Handling neurological disease with dignity

Jean Georges
Executive Director of Alzheimer Europe
The recent G8 dementia summit demonstrates that Alzheimer’s disease and dementia are increasingly being recognised as major global health challenges. Jean Georges, Executive Director of Alzheimer Europe, outlines how the organisation has contributed to this shift and looks at its past successes and future priorities.

What is your role within Alzheimer Europe (AE)? How have your previous experiences prepared you for this position?

Prior to taking up the position of Executive Director of AE in 1996, I worked as both a journalist and a parliamentary researcher for members of the Luxembourg and European Parliaments. This gave me a fair understanding of the (sometimes byzantine) workings of European institutions and a solid background in communication and dissemination.

When I began working for AE, our office was situated next to the day care centre of the Luxembourg Alzheimer’s Association, which gave us the unique opportunity to interact and talk with people with dementia on a daily basis. Furthermore, my father-in-law was diagnosed with Alzheimer’s disease and died three years ago. This provided me with important insights into the experiences of people with dementia and their carers from a personal perspective.

Since 1995, AE has successfully completed 15 projects. Would you like to highlight any of these as being particularly significant?

AE has been fortunate in receiving support from the EC’s public health, equal opportunities, disability and research programmes since 1995. Thanks to this support, the organisation has been able to conduct a whole range of successful activities, including:

• The development of a Carers’ Manual with practical advice on caring for a person with dementia and a children’s book on dementia, which have both been translated and published in nine European languages

• An inventory of legislation affecting people with dementia (guardianship measures, consent, patients’ rights, etc.)

• A website dedicated to the rarer forms of dementia

Specific large-scale projects include our European Collaboration on Dementia (EuroCoDe) project, which brought together 36 researchers to carry out a meta-analysis of prevalence studies and an analysis of social support systems across Europe, develop consensual guidelines on diagnosis, treatment and psychosocial interventions, assess the relevance of preventative strategies and evaluate the cost of dementia in Europe.

I am particularly proud of the work carried out as part of AE’s European Dementia Ethics Network, which brings together ethical experts, healthcare professionals and people with dementia and carers to analyse the literature on ethical issues and develop a report with recommendations. In the past years, we have looked at issues as diverse as advance directives, ethics of dementia research, restrictions of freedom, perceptions and portrayal of dementia, end-of-life care and assistive technologies.

An important recent achievement is the formation of a European Working Group of People with Dementia, which is comprised of 11 people with dementia from 11 member organisations who advise the organisation on its activities and make sure that the voices of people with dementia are included effectively in all our projects and activities. Their input has truly been amazing!

What projects is AE currently engaged in?

The association is involved in a number of research projects funded by the Seventh Framework Programme (FP7), where it represents the views of people with dementia and carers, takes part in ethical discussions, and supports dissemination and communication activities. These include:

• AETIONOMY

• AFE-INNOVNET

• EMIF-AD

• NILVAD

• PACE

• PharmaCog

• PredictND

With the support of an operating grant from the public health programme of the EU, AE is developing national reports describing care pathways in the different EU countries and a report on daily ethical issues that informal carers of people with dementia confront.

Aims of Alzheimer Europe

Alzheimer Europe (AE) was founded in 1990 by three pioneers of the Alzheimer movement: Franz Baro (Belgium), Michael Coote (Ireland) and Henk ter Haar (The Netherlands). The founding document of the organisation described the following aims:

• Raising public awareness

• Exchanging information

• Developing models for better care

• Increasing political advocacy

• Promoting research and training

The founding principles remain true today, though the aims have developed further. The adoption of the Paris Declaration by the member organisations in 2006 was of particular importance. This document is a political manifesto in which AE asked policy makers at a European and national level to make dementia a public health priority and to develop dementia strategies. This has been the key focus of the organisation’s campaigning over the past years.
In addition, with the support of corporate sponsors, the association is working on the establishment of a clinical trial database and an inventory of diagnosis and treatment guidelines. It is also developing guidelines to improve continence care for people with dementia, thanks to an educational grant from SCA Global Hygiene.

**Does AE work with other organisations to raise awareness about neurological diseases?**

AE is a founding member of the European Patients’ Forum (EPF). We collaborate actively with other patients’ and carers’ associations in the framework of EPF; for example, we work on joint campaigns and advocacy efforts on specific EU legislation of interest to the wider patient community, such as the clinical trials or medical devices directives.

Our organisation is also a member of the Patients’ and Consumers’ Working Party of the European Medicines Agency and collaborates with other organisations to improve the evaluation of new medicines and the involvement of patients in the benefit/risk analysis and pharmacovigilance of medicines.

AE works with a number of associations of healthcare professionals in the fields of dementia and neurology and has collaborated with organisations such as the European Alzheimer’s Disease Consortium, the European Union Geriatric Medicine Society, the European Federation of Neurological Societies, the European Association of Geriatric Psychiatry and the International Association of Gerontology – European Region. Of particular interest is our collaboration with the Interdem network, which brings together researchers in the field of psychosocial interventions and organises its meetings in conjunction with our annual conferences.

**To what extent is technology, from social media to assistive devices, affecting the experience of patients with dementia and neurological diseases?**

The development of new technologies has a significant impact on people with dementia and their carers. The use of social media and other communication technologies can be truly empowering, allowing people to communicate with others in similar situations and to break the social isolation they may be experiencing. I was delighted to see the extent to which the members of our European Working Group of People with Dementia are willing to embrace new technologies – such as e-mail, Facebook, Skype and Twitter – to communicate with one another.

Other examples of assistive technologies that can and are being used by people with dementia are:

- Devices to remind a person of the date and appointments, to facilitate communication or to take medication
- Smoke, water overflow and gas detectors
- Electronic tracking devices or tele-alarm systems
- Computer-assisted devices to encourage social interaction and stimulate the senses
- Socially-assistive robotics

In its report dedicated to assistive technologies, AE has suggested different frameworks to discuss the ethical issues linked to assistive technologies and to come to a decision about their use. The importance of consent, support of autonomy and respect of privacy are, among others, important ethical principles to consider in this context.

Every year AE hosts an annual conference. This year’s event is scheduled to take place on 20-22 October in Glasgow, UK, and will be based around the theme ‘Dignity and autonomy in dementia’. Could you provide a preview of what the event has in store?

AE’s conferences are unique networking opportunities as they bring together the research community in the care and psychosocial sector with healthcare professionals, representatives of Alzheimer associations, carers, policy makers and, of course, people with dementia.

Our European Working Group of People with Dementia play a very active role in the preparations for the conference and will be organising its own satellite symposiums, while being represented in the opening ceremony and various plenary and parallel sessions. People with dementia will also advise us in the selection of abstracts to ensure the language used by presenters is inclusive and non-discriminatory, and their input will be essential to the success of our conference.

The theme for of this year’s conference, ‘Dignity and autonomy in dementia’, will explore how recognising the human rights of people with dementia, their carers, partners and families is key to ensuring dignity and respect, as well as overcoming stigma. The event will showcase best practices in informing and empowering those affected by dementia to make vital decisions regarding their own support and care needs, as well as supporting their participation at local, national and international levels in shaping health and social care policies. The roles of peer support and dementia-friendly communities will also be addressed.

**Ethical issues**

Jean Georges expands on the importance of ethical issues within dementia research and care

The importance of ethical issues in dementia cannot be understated. It is for this reason that Alzheimer Europe (AE) decided that ‘basing its actions on ethical principles’ should be one of the key strategic priorities of the association. This led to the creation of the European Dementia Ethics Network, whose aim is to identify key ethical issues and set up expert working groups to analyse the literature and come up with recommendations. An ethical approach to dementia care is essential throughout the course of the disease, from the earliest symptoms to the end of life.

Key ethical issues are the right of persons with dementia to a diagnosis and active participation in all decisions affecting their lives. Furthermore, reconciling the need for privacy, dignity and autonomy and the importance of protecting patients’ rights are ethical considerations raised by technologies that monitor movements of patients in their home or a nursing home setting. New ethical questions will arise with the emergence of diagnostic tests that may predict whether a person may develop Alzheimer’s disease or another form of dementia.

This year, AE will work on day-to-day ethical issues that informal carers of people with dementia face. This will look into dilemmas such as truth telling and lying, the use of assistive technologies in the home, conflicting obligations, the use of monitoring devices, restraint, driving and placement in long-term care centres.
By putting dignity and autonomy at the heart of this year’s conference, we want to demonstrate the responsibility of national and international policy makers, local decision-makers, health and social care professionals and all of society in making change happen for people with dementia.

Combine all this with the well-known Scottish hospitality and this conference will be an opportunity not to be missed!

In what ways do you work with national governments and the European Parliament to shape policy and raise dementia awareness?

The key aim is to make dementia a European and national public health priority, and we have been very fortunate in having a European Parliament that has been extremely responsive to our campaign. In 2009, the European Parliament adopted ‘Written Declaration 80/2008’ on the priorities in the fight against Alzheimer’s disease, in which Members of the European Parliament (MEPs) called on the EC and Member States to recognise Alzheimer’s disease as a European public health priority and to develop a European Action Plan. According to this important call, the EU should promote pan-European research and collaborations in order to improve timely diagnosis and the quality of life for people with dementia and their carers. Furthermore, the Declaration explicitly recognises the important role of Alzheimer associations and asks for their activities to be supported. This declaration was signed by close to 60 per cent of MEPs.

A number of MEPs have shown their personal support for our campaign by joining the European Alzheimer’s Alliance, which has 72 Members from 23 Member States and from all seven political groups in the European Parliament.

After the next European Parliament elections, AE hopes to continue its collaboration with newly elected MEPs and to relaunch the European Alzheimer’s Alliance. Together with our national member organisations, we have just started our campaign for candidates to sign our European Dementia Pledge and to show their commitment to the 8.7 million people living with dementia in the EU.

How does AE ensure that it is effectively representing and communicating with each of its 36 member associations, both throughout the year and when asked to publish its position on a specific issue, such as anti-dementia drugs or genetic testing?

AE has put in place effective consultation mechanisms to ensure its positions accurately reflect the views of its membership. Our annual meetings are ideal opportunities to discuss and, if necessary, adopt joint policy statements. In between these annual events, we organise regular meetings with representatives of our member organisations active in public or government affairs. At these meetings, we discuss European policy advancements and exchange information on campaigns and policy developments at a national level.

All policy documents issued by AE have been sent for consultation to our members and if different views arise on specific issues the association will take no or a neutral position. So far, this has only occurred for the controversial question of the therapeutic cloning of embryos. In this case, AE was not able to adopt a consensual position due to the pronounced differences of opinion among its member organisations. On all other issues, such as our position on anti-dementia drugs and genetic testing, the organisation was able to achieve consensual positions endorsed by all our members.

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G8 Dementia Summit

Jean Georges muses over the outcomes of the Dementia Summit in London

Prior to the Summit, Alzheimer Europe (AE) and its member organisations launched a call, inviting G8 countries to:

• Include and consult Alzheimer associations and people with dementia in the decision-making process and the definition of a global research agenda

• Adopt a holistic approach to research to include psychosocial, care, socioeconomic and health systems research

• Substantially increase the funding dedicated to all areas of dementia research

• Promote dementia as a priority in other international bodies including the G20, the Organisation for Economic Cooperation and Development (OECD), the World Health Organization (WHO) and the United Nations (UN)

We were delighted by some of the outcomes of the meeting. The G8 Summit was a unique occasion where the leading industrial nations came together to make dementia a global priority. They set the very ambitious aim of developing a disease modifying treatment for Alzheimer’s disease by 2025 by promoting public-private partnerships and better coordinating research programmes on an international level. AE is currently collaborating with Alzheimer’s Disease International and other associations to ensure the voices of people with dementia, carers and Alzheimer associations are duly considered in this process.

Following the Summit, the UK Government recently appointed Dr Dennis Gillings as World Dementia Envoy. He plans to create a World Dementia Council to raise funds for dementia research. AE and our member organisations will continue to support and monitor the developments coming from the G8 process to ensure the research agenda gives hope to people looking for a cure, but also provides concrete answers and solutions for people currently living with the disease.