National Plan on Alzheimer disease and related disorders 2008-2012

Pr. Joël Ménard
National Plan on Alzheimer’s and related diseases 2008-2012

- Prepared by a commission at the request of Nicolas Sarkozy, between August 2007 and November 2007, discussed and acknowledged by the government at the end of January 2008
- Presented in Nice on February 1st, 2008 by the Président de la République
- Inspired by the report of the commission
- 3 themes, 11 objectives, 44 measures
ALZHEIMER’S MISSION
(August 1rst- November 8th 2007)

Societal viewpoint : the Steering Committee
- F. Bartoli (IGAS)
- F. Bourdillon (SFSP)
- Cordier (CNSA)
- C. Feuerstein (Univ.)
- JPh Flouzat (Aff.Soc.)
- B. Grézy (IGAS)
- Ph. Juvin (CG)
- B. Lavallart (S)
- B. Roques (Fac Pharma)
- RM Van Lerberghe
- JP Vial (CG)
- Ph. Vigouroux (DG, CHU)

Technical viewpoint : 8 working groups
- F. Forette, A. Fagot-Largeault
- B. Vellas, A. Colvez
- L. Buée, F. Checler
- O. Rascol, Ph. Amouyel
- B. Dubois, D. Campion
- G. Berrut, C. Jeandel
- M.-S. Desaulle, C. Blum-Boisgard
- J.-F. Dartigues, M.-E. Joel
The conceptual framework of the French Alzheimer Plan

« A patient-oriented national initiative »

**Administration**
4 Ministeries, 7 Directions
ARH, DDASS, CCAS, CNAMTS, CAV, InVS, INPES
France-Alzheimer

1,2 millions € / 5 years

**Medical et social care**
Hospital care (emergency and long duration stays)
Home care (respite care, residentiality, institutionalisation)
More than 8 professions in direct contact with the patient

**Medical care**
General Practitioners, Geriatricians, Neurologists, Neuropsychologists, Psychiatrists, Radiologists, Biologists, Pharmacists...

**Patients needs and Family support**

**Research**
Clinicians, Epidemiologists, Neuropathologists, Biochemists, Cell Biologists, Geneticists, Immunologists, Pharmacologists, Medicinal chemists ...

200 millions € / 5 years

200 millions € / 5 years
The French Alzheimer Plan
2008 – 2012

- Research
  - An international viewpoint

- Medical care
  - A national viewpoint

- People with dementia and carers
  - A local viewpoint
The objective criteria for health priorities are fully met in the case of patients suffering from Alzheimer’s disease and dementia, and their families:

- Large number of people affected
- Large number of Disability Adjusted Life Years lost (DALYs)
- Growing incidence and prevalence associated with ageing
- Emotionally difficult for close relatives
- Complex medical and social care
- High associated costs
# The burden of Alzheimer disease (dementia) in France (2000 – 2001)

## MEN

<table>
<thead>
<tr>
<th>Disease</th>
<th>Percentage</th>
<th>Death Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disease</td>
<td>8.9 %</td>
<td>65 - 94 %</td>
</tr>
<tr>
<td>Lung Cancer</td>
<td>5.7 %</td>
<td>98 %</td>
</tr>
<tr>
<td>Alcohol-related disease</td>
<td>4.5 %</td>
<td>23 %</td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>3.1 %</td>
<td>24 %</td>
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## WOMEN

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<tbody>
<tr>
<td>Alzheimer’s and related diseases</td>
<td>7.5 %</td>
<td>20 %</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>7.1 %</td>
<td>71 - 95 %</td>
</tr>
<tr>
<td>Nervous depressions</td>
<td>7.1 %</td>
<td>2 %</td>
</tr>
<tr>
<td>Breast Cancer</td>
<td>4.2 %</td>
<td>86 %</td>
</tr>
</tbody>
</table>

*Source: A. Lapostolle, A. Spira, Unite Inserm-Ined (U 569)*
The Demographic Challenge: projected trends of the number of elderly dependant people in France and of the potential number of family carers (base 100 in 2000)
The French Alzheimer Plan: 2008-2012

A financial effort
- 200 M for research
- 200 M for medical care
- 1,2 billion euros for medico-social support

Three main themes
- Develop our **understanding of the disease**: two objectives, fourteen measures
- Improve the **quality of life of people with dementia and their carers**:
  - six objectives, twenty measures
  - At the time of diagnosis
  - During follow-up
- **Mobilize society** for the fight against dementia by developing a voluntary approach and synergisms: three objectives, twenty measures
Alzheimer Plan Governance

- **Direct reporting to the Président de la République:** Florence Lustman, Inspecteur général des Finances, with a four member staff

- **Steering Committee:** once a month

- **Supervisory Committee:** every three months

- **Working session with the Président de la République:** every six months
Direct investment into research in favour of Alzheimer’s patients has been under-estimated in France over the past 30 years by comparison with cancer research, orphan diseases research ….

Consequences:

- 45% of quotes come from the USA, very active since 1978: for instance, French contributions in this field, although real, are less often cited than research on AIDS or Parkinson’s disease.
- The number of researchers and of clinical researchers concerned is low and their age pyramid is not optimal.
- The size and number of research teams is too low for a country with 6 million inhabitants of which the population of over 65 year olds is increasing fast.
The basis of a scientific policy for the first five years of the presidential plan

1. Reinforce the strengths
   - Facilitate the work of multi-disciplinary centres with a strong previous scientific production
   - Exploitation of population cohorts, participation in genome-scan studies, better use of experimental models already developed in France, particularly the microcebe

2. Attract new teams
   - Connected with existing teams, and opening new fields, i.e cellular biology, system biology, vascular biology, immunology
   - Centre of methodology, Centre of social and economical research

3. Attract young researchers: forty per year
   - CCA and AHU: coordinate a national programme
   - PhDs and post-doctoral researchers: settle a national policy

4. Train 1500 professionals in clinical epidemiology
   - Leadership of the IHESP - etiology, diagnosis, prognostic, therapeutic trials, meta-analysis

5. Recruit as Associate Professor industrial professionals to teach the international development of drugs and diagnostic tools
A Foundation for Scientific Cooperation

- **Objective**: to contribute to the discovery or validation of a diagnosis and/or treatment within 5 years

- **Scientific Cooperation Foundation set June 29th, 2008** and designation of its Administrative Council and its President (Mr. Lagayette), the Scientific director (Pr. Amouyel) and the President of the Scientific Council (Pr. Ménard), November 7th

- A national network of excellence
- Attract the best French and foreign researchers and give support to the best teams
- Develop partnerships with industry, including drug or diagnostic companies
- Develop relationships between all kinds of research: public and private; fundamental, clinical, biological, social science
<table>
<thead>
<tr>
<th>Working groups</th>
<th>Management committee</th>
<th>Scientific council</th>
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<tbody>
<tr>
<td>Patient care and Family support</td>
<td>J.-F. Dartigues (Bordeaux)</td>
<td>M.-E. Joël (Paris)</td>
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<tr>
<td></td>
<td>J.-F. Martin (IESP)</td>
<td>M. Poncet (Marseille)</td>
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<td></td>
<td>M.-A. Bloch (CNSA)</td>
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<td>Controlled Clinical Trials and Prospective Studies</td>
<td>Ch. Tzourio (Paris)</td>
<td>J. Ménard (Paris)</td>
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<td>B. Vellas (Toulouse)</td>
<td>A. Alpérovitch (Paris)</td>
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<td>J.-F. Dartigues (Bordeaux)</td>
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<td>Neuropsychology and Clinical Investigation</td>
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<td>M. Poncet (Marseille)</td>
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<td>F. Pasquier (Lille)</td>
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<td>M. Poncet (Marseille)</td>
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<td>Ch. Tzourio (Paris)</td>
<td>S. Lazdunski (Nice)</td>
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<td></td>
<td>Ph. Hantraye (Saclay)</td>
<td></td>
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<td>Biomarkers</td>
<td>F. Checler (Nice)</td>
<td>J. Ménard (Paris)</td>
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<td></td>
<td>J.-F. Dartigues (Bordeaux)</td>
<td>B. Roques (Paris)</td>
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<td>Genetics</td>
<td>D. Campion (Rouen)</td>
<td>A. Alpérovitch (Paris)</td>
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<td>Ph. Amouyel (Lille)</td>
<td>J. Ménard (Paris)</td>
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<td>Animal models</td>
<td>L. Buée (Lille)</td>
<td>S. Lazdunski (Nice)</td>
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<td>Ph. Hantraye (Saclay)</td>
<td>B. Roques (Paris)</td>
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<td>Cell biology and Neuropathology</td>
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<td>B. Roques</td>
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<td></td>
<td>L. Buée (Lille)</td>
<td>J.-F. Bach</td>
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<tr>
<td></td>
<td>Ph. Amouyel (Lille)</td>
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Research investments of the Alzheimer plan 2008-2012

- Basic research and Biomarkers (70 M) - 36%
- Clinical Research (45 M) - 23%
- Neuro-imaging (23 M) - 12%
- Epidemiology (14 M) - 7%
- Training (10 M) - 5%
- New research teams (6 M) - 4%
- Methodology (5 M) - 3%
- GWA studies (5 M) - 3%
- Animal models (4 M) - 2%
- Practices evaluation (2 M) - 1%
- Foundation (2 M) - 1%
- Human and social sciences (8 M) - 3%
Develop our understanding of the disease

- **Measure 22**: selection of projects from the hospital clinical research annual program. Thirteen projects selected from 36 submitted applications.

- **Measure 21 and 43**: grant applications to Agence Nationale de la Recherche
  - Seven selected national projects + 2 international projects from 45 submitted applications.

- **Measure 30**: identification of informative polymorphisms. GWA: 2500 patients et 9000 controls currently genotyped. Collaboration with other countries: Framingham, Cardiff… and others.

- **Measure 23**: supplementary applications for PH.D. and post-Doctoral allocations, and 10 hospital assistants involved in clinical research for all concerned specialties (19 candidates).
Develop our understanding of the disease

- **Measure 28**: automatisation of brain imaging readings
- **Measure 29**: initiation of hospital patients cohorts, support to 3C, Paquid
- **Measure 31**: grant applications for exploitation or creation of new experimental models
- **Measure 32**: selection of the Bordeaux CM2R to teach Clinical Epidemiology and Evidence-Based Medicine (1500 physicians)
- **Measure 33**: Two Associate Professor from the Industry
- **Measure 34**: personnalised, structured and computerized shared medical dossier in all Memory Clinics (30 common items) prepared by the Nice CM2R
Improving quality of life for patients and carers

Improving support and respite for carers

- Developing and diversifying respite care services
  - Evaluating existing facilities
  - Experimenting innovative respite solutions
  - Drafting specifications for a therapeutic dimension in all structures
  - Drafting a guide for respite centers
- Strengthening caregivers rights and education
  - 2 days’ training a year for carers
  - Support in returning to work
- Improving health monitoring for family caregivers
Labelling 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)

- call for experimentation in July 2008
- more than 100 applications for 15 experiments to be selected in November 2008
- 1000 “coordinators” (case managers) over the whole territory
Improving quality of life for patients and carers

Enabling patients and their families to choose support at home

- Reinforcing home support, favouring home intervention of specialised professionals
  - 500 specialist teams in home nursing services
- Improving home-support using new technologies
  - Call for project targeting home automation and ICT
Improving quality of life for patients and carers
Improving access to diagnosis and ensuring a continuous chain of care

- Developing and implementing a framework for diagnosis announcement and follow-up
  - *practice guidelines for the diagnosis and management of dementia (HAS, 30/5/2008)*
- Experimenting new payment terms for health professionals
- Alzheimer information card for patients in case of emergency situations
  - 100 000 *edited cards - 7300 distributed as of sept. by France Alzheimer on physician request*
- New local memory centers in zones without any
- New research and resources memory centers in zones without any
  - 3 CM2R in Auvergne, Corse and Limousin
- Strengthening the most active memory centers (122)
- Monitoring adverse drug reactions
- Improving correct use of drugs
  - *Study 10-2008 : 18% of Alzheimer patients prescribed with antipsychotics*
CE QUE L’ON SAIT


Les prises en charge sont tout à fait différentes mais mal établies et peu connues des professionnels. En tout état de cause, le fréquent recours observé aux médicaments neuroleptiques ou autres sédatifs n’est pas indiqué, a fortiori au long cours. Seuls les psychoses et syndromes délirants avérés relèvent d’un traitement par neuroleptiques au long cours.

L’indication des neuroleptiques au long cours n’est pas indiquée dans les troubles du comportement.
Improving quality of life for patients and carers

Improving residential care

- **Creating specific units** for people with behavioural problems within nursing homes
  - Day units / day and night units
  - 12,000 new places
  - Reinforcing 18,000 places
  - 180 M investment credits in 2008

- **Creating specialized cognitive behavioural units** within rehabilitation services
  - 120 structures (24 in 2008)

- **Setting up residential services for young patients**

- **Creating a national reference centre for young patients**
  - Call for project - 5 November 2008
Improving quality of life for patients and carers

Developing skill sets and specific training for all care professionals

- New jobs of case-managers and « gerontology assistants » (Level 4)

- Training for ergotherapeuts and psychomotricians

- Training for all staffs
Supplementary measures

- Opinion and knowledge survey (INPES)
  - 2008 and 2011
  - 2,000 participants, after a qualitative study (130 participants)

- A medico-economic study (DREES)
  - Costs at home and in institutions, according to disease stage
  - From the viewpoint of families and community


- A coordinated surveillance system (12 sources)
Prévalence dans la Population des ≥ 60 ans :
2,7%
Health System utilisation by patients with 100% coverage of their expenditures for Alzheimer disease and related disorders (ALD 15)

<table>
<thead>
<tr>
<th>N = 298.451</th>
<th>GPs</th>
<th>Neuro-psychiatrists</th>
<th>Specialists</th>
<th>Nursing care</th>
<th>Kinesitherapy</th>
<th>Transports</th>
<th>Hospital admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>60-69 years</td>
<td>1.01</td>
<td>7.01</td>
<td>0.85</td>
<td>1.32</td>
<td>1.45</td>
<td>3.83</td>
<td>1.71</td>
</tr>
<tr>
<td>70-79 years</td>
<td>1.00</td>
<td>6.81</td>
<td>0.83</td>
<td>1.14</td>
<td>1.42</td>
<td>1.71</td>
<td>1.47</td>
</tr>
</tbody>
</table>

Kusnik-Joinville O et al., CAMTS 2008 (in preparation)
Mobilising around a key social issue

Providing information and increasing awareness amongst the general public

- Setting up a telephone helpline and local web sites for local information and orientation
- Holding regional conferences to support the implementation of the plan
- Studying disease knowledge and attitudes
  - Qualitative study in October 2008 (InPES)
Selected ethical issues

1. Early diagnosis in the absence of disease-modifying treatment: scientific dream, medical or social request, or quality of life impairment for several years?

2. Clinical research: equipoise, freedom of choice, reality of the informed consent, patient and family comfort, individual and collective benefit/risk ratio?

3. End of life management: whom, when, how? anticipated directive, and selection of a reliable substitute?

4. Inclusion of these specific considerations into the general framework: charity, harm, autonomy and equity.
Mobilising around a key social issue

Promoting an ethical debate and approach

- Creating a national center for ethics on dementia
  - Call for project - 5 November 2008
- Adapting the legal status of those with dementia
- Organizing conferences about the autonomy of patients
  - Patient representation
  - GPS bracelets
- Informing patients and families about trials implemented in France
  - Agreement with ONRA (Toulouse) for access through Internet to the therapeutic and diagnosis research protocols performed or scheduled in France
Mobilising around a key social issue

Making dementia a European priority

- Making the fight against Alzheimer’s disease a priority for the European Union
  - Conclusions adopted at the Competitiveness Council on September 26th, 2008
  - Reinforcement of the international cooperation
    - Bilateral contacts with British and German partners
    - Contacts with Québec and European and international patient associations
  - Adopting conclusions at the Health Council on December 15th, 2008
- Publicizing and promoting research at the European level
  - September 22th: Meeting of financing and research agencies
  - European Conference on October 30-31st, 2008
  - Québec: Chronic disease and Aging Symposium on November 6th