch marks the start of the most ambitious European project for tackling bottlenecks in Alzheimer’s disease research and drug discovery.

This hugely ambitious project brings together top scientists from 12 academic institutions, 11 global pharmaceutical companies, 5 small and medium sized enterprises (SMEs) with patient representation from Alzheimer Europe.

It is hoped that by the end of this 5-year project, PharmaCog will have a) validated the tools necessary to streamline Alzheimer’s disease drug discovery and accelerate effective medicine to patients, b) set the standard for European drug discovery providing optimised and validated protocols, c) provided the infrastructure to sustain world class drug discovery in Europe and d) disseminated the results obtained from health professionals to patients.

Ultimately, PharmaCog should provide the tools needed to define more precisely the potential of a drug candidate, reduce the development time of new medicines and thus accelerate the approvals of promising new medicines.

Alzheimer Europe will represent the interests of people with dementia and their carers in this consortium and ensure the dissemination of research results to a lay audience. PharmaCog will also work closely with the European Medicines Agency, as an associated partner of this project, to share project progress and discuss the implications for drug development in Europe.

The PharmaCog consortium consists of the following partners coming from 10 different EU Members States:

1. Alzheimer Europe (Luxembourg),
2. AstraZeneca (United Kingdom),
3. Boehringer Ingelheim (Germany),
4. Centre National de la Recherche Scientifique (France),
5. Eli Lilly and Company (United Kingdom),
6. Exonhit Therapeutics (France),
7. F. Hoffman-La Roche (Switzerland),
8. GlaxoSmithKline (United Kingdom),
9. H. Lundbeck (Denmark),
10. Innovative Concepts in Drug Development (France),
11. Innovative Health Diagnostics (France),
12. Institut d'Investigacions Mèdiques August Pi i Sunyer (Spain),
13. Institut de Recherche Servier (France),
14. Institut National de la Santé et de la Recherche Médicale (France),
15. Istituto di Ricerche Farmacologiche “Mario Negri” (Italy),
16. Janssen Pharmaceutica (Belgium),
17. Merck (Germany),
18. Novartis Pharma (Switzerland),
19. Ordine Ospedaliero di San Giovanni di Dio Fatebenefratelli (Italy),
20. Quallissima (France),
21. SAS Alzprotect (France),
22. UCB Pharma (Belgium),
23. Universidad de Murcia (Spain),
24. Università degli Studi di Foggia (Italy),
25. Università degli studi di Verona (Italy),
26. Universität Leipzig (Germany),
27. Universitätsklinikum Essen (Germany),
28. Université de la Méditerranée, Aix-Marseille II (France),
29. Université de Lille 2 (France).
**PolicY Watch**

20 Developing national dementia plans across Europe
We speak with Charles Scerri (Chair of the National Dementia Strategy Group in Malta), Antigoni Diakou (President of the Pancyprian Alzheimer Association), Dr Christos Patsalides (Minister of Health, Cyprus) and Teresa Caeiro (MP, Portugal) about progress made in their country to create a national dementia plan.

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Alzheimer Portugal reports on its recent conference in Lisbon.

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Sirpa Pietikäinen, MEP (Finland) talks about the key challenges that face people with dementia and their carers in Finland.

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Prof. Philippe Amouyel, Chair of the Management Board of the Joint Programming Initiative on Neurodegenerative diseases, including Alzheimer’s disease, speaks to Alzheimer Europe about how he hopes the Initiative will address some key challenges.
DEVELOPING NATIONAL DEMENTIA PLANS ACROSS EUROPE

At European level there is much activity ongoing to ensure action is taken to address the challenges dementia presents. In this section of the magazine we hear about work being carried out to develop national plans in Malta, Cyprus and Portugal.

Malta

Dr Charles Scerri, Chair of the National Dementia Strategy Group in Malta and General Secretary of the Malta Dementia Society, talks with Alzheimer Europe about the need for a national dementia strategy and the aims of the Strategy Group.

Alzheimer Europe: Dr Scerri, as Chair of the National Dementia Strategy Group, could you explain why the Strategy Group was set up in May 2009 and what were its objectives?

Charles Scerri: One of the most important challenges facing the Maltese society is the ever-increasing number of the elderly population. Individuals above the age of 65 years will double by the year 2050. As a result, neurodegenerative diseases normally associated with old age, such as many forms of dementia, will also rise proportionately. This was highlighted by a recent research study indicating that two percent of the general population in Malta will have dementia in the next 40 years, double the current data. This will bring about a significant demand not only on healthcare services but also on the society in general as most of the care is provided in the community. Therefore, the need to have an appropriate dementia strategy in place was a tangible reality. The setting up the National Dementia Strategy Group in May 2009 was the idea of the Maltese Parliamentary Secretary for the Elderly and Community Care following the Paris Conference “The Fight Against Alzheimer's Disease and Related Disorders” in October 2008. President Nicolas Sarkozy’s closing speech provided us with the impetus to embark on such an ambitious project. Furthermore, other European countries are already working on their national plans and Malta needs to follow in the same direction. The task of this Group was to design a strategy that would provide a clear pathway for improving dementia services in Malta.

AE: What do you believe the aims of a National Dementia Strategy should be?

CS: The aim of the National Dementia Strategy is to map out the strategic direction for improving services for people with dementia and their care-givers in the Maltese islands. This will be a challenging task and will necessitate considerable financial investment and the participation of various stakeholders. The latter is of utmost importance during the implementation phase and in fact during the consultation process, the National Dementia Strategy Group carried out a series of meetings with the many stakeholders involved. Moreover the general public was also invited to contribute through a specifically-
designed questionnaire and the results of this exercise were incorporated in the final report.

AE: The Strategy Group’s recommendations were presented to the national health authorities in January 2010. Which do you consider to be the key recommendations which were made?

CS: The report “Inspiring New Frontiers – The Malta Dementia Strategy” highlights ten key recommendations. The latter recognize the need to increase dementia awareness at all levels by providing good-quality information, improving early diagnosis and intervention, improving the quality of acute and long-term dementia care, developing appropriate community support and improving end-of-life services together with strengthening legal and ethical issues regarding individuals with dementia and their care-givers. Each recommendation is supported by suggestions aimed at achieving these outcomes.

AE: What reaction to the recommendations do you hope for from policy makers?

CS: The report was presented to the Parliamentary Secretary for the Elderly and Community Care at the end of January 2010. Therefore, it is still early to get a formal reaction from the government authorities. The recommendations put forward will entail significant amount of work spread over a number of years. The report recognizes the need for training and improvement of services, all of which requires planning and financial investment. It also makes an emphasis on moving away from the disease model thus favouring a patient-centred approach. Consultation with stakeholders emphasized on the need to start addressing dementia at a national level and thus the gradual implementation of these recommendations at the earliest. Establishing a National Dementia Strategy Board that will coordinate the implementation process would be a step in the right direction in ensuring that the targets are effectively met.

AE: Thank you for this interview and we wish you every success in ensuring a National Dementia Strategy becomes a reality in Malta.

Cyprus

In January 2010 the Pancyprian Alzheimer Association was asked to cooperate on the development of the Cyprus Strategic Plan for Alzheimer’s disease. Alzheimer Europe asks Antigoni Diakou, President of the Association, about how they have raised awareness of the need for such a plan and what their expectations are.

Alzheimer Europe (AE): How has the Pancyprian Alzheimer Association raised awareness of the need for a Strategic Plan against Alzheimer’s disease in Cyprus?

Antigoni Diakou (AD): For the last 14 years, since its foundation, the Pancyprian Alzheimer Association has been working hard to raise awareness about Alzheimer disease amongst the Cypriot population.

We believe we have succeeded in doing this to a great extent, but a lot remains to be done in all other areas that concern the welfare
of people with Alzheimer disease and their families.

In order to achieve as much as possible, during all these years, we have invested in building a strong alliance between the Pancyprian Alzheimer Association and the Cyprus Ministry of Health. We strongly believe in team work and synergy with both the government and the public.

For the last 10 years, the President of the Pancyprian Alzheimer Association has participated in a Multidisciplinary Committee which has been set up by the Ministry of Health to deal with Alzheimer issues.

Through our collaboration, we have made progress for the benefit of people with Alzheimer's disease and their families. For example, one of the medications is given free of charge in state hospitals and the others are provided by co-payment, training has been offered to doctors and nurses, conferences have been held, tv and radio broadcasts have been organized and many activities during the campaigns for Alzheimer International Day have been run jointly.

As President of the Pancyprian Alzheimer Association, I consider it my obligation to fully inform and urge the members of this Multidisciplinary Committee to keep up with European developments in relation to Alzheimer’s disease. In 2008, representatives from this committee and myself attended the French Conference “The fight against Alzheimer's disease and related disorders”, whereby we all came to appreciate the highly regarded French plan. Our participation at the French conference enabled us to develop common understanding and made us think of how we could best contribute towards the fight against Alzheimer's disease.

Following that conference, as an NGO, we succeeded in personally contacting and persuading all of our Cypriot MEPs to sign the Written Declaration 80/2008.

We also intensified our initiatives and ensured that our Minister of Health Dr Christos Patsalides was not only informed about these activities but he was also personally involved; whenever he could personally attend to support us he did so. For example, he joined us during our campaign of 2008 Alzheimer Disease International Day and gave a press conference which guaranteed publicity for our cause. In 2009, the Middle Eastern conference was put under his auspices and he again called a press conference. Also in 2009, the Minister inaugurated a Day Care Centre, another initiative of our NGO, in the presence of a cypriot MEP and two national MP’s. His speech denoted the great importance he places on fighting Alzheimer disease.

All of the above are but examples of how through hard work we have proved ourselves to the Minister and we believe we have in this way gained his respect to listen to our needs for the benefit of our cause.

Following the example of the many other European fellow countries which have, or are in the process of developing, national strategic plans against Alzheimer’s disease, we felt legitimized to act in a similar way. Thus in January 2010, as an NGO we requested a meeting with the Minister of Health to discuss the need for a Strategic Plan against Alzheimer’s disease in Cyprus.

At the meeting, we had invited Dr. Magda Tsolaki, President of the Greek Association of Alzheimer's Disease and Related Disorders, to join us and reinforce us by discussing the Greek
experience. Her presence proved indeed to be catalytic and our Minister of Health was more than receptive to lead the way for the development of our National Strategic Plan. During the meeting, we presented to our Minister the latest issues of the Alzheimer Europe Magazine and the Newsletters, highlighting the fact that many European countries are developing National Plans. We believe that such documentation added value to our request for the development of the Cyprus Strategic Plan. The Minister was more than positive and proceeded to ask for the setting up of a National Committee in which both representatives from the Ministry of Health and our NGO should participate to draft the Cyprus Strategic Plan against Alzheimer’s disease.

AE: The Pancyprian Alzheimer Association has been asked to co-operate with the Ministry of Health in the Development of a Strategic Plan. What are your hopes and expectations from this process?

AD: As an NGO, I expect the process of co-operating with the Ministry of Health in developing our National Strategic Plan, to be a great learning opportunity leading to change in the way people with Alzheimer’s disease and their families are regarded by the wider Cypriot community.

We are determined to continue to invest in efforts of synergy, transparent dialogue and reaching consensus with the Ministry of Health, so as to fully address the needs of people with Alzheimer’s disease and their families for an improved quality of life.

We also expect that the crucial key role of our NGO in raising awareness and informing the public, will be brought forward and even further empowered by the National Strategic Plan.

We hope that our co-operation will finally lead to the implementation of a coherent Strategic Plan of European standards with a realistic budget and time frame.

“I expect the process of co-operating with the Ministry of Health in developing our National Strategic Plan, to be a great learning opportunity leading to change in the way people with Alzheimer’s disease and their families are regarded by the wider cypriot community.”
Antigoni Diakou
Cyprus

Pancyprian Alzheimer Association (PAA): Dr Patsalides, in your capacity as Minister of Health of Cyprus, you have pledged your support in the fight against Alzheimer’s disease and have called for the preparation of the Cyprus Strategic Plan for Alzheimer’s disease. Could you explain why you think there is a need for a Strategic Plan in Cyprus.

Christos Patsalides (CP): Alzheimer’s disease poses a growing challenge. It affects the lives of a great number of Cypriots, who either suffer from this disease or care for someone who does. According to the most recent local survey, 14,000 persons older than 60 years suffer from different types of dementia, and, from those, 9,500 suffer from Alzheimer’s disease. As the population of Cyprus grows older, the number of these cases is expected to expand rapidly in the coming years, thus increasing the burden the disease places on individuals and families. Less appreciated are the economic impact and the pressure for the health system and society in general, which will only increase as the prevalence of Alzheimer’s disease rises.

Portugal

During Alzheimer Portugal’s conference in October 2009, Portuguese MPs pledged their support to develop a Portuguese Alzheimer’s Plan. In this article, Alzheimer Portugal speaks with MP Teresa Caeiro about the challenge dementia and Alzheimer’s disease present as well as the action required to address them.

Alzheimer Portugal: Alzheimer’s Disease and other forms of dementia now affect 7.2 million people in Europe. In Portugal there are, an estimated 153,000 people with dementia, 90,000 of whom have Alzheimer’s disease. How do you evaluate the response of states to this problem?

Teresa Caeiro (TC): Mental health, dementia and Alzheimer’s disease will certainly be one of the great challenges of twenty-first century European societies: A challenge that can only be faced with a combination of efforts in different areas such as health, social security and employment. The response of European states has not been consistent, in terms of the speed and style. In Portugal, we need to catch up and deal with the seriousness of the problem and with the political commitment, also with the disease itself and its effects on those people with dementia, their families and society. Unfortunately, it is an area where there are inadequacies at all levels: in access to medical expertise in public health as well as in the home care to patients and to their families, but also with regard to social facilities which are able to receive these patients.

AP: Given the characteristics of its population - ageing and economic weakness – which, in your view, should be the policy priorities which would ensure that people with dementia and
A Strategic Plan is needed to assist and ensure that the problem is tackled in a coordinated, comprehensive and cost-effective way.

PAA: What do you consider to be the key issues which should be addressed within the Strategic Plan?

CP: The following are considered to be the key issues to be addressed within the Strategic Plan:
- To improve public and professional awareness about the disease, for earlier diagnosis and intervention as well as a way to eliminate the associated stigma.
- To improve further existing capabilities for early diagnosis and intervention, through joint efforts of various health professionals of private and public sector
- To plan for the provision of higher quality primary, secondary and tertiary health care for the patients as well as the provision of good quality information, professional support and advice for those diagnosed with the disease and their carers
- To develop a supportive social network for the patients and their carers, at home, in the community as well as special care homes.

Within the Strategic Plan, the role of various stakeholders, involved in each of the above issues, will be specified.

their caregivers are supported? What measures are present in this term?

TC: We must have Alzheimer’s disease among the social and public health priorities in Portugal. First, it is necessary to make a realistic assessment of the situation of Alzheimer’s disease in Portugal and an epidemiological facts projection in the short, medium and long term. Only then can we properly assess the needs that are unmet and act (politically and socially) accordingly. Next, you need to make this disease a budgetary and legislative priority, channelling funds (directly or indirectly) for the construction of an effective diagnostics, support, monitoring, treatment and care network to patients and their families. It is a priority to create legislation for caregivers, particularly for family caregivers, because the overwhelming majority of people with dementia are increasingly dependent on one or more family members. These, in turn, are dependent on this assistance as it becomes increasingly difficult to reconcile caring with jobs and reduced family budgets. Indeed, it is often the case that, family members are forced to stop working to be caregivers, which may remove the only source of income of the household.

I assume that it is the obligation of both the state and society to work together in this effort and support the families that (intentionally or unintentionally) care for people with dementia. I think there is an urgent need for a specific financial support aimed at helping these caregivers.

AP: What is the role of patient associations and the non-governmental sector?

TC: I cannot imagine a system of social protection without a close and competitive non-governmental sector. The state is responsible to ensure the existence of a non-governmental sector and to be a regulator aware of their activities and of the funding needed to achieve the European social model that we can all be proud of.

The quality of the presentations about Alzheimer’s disease ensured that the conference “Alzheimer’s disease: What Policies?”, which took place in Portugal last October, was a success. Hosted by Alzheimer Portugal, this conference gave more than 250 people the opportunity to find out more about the current policies in several European countries.

The success of the conference was also due to the attendance of the Portuguese MPs Teresa Caeiro, Maria Antónia Almeida Santos, Fernando Negrão, João Semedo and Bernardino Soares. Alzheimer Portugal were honoured that these MPs, who represented all the Portuguese political parties, had accepted their invitation to support the goals of the Conference: discussing dementia policies.

Maurice O’Connell, President of Alzheimer Europe, and Jean Georges, the Executive Director, reported on the state of dementia in Europe and made a very positive overview of the European dementia movement. Under the leadership of Alzheimer Europe, the movement has made significant progress since the Paris Declaration, signed in 2006. Several European countries have created and are implementing plans, national strategies or significant policies for dementia. The European Commission, the Council and the European Parliament now recognise dementia as a European priority. We were encouraged by the Communication made by the Commission to the Parliament and the European Council about the European Initiative on Alzheimer’s disease and other dementias of 22 July 2009 and the Commission proposal for a Council Recommendation on measures to combat neurodegenerative diseases, particularly Alzheimer’s disease, through a joint research program.

Mary Marshall, Emeritus Professor at the University of Stirling, Scotland, reflected on the wide picture of a disease that knows no borders and spreads around the world, at a disturbing speed.

Professor Charles Scerri, of the Malta Dementia Society, Andrew Chidgey, of the Alzheimer’s Society UK, both responsible for the implementation of National Dementia Strategies in their countries, and Federico Palermiti, Head of the Department of Social Studies of Fondation Méderic presented, in detail, the different National Plans for Alzheimer’s Disease.

In Portugal, given the lack of protection for the estimated 153,000 people with dementia and their caregivers, we were reminded that we must seize the opportunity created by this favorable European context.

In his presentation on the Portuguese situation, Dr Celso Pontes, a Portuguese neurologist and Member of the Alzheimer Portugal Scientific Committee, made it clear that very little is known about dementia in Portugal: How many people are diagnosed? How many people are accompanied by a specialist, treated, and receive non-pharmacological intervention? Where are these people? At home, alone or with their families? In nursery homes or attending day care? Do they have access to home support services? And the caregivers, do they have any help? What are the direct and indirect costs associated with dementia?

In Portugal, given the lack of protection for the estimated 153,000 people with dementia and their caregivers, we were reminded that we must seize
Dr Celso Pontes made it clear that very little is known about dementia in Portugal.

the opportunity created by this favorable European context, as well with the work and information gathered and organised by Alzheimer Europe, in projects such as Lawnet or EuroCoDe.

This demonstrated the need for a National Dementia Plan in Portugal.

Three aspects seem fundamental to a supportive environment for the creation of a National Plan for Dementia.

I. The gathering and organising of information in order to obtain a general view of the national situation. We must know before we act!

II. The execution of a nationwide campaign to improve awareness of the symptoms and early signs of dementia, and to combat the stigma associated with the disease, in order to reduce isolation and loneliness.

III. The organisation of a national debate involving all stakeholders – people with dementia, carers, policy makers, social and economic professionals, and the media, in order to clarify the urgent need to develop a national plan of Alzheimer intervention covering three main lines of action:

a) To improve the quality of life of people with dementia and their caregivers, including issues associated with the pharmacological and non-pharmacological intervention, with social support and facilities through the creation and implementation of specific health and social support policies.

b) To carry out research about the causes, prevention and diagnosis of Alzheimer’s disease and gathering of epidemiological data.

c) To create a legal framework defining the rights of people experiencing disability, including the legal framework of care, intervention and research.

Before a responsive and demanding audience Teresa Caeiro, Maria Antónia Almeida Santos, Fernando Negrão, João Semedo and Bernardino Soares discussed the national situation and the priorities for dementia:

- Alzheimer’s disease and other forms of dementia currently affect 7.3 million Europeans, 153,000 of which are Portuguese, and it is anticipated that with the ageing population, this number will double by 2020;
- This disease is the leading cause of dependence, resulting in a considerable burden for caregivers and the Health Systems and Social Protection;
- A political commitment in the field of research, prevention, treatment, care and social protection, and the improvement of the legal framework of the Rights of People with Disabilities are essential;
- Alzheimer’s disease is a public health and social policy priority.

These MPs have assumed the commitment to propose the creation of a Working Group within the framework of the Parliamentary Health Committee and pledged to promote the discussion and monitoring of the Alzheimer’s disease challenge, namely through the improvement of research, prevention, early diagnosis, treatment, access to care and quality of life of people with this disease.

Alzheimer Portugal is deeply grateful to all national and international participants and to the MPs for their support to this initiative, helping to create a more aware, responsive and responsible society.
Ms Pietikäinen, what are the key challenges that people with dementia and their carers face in Finland?

I would like to focus on three key points. They are early diagnosis, quality of care and services, and looking after the carers. Early diagnosis allows for many of the symptoms to be treated and thus enhances the possibilities to sustain normal daily life. Also, it is of vital importance to the patient, and his or her family, to understand the nature of the disease which reduces the stress that rises from uncertainty. It also allows them more time for many critical decisions in life to be made.

The level of care and services still vary a lot locally. Despite of nationwide standards there is an urgent need of better monitoring institutions and services locally.

Caregiving is one of the hardest jobs one can imagine and looking after the carers is of utmost importance. It consists not only of guaranteeing the financial resources but especially taking care of the physical and mental well-being of the carers.

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?

Yes, there are. The public attention is mainly on demographic change and its fiscal consequences. Much less has been discussed about how to cope with the rising amount of people with memory related illnesses.

But, I’m convinced that the awareness is about to rise and there are good signs of it in the political arena. The Ministry of Social and Health Care has given some recommendations and it is preparing a new law considering elderly people, so, at governmental level, I see that the issue is rising on the political agenda.

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

I am quite convinced that Finland will follow. I have taken up the issue of the plan into public discussion and I have had conversations about it with many of our politicians. Our Minister of Health and Social Services has taken the initiative very seriously and her Ministry has given a promise of a national memory-illness plan.

The plan should follow the guidelines of the famous Finnish North-Carelia – project which combined research and guidance and managed to reduce significantly cardiovascular diseases. In the same manner, we can combine the general research on memory-related illnesses with the monitoring of personal brain health, with information on the living-habits and thus increase the public knowledge of these illnesses.
AE: What do you believe should be the three policy priorities for Finnish policy makers to improve the lives of people with dementia and their carers in your country?

SP: The main priorities are linked to the three points I mentioned earlier and the national plan. As a part of the plan I would like to emphasize one very important issue: the status of the national Alzheimer or other memory-illness organisations.

Organisations have experience and knowledge on the overall situation and all aspects of the quality of care, including practices in institutions and support provided by the local authorities. This knowledge can be utilised if organisations could be legally recognised advocates in issues considering the memory-illnesses and the overall situation of the patients.

The principle is the same that the environmental organisations were given in the treaty of Århus. They can start a legal process on behalf of patients’ interests, for example in cases of neglect. This is even more important now, when we have noticed in Finland that there is an urgent need to introduce adequate quality control of long term care.

AE: Finally, 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?

SP: Yes, I will support it with great pleasure. I have discussed the issue also in the European Parliament and I hope that it wouldn’t be too long before the new commission present the plan Parliament has asked for.

Priorities of collaboration start from preventing brain diseases. Special attention should be paid to information to the public, with guidance on the ways to avoid these diseases. Through research we also need more information on the mechanisms of brain diseases and get new means to prevent and treat them.

Last, but not least, comes the question of quality of life. We simply have to make sure that as many people as possible can maintain their functional capacity. We also have to secure the best possible quality of life for people with memory-related illnesses and their carers and close ones. From my own experience as a carer I know that there are also always many small happy moments in everyday life. With the right and adequate support these moments are not too much overshadowed.

“From my own experience as a carer I know that there are also always many small happy moments in everyday life.”

Sirpa Pietikäinen
The European Parliament confirms new European Commission and approves a set of principles for cooperation between the two institutions

At its plenary sitting of 9 February 2010, the European Parliament approved the new European Commission led by President José Manuel Barroso. Of particular interest to the activities of Alzheimer Europe and our member organisations are the following appointments:

- John Dalli (Malta) is the new Commissioner for Health and Consumer Policy,
- Laszlo Andor (Hungary) is the new Commissioner for Employment, Social Affairs and Inclusion,
- Máire Geoghegan-Quinn (Ireland) is the new Commissioner for Research, Innovation and Science,
- Viviane Reding (Luxembourg) has been given the Justice, Fundamental Rights and Citizenship portfolio and
- Androulla Vassiliou (Cyprus) has been given the Education, Culture, Multilingualism and Youth portfolio.

The new Commission will have a 5-year mandate and stay in office until 31 October 2014.

The Spanish Presidency of the EU presents its priorities

On 1 January, Spain took over the Presidency of the EU from Sweden.

This Presidency set out the following 4 priorities:

- the full implementation of the Treaty of Lisbon,
- the coordination of economic policies to promote recovery and sustainable growth throughout Europe,
- strengthening of the European Union’s foreign policy to turn it into a real global player,
- fostering a Europe of rights and freedoms at the service of citizens.

The European Medicines Agency organises stakeholder meeting on new dementia developments

At a meeting organised by the European Medicines Agency in London on 11 January 2010, experts discussed the latest developments as to potential biomarkers for the diagnosis of Alzheimer’s disease and for the use of such biomarkers for the assessment of disease progression. Experts provided overviews on CSF, blood based and neuroimaging biomarkers and their potential use in clinical trials.

The EESC adopts its opinion on the Commission’s Communication on Alzheimer’s disease

At its plenary sitting of 16 December 2009, the Section for Employment, Social Affairs and Citizenship of the European Economic and Social Committee adopted its opinion on the Communication from the Commission to the European Parliament and the Council on a European initiative on Alzheimer’s disease and other dementias. In its conclusions, the EESC welcomes the Commission’s Communication and it recognises it is an issue of critical importance in Europe which has implications for individuals, families and society, given the ageing population.

The European Commission discusses how to proceed in their Alzheimer’s initiative with Member States

The European Commission organised a meeting on 14 December 2009 to discuss with representatives of Member States on how best to progress
with their planned Alzheimer’s initiative in respect of the Joint Action. Delegates (including representatives from Belgium, France, Germany, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Poland, Slovak Republic, Sweden and representations from the UK and Finland) discussed the financing and calls for new projects as well as coordination of the Joint Action. Topics for discussion between Member States were suggested (including early detection, prevention, health determinants and promotion of healthy brain lifestyle, epidemiology and registration, network of rights and autonomy, coordination with Joint programming initiative, training and workforce issues and best and bad practices – Dementia care models).

The European Council calls for a new EU 2020 strategy

At its meeting of 10/11 December, the European Council called for a new EU 2020 strategy. This is a follow-up of the Lisbon strategy that was launched ten years ago to face the EU challenges. In view of the economic and social impact of the crisis, the challenges posed by ageing populations, increasing inequalities and climate change, the EU will evaluate the impact of the Lisbon strategy and propose a way forward. The aim is to further improve competitiveness and increase the EU’s sustainable growth potential. The policies must be refocused towards long-term reforms. The European Commission has launched a consultation on the future strategy.

The Competitiveness Council presents its conclusions on the joint programming of research activities in Alzheimer’s disease

The Competitiveness Council of 3 December 2009 presented its conclusions on the joint programming of research activities in Alzheimer’s disease. The Member States do recognise the need to adopt specific national plans and strategies for Alzheimer’s disease and related disorders in order to alleviate the burden on society in general and on healthcare systems. They also emphasise that the joint programming in research on neurodegenerative diseases will contribute to the reduction of fragmentation of research efforts of the Member States and encourage the pooling of skills, knowledge and resources, to advance research on the prevention, diagnosis and treatment.

The Council of Ministers adopts conclusions on healthy and dignified ageing

Following on from the conclusions made in September at the Swedish Presidency Conference on Healthy and Dignified Ageing, the Council of Ministers took the decision to adopt them at the Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council meeting on 30 November – 1 December 2009. The Council emphasised that “Many diseases, in particular Alzheimer’s and other neurodegenerative diseases, affect the individual as well as relatives and friends. Therefore, there is an increased need to develop support for informal or family carers.”

The Council rejects compromise on the proposal on cross-border healthcare

At the Employment and Social Affairs Council meeting on 1 December 2009, a blocking minority (Spain, Hungary, Poland, Portugal, Greece and Romania) rejected the compromise proposal on cross-border healthcare put forward by the Swedish Presidency. “The Directive now has to go through a second reading in the European Parliament.”
JOINT PROGRAMMING ON ALZHEIMER’S DISEASE

The EU’s Joint Programming Initiative on Neurodegenerative diseases, including Alzheimer’s disease, was launched in 2009 and now includes some 24 Member States. In this article, Alzheimer Europe speaks with Professor Philippe Amouyel, Chair of the Management Board of the pilot Joint Programming Initiative.

Alzheimer Europe (AE): Professor Amouyel, you are leading the Joint Programming Initiative on combating neurodegenerative diseases in particular Alzheimer’s disease. Could you explain how this initiative was developed and what the aims of the initiative are?

Philippe Amouyel (PA): Today in Europe, only about 5% of the total public funding of research is common to European countries through the 7th Framework Programme for Research and Technological Development, and about 10% to support intergovernmental schemes or organisations. Conversely, 85% of research budgets are spent on national programmes exclusively. When we compare this to the US, despite the competences and skills distributed all over Europe and the high quality research being performed, European research is perceived to be especially fragmented and less efficient. One research field, which is amongst the most affected not only by a poor level of investment but also by the high degree of fragmentation and lack of coordination, is dementia and Alzheimer’s disease.

To provide a method allowing to reduce these limitations, a Communication to the European Parliament, the Council, the European Economic and Social Committee and the Committee of Regions was published in July 2009 by the European Commission introducing a new concept of collaboration among owners of national research programmes: this is joint programming. It can be defined as “a process in which Member States define a common vision and a strategic research agenda, in order to address a major societal challenge for which the scale and the scope of their national programmes alone may not reach adequate proportions”. Participation of Member States and Framework Programme Associated Countries in such a process is carried out “on a voluntary basis and according to the principles of variable geometry and open access”.

This Communication was published just after France assumed the Presidency of the European Union for 6 months. Almost simultaneously, the President of the French Republic, Nicolas Sarkozy, had decided to make the fight against Alzheimer’s disease and related disorder a national priority, through a global mobilisation of medical, social and research forces. The French Minister of Research and Higher Education, Mrs Valérie Pécresse took the opportunity of this announcement to set up a working group, which she personally headed, entitled “The Health Challenge of an Ageing European Population: Fighting Degeneration” in Versailles during the informal Competitiveness Council organised in Versailles, 17th July 2008.

This working group agreed on the urgency to act in an ageing Europe upon the challenge due to the explosion of neurodegenerative diseases, and it recommended that the Member States under the Competitiveness Council, would launch a joint
programme of research on these diseases, combining socio-economic and medico-biological issues.

Joint programming is neither another programme, nor any new tool to add to the extensive tool box of the existing national, intergovernmental or Framework Programmes. The focus of Joint Programming is not on spending the money, but about assigning the money. In a programming cycle, implementation follows and results from strategic steps which include horizon scanning, scenarios and impact assessments, budget arbitrations, prioritisation, evaluations, criteria and indicator setting. Joint Programming intends to cover those steps but in a specific configuration of countries willing to go together for the same ambitious objective.

**AE:** Member States can decide on a voluntary basis whether they take part in a Joint Programming Initiative. Could you let us know which countries will be taking part in this initiative?

**PA:** Not only Member States can decide on a voluntary basis whether they take part in a Joint Programming Initiative. Given the importance of the theme in Europe, we immediately open this initiative to all the Member States and associated members of the Programme Committee of the Health thematic priority of the 7th Framework Programme. At the very beginning we were 11 countries that prepared and approved a declaration of intent in November 2008. Today 24 countries are participating including: Albania, Belgium, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Luxemburg, the Netherlands, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom.

A management structure, the Management Board, has been established that meets since 18th June, 2009 at least three times a year. A Chair headed by France, assisted by a Vice-Chair headed by Sweden, coordinates the work plan of this initiative. An executive board, including Germany, the Netherlands and Italy, meets every month to implement the work plan. An international scientific advisory board composed of fifteen top-ranking scientists from all over the world equally distributed within the three main challenges, i.e. basic research, clinical research and social and health care research has been nominated. This scientific advisory board will meet next spring and will be in charge to propose scientific priorities in order to allow the Management Board to build up the scientific research agenda.

**AE:** What will be the key challenges that you believe the Joint Programming Initiative should address?

**PA:** The ultimate goal is obviously to find a cure for the disease and to enable early diagnosis for early, targeted treatments. However, the time necessary to reach this goal is not predictable. In the meantime, it is essential to implement solutions that can alleviate, even partially, the plight of families and the economic burden brought about by the increasing prevalence of this disease in our ageing populations. All these elements constitute the bases of a shared vision on which a scientific research agenda will have to be built. This scientific research agenda must address three main challenges.

The first challenge is scientific. Although our understanding of the mechanisms of the disease has greatly improved over the past few years, we are far from the full picture and there is no immediate prospect of finding therapies that may be
effective in slowing or halting disease progression. For instance, research on genetic susceptibility, competitive animal models or new biomarkers must be supported.

The second challenge is medical. The general practitioners, specialists, and other caregivers have at their disposal batteries of tests, from simple to more complex, to clinically explore brain function and help establish a diagnosis. However, the organisation of the care system at all stages of the disease needs further consideration. How is the relationship best managed between those involved in diagnosis, symptom management and social care as the disease progresses from a medical problem into a medical and social problem? What therapeutic strategies (both drug and non-drug) have demonstrated effectiveness in appropriate randomised studies? Do we have clinically meaningful endpoints, for example, is effectiveness judged according to the comfort of the sick, of those who live with her or him, or on the judgement of the evolution of the disease, or even on a recovery which is for now so far out of reach?

The third challenge concerns social care and health services. An environment must be created around the patient and his/her family, which adapts to the evolution of abnormal behaviour in everyday life. For instance, home automation, smart homes, domotics must be developed. Simple adaptions to the environment and support for caregivers at the onset of illness requires a continual gradual increase of energy and skills. At what stage should one consider leaving their home for life sites? And how would these structures be organised with enough trained and valued staff, able to deal with conditions of varying severity?

A work plan has been prepared among the participants. This work plan is organised around five work packages with work package leaders from all over Europe: management and coordination (France), development of the strategic research agenda (UK and Italy), implementation of this strategic research agenda (Germany and Turkey), communication and dissemination (Ireland), framework for monitoring and evaluation of the pilot initiative (the Netherlands). Finally, the essential objective of this action is to promote new initiatives around research excellence intended to offer a competitive and attractive image of European research carried out for the greatest benefit of Europe’s populations and economies.

AE: The current 7th Framework Programme supports research in the field of Alzheimer’s disease and the European Commission has also launched a European Alzheimer’s Initiative to address some of the public health questions posed by Alzheimer’s disease. How will the Joint Programming Initiative collaborate with these other European programmes?

PA: Indeed several funding programmes do exist in Europe at a national and international level. A strong willingness exists to coordinate similar programmes aimed at transnational European added value while not undermining existing opportunities and avoiding unnecessary duplication with national programmes.

Eighty-five percent of public research budgets of European countries are fully controlled at a national level, with probably less than 1% of the amount being reoriented to collaboration or coordination between countries. As a consequence, individual national research programmes may unnecessarily duplicate each other from an
international perspective. Although a limited experience with transnational calls for proposals is available from e.g. Nordic or German-speaking countries, as well as within the ERA-NET scheme, the diversity and complexity of national procedures largely preclude the setting up of cross-border programmes and discourage researchers from accessing research funding across borders.

Thus no real collaborative European endeavour is easily conceivable to tackle a societal challenge on the scale at which neurodegenerative progression and the development of dementia and Alzheimer’s disease is taking place. Increasingly the imperative is emerging of the need to encourage a fraction of those budgets be spent on common objectives, but in a reasonably integrated way between countries willing to share risks and benefits on a much larger scale.

In addition to the Joint Programming Research initiative managed by voluntary countries themselves, the Commission has launched in the Work Plan 2010 for the implementation of the Second Health Programme a Joint Action specifically on Alzheimer’s disease and other dementias. The objective of this action are: to support the improvement of collection of better epidemiological data on dementias in Member States, to analyse existing early detection tools for cognitive decline at European and national level in order to define best practices recommendations and to establish a platform to assess existing practices on rights and to preserve autonomy of persons suffering from dementias. The promotion of the dementia dimension in health determinants actions at EU level in order to define a healthy brain lifestyle set of recommendations is also considered. According to the topics retained, this action would strongly benefit of taking into account the conclusions of the EuroCoDe (European Collaboration on Dementia) Project coordinated by Alzheimer Europe. This joint action is under progress and France is acting as a coordinator. As Chair of the Joint Programming initiative, I am fully informed of this Joint Action and had the chance to exchange in depth with the French organisation HAS (Haute Autorité de Santé) responsible for the preparation of the Joint Action. A specific work package dealing with the coordination with the Joint Programming initiative is planned.

AE: As head of the National Scientific Foundation for Alzheimer’s disease and related disorders in France, you have of course experience in supporting research on a national level. What would you consider as the key achievements and successes of this Foundation since its establishment in 2008?

PA: With an estimated total number of 850,000 cases over 75 years in France and 1 out of 5 deaths, Alzheimer’s disease and related disorders fully met objective criteria for health priorities. To go beyond statistics, over 100 experts from all fields, managed by Professor Joël Ménard, an outstanding physician and scientist fully aware of public health challenges, met for 3 months at the end of 2007 to propose actions against this threat. Research was at the heart of their discussions. Following the report of these experts, the President of the French Republic, Nicolas Sarkozy, decided to launch, on 1st February, 2008, a five-year national plan on Alzheimer’s and related disorders with three major keywords: improve the quality of life of patients and their families, understand to be able to act, mobilise for a societal challenge. This second keyword is fully devoted to research and underlies specific orientations: reinforce the strengths, attract new teams in the field, support young researchers, reinforce the best clinical centers, increase interaction with pharmaceutical industries and biotech companies.

This large cooperation of researchers from all domains, from all countries and from both the academic and the private fields, is the only way to accelerate significantly the provision of solutions to fight efficiently these terrible diseases.
To secure and speed up the implementation of this scientific policy a National Foundation on Alzheimer’s disease and related disorders was created in June 2008. This non-profitable private foundation ensures today an efficient and highly reactive programming of research in the field of Alzheimer’s disease and related disorders in France. The Foundation launches calls for proposals according to the priorities identified and interconnects multiple other funding sources (ANR, PHRC, Inserm, CNRS, CNSA, Universities, European funds...). It also encourages public-private partnerships, reinforces productive teams and attracts new skills. For instance, during the first two years, several specific calls for proposals have been launched, two on experimental models, two on human and social sciences, one on the creation of a National Center for Imaging... Several large structural projects have been founded, the follow-up of the large prospective study, the Three Cities study and a European GWAS collecting more than 20,000 samples including 6,000 cases of Alzheimer’s disease. This last work allowed discovering two new genetic susceptibility factors for Alzheimer’s disease. The Foundation participates actively in the European pilot Joint Programming Initiative, and in a French-Canadian collaborative action. This large cooperation of researchers from all domains, from all countries and from both the academic and the private fields, is the only way to accelerate significantly the provision of solutions to fight efficiently these terrible diseases.

AE: Professor Amouyel, we thank you for your willingness to share your views and wish you and the Joint Programming Initiative all success.
Dementia in The News

Dementia in Society
A look at how dementia is reported and portrayed in literature and the arts.

Living with dementia
A carer from Spain speaks with the Spanish Alzheimer Association, Confederación Española de Familiares de Enfermos de Alzheimer y otras Demencias (CEAFA), about his experience of caring for his wife who had Alzheimer’s disease.

Spotlight on Greece
The Greek Association of Alzheimer’s disease and related disorders celebrates its 15th anniversary this year. Nina Kotras, Executive Director, speaks of the highlights and hopes she has for the Association.

Putting a face to commitment
Alzheimer Europe reports on the appointment of Thierry Jarlet (as Director General, France Alzheimer) and of Mattias Karlsson (as Chairman of the Dalarnas Iän Association, Sweden) as well as the departure of Neil Hunt (former Chief Executive of the Alzheimer’s Society, UK).

Mattias Karlsson becomes Chairperson of local Swedish Alzheimer Association

Michael Reagan
“You can’t hide from it. What you need to say is what can I do to help?”

Nina Kotras talks about the Greek Association’s work over the last 15 years
DEMENTIA IN SOCIETY

A look at how dementia is reported and portrayed in literature and the arts

Awards given for medical research in Alzheimer’s disease

Recognition of new approaches to Alzheimer’s research was given to four researchers who received MetLife Foundation Awards for Medical Research into Alzheimer’s disease on 25 February 2010. Awards were given to Todd E. Golde, professor of neuroscience at the University of Florida and Edward H. Koo, professor of neuroscience at the University of California who identified the “gamma-secretase modulators that decrease production of the highly toxic 42 amino acid form of Aβeta” and also to Eckhard Mandelkow, director of the Max-Planck-Institute for Molecular Biology in Hamburg, Germany and Eva-Maria Mandelkow, principal investigator of the Max-Planck Institute, who have been seeking therapies through analysis of the pathological folding of tau protein.

Actor Simon Callow talks about Alzheimer’s disease and raises awareness of the need for research

Actor Simon Callow has spoken movingly about his experience of his mother having Alzheimer’s disease and also his friend, play agent, Peggy Ramsay. In the Times newspaper article (15 February 2010), he reflects on his reaction to his mother’s behaviour, saying “One watches. One waits. One tries to be there for her. And one peers into one’s own future, and trembles.”

Mr Callow also explained the particular concern the symptoms associated with dementia have for actors “For those of us who get by on our wits — writing, learning, framing opinions, expressing experience — this is an unspeakable horror. ‘O! let me not be mad, not mad, sweet heaven.’ Acting, contrary to popular belief, is all about thinking. If the brain fails us even a little – a forgotten line, a missed cue – we go into a funk. And to watch these bright, forceful, intelligent women clouded over and mentally expunged by this malign spell has been nearly unendurable. But of course it affects everyone: one in 14 people over 65, one in five over 80.”

At the end of his article Mr Callow talks about the importance of research and in particular of the Edinburgh-based project: “The Disconnected Mind” which traces mental development and cognitive abilities, by retesting people whose IQ tests were recorded in 1947 (when the participants were 11 years old). The project also factors in social background and diet.

Sir Terry Pratchett gives Dimbleby lecture on assisted suicide

“Shaking hands with death” was the title of the lecture author, Sir Terry Pratchett, gave at the 2010 Dimbleby lecture on 1 February 2010. He called for an assisted suicide tribunal to be set up whereby people could apply for permission to end their lives at a time of their own choosing. He said the tribunal would “act for the good of society as well as that of the applicant … and ensure they are of sound and informed mind, firm in their purpose, suffering from a life threatening and incurable disease, and not under the influence of a third party.”

Of the medical profession he said “It seems sensible to me that we should look to the medical profession, that over the centuries has helped us to live longer and healthier lives, to help us die peacefully among our loved ones in our own home without a long stay in God’s waiting room”.

Sir Pratchett, who has fronto-temporal dementia, explained, “if I knew that I could die at any
Musicians raise awareness of Alzheimer’s disease

Bass guitarist, Stuart Hamm and musician Andy Edwards have recorded an album and shot a video to raise awareness of Alzheimer’s disease. Andy’s mother, Avis (aged 67) was diagnosed with dementia a year ago and this motivated him to write the music and ask Stuart Hamm if he would play on the album. “Into my distance” has three instrumental tracks and is available as a video on YouTube. Proceeds from the video will be donated to the Alzheimer Research Trust.

Ex-talk show host, Sir Michael Parkinson, talks of his experience with dementia and the importance of dignity in care

In his capacity as the UK government’s Dignity Ambassador, Sir Michael Parkinson has written a report about his experience of caring for his mother who had dementia and highlighted the importance of dignity in care for older people. It was published in January. He said: “I gained first hand experience of the National Health Service and care services during my mother’s illness with dementia. It struck me that whilst there are some excellent examples of care, where people are given the dignity and respect they need and deserve, much more needs to be done.”

TIME magazine lists the discovery of new Alzheimer’s genes among their “top 10 medical breakthroughs 2009”

As part of its “Top 10 of everything” list, TIME magazine has listed, under the top 10 medical breakthroughs 2009, the genes CLU and PICALM, the discover of which, says TIME, is the first of its kind for 15 years.

Researchers, led by Prof Julie Williams (Alzheimer’s Research Trust’s Chief Scientific Adviser), uncovered the two genes in September. Prof Williams explained “Both CLU and PICALM” highlight new pathways that lead to Alzheimer’s disease. The CLU gene produces clusterin which normally acts to protect the brain in a variety of ways. Variation in this gene could remove this protection and contribute to Alzheimer’s development. PICALM is important at synapses – connections between brain cells – and is involved in the transport of molecules into and inside of nerve cells, helping form memories and other brain functions. We know that the health of synapses is closely related to memory performance in Alzheimer’s disease, thus changes in genes which affect synapses are likely to have a direct effect on disease development.”

President Reagan’s son continues to raise awareness of Alzheimer’s disease

During the US National Alzheimer’s Awareness month (November), Michael Reagan, the son of former US President, Ronald Reagan, continued to raise awareness of the disease by appearing on TV. Michael Reagan encouraged people with dementia and their carers to “come out from behind the curtains and admit it, like my father admitted in 1994, that the disease is in the family. Don’t hide a loved one. Be honest with your friends. Be honest with your family. You can’t hide from it. What you need to say is what can I do to help?”

“Don’t hide a loved one. Be honest with your friends. Be honest with your family. You can’t hide from it. What you need to say is what can I do to help?”

Michael Reagan

time I wanted, then suddenly every day would be as precious as a million pounds. If I knew that I could die, I would live.”

“Don’t hide a loved one. Be honest with your friends. Be honest with your family. You can’t hide from it. What you need to say is what can I do to help?”
Ten years ago, after a whole working life in a well-known furniture company, my wife and I decided to buy a house beside the coast, where we could spend the remainder of our days. We left behind a whole life, family, friends and began a new future, full of dreams and hopes.

At the beginning everything was ok: we loved the house, the weather was perfect, even our neighbours received us as if they had known us for a long time. For three years everything was great.

However, something began to change at the fourth year. My wife started forgetting the keys at home when we were going for a walk, she didn’t find her purse when shopping or left the cooker or the taps on. Now and then she got angry (I think with herself) and after a while she calmed down and acted as if nothing had happened. Sometimes she behaved as if I were a complete stranger to her. It was very confusing. At first, I didn’t think these things were particularly important.

During one of our regular blood pressure check ups, I told the doctor about my wife’s unusual behaviour. When I saw the expression of his face I realised that something was wrong. I couldn’t imagine what was going to hit me.

Several visits to various specialists followed. The worst of which was when one of the specialists asked me to go to his consulting room and with some medical reports in front of him, told me, in a hard voice: “I’m sorry, I’m afraid I have bad news. Your wife has a mental disorder, probably Alzheimer’s”. I felt a shiver down my spine while the doctor explained the disease to me. I could hardly understand what he was telling me, I paid attention to a leaflet that he gave me. It was about an Alzheimer’s Association, about relatives who were going through (or had gone through) the same situation as me. I remember that when I got home, I hid all the reports the doctor gave me, I went to my wife, I hugged her and, holding back my tears, I told her that everything was ok, that there wasn’t any need to be worried, that we would be always together just as we had planned when we retired and moved to the coast.

“Alzheimer”, what a weird word. I remember, when I was working, that I often used this word, in an ironical way, to talk about the suppliers who delivered the wrong orders to the company. Now, I regret having used this word in a disparaging way. Now, I understand the real meaning that the word “Alzheimer’s” conveys.

After this, the internet became my shelter and hope. I would spend endless hours in front of the computer reading and reading again everything about Alzheimer’s. I found an incredible amount of information, but this didn’t solve my doubts, rather it increased them. Then I remembered the leaflet that the doctor had given me and after thinking about it, I decided to give it a go and so I phoned the Spanish Alzheimer association (CEAFA). At the beginning, I wasn’t very excited about the idea of sharing “our secret” with other...
people; the fact that my wife was suffering from Alzheimer's and that some strangers knew about it, that was something very shameful for me.

However, after my doubts, I went to the Alzheimer headquarters where I was given the support that I needed; not only information about the services offered but information on the disease itself and the issues which surround it. The Association understood me and this is what helped me the most.

To sum up, the Association encouraged me to share “our problem” not only with the family but also with our friends and neighbours. Then, soon I realised that my wife's problem wasn't the only case of Alzheimer's in the neighbourhood. People, that I hadn’t met before and I hadn’t talked to (“What disgusting people they are!” I used to think), were going through the same “bloody” reality as I, every single day. How they couldn't think it disgusting when they had that terrible problem in their own houses!

I remember one day, just before lunch time, I saw in front of my garden a girl running by, who dropped her shopping bag. I stood up to help her, I didn't say anything: I simply showed her a friendly smile. She returned my smile and thanked me for my help. She told me that she was in a hurry because she had to go home to help her grandma to feed her grandpa who suffered from Alzheimer's. At that moment I was in shock, I couldn't react, and from that instant a strong friendship grew between our two families. How important is a simple smile!!

During the next two years I cared for my wife, whilst at the same time watching her deteriorate. At the beginning it was quite easy to help (taking her to the Association to take part in their cognitive stimulating activities) but she got worse and eventually she couldn’t go out of our home anymore. It was then that the Association sent people to help me with my wife. Apart from that, it wasn’t unusual to be visited by our neighbours, who helped us (with the excuse of saying hello). Those were very hard years that lasted even after my wife’s death.

I will never be thankful enough to all my friends for not leaving me alone during all those years. Even so, the pain of my wife’s death remains with me. However, I think I am lucky to be able to share my experience with all those people who are facing what my wife and myself had to face together. Now I have become a volunteer of the Alzheimer Association, which helped me when I needed it the most.

There were 690,992 people with dementia in Spain in 2006.
GSK’s goal is to improve the quality of human life - not just through our medicines and vaccines, but also through our work with communities around the world.

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SPOTLIGHT ON GREECE

The Greek Association of Alzheimer’s disease and related disorders celebrates its 15th anniversary this year. Nina Kotras, Executive Director, speaks of the highlights and hopes she has for the Association.

The Greek Association of Alzheimer’s Disease and Related Disorders, was established in 1995. The objectives of the Association are to support research on the causes of the disease, the improvement of the diagnosis, the treatment and the care provided for the Alzheimer’s disease and related disorders. We now has 31 member organisations.

Amongst our many achievements, I am particularly proud of:
1. The establishment of a “Care Unit for people with Alzheimer’s disease” (which had the support of the European Union and the Ministry of Health). The original Day Centre has been expanded and a new Centre added. There are also two further Day Centres (Pylaia and Chariseio Old people’s home). We hope to create more centres in the future.
2. The creation of research groups, made up of physicians, biologists and psychologists, which aim to exchange information and ideas on the development of research for people with dementia.
3. Our promotion of programmes on research, education and training.
4. Our information and advice services on dementia problems, including our 24-hour helpline. We also offer specialised:
   a) our services from diagnosis, neuropsychological assessment, physiotherapy, physical exercise to educational programmes for people with early dementia;
   b) our cognitive therapy services, including memory, attention and language exercises, reality orientation, ecological multisensory tasks, cognitive tasks, attention and executive function rehabilitation programme, dual task practice teaching of strategies, cognitive motion therapy and cognitive music therapy and psychotherapeutic programmes such as stress management techniques, passive music therapy, art therapy, occupational therapy, reminiscence, relaxation techniques programme, mental imagery therapy and counseling;
   c) our caregiver services, such as family therapy, individual counselling, educational programme, relaxation techniques programme and support groups and counselling are all offered by our Association.
5. Our care at home team. This team consists of a doctor, dentist, psychologist and social worker who offer support by visiting people at home or have the final stages of dementia or who are unable to get to a Centre themselves.
6. The organisation throughout the year of presentations and seminars by health professionals and informal carers. These include weekly lectures but also the Pan-Hellenic Interdisciplinary Conferences. Six Pan-Hellenic Inter-Scientific Alzheimer Conferences have been carried out until now along with the 13th European Alzheimer Conference in Thessaloniki and the 25th International Conference carried out on 10-13 March 2010. We are also active members of international and European Alzheimer conferences.

It is fortuitous that in 2010 we have the honour of hosting Alzheimer International’s annual conference in Thessaloniki, the very city where the Greek Alzheimer Association started its hard work 15 years ago.
ALZHEIMER EUROPE PUBLICATIONS

DEMENTIA IN EUROPE YEARBOOKS

Our Yearbooks present the findings from various Alzheimer Europe projects, each year focusing on different issues linked to dementia. The Yearbook for:

- 2009 is dedicated to a comparison of national laws in Europe with regard to healthcare decision making by people with dementia.
- 2008 contains the outcome from four of the workgroups on the European Collaboration on Dementia (EuroCoDe) project.
- 2007 highlights the findings of a survey on social support systems amongst Alzheimer Europe’s member organisations.
- 2006 provides a European overview of the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the provision of home care.

The annual accounts are contained at the back of each Yearbook.

Cost: EUR 10 (plus EUR 6 handling and postage)

ALZHEIMER EUROPE REPORTS

The Alzheimer Europe Reports focus on specific aspects of dementia. Topics covered include end-of-life care, advance directives and the state of dementia care in Europe.

Each Alzheimer Europe Report focuses on specific aspects of dementia.

- “End-of-life care for people with dementia” (2008): This practical guide is for all those involved in this delicate and demanding stage of dementia and is available in English and German.
- “The use of advance directives by people with dementia” (2006): This includes Alzheimer Europe’s position on advance directives as well as giving background information (legal, ethical, medical, personal and practical issues) in the case of dementia.
- Alzheimer Europe Survey “Who cares? The state of dementia care in Europe” (2006): This presents the results of a survey carried out by Alzheimer Europe which revealed a shocking picture of the level of commitment by carers, a significant lack of information for carers at the time of diagnosis, a lack of basic support services as well as the need of carers to contribute financially to existing services.

Cost: EUR 5 (plus EUR 4 handling and postage)
CARE MANUAL

Written for carers, the Care Manual provides general information on Alzheimer’s disease, as well as specific information on symptoms and how to cope. It is published in several languages.

Cost: Please see website for details of costs, supplier and language versions.

CHILDREN’S BOOK

Written as a story through the eyes of a child, this book aims to help child gain awareness of Alzheimer’s disease and is available in several language versions.

Cost: Please see website for details of costs, supplier and language versions.

DEMENTIA IN EUROPE MAGAZINE

The Dementia in Europe magazine is dedicated to covering dementia policy. Developments at both the European and national level are reported on as well as interviews with key policy makers.

- Issue 4 (December 2009): Highlights include the European Parliamentary lunch debate on European action on dementia, the 19th Annual Alzheimer Europe Conference in Belgium, the Dutch national dementia plan, the exchange of best practices on dealing with behaviour symptoms at home, the Swedish Presidency on dignified ageing and snapshots of the 2009 World Alzheimer’s Day.

- Issue 3 (May 2009): This issue carries interviews the European Health Commissioner, Androulla Vassiliou, the Czech Health Minister, Daniela Filipová and MEP for Greece, Maria Eleni Koppa. There is also a special section dedicated to several MEPs who evaluated the achievements of the 2004-2009 European Parliament in regard to helping people with dementia and their carers. The English Dementia Strategy is reported on and the legal rights for people with dementia in Norway are considered.

- Issue 2 (December 2008): The French Presidency Conference on Alzheimer’s disease is covered, as is the EuroCoDe project, the European Ethics network. Jan Tadeusz Masiel, MEP, (Poland) discusses the situation for people with dementia in Poland and current treatment options for dementia are reported on.

- Issue 1 (June 2008): out of print – can be downloaded from our website

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PUTTING A FACE TO COMMITMENT

LOCAL SWEDISH ALZHEIMER ASSOCIATION CHAIRMAN ATTRACTS MEDIA ATTENTION

Great media interest has been achieved by the recent appointment of the new chairman in the local Alzheimer association in Dalarnas län, Borlänge. Mattias Karlsson, who is only 28 years old, has been interviewed on the radio and newspapers as it is unusual to have such a young person in this position. Mattias’ father was diagnosed with Alzheimer’s disease two years ago, aged 52 and this has motivated Mattias into action. Information can be found on his blog: mlesliek@hotmail.com and also on facebook: Alzheimerforeningen i Dalarnas län where the local organisation has a page.

NEIL HUNT LEAVES POSITION OF CHIEF EXECUTIVE OF THE ALZHEIMER’S SOCIETY

After nearly seven years in the role as Chief Executive of the Alzheimer’s Society, Neil Hunt left the position on 26 January 2010.

On his departure, he said: "I have decided that after nearly seven years in post, now is the time to seek new challenges. The dementia agenda has changed beyond all recognition in recent years. No longer will this condition be ignored in the way it once was. I am confident that as a health priority we see a new determination to address the challenges it brings to individuals, families and to us all as a nation.

“Alzheimer’s Society has also been substantially remodelled. It is a stronger, more confident organisation with a clear management line embracing all branches, staff and volunteers, enabling it to rise to the challenge of meeting the needs of 700,000 people. I will miss the job but this is the time to leave.”

Alastair Balls, Chair of Alzheimer’s Society, said: “Neil has made a tremendous contribution to Alzheimer’s Society and to people living with dementia. The National Dementia Strategy for England and the similar plans for Wales and Northern Ireland are testament to his outstanding energy and vision. The whole Society wishes him well in his next role.”

Ruth Sutherland, Chief Operating Officer of Alzheimer’s Society will become Acting Chief Executive until a replacement is appointed.

Alzheimer Europe, who has enjoyed a strong and productive collaboration with Neil in his role as Alzheimer Europe Board member since 2008, would like to take this opportunity to wish Neil every success in his new challenges.

NEW DIRECTOR APPOINTED FOR FRANCE ALZHEIMER

Thierry Jarlet, a former Director of Communication and Administrative Affairs of the Commission Nationale Informatique et Libertés (CNIL), and Consultant on the theme of efficacy creation of value versus ethics/authenticity, commenced work in his new role of Director General for France Alzheimer on 31 January 2010.

“The National Dementia Strategy for England and the similar plans for Wales and Northern Ireland are testament to his outstanding energy and vision.”

Alistair Balls speaking about the role Neil Hunt had played as Chief Executive of the Alzheimer Society.
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