National French plan for "Alzheimer and related diseases" 2008-2012

30 June 2011

Florence Lustman
Inspecteur général des finances en charge du plan Alzheimer
As you know Nicolas Sarkozy has chosen to make the fight against Alzheimer’s one of the priorities of his term as President of the French Republic. Immediately after his election he set up a Commission chaired by Professor Joel Menard which drafted a very ambitious plan, and he endorsed and launched the Alzheimer’s plan on the 1rst of February 2008. Ever since, he has kept a close eye on the implementation, and he asks me for a detailed report every 6 months.

Actually this plan is not the first French Alzheimer plan but the two previous ones were very much health oriented, they led to the development of a network of memory centres and a number of day care centres and permitted the 100% coverage of medical expenditures related to Alzheimer’s. Yet the statement of the Menard Commission was that a lot had still to be done to improve the quality of life of patients and carers. And the Commission decided to focus this third plan on the need of the couple patient/carer and to address all the situations this couple would face throughout the progression of the disease. It finally came up with a global approach which is quite innovative.

In short the plan has 3 dimensions
- First - improving the quality of life for patients and carers
- Second – knowledge for action
- Third – mobilising around a social issue

And deploys sizable resources up to 1, 6 billion € in new expenditure over a 5 year period:
- 1,2 billion € for medico social support
- 200 millions € for medical care
- 200 millions € for research

Let us come back shortly on each of the 3 dimensions.

1 - Knowledge for action

The global objective is to discover or validate a diagnosis test or a treatment within 5 years and to achieve this objective, a Foundation for Scientific Cooperation, has been set-up on June 2008 (Director: Pr. Ph. Amouyel and Pdt of the scientific board: Pr. Joël Ménard). This foundation’s ambition is to:
- build a national network of excellence
- attract the best French and foreign researchers and give extra support to the most competitive teams
- develop partnerships with industry, including drug companies in order to give the place they deserve.
- develop relationships between all kinds of research, public and private, fundamental, clinical, epidemiological, social and human sciences

2 - Improving quality of life for patients and carers in all the situations they will face throughout the development of the disease:

2.1 Improving access to diagnosis and ensuring a continuous chain of care
- Developing and implementing a framework for diagnosis announcement and follow-up
- Experimenting new payment terms for health professionals
- Developing an Alzheimer information card for patients in case of emergency situations (10 000 cards printed in 2008 to be distributed by France Alzheimer on request)
- Creating new local memory centres and 3 new research and resources memory centres in zones without any and strengthening the most active memory centres : 65 memory clinics have been created and 202 strengthened, 2 out of the 3 research centres have been set up. 444 hospital memory centres cover the whole French territory giving an easy access to diagnosis to patients all over France.
- Creating a center for young Alzheimer’s patients : set up in February 2009, the center for young Alzheimer’s patients has local medical and medico-social correspondants in every area of France who can address the specific questions asked by those patients.
- Monitoring adverse drug reactions
- Improving correct use of drug: in 2007, 17% of Alzheimer patients were prescribed with antipsychotics which is far too high as a percentage. (15,7 % in 2009)
2.2 Improving also support and respite for carers

2.2.1 Developing and diversifying respite care services

- Creating new places
- Evaluating existing facilities
- Drafting specifications for a therapeutic dimension in all structures
- Drafting a guide for respite centers
- Experimenting innovative respite solutions: a call for projects has been launched in Jan 09, 11 experiments are currently run, testing multiservice platforms including for example home activities, discussion groups, holiday stays, cultural and artistic activities, sensory stimulation + day care and night care:

<table>
<thead>
<tr>
<th>Platforms for support and respite</th>
</tr>
</thead>
<tbody>
<tr>
<td>plans (examples)</td>
</tr>
<tr>
<td>Day care center</td>
</tr>
<tr>
<td>Home respite</td>
</tr>
<tr>
<td>Night sitting</td>
</tr>
<tr>
<td>Night care center</td>
</tr>
<tr>
<td>Temporary accomodation</td>
</tr>
<tr>
<td>Familial care</td>
</tr>
<tr>
<td>Home activities</td>
</tr>
<tr>
<td>Discussion groups</td>
</tr>
<tr>
<td>Individual coping</td>
</tr>
<tr>
<td>Holiday stays</td>
</tr>
<tr>
<td>Cultural and artistic activities</td>
</tr>
<tr>
<td>Other activities for the couple</td>
</tr>
<tr>
<td>Rehabilitation workshop</td>
</tr>
<tr>
<td>Physical activities</td>
</tr>
<tr>
<td>Sensory stimulation</td>
</tr>
</tbody>
</table>

2.2.2 Strengthening caregiver’s rights and training

- Designing the format of a “2 days” training program for carers to help them cope with the disease. So far 3000 family carers have been trained.
- Improving health monitoring for family caregivers

2.2.3 Strengthening coordination between all actors

The most innovative measure of the plan certainly is the labelling of integrated access points (« MAIA - maisons pour l’autonomie et l’intégration des malades d’Alzheimer » - houses for autonomy and integration of people with Alzheimer’s disease). In 2008 and 2009 we ran successfully 15 out of 17 experiments of this new concept, which aims at a deep integration of social and health services for the benefit of patients, and a simple, identified and personalized access to these services. Since the concept proved to be effective, we are now extending this
solution over the territory: 40 more in 2011, 100 more in 2012, the whole territory due to be covered by the end if 2014 by 400 to 600 MAIA.

In each MAIA, for patients presenting complex cases (numerous pathologies, patients alone…), case managers are “conductors” of social and health care, providing the link between the teams and guaranteeing real multidisciplinary care suited to each patient’s situation. The plan aims at providing 1000 case managers (an average 2 in each MAIA).

2.2.4 Enabling patients and their families to choose support at home

Families and patients have clearly expressed their preference for staying at home as long as possible

Reinforcing home support in favouring home intervention of specialised professionals.101 rehabilitation teams are currently operational. In 2012, 500 will be available.

Improving home-support using new technologies: national and European calls for research project are targeting home automation and ICT.

2.2.5 Improving residential care which remains necessary in a number of cases

- Creating specific units for patients with behavioral problems within nursing homes:
  - 1800 specially adapted treatment and activity units (PASA) will be created to offer to 12 to 14 residents with mild to moderate behavioural problems, social and therapeutic activities during the day in a specially adapted living area in a calm environment with space to walk around. 165 are already operating.
  - For patients with severe behavioural problems, residential reinforced structures (UHR) will be developed in the form of small units able to house about a dozen people day and night, providing both accommodation and activities and satisfying all the criteria for a suitable care and activity unit. 86 of them are already operating.
- Creating specialized cognitive behavioral units within rehabilitation services: 120 structures will be created by 2012: 49 have been created so far.
- Setting up residential services for young patients

2.2.6 Developing skill sets and specific training for all care professionals which are key to the implementation of the plan

- New competences: case-managers and « gerontology assistants »
- Training for ergotherapeuts and psychomotricians
- Training for all staffs

3 - Mobilising around a key social issue

3.1 Providing information and awareness among the general public

3.2 Promoting an ethical debate and approach

A national centre for ethics has been identified. This centre organizes conferences about patient representation, the use of technology (gps bracelets), young patients…

3.3 informing patients and family about “trials” implemented in France

4 - Making dementia a European priority:

As announced alongside President Barroso on1st of July 2008 at the beginning of the French presidency of the European Commission, Nicolas Sarkozy has decided to take the fight against A.D to the European level.

Europe can foster a better understanding of the disease and greater coordination for its research excellence. Europe can foster experience-sharing and efforts to develop common principles on the quality of the disease management. Europe can develop ethics on Alzheimer’s management, built on its values.

Practically, elaborating on the work of the pan European conference held in Paris at the end of October 2008, the competiveness council of ministers and the health council adopted key decisions in December 2008. They decided to:
- Identify research on neurodegenerative diseases and Alzheimer in particular, as a pilot joint programming initiative to be launched in 2009.
- Call on member states to establish national measures
- Call on the Commission to adopt by 2009 an initiative on research, exchange of best practices, improvement of epidemiological dates and patient rights.

The Joint programming initiative on neurodegenerative diseases (JPND) is now in progress involving 23 European countries. Its ultimate and still far away goal is to find cures for neurodegenerative diseases and to enable early diagnosis for early targeted treatments. However, in the interim, the JPND will identify common research goals that would benefit from joint action between countries in order to accelerate progress on solutions that can alleviate the symptoms, and lessen the social and economic impact for patients, families and health care systems.

An initial important objective is the drafting by the end of 2011 of a strategic research agenda (SRA), which will define the strategic and scientific priorities that would benefit from coordination at the European level. Series of SRA workshops are currently underway to identify the specific priorities in biological, clinical and social research related to neurodegenerative diseases.

A first transnational call was launched in May 2011 for a biomarker optimisation and harmonisation.

A mapping exercise has also begun to get an up to date overview on the current scale and scope of research in neurodegenerative diseases amongst European member states by the end of 2011.

An other important European action already including 19 countries is the ALCOVE joint action launched on 1st April 2011 for a 2 year period. Based on a collaborative business model for organisational, functional and financial sustainability, ALCOVE will support effective collaboration for improving the AD public health problem in Europe. It will bring better knowledge and development of risk prevention and care recommendations to facilitate policy and health care decision making in European countries.

The main outcome of ALCOVE will be the establishment of a network for risk prevention and care of dementia in Europe, with the hope that European countries not yet involved in this action will, in the future, join this network. Exchange of information among agencies will be increased, avoiding duplication of work in the field of AD and other dementia in Europe.

Numerous national, regional and local organisations across Europe, both for risk prevention and care of dementia, will work using similar models and recommendations – i.e. refer to these recommendations in their national guidelines or account for them in their specific health project plans. Information for risk prevention and care of dementia, training and care models, will be made available for each country. Availability of this information allows countries to focus/ redirect resources to their specificities in order to adapt recommendations to each situation, allowing better efficacy. Thus, reduction of duplication of work for some aspects allows implementing the risk prevention and good practices of care for AD more frequently which leads to an improvement of the quality of healthcare. Finally, thanks to the network, emerging and future developments in the domains of risk prevention and care improvement, when feasible, will be more easily disseminated and implemented.

The monitoring of the misuse of psychotropic drugs will be an example of the usefulness of this network in the 4 thematic fields covered by ALCOVE:
- improvement of the use of epidemiological data
- improvement of risk prevention and timely diagnosis
- improvement of existing practices and dementia care models
- autonomy and dignity of people with dementia from an ethical and legal perspective to improve their quality of life.