



Alzheimer Europe's main aims are by co-operation to raise awareness of dementia and to support the sufferers and their carers.

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EXECUTIVE SUMMARY

- Alzheimer's disease is the most common form of dementia. The on-going consultation must also consider the rarer forms of dementia.
- Alzheimer's disease is a major European public health issue across Europe.
- The present picture of people with Alzheimer's disease and their carers shows the following picture :
 - The very nature of Alzheimer's disease is that people will be more inclined to be treated next to a familiar environment rather than travel long distances (whether in their home country or abroad).
 - Alzheimer's disease affects primarily an ageing population who may not be used to traveling.
 - Unequal reimbursement of dementia treatments can be observed across the 27 EU Member States.
 - Significant market access delays for dementia treatments are seen in Europe
 - Access to existing treatment at the time of diagnosis vary considerably across Europe
 - People with Alzheimer's disease need specific care
 - Care is not uniform across Europe and shows many disparities
- Alzheimer Europe's expectations from the Framework :
 - The strategy must ensure that the specificities of diseases are taken into account, including Alzheimer's disease and other neurodegenerative diseases.
 - The strategy must above all be an opportunity to address the European inequalities around dementia and Alzheimer's disease.
 - The strategy must respect the individuals. The Open Method of Coordination is a welcome tool. Alzheimer Europe and its member associations are willing to contribute and share their expertise.
 - Mobility of health professionals must follow robust criteria to ensure quality and safety.
 - Language is an important factor to take into account.
 - Legal issues must be considered : in particular, the 2000 Hague Convention for the International Protection of Adults must be further promoted and ratified by all EU Member States. The same applies to advanced directives.
 - Robust information about patient mobility, its modalities and legal aspects must be shared with the European citizens. Patients organisations, as recognized information providers have a key role to play.
 - The benefits of the exercise should be to upgrade the national healthcare services rather than looking for the lower common denominator.
 - Cross-border care and patient mobility should not lead to the wreckage of the European social model

The present document constitutes the contribution of Alzheimer Europe to the European Commission's consultation on Community Action on health services.

The Commission's 2007 strategy includes the development of a Community framework for safe, high quality and efficient health services in the EU. The framework will reinforce the cooperation between the Member States and provide certainty over the Community law to health services and healthcare. As such, the Commission will respond to various stakeholders' asking for greater clarity over the meaning of Community law in general terms for health services.

The Commission now has to square the circle between the citizens' need for high quality health services, the rights to healthcare recognised in the European Treaty and the Charter of Fundamental Right of the EU, the sovereignty of the Member States over the provision of healthcare services.

The various rulings of the Court of Justice recognise that free movement also applies to health services, regardless of how they are organised and financed at national level.

Alzheimer's disease is the most common form of dementia. Dementia is defined as a progressive alteration of an individual's memory functions and other functions that significantly impairs the individual's capacity to function in an autonomous manner.

For people with Alzheimer's disease, the European context is very mixed regarding access to diagnosis, treatment, care and support services. There is no one-size-fit-all recipe and the framework must take this diversity into consideration. The framework must be an opportunity to address the inequalities while respecting the individual.

The other common form of dementia is vascular dementia (between 25% and 50% of all cases with dementia).

Other rarer forms of dementia have been identified and must certainly be considered too by the Commission.

Alzheimer Europe welcomes the Commission's initiative insofar as it will give a legal clarity to the Treaty provision of free movement of patients, professionals and health services and will support the Member States to optimally benefit from mutual cooperation.

The case of people with Alzheimer's Disease

Alzheimer's Disease is the most common form of dementia. It is a neurodegenerative disease with a long lasting silent pre-clinical phase with no clinical signs. It develops over 10 to 20 years and is diagnosed late (2 to 3 years after onset of the clinical manifestations). The disease triggers a slow and gradual deterioration of a person's ability to function, affecting memory, attention, concentration, language and thinking.

Therefore, the very specificity of this disease shows that patients will be inclined to stay at home or in a familiar environment rather than be exposed to stressful trips in order to have access to screening methods or medical consultations, whether in their home country or abroad.

To date, it is estimated that around 6.1 million people are affected by dementia in the 27 EU Member States, representing about 1.3% of the population¹.

The likelihood of developing dementia increases with age. With the ageing of the population, the percentage of people affected by Alzheimer's disease is expected to increase dramatically, thus making this disease a major public health issue². In 2050, Europe's population will be slightly smaller and significantly older: the elderly population (aged 65+) will rise by 77%. In 2050, Europe will have two people of working age for every elderly citizen³. In Germany for instance, the number of people suffering from dementia should rise to 2 million by 2050⁴.

The majority of people with Alzheimer's disease are of the older generations who may not be necessarily used to traveling. In addition, age is a factor that hinders sick people from traveling to seek a medical advice.

There is no cure for Alzheimer's disease. Nevertheless, treatments are available that may temporarily slow down the progression of the symptoms. **Equal access to treatment and services is still very different between the 27 Member States⁵** (with Latvia, Malta and Romania who do not reimburse any of the treatment available, and the UK NICE recommendations that restrict the reimbursement of anti-dementia medicines to people in the moderate stages of the disease and excludes those with mild Alzheimer's disease⁶).

Access to services is also most unequal across Europe and around 86 % of the people with Alzheimer's disease are looked after at home by a close relative⁷.

People with Alzheimer's disease face significant market access delays for the few medicines that exist : while differences in market authorisations point out significant delays in some countries for the approval of new medicines, these delays are further exacerbated by the time it takes for pricing decisions to be made and for products to be launched, as well as for new treatments to be included in the reimbursement systems⁸. Delays from 6 months up to over 4 years have been identified. Cyprus, Austria, Belgium and Hungary falling in this category.

Alzheimer Europe's work has highlighted significant differences between European Member States as to the numbers of people with Alzheimer's disease having access to existing treatments⁹⁻¹⁰. The percentage of patients treated at the time of diagnosis varies from 3% in Hungary, to around 7% in Bulgaria, the Czech Republic and the Netherlands, to 50 % in France, and 97 % in Greece, although this last figure does not reflect the reality on the ground and may in fact result from parallel trade exports.

¹ Dementia in Europe – Yearbook 2006, 2006, Alzheimer Europe

² Paris Declaration, 2006, Alzheimer Europe.

³ Rapport de la Commission Européenne, Affaires Economiques et Monétaires sur l'impact du vieillissement sur les dépenses publiques, Rapport spécial n° 1/2006

⁴ Bickel, H. – Demenzen im höheren Lebensalter : Schätzungen des Vorkommens und der Versorgungskosten, Zeitschrift für Gerontologie und Geriatrie, 2001, 23, 108-115

⁵ Dementia in Europe – Yearbook 2006, op. cit.

⁶ www.alzheimer-europe.org

⁷ Who cares ? The state of home care in Europe, Alzheimer Europe, 2006

⁸ Dementia in Europe – Yearbook 2006, op. cit.

⁹ Access to diagnostic evaluation and treatment for people with dementia in Europe, D. Wilkinson, K.T.T. Phung, A. Burns, J. Georges, F. Ronholt Hansen, S. Iliffe, C. Marking, M. Olde Rikkert, J. Selmes, G. Stoppe, N. Sartorius, in press Int. J. Geriatric Psychiatry

¹⁰ Who cares ? The state of dementia care in Europe, 2006, Alzheimer Europe

Home care

People with Alzheimer's disease are cared for at home by a close relative (spouse, brother or sister, son or daughter). Very often the carer has to give up a paid job to look after a loved one, thus jeopardising his/her pension rights¹¹, social life and being possibly faced with mental health problems.

There again, because of the specificity of Alzheimer's disease, **the people affected by the disease have various needs that differ from one person to the next and change over time.** The level of commitment from the carer is enormous : one in five carers of people with Alzheimer's disease in the mild stages reported that they provided more than 10 hours' care each day. For people with people with Alzheimer's disease in the late stages, one in two reported providing more than 10 hours' care a day.

Many carers also revealed they lack basic support services to help them cope with their caring role.

Tremendous differences exist between the European countries, particularly in terms of state responsibility, funding, role of families and the actual availability of home care services. Differences were also detected within the countries¹².

The common issues emerging are the lack of specific reference to people with dementia in laws and documents addressing the provision of home care services, limited reference to any actual obligation on the part of the State to provide home care services and the involvement of families, lack of emphasis on home care services for the elderly and/or disabled and the role of voluntary organisations and NGOs.

The case of other forms of dementia

The work that Alzheimer Europe¹³ has done on rare forms of dementia show that the number of people affected is by definition low so very little has been done to provide this population with the same information as for the population with more common forms of dementia.

Rare forms of dementia include fronto-temporal degeneration (5%) and Lewy body (5%). Some 30 diseases or disease groups which are either rare themselves or lead to dementia have been identified. These rarer forms of dementia merit equal attention, especially within the context of the current consultation.

Expert assessment and accurate diagnosis for these rare forms of dementia are often lacking. Drug treatments for rare dementia currently do not exist.

For this very population, **centres of excellence** must be identified to ensure that early diagnosis is made and that appropriate measures are taken. The Commission must address the modalities for consultation in such centres as well as modalities for an accompanying person to come along too. The Commission must remember that

¹¹ EPOCH Project (Equality in the Provision Of Care at Home). Alzheimer Europe, 2001

¹² Dementia in Europe – 2006 Yearbook, op. Cit.

¹³ Rare forms of dementia, Alzheimer Europe, 2000-2002. This European project set up a database which includes information on rare forms of dementia such as the disease name and synonyms, a description of the disorder along with its symptoms and causes, the epidemiological data available and treatment, information on clinical trials and diagnostic procedures.

<http://www.alzheimer-europe.org/?content=showarticle&lm2=C662CECB3328> and <http://www.alzheimer-europe.org/?lm2=481BC1083264>

people with dementia are a very fragile population that may not be able to function alone but needs assistance.

Alzheimer Europe's expectations from the framework

People with Alzheimer's disease represent a very specific part of the population that also needs access to specific, high quality, safe and efficient healthcare as well as services at home. This population may not fall into the different types of patients actively seeking access to healthcare in another country as defined by the Commission's Communication.

The same applies to people with rarer forms of dementia. Nevertheless, in the case of people with rarer forms of dementia, centres of excellence must be identified to ensure that this population also benefits from the same access to disease specific, high quality, safe and efficient healthcare.

The Framework provisions on access to healthcare services must take into account the various forms of dementia as well as the European disparities around Alzheimer's disease. It is essential that the individual's specific health needs are respected at all times.

Alzheimer Europe's position is that all Member State be in a position to provide early diagnosis, early access to treatment and adequate services or respite care to the people with dementia or Alzheimer's disease. **The current disparities that exist between the Member States must disappear, taking into account the highest common denominator**

The Open Method of Coordination is a tool to address European disparities. Alzheimer Europe welcomes this tool to learn from best practice and implement similar initiatives in the European countries that are lagging behind or could significantly improve the services for people with Alzheimer's disease and their carers. This applies for both Alzheimer's disease and other forms of dementia, including the rarer forms.

Alzheimer Europe welcomes the mobility of health professionals within Europe. However, common standards must be defined, based on the highest common denominator. It is imperative that the health services lagging behind benefit from the Framework rather than the more advanced countries regress.

Equally, the disparity in training of health professionals in Europe must be addressed to ensure a safe and qualitative provision of medical services in the EU.

Language is an important factor to take into account, especially for people with Alzheimer's disease. These people need to feel safe and confident with their health professionals. This starts with speaking fluently in the patient's mother-tongue and understanding the subtleties of the language.

Legal aspects

Alzheimer Europe's philosophy is respect for the human right to dignity, self-respect and autonomy of people with dementia.

Alzheimer Europe believes that every person informed of a diagnosis of Alzheimer's disease should be informed of the possibility of taking decisions about his future (treatment, guardian, palliative care, end-of-life, etc.) and be able to get the help of a

professional in taking those decisions. A legal framework should ensure the respect of wishes expressed in this way.

As such, part of its health strategy, Alzheimer Europe urges the Commission to consider important legal issues as people with dementia lose their mental capacity as the disease progresses.

The Commission must consider the **Hague Convention of 13 January 2000 on the international protection of adults**. This Convention was adopted in response to the lengthening of the lifespan accompanied by an increase in illness attached to old age. Population movements such as retired persons moving abroad to spend their last part of their lives have inspired this Convention that handles the management of the properties of the people moving abroad as well as inheritance issues. To date, only one country has ratified this Convention and the Commission should urge the EU Member States to ratify too.

The Commission should also consider including a section of **advanced directives** in its Strategy. Alzheimer Europe carried out a comparative analysis of legislation affecting people with dementia and their carers and developed recommendations on how to improve the legal rights of people with dementia.

Answer to the Consultation questions

Question 1 : what is the current impact (local, regional, national) of cross-border healthcare on accessibility, quality and financial sustainability of healthcare systems, and how this might evolve ?

It is unlikely that patient mobility will be represented by a huge number of people with Alzheimer's disease who will prefer to be followed in a familiar environment.

Nevertheless, the Commission must consider cases where a person with Alzheimer's disease benefiting from a rather optimal service in the home country moves to another country, to permanently stay with a relative/carer, and where the services provided there are less than that of the home country. Which member state will be in charge of the patient ? How will the host member state be able to secure the same level of service provision ? Who will take up the additional costs that may follow ?

Patient mobility pumping on the capacities of the host country must not lead to any downgrading of the host country services. National health services must plan for foreign patients accessing their services and not deprive their national citizens. This should on the contrary lead to improvement and upgrading of the facilities offered.

Some EU countries regret that their health professionals move to countries where they are most frequently better paid. It is essential that the strategy provides for measures that retain the health professionals at home rather than deplete the medical contingent. It is also a way to ensure that the national patients can have access to enough resources at home.

Question 2 : what specific legal clarification and what practical information is required by whom (eg. authorities, purchasers, providers, patients) to enable safe, high quality and efficient cross-border care ?

The authorities must make available all practical information regarding the conditions for access to cross-border care. The information must contain the conditions under

which diagnosis or treatment can be accessed abroad, how is the patient transferred abroad (alone ? with a relative ? in the latter case, who takes up the additional costs ?), the financial practicalities (does the patient pay and gets reimbursed by the home country or is it an agreement between the Member States ?), how is follow-up or rehabilitation taken care of, the conditions for check ups or additional treatments.

This information must be relayed by the health professionals, NGOs and patient organisations, insurers.

This practical information must include a list of recognised and reputed health professionals, medical centers, hospitals. A track record of health professionals who have been barred from the profession must be available to all EU member states to ensure safety of the patients.

Legal information for each parties responsibilities and duties must be spelled out : practicalities to seek redress must be given to the patients. Equally, the health professionals must provide a clear description of what the patient can expect and seek legal help in case a patient brings them to Court. The country of jurisdiction must be clearly defined.

Patient organisations, like Alzheimer Europe who has a track record of providing information, must be considered as prime partners to share and convey legal information.

Finally, the patient records must be in the patient's mother tongue, otherwise expressed by the patient. This is important as the patient can ask to have access to his/her record at their convenience. This language issue is also important when the patient needs to be followed in his/her home country. The medical professional must understand the patient's track record while being treated abroad.

Question 3 : which issues (eg. clinical oversight, financial responsibility) should be the responsibility of the authorities of which country ? Are these different for the different kinds of cross border healthcare described in section 2.2 above ?

Once a Member State has authorised cross-border care for a patient, the clinical oversight and consequent responsibility must be the responsibility of the service provider. Nevertheless, the Member State authorising access abroad must be accountable to direct the patient to a respected centre, with a clear track record of qualitative, safe and efficient service.

The same applies for telemedicine, remote diagnosis, prescriptions or laboratory services.

It is imperative that the Member States put in place robust memoranda of understanding or cooperation contracts to clearly spell out each party responsibilities.

Finally, patient confidentiality must remain a primary consideration.

Question 4 : who should be responsible for ensuring safety in the case of cross-border healthcare ? If patients suffer harm, how should redress for patients be ensured ?

The Member States who allows a patient to access a foreign health care service must be responsible for ensuring the safety of cross border care. This also includes

the transfer of the patient abroad. The host member state must be liable for any oversight or legally or professionally recognised wrong doings.

Should a patient seek redress, this must be made in his/her mother tongue in a jurisdiction as close to home as possible to prevent further stress.

The Member States must also provide rehabilitation, be it at home or abroad and any follow-up procedures that may be needed after the initial cross-border care. This must not be a one-off situation.

The patients have rights but they also have duties. While the Treaty requires the member states to provide a good level of health to the citizens, the patients must remember that they deal with a complex system where the payer is the Member State. Should the patients push for an autonomous choice, regardless of the Member States provisions, then the risk to move to private healthcare could loom on the horizon. This would lead to most unequal situations. This must be avoided and the European social model must stay in place.

In conclusion

Alzheimer Europe hopes that the Commission's framework will be an **opportunity to address the deficiencies of some Member States in tackling Alzheimer's disease and other neurodegenerative diseases**. This initiative must carefully take into account the specificities of dementia. It must be an opportunity for all European people with Alzheimer's disease and other forms of dementia to be equally diagnosed, treated and cared for across the 27 EU Member States.

The exercise must be an opportunity to bring the level of healthcare upwards.

The Member States have a lot to learn from each other and use the Open Method of Coordination. **Patients organisations like Alzheimer Europe and its members are most willing to bring their expertise within the framework of the Open Method of Coordination.**

The specific role of patient organisations as providers of information makes them natural partners in disseminating the information around patient mobility.

Finally, Alzheimer Europe is adamant that the discussions on healthcare services, cross-border care and patient mobility will not be an incentive for the Member States to pull out from the European social model currently in place. Should this exercise be an incentive for the Member States to encourage patients to resort to private healthcare insurance, we would then face serious inequalities in Europe. *Health as wealth* would no longer be a European mantra and the goals of the Lisbon agenda would certainly not become reality.

This paper represents the views of its author on the subject. These views have not been adopted or in any way approved by the Commission and should not be relied upon as a statement of the Commission's or Health & Consumer Protection DG's views. The European Commission does not guarantee the accuracy of the data included in this paper, nor does it accept responsibility for any use made thereof.