

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

1 February 2008

Contents

10 KEY MEASURES

FUNDING SUMMARY FUNDING SUMMARY BY MEASURE

SECTION I. IMPROVING QUALITY OF LIFE FOR PATIENTS AND CARERS

<u>Objective 1</u>	<u>Increasing support for carers</u>	13
<u>measure 1</u>	<u>Developing and diversifying respite structures</u>	14
<u>measure 2</u>	<u>Consolidating rights and training for carers</u>	16
<u>measure 3</u>	<u>Improving health monitoring for family carers</u>	18
<u>Objective 2</u>	<u>Strengthening coordination between all actors involved</u>	19
<u>measure 4</u>	<u>Quality labelling throughout the country for "single points of contact", the "Maisons pour l'Autonomie et l'Intégration des malades Alzheimer" (MAIA)</u>	21
<u>measure 5</u>	<u>Establishing "coordinators" throughout the country</u>	24
<u>Objective 3</u>	<u>Enabling patients and their families to choose support at home</u>	26
<u>measure 6</u>	<u>Reinforcing support at home, advocating services by trained staff</u>	27
<u>measure 7</u>	<u>Improving support at home using new technologies</u>	29
<u>Objective 4</u>	<u>Improving access to diagnosis and care pathways</u>	30
<u>measure 8</u>	<u>Preparing and implementing a system for giving the diagnosis and providing counselling</u>	31
<u>measure 9</u>	<u>Experimenting new payment terms for health professionals</u>	33
<u>measure 10</u>	<u>Creating an Alzheimer's disease information card for each patient</u>	34
<u>measure 11</u>	<u>Creating memory units in areas that are not covered</u>	36
<u>measure 12</u>	<u>Creating "memory resource and research centres" in areas that are not covered</u>	37

<u>measure 13</u>	<u>Reinforcing the very active memory units</u>	38
<u>measure 14</u>	<u>Monitoring drug-related iatrogenic accidents</u>	39
<u>measure 15</u>	<u>Improving correct use of drugs</u>	41
<u>Objective 5</u>	<u>Improving residential care for better quality of life for Alzheimer's disease sufferers</u>	42
<u>measure 16</u>	<u>Creating or identifying specific units for patients suffering from behavioural problems within EHPADs</u>	43
<u>measure 17</u>	<u>Creating specialized units within health care rehabilitation and follow-up (SSR) departments for Alzheimer's patients</u>	46
<u>measure 18</u>	<u>Accommodation for young patients</u>	48
<u>measure 19</u>	<u>Identifying a national reference centre for young Alzheimer's patients</u>	49
<u>Objective 6</u>	<u>Recognising skills and developing training for health professionals</u>	51
<u>measure 20</u>	<u>A specific career and skills development plan for Alzheimer's disease</u>	52
<u>SECTION II. KNOWLEDGE FOR ACTION</u>		53
<u>Objective 7</u>	<u>Making unprecedented efforts in research</u>	53
<u>measure 21</u>	<u>Creating a foundation for scientific cooperation to stimulate and coordinate scientific research</u>	54
<u>measure 22</u>	<u>Developing clinical research of Alzheimer's disease and improving evaluation of non-drug therapies</u>	56
<u>measure 23</u>	<u>Doctoral and post-doctoral grants</u>	57
<u>measure 24</u>	<u>New assistant surgeon and hospital teaching assistant positions</u>	58
<u>measure 25</u>	<u>Research in human and social sciences</u>	59
<u>measure 26</u>	<u>Support for research groups working on innovative approaches</u>	60
<u>measure 27</u>	<u>Support for methodological research groups in human and social sciences</u>	61
<u>measure 28</u>	<u>Creation of a body of research in automatic image processing</u>	62
<u>measure 29</u>	<u>Studying large patient populations (cohorts) with long-term monitoring</u>	63
<u>measure 30</u>	<u>High-speed genotyping</u>	64
<u>measure 31</u>	<u>Exploiting the genome sequencing of the microcebe</u>	65
<u>measure 32</u>	<u>Training in clinical epidemiology</u>	66
<u>measure 33</u>	<u>Developing links between public research and industry</u>	67

<u>Objective 8</u>	<u>Organising epidemiological surveillance and follow up</u>	68
<i>measure 34</i>	<i>Setting up epidemiological surveillance and follow up</i>	69
<u>SECTION III. MOBILISING AROUND A SOCIAL ISSUE</u>		70
<u>Objective 9</u>	<u>Providing information for general public awareness</u>	70
<i>measure 35</i>	<i>Setting up a telephone helpline and a website for information and local advice</i>	71
<i>measure 36</i>	<i>Holding regional conferences to support the implementation of the plan.....</i>	73
<i>measure 37</i>	<i>Studying disease knowledge and attitudes.....</i>	74
<u>Objective 10</u>	<u>Promoting ethical considerations and an ethical approach</u>	75
<i>measure 38</i>	<i>Creating a space for ethical thought about Alzheimer's disease</i>	76
<i>measure 39</i>	<i>Launching a discussion about the legal status of Alzheimer's patients in institutions</i>	78
<i>measure 40</i>	<i>Organising regular meetings focusing on the autonomy of people suffering from Alzheimer's disease</i>	79
<i>measure 41</i>	<i>Informing patients and their families about trials implemented in France</i>	80
<u>Objective 11</u>	<u>Making Alzheimer's disease a European priority</u>	81
<i>measure 42</i>	<i>Making the fight against Alzheimer's disease a priority for the European Union during the French presidency</i>	82
<i>measure 43</i>	<i>Publicizing and promoting research across Europe</i>	83
<i>measure 44</i>	<i>Holding a European conference in autumn 2008</i>	84

10 key measures

...to improve diagnosis...

Measure 8 Preparing and implementing a system for **giving the diagnosis and providing counselling**

Measure 13 Reinforcing the very active **memory units**

...to provide better treatment and support...

Measure 4 *Quality labelling throughout the country for "single points of contact", the "Maisons pour l'Autonomie et l'Intégration des malades Alzheimer" (MAIA)*

Measure 5 Establishing "**coordinators**" throughout the country

Measure 6 **Reinforcing support at home**, advocating services by trained staff

Measure 16 *Creating or identifying specific units for patients suffering from behavioural problems within EHPADs*

Measure 19 *Identifying a national reference centre for young Alzheimer's patients*

...to help more and more effectively...

Measure 1 *Developing and diversifying **respite structures***

Measure 35 *Setting up a **telephone helpline and a website** for information and local advice*

...to speed up research...

Measure 21 *Creating a **foundation for scientific cooperation** to stimulate and coordinate scientific research*

Funding summary

1.6 billion euros over 5 years

300 million euros in 2008

The medico-social aspect over 1.2 billion euros

Spending will amount to 254 million euros in 2008.

Funding will be provided by the health insurance system and the National Fund for the Autonomy of Elderly and Disabled People (Caisse nationale de solidarité pour l'autonomie des personnes âgées et des personnes handicapées, CNSA).

The health aspect over 200 million euros

Health spending will represent 23 million euros in 2008, most of which will come from the health insurance system.

The research aspect 200 million euros

The creation of a Foundation for Scientific Research will make it possible to stimulate and coordinate research into Alzheimer's disease in France and to attract public and private resources to the issue.

In 2008, 29 million euros of spending are planned (including an initial capital subsidy from the state for the Foundation for Scientific Cooperation of €14.4 million).

	2008	2009	2010	2011	2012	total spending associated with the measures
Medico-social aspect	254	134	202	274	379	1242
<i>operating costs</i>	74	134	202	274	379	1062
<i>investment</i>	180					180
Health aspect (excluding clinical research)	23	44	48	53	59	226
Research aspect	29	42	38	46	45	201
TOTAL	306	220	288	373	482	1669

Funding summary by measure

in M€

<i>title</i>	<i>2008</i>	<i>2009</i>	<i>2010</i>	<i>2011</i>	<i>2012</i>	<i>total spending on the measure</i>	
SECTION 1	IMPROVING QUALITY OF LIFE FOR PATIENTS AND CARERS						
Objective 1	Increasing support for carers						
measure 1	Developing and diversifying respite structures	21.3	27.6	33.9	40.2	46.5	169.5
measure 2	Consolidating rights and training for carers	2.5	3.5	3.5	3.5	3.5	16.5
measure 3	Improving health monitoring for family carers		5	5	5	5	20
Objective 2	Strengthening coordination between all actors involved						
measure 4	Quality labelling throughout the country for "single points of contact", the "Maisons pour l'Autonomie et l'Intégration des malades Alzheimer" (MAIA)	5.3	5.3	5.3	5.3	6.7	27.9
measure 5	Establishing "coordinators" throughout the country	2.5	6.0	15.0	30.0	60.0	113.5
Objective 3	Enabling patients and their families to choose support at home						
measure 6	Reinforcing support at home, advocating services by trained staff	4.0	15.0	30.0	45.0	75.0	169.0
measure 7	Improving support at home using new technologies		2	2			4.0
Objective 4	Improving access to diagnosis and care pathways						
measure 8	Preparing and implementing a system for giving the diagnosis and providing counselling	0.10					0.10
measure 9	Experimenting new payment terms for health professionals						
measure 10	Creating an Alzheimer's disease information card for each patient	0.11	0.11				0.22

measure 11	Creating memory units in areas that are not covered	6.92	9.38	9.38	9.38	9.38	44.44
measure 12	Creating "memory resource and research centres" in areas that are not covered	1.14	1.14	1.14	1.14	1.14	5.7
measure 13	Reinforcing the very active memory units	7	11.3	12.3	12.3	12.3	55.2
measure 14	Monitoring drug-related iatrogenic accidents	0.2					0.2
measure 15	Improving correct use of drugs						
Objective 5	Improving residential care for better quality of life for Alzheimer's disease sufferers						
measure 16	Creating or identifying specific units for patients suffering from behavioural problems within EHPAD						
	creating 12,000 Alzheimer's-specific places	12	24	36	48	60	180.0
	adapting staffing for 18,000 existing places	25.5	50.4	75.6	100.8	126	378.0
	investment – reconstruction and adaptation of 15,000 places	180.0					180.0
measure 17	Creating specialized units within health care rehabilitation and follow-up (SSR) departments for Alzheimer's patients						
	<i>operation</i>	2.40	7.80	13.20	18.60	24.00	66.00
	<i>investment</i>	2.40	5.40	5.40	5.40	5.40	24.00
measure 18	Accommodation for young patients	0.2					0.2
measure 19	Identifying a national a national reference centre for young Alzheimer's patients	0.6	0.6	0.6	0.6	0.6	3.0
Objective 6	Recognising skills and developing training for health professionals						
measure 20	A specific career and skills development plan for Alzheimer's disease						

SECTION II.	KNOWLEDGE FOR ACTION						
Objective 7	Making unprecedented efforts in research						
	Calls for projects by the Agence nationale de la recherche and research within organisations	10.00	15.00	15.00	15.00	15.00	70.00
measure 21	Creating a foundation for scientific cooperation to stimulate and coordinate scientific research	0.26	0.32	0.32	0.32	0.32	1.54
measure 22	Developing clinical research of Alzheimer's disease and improving evaluation of non-drug therapies	3.00	6.00	9.00	12.00	15.00	45.0
measure 23	Doctoral and post-doctoral grants	1.10	1.10	1.10	1.10	1.10	5.5
measure 24	New assistant surgeon and hospital teaching assistant positions	0.00	0.84	0.84	0.84	0.84	3.4
measure 25	Research in human and social sciences	0.00	2.06	2.06	2.06	2.06	8.24
measure 26	Support for research groups working on innovative approaches	0.00	1.42	1.42	1.42	1.42	5.68
measure 27	Support for methodological research groups in human and social sciences	0.00	1.23	1.23	1.23	1.23	4.92
measure 28	Creation of a body of research in automatic image processing	0.00	8.00	3.00	8.00	4.00	23.00
measure 29	Studying large patient populations (cohorts) with long-term monitoring	1.15	2.72	2.72	2.72	2.72	12.03
measure 30	High-speed genotyping	3.20	2.15	0.00	0.00	0.00	5.35
measure 31	Exploiting the genome sequencing of the microcebe	0.20	1.24	1.24	1.24	1.24	5.16
measure 32	Training in clinical epidemiology	0.20	0.20				0.40
measure 33	Developing links between public research and industry	0.00	0.16	0.16	0.16	0.16	0.64
Objective 8	Organising epidemiological surveillance and follow up						
measure 34	Setting up epidemiological surveillance and follow up	1.1	0.3	0.3	0.3	0.3	2.3

SECTION III	MOBILISING AROUND A SOCIAL ISSUE						
Objective 9	Providing information for general public awareness						
measure 35	Setting up a telephone helpline and a website for information and local advice	0.7	0.2	0.9	0.9	0.9	3.6
measure 36	Holding regional conferences to support the implementation of the plan		2.3				2.3
measure 37	Studying disease knowledge and attitudes	0.1					0.1
Objective 10	Promoting ethical considerations and an ethical approach						
measure 38	Creating a space for ethical thought about Alzheimer's disease	0.4	0.4	0.4	0.4	0.4	2.0
measure 39	Launching a discussion about the legal status of Alzheimer's patients in institutions						
measure 40	Organising regular meetings focusing on the autonomy of people suffering from Alzheimer's disease	0.03	0.03	0.03	0.03	0.03	0.2
measure 41	Informing patients and their families about trials implemented in France	0.05	0.05	0.05	0.05	0.05	0.3
Objective 11	Making Alzheimer's disease a European priority						
measure 42	Making the fight against Alzheimer's disease a priority for the European Union during the French presidency						
measure 43	Publicizing and promoting research across Europe						
measure 44	Holding a European conference in autumn 2008	0.3					0.3
		306	220	288	373	482	1669

Section I.Improving quality of life for patients and carers

Objective 1

Increasing support for carers

Too often, family carers feel as if they have been left alone to face their difficulties, despite the progress made in support and the increased numbers of respite facilities. The government cannot let this situation continue; national solidarity must support the family solidarity shown by family carers.

Over 70% of carers spend more than six hours a day caring for the patient. This extra domestic workload is imposed while many carers are still working. Patients and their families are confronted with many difficulties, and there are three specific points where the burden is particularly heavy: receiving the diagnosis, the organisation of support when care has been stabilised and the management of crises. The primary consequence of Alzheimer's and related diseases is deterioration in the health of those around the patient and a major loss in quality of life.

Home care must no longer be a synonym for solitude for those who look after and accompany patients.

Carers must be able to call on professional help and, where necessary, new so-called "respite" facilities. From this viewpoint, three objectives must be fulfilled: developing professional help in the home, creating flexible, innovative respite solutions and guaranteeing the solutions available to all patients throughout the country.

Respite solutions are not always appropriate for carers' needs and not always flexible enough, and sometimes they may be only accessible with difficulty or not even available at all in a given area.

The plan takes these requirements into account and proposes experimenting with a wide range of respite and support services, such as mobile on-call day and night care, home nursing etc. in order to see which services are the most useful for both the patient and the carer. Then, the **most effective solutions should be generalised**, making sure that all the appropriate systems are available in a given area. In addition, a very specific set of specifications will be drafted to give all day care facilities a therapeutic dimension.

This qualitative progress, presented as measure 1, will be accompanied by a continuing quantitative effort to create new places, already begun in 2008.

Moreover, the impact of measures to fund transport to these facilities, implemented for 2008, will be evaluated so that they can be adapted to suit families' needs better.

Carers will receive greater recognition from society with the adoption of a specific status (measure 2) providing eligibility for training and help in returning to work. It is only to be expected that carers who, in looking after a close relative, provide a service to society should receive more recognition and benefit from specific support in finding a job if they wish.

More generally, the plan provides for combined support for both the patient and the carer, aiming particularly to combat carers' feelings of isolation and changes in their health. As part of follow-up from the primary-care doctor, carers will receive greater support and assistance (measure 3).

1. Objective

The aim is to offer a **diverse range of respite facilities in each area corresponding to the needs of patients and carers, and to guarantee their accessibility.**

In order to ensure a free choice for as long as possible between care at home and institutionalisation, it is essential for carers to have access to flexible solutions that suit their needs for periods of respite which are also an opportunity for treatment and evaluation for the patient and the people involved. In this way we can prevent the crisis situations that often result in permanent institutionalisation. The objective is thus threefold: to provide high-quality care for the patient, while guaranteeing a period of respite for the carer suited to his or her needs and enabling access to these structures with appropriate financial measures.

2. Context

The greatly accelerated creation of new places

In order to support carers better and widen the diversity of options available to both patients and their families, the public authorities have developed a range of respite structures that are now receiving sustained attention.

- In 2008, **2,125 day places and 1,125 temporary accommodation places** were created.

Another possibility that will be provided is the **financing of transport for Alzheimer's patients to day care centres.** This measure is a response to a pressing need on the part of families, but its effects need to be evaluated.

- A very ambitious rate of creation of new places will be maintained throughout the duration of the plan. **11,000 day care places or equivalent and 5,600 temporary accommodation places.** In view of the existing facilities (7,000 and 3,600 places respectively), this represents unprecedented increase.

Beyond the objective of creating new places, which remains central, four requirements emerge.

3. Measures

Evaluation of existing facilities

We need to know more about the factors that make the installation and use of day care facilities a success or a failure. **A study will be launched by the National solidarity funds for autonomy CNSA,** which will explain the differences between structures and give the impact of new measures such as **reimbursing transport costs.** **If the latter initiative proves flawed, it will be reformed in 2009 to make sure families' needs are fully met.** The study will also be a chance to check **that good use is being made of temporary accommodation,** and otherwise to **recommend ways of guaranteeing the availability of places.**

Experimenting with innovative respite solutions and then making them more widely available

We need to offer carers new solutions that are more flexible and better suited to their needs. In a given area (covered by a "single point of contact"), a variety of structures corresponding to carers' needs must be available. To achieve this, several different innovative respite arrangements will be tested as part of the experimentation in progress, located in areas with varied profiles: day accommodation, night accommodation, mobile day and night care, care at home, psychological support and various types of temporary accommodation etc. The use of these facilities will be evaluated, as will their medico-economic benefit, and the obstacles, including legal barriers, in the way of their implementation.

After these trials, the innovative respite packages will be developed so that each area can benefit from a range of respite structures corresponding to the needs of patients and carers.

Drafting a set of specifications to give all respite structures a therapeutic dimension

In parallel with these experiments, the National Social and Medico-Social Evaluation Agency (Agence nationale de l'évaluation sociale et médico-sociale, ANESM), in partnership with the National Health Authority (Haute Autorité de Santé, HAS), will establish specifications for the various reception and accommodation facilities that emphasise the quality of care and the intervention of professionals specifically trained to deal with cognitive disabilities, in order to guarantee high-quality care and a real benefit for the patient.

No distinction should be made between respite structures for the carer and temporary care structures for the patient: all respite structures should have a strong therapeutic dimension, a real care project for patients.

Drafting a guide for creating day care centres and opening respite places, to remove certain brakes on initiatives. This guide will be drafted in partnership with associations and foundations.

4. Actors

Steering committee involving the state (the Directorate General for Social Action (Direction générale de l'action sociale, DGAS) and the Directorate General for Health (Direction générale de la santé, DGS)), the National Fund for Autonomy of Elderly and Disabled People (Caisse nationale de solidarité pour l'autonomie des personnes âgées et des personnes handicapées, CNSA) and the assembly of French *départements* (Assemblée des départements de France, ADF), in partnership with the National Employees' Pension Fund (Caisse nationale d'assurance vieillesse des travailleurs salariés, CNAVTS), France Alzheimer, the National Social and Medico-Social Evaluation Agency (Agence nationale de l'évaluation sociale et médico-sociale, ANESM) and the National Health Authority (Haute Autorité de Santé, HAS) to redefine day care.

5. Schedule

2008: study of day care by the CNSA (part of its 2008 study programme) 2008: widening the range of care solutions, establishing a new typology of structures in which trials can be carried out and drafting specifications (ANESM, HAS) for each one.

2008: experimenting with different types of temporary reception and accommodation facilities, to be developed across the country from 2009.

6. Funding

- **The trials** represent a cost of **€2.5 million per year** (duration: 2 years), corresponding to the launch of ten trials of different packages in areas with different profiles.
- The additional funding for these day care centres added to the new places already planned, and the funding for transport, represents a total of **€169.5 million** over the period of the plan.

7. Evaluation

Process indicators

The availability in 2009 of a study of the requirements expressed, the relevance of the flexible and innovative solutions proposed and the satisfaction of users according to several archetypal district profiles

Establishment of specifications for the therapeutic dimension of day care

Result indicators

Adherence to the specifications by all day care units by 2012

Number of platforms created/number of Alzheimer's patients registered

Availability in 2012 of a range of respite services in each district

measure 2
Consolidating rights and training for carers

1. Context

The primary consequences of Alzheimer's and related diseases for carers often include considerable disruption to their daily lives, psychological suffering and a degradation of their health. Associations such as France Alzheimer, founded in 1985, have been set up to provide information to family carers and combat their isolation. Over the years many other bodies have become involved in supporting and helping carers.

The national conference on the family held on 3 July 2006 gave priority in its recommendations to acknowledge and support family carers for elderly people suffering from a loss of autonomy. Along the same lines as the work of the family conference, a guide for family carers has been produced.

2. Objective

Carers' rights and access to training must be reinforced further, and carers who wish it should be helped in returning to work.

3. Measures

Training for carers

Alzheimer's disease is a real ordeal for the family of the patient, and daily care for sufferers is all the more difficult in that the family carers have never been trained. Loss of memory, behavioural problems and bursts of violence are all symptoms the carer does not know and cannot anticipate. On the other hand, carers are unaware of the appropriate behaviour that would help limit as far as possible certain consequences of the disease. There is thus a need to offer families looking after a relative suffering from Alzheimer's disease the knowledge they need, providing the essential tools for understanding the patient's difficulties, adapting the environment and maintaining relationships.

Two days' training a year will be offered to each family carer.

Specifications will be drawn up by the ANESM in partnership with the HAS covering the patient-carer relationship, care techniques, non-verbal communication and stress management.

Actors

The CNSA in partnership with the Ministry for Social Affairs, the Ministry of Health, the ANESM and the HAS for the specifications, with the addition of the special expertise of France Alzheimer.

Schedule

2008-2012

Funding

€2.5 million per year

Evaluation

Process indicators

Drafting and validation of specifications

Inclusion of family carer training in section IV of the CNSA budget *Results indicators*

Number of people trained/number of carers

Implementation of support in returning to work

When family carers, who in supporting a relative have given their time to the community and have often had to give up their employment, wish to return to work, this ambition must be supported. Financial help, to help return to work, amounting to €1000 will be offered.

In addition, the state employment service will take particular care in supporting family carers and offer them appropriate training.

Actors

Ministry for Employment, Ministry for Social Affairs

Schedule 2009

Funding €1 million
per year

Evaluation

Results indicators

Number of people who benefit from the measure/number of carers

measure 3
Improving health monitoring for family carers

1. Context

The role of family carers in looking after Alzheimer's sufferers is an essential one. Patients are confronted with many difficulties, including three specific periods when the burden is particularly heavy: information regarding the diagnosis, organisation of support and management of crises. These difficulties are not without consequences for the carers' health, and over half the patients' partners develop depression. There is a risk of excess mortality in over 60% of carers within the three years following the onset of their relative's disease.

In order to ward off this risk, **it is essential that the carer's health be taken into account** so that appropriate medical care, psychological or social support, respite facilities or home help can be offered where appropriate. Simple tools are available to measure and monitor "the caregiver's burden", such as the MINI ZARIT scale.

The primary-care doctor provides medical follow-up for the patient, working closely with the carer. He or she has built up a close and trusting relationship with the carer and knows his or her difficulties. **The doctor is thus best placed to identify the carer's suffering, evaluate it and refer him or her to his or her own doctor (if different).** It is thus important to improve the training of health professionals, including the use of tools to evaluate suffering, and to provide information for carers and professionals at specific information points (*MAIA - see measure 4*).

2. Objective

Take more account of the family carer's health in monitoring Alzheimer's patients.

One consultation per year for each carer upon request.

Enabling **70% of carers** for long-term patients (Affection de longue durée, ALD) to benefit from this consultation.

3. Measures

- Including this dimension in the ALD recommendations for Alzheimer's disease
- Identifying this theme in continuing training for doctors
- Actions to raise the awareness of carers at the special information point (*MAIA - see measure 4*)

4. Actors

Supervision Departement of Health DGS, Department of Social Security (Direction de la sécurité sociale, DSS)

Partners doctors' unions, learned societies - the French Geriatrics and Gerontology Society (Société française de gériatrie et gérontologie, SFGG), the French Neurology Society (Société française de neurologie)

5. Schedule

Implementation in 2009

6. Funding

Sources of funding: **health insurance system**

Cost: **€5 million** per year from 2009, i.e. **€20 million** over the term of the plan.

7. Evaluation

- Action taken according to the schedule
- Research/action comparing the health of carers who have benefited from this follow-up with those who have not.

Objective 2

Strengthening coordination between all actors involved

The aim is to provide patients and their families with a personal and evolving response by strengthening coordination between the actors involved.

Too often, people suffering from the disease and their families feel that they are insufficiently supported after the pronouncement of the diagnosis and then in the various stages of the disease. It is important to end the confusion of families who do not know whom to contact, lost among this multitude of poorly-connected, separate sources of help.

The current system has developed in a variety of forms, leading to a multiplicity of types of support. On average, elderly dependent people benefit from the intervention of three professionals, and a quarter is in contact with six or more. Care and treatment services have been lumped together without clearly defining fields of competence of either actor or the ways in which information is communicated and shared. The shock of the diagnosis is completed by the absence of a coordinated response and the lack of a consistent point of contact able to answer the many questions that arise: who will monitor the patient? What help is available in the home? What care structures exist? Which professionals are supposed to intervene?

In order to overcome the complexity, which equally confronts patients, their families and professionals the plan proposes "integrating" the support and the healthcare provision, with real coordination between actors and funders in order to simplify the daily lives of patients, improve the well-being of carers and provide better care and services for all. More than anyone else, people suffering from this disease and their families need identifiable places they can go to obtain, information and coordinated care. They need to be followed-up by a single contact able to respond to their requests. They need a life project, based on a full evaluation of their situation, which is often complex and evolving.

To achieve this, the plan provides for the elaboration of a **complete care and support path, seen from the viewpoint of the patient and his or her family** in order to organise the system around their needs. The plan proposes multi-professional and multi-disciplinary social, medical and paramedical care with objectives shared by the various actors. This relies on setting up:

- **a single point of contact** on the basis of existing structures, with a "***Maison pour l'autonomie et l'intégration des malades Alzheimer (MAIA)***" quality labelled (centres for the autonomy and integration of Alzheimer's patients);
- **professionals coordinating medical and social interventions**, responsible for the long-term follow-up and coordination of the various interventions made on behalf of patients with complex cases, known as "**case managers**" ("**coordonateurs**"). This system, designed initially for Alzheimer's patients, will then be extended to all elderly dependent people.

By 2012, every Alzheimer's patient and his or her carer will be able to get in touch with a single point of contact to access treatment and services, and will be followed up by a specific contact person who, in complex cases, will act as a real care and support coordinator.

This support will continue over time. As soon as the diagnosis is made, the patient and his or her family will be referred to a specific coordination centre with a "MAIA" quality label, where a coordinator will be appointed according to the situation of the patient and family. Working with the primary-care doctor, the coordinator will be responsible for implementing the first recommendations formulated in the memory unit, evaluating the patient from a multidisciplinary viewpoint and arranging a visit from the Personal Autonomy Benefit (Allocation personnalisée d'autonomie, APA) team if this has been requested. The coordinator can then be contacted by the patient and carers for support during the various phases of care: setting up treatments and services at home, respite periods for the carer etc. He or she will provide a permanent link between the various professionals dealing with the

patient. The single four-digit "Alzheimer's" telephone number will give access at any time to the nearest "MAIA" and the coordinators who work there.

This personalised support will be complemented as part of the ongoing discussion about improving the management of dependence through measures aiming to improve the evaluation of elderly dependent people, construct personalised support plans and define baskets of goods and services. The plan will also include measures aiming to relieve the remaining burden on families.

Quality labelling throughout the country for "single points of contact", the "Maisons pour l'Autonomie et l'Intégration des malades Alzheimer" (MAIA)

1. Objective

Better coordination between care, information and support structures should enable a **personalised care pathway** to be defined for each Alzheimer patient corresponding to the situation of each family. We need to offer a **graduated response to suit each situation**.

2. Context

Several measures have been put in place in France over the last twenty years to try to respond to the lack of coordination, including the Local Centres for Information and Coordination (Centres Locaux d'Information et de Coordination, CLIC) and the gerontology networks. They have made a number of notable advances, but their areas of intervention remain different - mainly social for the former, and health-care related for the latter. It is important to end the confusion of families who do not know whom to contact, and who are lost among the many poorly-connected, separate sources of help.

3. Measure

A coordination centre bringing together the health sector and the medico-social sector will be created (on the basis of existing facilities, without superimposing a new structure): it will constitute a "**single desk**", a "**single point of contact**" for users.

Bringing together existing provision will make it possible to:

- *create a clearly identified area* for welcoming and listening to Alzheimer's patients and their families and evaluating their situation in complex cases from the viewpoint of a variety of disciplines;
- *share resources* in terms of recruiting social, medical, paramedical and administrative staff, acquiring and sharing logistical or technical resources, and acquiring and developing shared services: services at home such as meal deliveries, transport etc.;
- *draft new care strategies* involving different sectors and bringing together complementary skills;
- *take an interdisciplinary approach to the patient*, setting up continuous care adapted to his or her needs; the single medico-social contact and the case manager have their offices in the coordination centre;
- *define training actions*;
- *define actions to support carers*;
- *facilitate action to improve the evaluation of activities and of quality of service (circulating procedures, references and recommendations for good practice)*;
- *evaluate practice*;
- *set up a system of single contacts for everyone suffering from the disease and of single coordinators for complex cases*.

These "Centres for the Autonomy and Integration of Alzheimer's Patients" will represent a real single point of contact, a place for directing care, with the advice of doctors and social workers, to construct a personalised care pathway with the help of the coordinator; they will be a place where a variety of professionals are continuously available, enabling multidisciplinary care at a single location in contact with the coordination network; they will be a source of information for families, who too often do not know about temporary accommodation solutions. Carers will also be supported and assisted in these centres, with at least one annual appointment to assess their needs and their state of health.

Once the diagnosis has been given, these "MAIAs" and the coordinators can be contacted by the patient and his or her family using a single national telephone number that connects to the nearest facility. This single number will ensure a simple link from patients and their families to the professionals, ending the confusion experienced by families when faced with the complexity of the system and their feeling of isolation in crisis situations, thus helping to facilitate care at home.

In order to structure these centres in *départements* (administrative districts) where the current situation varies widely, **trials will be launched**. These experiments may be based on a CLIC, a gerontology network, an experiment in coordination, treatment and service platforms operated by independent nurses or a case management structure. The coordination of the existing responses is essential: the CLICs, APA teams, social services provided by local social action centres (Centres communaux d'action sociale, CCAS) or the *département*, nursing services at home (Services de soins infirmiers à domicile, SSIAD) or flexible care and support services at home (Service polyvalent d'aide et de soins à domicile, SPASAD), gerontological networks and treatment and service platforms operated by independent nurses. The role should also include disseminating information for families provided by the CCAS, pension funds, town halls, councils, mutual health insurers, home care services and family information points.

Upon request these trials may be based on the *Département* Centre for Disabled People (Maison départementale des personnes handicapées, MDPH) to test the viability of creating local autonomy centres. Indeed some MDPHs have already begun moving closer to their local CLICs, particularly with regard to shared evaluation teams. Some *département* councils may choose to include the development of joint facilities for disabled people and dependent elderly people in their service quality support agreements with the CNSA.

These trials will be supported by project teams supplying supervision, evaluation and methodological support. They will be evaluated regularly.

Following the trials, in districts defined in each *département* by the local council and the Regional Health Agency (Agence régionale de la santé et de la solidarité, ARS), these single coordination centres will be structured according to the models established by the trials. The *départements* will be responsible for structuring these centres, with the support of the ARS, governed by a framework agreement. The centres will have a "Maisons pour l'Autonomie et l'Intégration des malades Alzheimer" (MAIA) quality label. If they are brought together with the MDPHs, they will become "Maisons départementales pour l'autonomie" (*département* centres for autonomy).

A team from the CNSA, liaising with the DGAS and the DGS, will be available to provide support in this structuring process; it will also be responsible for making sure the centres are set up uniformly across the whole country. An evaluation will be carried out by the CNSA in 2012 to ensure that these single centres of contact have been set up successfully according to the initial specifications.

4. Actors

Ministry of Social Affairs, Ministry of Health, CNSA, ADF, France Alzheimer.

5. Schedule

Trials: 2008-2010

Adaptation of the Alzheimer's telephone number for the coordination system: 2009

Setting up coordination centres throughout the country: 2010-2012

6. Funding

Project team responsible for supervision and evaluation: **€0.7 million per year**
Funding for local trials: **€4.6 million per year** (state and CNSA)

Département council/CNSA support agreements will include the creation of the coordination centre. A team will be put together by the CNSA, the DGS and the DGAS to monitor their establishment in all *départements*, supporting the *départements* and ensuring equity across the country.

Evaluation of the establishment of the centres: **CNSA, €1.4 million**

7. Evaluation

Process indicators

Number of trials set up

Result indicators

Number of objectives achieved at each site (single point of contact, single contact person, single evaluation tool, support and treatment plan, shared information point)

Modification of professional practice

Degree of coordination at a site

Provision of telephone guidance on the Alzheimer's number

User satisfaction

measure 5

Establishing "coordinators" throughout the country

1. Context

The complexity of Alzheimer's disease, in which behavioural problems come together with sometimes dramatic social consequences and dependence, requires better coordination between health professionals and medico-social workers in order to offer patients and their families a tailored, effective care pathway.

2. Objective

The major difficulty lies in coordinating care professionals to support patients in their daily lives. The Plan thus proposes to create a coordinator. This single correspondent, responsible for the care provided as a whole, must be the direct point of contact for the patient and the primary-care doctor. His or her long-term mission, including any episodes in hospital, covers both the health and the social aspects, such as evaluating and elaborating an individual project, providing a link with the various care professionals and following up the actions taken.

3. Measure

A coordination role will be created on the basis of current "case management" trials, which will be completed in order to refine the tasks of coordinators, their training needs, profile and the number of people they are likely to handle.

Managing the progress of dependent elderly people requires an ever-greater level of technical and organisational skill in carers. It also calls for more and more time spent on organisation. The creation of a coordination role based on a professional function such as a nurse or a social worker is thus an emerging need, which will be dealt with in the Medico-Social Careers Plan.

The coordinator is a "conductor" of social and health care, providing the link between the teams and guaranteeing real multidisciplinary care suited to each individual's situation.

He or she operates as soon as the diagnosis is given, when the patient is referred to a specific centre by the memory unit, the CM2R or the primary-care doctor. He or she will then be responsible for producing a treatment and support plan and facilitating its implementation, providing his or her expertise to the patient and family in the health and social fields continuously, including times when the patient is hospitalised. He or she can be reached at the MAIA using the standard telephone number.

He or she takes part in evaluating needs and planning services, provides liaison with care professionals, particularly the primary-care doctor, who has a crucial medical role in follow-up, and follows up the provision of the planned services. The primary-care doctor is the guarantor of continuity of care for Alzheimer's patients because he or she knows the person in their environment. The doctor, communicating with the patient and carers, is thus the coordinator's direct contact for all aspects relating to healthcare.

In addition, liaising with home help services, the coordinator monitors the quality of care at home; he or she helps carers by guiding them towards support structures and examining respite and temporary accommodation options with them to guard against crisis situations; he or she organises a more fluid transition between care at home and institutionalisation; liaising with the public authorities, the CCAS and the APA teams, he or she helps put together applications for social benefits; he or she provides guidance in seeking legal support (guardianship) etc.

In terms of initial training, these professionals may be nurses coordinating home care services, home help managers, CLIC staff or APA medical team members, social workers, members of health networks or independent nurses. Specific training will be put in place by 2009 as part of the Careers Plan.

The coordinators will be employed by the MAIA.

The trials in progress will be continued and completed in 2008, so that the training actions can be begun in 2009 and the objective of **1000 coordinators in MAIAs throughout the country can be achieved by 2012**. This initial estimate of requirements will be refined and may be increased at a later date.

4. Actors

Ministry of Social Affairs, Ministry of Health, ADF in partnership with the CNSA, the CNAVTS and the National Employees' Health Insurance Fund (Caisse nationale d'assurance maladie des travailleurs salariés, CNAMTS).

5. Schedule

Trials and creating the training tool: 2008 Training and setting up coordinators: 2009-2012

6. Funding

Trials and creating the training tool: €2.5 million Training: part of the Medico-Social Careers Plan

Coordinator pay: ~~€60 million~~ **€60 million per year** for 1000 coordinators in a full year, with the number increasing steadily from 2009. This represents a global financial commitment of **€113 million over the term of the plan**.

7. Evaluation

Process indicators

Production of a training tool

Professional training

Identification of a sufficient number of coordinators in each district

Results indicators

1000 coordinators throughout the country in 2012

Objective 3

Enabling patients and their families to choose support at home

Care at home remains the preferred option for most French people. The government wishes to respond to this desire by guaranteeing a free choice for as long as possible between care at home and accommodation in a specialized care clinics for dependent elderly people.

In the case of Alzheimer's patients, this means first improving the range of home treatments and services, so that comfort, safety and autonomy of these patients is ensured in the essential activities of daily life. While physical dependence is already well provided for, psychological dependence is not yet sufficiently taken into account, and cognitive rehabilitation activities at home are underdeveloped, as is the adaptation of housing to the specific nature of this disability. These are very important elements, contributing to the prevention of behavioural problems in people affected by cognitive damage.

Measure 6 therefore proposes to reinforce the range of available home treatment and care services. Recruiting specially trained staff and the option of having an occupational therapist or a psychomotor therapist visit the home would represent a real improvement for care at home. These interventions could help prevent or manage crisis situations, which often result in removal to a care clinic. These interventions at home will be made possible by reinforcing flexible home care and support services (SPASAD) and providing better coordination between independent professionals.

This reinforcement of home care will constitute valuable support for carers, and will enable a truly free choice between home care and care in a specialised institution, bolstered by the increase in the rate of creation of new home treatment and support availabilities provided for by the Senior Citizens' Solidarity Plan (Plan Solidarité Grand Age, PSGA), already undertaken in 2008.

The free choice of home care also involves better adjustment of housing to the specific nature and needs of Alzheimer's disease. Here too, although adjustment work has long been carried out for physical dependence, psychological dependence is somewhat neglected. Measure 7 specifies that home adjustments using new technologies should be encouraged. Current thinking on improving care for dependent people has added housing adaptation works in the basket of services and treatments offered, following an assessment taking account of both physical and psychological dependence carried out as part of the multidisciplinary evaluation.

These measures are part of a global framework designed to facilitate support at home by coordinating professional care workers through the creation of a single point of contact and the drafting of a care plan and to increase support for carers by creating new respite solutions and recognising the status of carers.

Finally, these measures are in line with the government's global thinking in terms of improving care for dependence, which will examine the financial aspect of care at home.

measure 6
**Reinforcing support at home, advocating services
by trained staff**

Context

Care personnel are not sufficiently trained to deal with Alzheimer's sufferers in many essential aspects of daily life. This lack of training also applies to appropriate actions to help the patient feel safe, non-verbal communication skills and dealing with cognitive deficit.

1. Objective

The creation of training for gerontological assistants, accessible in the form of continuing training, would respond to this need, as would the new offer of training adapted to the specific challenges of psychological dependence.

Specialized teams including gerontological assistants, psychomotor therapists or occupational therapists can then be set up.

For example, given a medical prescription, occupational therapists and psychomotor therapists could visit the home and, as soon as the diagnosis has been made, provide patient education, assessment of housing adjustments, rehabilitation and cognitive stimulation and where appropriate, in crisis situations, help with behavioural problems.

These specialized teams will considerably improve the care given to Alzheimer's patients, but also all dependent elderly people: it will improve their quality of life and that of their families, creating the conditions for a real choice between care at home and care in an institution.

Patients will be directed by the single point of contact towards reinforced flexible home care and support services or towards independent coordination teams providing these services, according to the district.

2. Measure

The newly-created flexible home care and support services (Services Polyvalents d'Aide et de Soins à Domicile, SPASAD) offer both treatment and personal assistance. These structures are therefore particularly well suited for the interdisciplinary care required by Alzheimer's disease, since they can provide most of the benefit of home nursing services (services de soins infirmiers à domicile, SSIAD) while also offering specially trained personnel. SSIAD pricing will need to be adapted according to the results of experiments that are currently in progress in order to assist in the recruitment of these professionals.

On this basis, 500 specialist teams, will be created between 2009 and 2012, thus providing a home care service capacity of 5000 ,

These must be spread equitably across the country. This reinforced improvement in the capacity of home care services to care for more patients is part of the overall progress in numbers of home care and treatment availabilities, begun in 2007.

In parallel, coordination between independent professionals will be encouraged, with teams that include both occupational therapists and psychomotor therapists. Discussions will be held involving the National Health Authority (HAS) to enable the payment of professionals without state health insurance approval on the model of what has been established for paying for chiropody treatment for diabetics.

The coordination between these teams and others involved - psychiatrists, neuropsychologists - will be provided by the coordinator working with the prescribing primary-care doctor. It is very important for these professionals be also able to intervene on behalf of the patient.

Finally, to enable the recruitment of all these professionals, the Career Plan will include not only the creation of training for gerontology care assistants, but also the issue of training for occupational therapists and psychomotor therapists provided by the regions.

4. Actors

CNSA, Ministry of Social Affairs, Ministry of Health in partnership with the HAS.

5. Schedule

2008: adaptation of SSIAD pricing

2008: HAS and DSS study of the coordination of independent professionals

2008: study of how training can be provided for occupational and psychomotor

therapists 2009-2012: creation of teams through gradual increases in numbers

2009: setting up coordination of independent professionals

6. Funding

€169 million in total, €75 million in a full year for the creation of **500 specialist teams** with a gradual increase in numbers

7. Evaluation

Process indicators

Modification of article D 312-2 of the Social Action and Families Code (Code de l'Action Sociale et des Familles) to complete the list of SSIAD professionals working in the home (gerontology assistant, psychomotor therapist, occupational therapist)

Creation of new training centres for occupational and psychomotor therapists

Results indicators

Number of specialist SSIAD availabilities created/number of Alzheimer's patients (ALD) with home care

Number of SPASAD availabilities created

Number of social and medico-social groups (groupements de coopération sociale et médico-sociale, GCSMS) created incorporating SSIAD services

Number of units to coordinate independent Alzheimer's practitioners created

Number of Alzheimer's patients cared for at home/number of Alzheimer's patients in institutions (ALD)

Number of professionals trained

1. Context

Keeping patients at home depends also on whether or not it is possible to adapt the home to favour independent living and avoid accidents. While adjustment for physical disabilities is a field that is starting to gain professional recognition, adjusting housing for cognitive deficits still needs to be initiated and developed strongly, through the use in particular of new technologies.

The necessary improvement in dealing with dependence requires a housing assessment to be carried out, taking account of both physical and psychological dependence, as part of the APA team's multidisciplinary evaluation, but it also requires clear solutions for funding housing adjustments for families to be proposed, including home automation technology, that these expenses are included in the support plans put in place.

2. Objective

The development of home automation and new information and communication technologies to help people suffering from Alzheimer's disease must be supported, by means such as the launch of a national multidisciplinary call for tender, which could be developed based at the competitive cluster focusing on gerontological technologies created in Grenoble in late 2007. Any such project must be accompanied by ethical considerations respecting the patient, involving the ANESM and the HAS.

3. Measure

Extending the call for projects led by the National Research Agency (Agence nationale pour la recherche, ANR) and the CNSA covering healthcare technologies, a call for tender specifically targeting home automation and ICT designed to compensate for the loss of orientation and autonomy characteristic of Alzheimer's disease will be launched in 2009.

4. Actors

CNSA, ANR

5. Schedule

2009

6. Funding

€4 million in 2009-2010.

7. Evaluation

Number of responses to the call for tender

Objective 4
*improving access to diagnosis
and care pathways*

Preparing and implementing a system for giving the diagnosis and providing counselling

1. Context and issues

An Alzheimer's diagnosis is established on the basis of an evaluation of cognitive, memory, executive and instrumental functions, and is usually made at a specialized consultation with a neurologist or a memory centre at the request of the patient's primary-care doctor.

For this slowly evolving disease, which is so harrowing and disruptive for the patient and his or her family, giving the diagnosis may require a **repeated and concerted approach** involving a variety of professionals based on good practice.

Given the specific characteristics of this disease, which call for long-term social care above and beyond the medical treatment itself, the diagnosis must be given as part of a package of information for the patient and the family, not only about the disease itself but also about how the treatment plan will work and the possibility of social support. This information about the disease involves mobilising all healthcare professionals and particularly the **future case coordinators**.

The process includes a first stage after giving the diagnosis which should take place, during a specialist memory consultation, whether this is with an independent neurologist or in a public or private hospital, and a second stage of confirmation of the diagnosis, explanation and support during consultations with the primary-care doctor.

It is therefore important to define good practice for the announcement, along the lines of the approach provided for, in the implementation of the national cancer plan, covering all the situations likely to be encountered and the role of each partner (carer, primary-care doctor, independent neurologist, hospital team, patients' associations, medico-social partners etc.) involved with the patient.

The PLASA¹ research programme is due to publish its conclusions in March 2008. Based on these data and previous studies, **the HAS will draw up recommendations for how Alzheimer's follow-up should be provided and the role of each actor**.

2. Objective

To improve conditions around the communication of the diagnosis and the provision of support at all stages of the disease.

3. Measure

Description of the measure

-Drafting and validating a system of reference for communication of diagnosis and the associated support (good practice, roles of actors, tools for sharing information, conditions for follow-up for the carer-patient couple);

-Setting up training for the professionals concerned;

-Implementing the announcement arrangements in specialist units (inside or outside hospitals);

-Implementing the announcement and support arrangements with primary-care doctors, adapting current pricing where necessary.

¹ The PLASA study, "Plan de Soins et d'Aide spécifique à la maladie d'Alzheimer" (care and support plan specific to Alzheimer's disease, a hospital clinical research programme or Programme hospitalier de recherche clinique, PHRC, 2002 and 2006) tests the effectiveness of a support and care plan in dealing with loss of autonomy, the carer's burden and recourse to treatment. This multicentric randomised study followed 1121 patients suffering from Alzheimer's disease for four years. Half the randomised patients were followed up according to the recommendations of the Treatment Plan, and the other half according to the usual practice of the centres.

Implementation details

Drafting of the arrangements by a working group.

Validation of the arrangements by a consensus group working with the HAS.

Producing a reference system on the basis of the recommendations.

Creating specific training

Adapting of pricing where necessary the application of the reference system to the practitioners concerned (primary-care doctor, independent neurologists, external hospital "Alzheimer's assessment" pricing for memory units).

4. Actors

a- Supervision: DGS/DSS

b- Partners: National Union of Health Insurance Funds (Union nationale des caisses d'assurance maladie, UNCAM), HAS, the Hospitalisation And Care Organisation Department (Direction de l'hospitalisation et de l'organisation des soins, DHOS), the National Institute for Prevention and Health Education (Institut national de prévention et d'éducation pour la santé, INPES)

5. Schedule

- 2008: Preparation of the content of the arrangements

- End of 2008-2009: Validation of the arrangements by a consensus group

- 2009: Implementation trials

- 2009-2012: Generalisation of the arrangements within and outside hospitals

6. Funding

Drafting the arrangements

Preparatory work: **€0.1 million** for the conference

Source: state budget - Ministry of Health

Implementation of the arrangements

Reinforcement of memory units.

Adapting pricing for independent professionals.

7. Evaluation

Arrangements in place in over 50% of specialist units by 2010 Reduction of the caregiver's burden (ZARIT) at the beginning of the disease

Number of trial doctors

Number of patients concerned

External evaluation based on indicators to be defined (satisfaction, cost etc.)

measure 9

Experimenting new payment terms for health professionals

1. Context and issues

The organisation of healthcare for patients suffering from Alzheimer's disease must be based around the primary-care doctor.

As soon as the diagnosis is given, he or she will provide the most appropriate healthcare, often multidisciplinary, liaising constantly with the MAIA contact person or coordinator.

In this context, we need to check whether the current double remuneration for independent health practitioners (fee for service and fixed payment for ALD long-term conditions) is suitable, particularly for work within multidisciplinary health centres.

2. Objective

To improve the quality of multidisciplinary peripatetic care for patients suffering from chronic diseases, and particularly patients, suffering from Alzheimer's disease.

3. Measure

Starting this year, experiments will be carried out to test new methods of remuneration for health professionals and funding for health centres and multidisciplinary health centres, either complementing or replacing fee for service.

These tests will apply mainly to general practitioners, certain specialists and paramedical professionals. Priority will be given to group practices and health centres.

The tests may make simultaneous use of several systems such as fixed sums for each pathology, fee for service, incentives to reach individual targets or salaries.

4. Actors

a- Supervision: DSS

b- Partners: DHOS, UNCAM, professional unions, HAS

5. Schedule

- 2008: Drafting the content of the arrangements and call for applications

- 2009: Implementation of the experiments

6. Funding

Health insurance system.

Creating an Alzheimer's disease information card for each patient

1. Context and issues

Over 15% of people suffering from Alzheimer's disease visit hospital emergency departments due to other complications or a worsening of their state of health. It can be difficult for first-line healthcare professionals (general practitioners, accident and emergency doctors etc.), who do not always have information on patients and on how to deal with complications of Alzheimer's disease, to treat patients in emergency situations.

In the absence of information about the disease, carers can also experience difficulties in using the health system and the support available.

The quality and continuity of care can thus be adversely affected in emergency situations by a lack of information on the patient and the disease.

2. Objective

To improve the coordination of care and treatment, particularly in emergency situations, for Alzheimer's patients by creating an information tool shared between health professionals, patients and carers.

3. Measure

a. Description of the measure:

Providing upon request, to all patients living outside a medical institutional framework, a credit-card-sized "personal treatment and information card",

- A "treatment and emergency card for Alzheimer's sufferers" will be produced, modelled on the emergency information cards² in place for approximately twenty rare diseases (Marfan syndrome, haemophilia etc.) which can pose problems in emergency situations,
- The card will be confidential and subject to medical confidentiality. It will be offered, filled in, signed and explained to the patient and his or her carer by the doctor coordinating care as part of an announcement or follow-up consultation.
- It will include:
 - o a **section for health professionals**, giving the names and contact details of the patient, the trusted person, the main carer and the health professionals coordinating care, information about the patient and recommendations for emergency care
 - o a **section for the patient and carer** containing information about the disease, care advice and details of support available.

b. implementation details

- The content of the card will be drafted under the guidance of the France Alzheimer association by a **working group** involving the DGS, health professionals and representations of learned societies.
- The card will be produced with the support of the Ministry of Health, Youth Affairs and Sport and the France Alzheimer association.

² The card can be viewed at the ministry website: www.sante.gouv.fr, theme +, rare diseases section.

- The card will be distributed by the France Alzheimer association to all health professionals who request it in writing using an application form that does not specify the patient's name.
- **An information campaign about the card** aimed at patients and their families, the general public and healthcare professionals will be conducted by the INPES and France Alzheimer.

4. Actors

a - Supervision
DGS, France Alzheimer

b - Partners
SFN, SFGG, Association of French-Speaking Independent Neurologists (Association des Neurologues Libéraux de langue Française, ANLF), INPES, UNCAM

5. Schedule

- Production of the prototype: November 2007
- Publication December 2007
- Distribution of the card: 100,000 per year for two years.

6. Funding

Funding amount

€0.11 million in 2008

€0.22 million throughout the plan

Sources of funding

state budget - Ministry of Health

7. Evaluation

- Number of cards produced and distributed per year
- Surveys of patient and carer satisfaction
- User satisfaction surveys: accident and emergency doctors, neurologists, general practitioners, geriatricians

measure 11

Creating memory units in areas that are not covered

1. Context and issues

A major effort has been made in recent years to ensure that each health district (territoire de santé) has its own memory unit (consultation mémoire).

On 31 December 2006 there were 366 memory units located in short-stay institutions throughout the country, of which 234 were recognised by regional hospitalisation agencies (agences régionales d'hospitalisation, ARH). A large degree of regional diversity remains. This is why it is necessary to **create 38 memory units** to enable each region to reach a satisfactory level of facilities.

2. Objective

To cover the whole country with specialized diagnostic and follow-up units

3. Measure

a- Description of the measure

Creation of 38 new memory units

b- Implementation details Circular for funding from ARHs

4. Actors

Supervision: DHOS

5. Schedule

Duration of the plan

6. Funding

- Funding amount

A memory unit requires a multidisciplinary team including practitioners in neurology, geriatrics or psychiatry, a psychologist or speech therapist and secretarial provision.

Creation of 38 memory units over the term of the plan: **€6.68 million over 5 years**

For 2008: **creation of 24 memory units, i.e. €4.224 million for new measures and additional funding for the memory units created in 2007 (€2.7 million)**

- Sources of funding

Health insurance system: national targets for health insurance spending (Objectif national des dépenses d'assurance maladie, ONDAM), health establishments, missions of public interest and support for contracting (Missions d'intérêt général et d'aide à la contractualisation, MIGAC)

7. Evaluation

- Monitoring of activity figures for new memory units six months after they open: number of active patients, unit opening times
- Number of memory units

Creating "memory resource and research centres" in areas that are not covered

1. Context and issues

There are currently 25 CMRRs in 23 regions. Each region should have at least one CMRR, which is a specialist centre providing diagnosis in the most complex cases and for the earliest forms.

Three additional CMRRs (Auvergne, Corsica, Limousin) remain to be created to reach the territorial coverage objective.

The CMRRs carry out clinical research and training activities; they lead and organise the regional and/or interregional provision in partnership with memory units. Finally, they deal with the ethical questions raised by Alzheimer's disease.

2. Objective

To cover the whole country with specialist diagnostic, support and research units. In addition, the research personnel at all CMRRs will be strengthened on the basis of calls for tender, including the hospital clinical research programme (programme hospitalier de recherche clinique, PHRC) call for projects.

3. Measure

Funding the creation of three CMRRs in regions that are not yet covered.

4. Actors

Supervision: DHOS

5. Schedule

- Implementation during **2008**.

6. Funding

The estimate of staffing needs is based on the average of the 25 existing CMRRs **Cost for 3 CMRRs: €1.14 million**

Health insurance system: national targets for health insurance spending (Objectif national des dépenses d'assurance maladie, ONDAM), health establishments, missions of public interest and support for contracting (Missions d'intérêt général et d'aide à la contractualisation, MIGAC)

7. Evaluation

The activity of these three CMRRs will be compared with that of the 25 other CMRRs in the 2008 DHOS survey.

1. Context and issues

The specific nature of Alzheimer's disease and its inescapable consequences make a suitable system for announcing the diagnosis essential. Although the announcement in some units is sometimes organised, shortage of staff and training do not allow a multidisciplinary team to offer the patient and his or her family enough time to properly absorb the information at the onset of the disease.

A high-quality service will involve first, listening to the requirements of the person concerned and his or her carers, and then offering, on request and according to the social and psychological context, the necessary support and the fundamentals of the care and support plan, emphasising the essential ease of access to the primary-care doctor.

This task is one of the main missions of a memory unit, and it must be protected regardless of the size of the number of patients.

We therefore need to reinforce the resources of units with a high degree of activity, since the result of the analysis of the activity of the 366 memory units gives wide operational divergences .

Based on the data from the DHOS survey, this measure consists of reinforcing the memory units among the 234 approved units **which have the highest degree of activity**. This targeted reinforcement, with particular regard to neuropsychologists, aims to shorten waiting times for specialist memory assessments and guarantee the quality of the arrangements around for the disease announcement.

2. Objective

To supplement the resources of the 122 approved memory units with a high degree of activity to guarantee the quality of the arrangements for announcing the diagnosis.

3. Measure

Increasing by 20% the resources of the 122 memory units with a high degree of activity

4. Actors

Supervision: DHOS

5. Schedule

Implementation throughout the term of the plan

6. Funding

Funding amount

Total cost of the measure: **€12.3 million, including €7 million in 2008**

Sources of funding

Health insurance system: national targets for health insurance spending (Objectif national des dépenses d'assurance maladie, ONDAM), health establishments, missions of public interest and support for contracting (Missions d'intérêt général et d'aide à la contractualisation, MIGAC)

7. Evaluation

Specific monitoring of how activities evolve at these 122 reinforced units within the annual DHOS survey.

Monitoring drug-related iatrogenic accidents

Setting up a geriatric drug safety network and surveying the prevalence of drug-related iatrogenic accidents in Alzheimer's patients via regional drug safety centres.

1. Context and issues

Drug-related accidents arising in subjects suffering from Alzheimer's disease, and more generally in the very elderly, are inadequately reported to drug safety centres and the drug risk is incompletely evaluated in this population.

2. Objective

To improve knowledge of iatrogenesis in Alzheimer's patients and develop surveillance.

3. Measure

Developing partnerships with geriatrics centres or correspondents: The Regional Drug safety Centres (Centres régionaux de Drug safety, CRPV, of which France has 31), due to their integration within university hospitals and their regionalisation, have already developed partnerships with geriatrics departments and correspondents in health centres or in independent practice with a high degree of contact with elderly patients. Certain CRPVs (such as Limoges and Caen) have also developed more specific gerontological approaches for collecting details of undesirable side-effects and researching medication in elderly people.

Training and informing geriatricians:

The CRPVs have an important role in the correct use of medication through three strongly developed activities:

- 1.- collecting details of undesirable side-effects, accompanied by dialogue between the person making the report and the centre to evaluate the issue and return conclusions about the case.
- 2.- requesting information about medication in order to respond to over 20,000 increasingly complex questions a year.
- 3.- drug safety training as part of the curriculum for health professions and in continuing training. Currently the CRPV network provides over 2,700 hours of training.

These activities that are already in place could be targeted more at the specific aspect of training and information for geriatricians and health professionals providing care for elderly people and especially Alzheimer's patients.

Undesirable side-effects from the National Drug safety Database -						
Age	Serious		Not serious		Total	
	Number	%	Number	%	Number	%
Under 60	5135	49.1%	6345	62.5%	11480	55.7%
60-69	1463	14.0%	1438	14.2%	2901	14.1%
70-79	1909	18.3%	1331	13.1%	3240	15.7%
80-89	1582	15.1%	843	8.3%	2425	11.8%
90 and over	371	3.5%	189	1.9%	560	2.7%
Total	10460		10146		20606	

Source: AFSSAPS

Surveying the prevalence of undesirable side-effects in Alzheimer's patients

Carrying out a survey of prevalence with the method used in the 1998 hospital survey "Iatrogénie médicamenteuse : estimation de sa prévalence dans les hôpitaux publics français" (Drug-related iatrogenesis: estimation of its prevalence in French public hospitals). However, in order to obtain a representative sample of the population of Alzheimer's patients, the survey should be carried out in both public and private institutions and should include residential centres for elderly dependent people (établissements d'hébergement pour personnes âgées dépendantes, EHPADs).

4. Actors

a-Supervision

The French, Health Product Safety Agency (Agence française de sécurité sanitaire des

produits de santé, AFSSAPS) and the network of CRPVs, particularly for strengthening the development of partnerships with geriatrics centres and correspondents and implementing the prevalence survey.

b-Partners

The HAS and the Ministry of Health, particularly for the training and information for geriatricians, with a high degree of synergy with the HAS responsibility for evaluating clinical practice.

5. Schedule

The training/information activities already exist, but need to be reinforced during 2008. The same schedule can be applied to developing partnerships with geriatrics centres/correspondents. The prevalence survey could be carried out in October 2008 (protocol to be prepared, CNIL data protection approval, logistics etc.), with data published in November/December 2008, analysis and report in January/March 2009 with a report published in April 2009.

6. Funding

Funding amount

€0.2 million for the prevalence survey.

Actions relating to developing partnerships and training/information would need to be supported by setting aside sessions for the CRPVs (at least 1 weekly session per CRPV).

Sources of funding

State budget - Ministry of Health - AFSSAPS

7. Evaluation

Increase in the rate of reporting undesirable side-effects in patients aged over 70.

1. Context and issues

Patients suffering from Alzheimer's disease are particularly sensitive to drugs, and particularly psychotropic drugs. They are frequently prescribed psychotropic medication, due in particular to the behavioural problems that arise in certain phases of the disease and to many associated pathologies. The risks of addiction and drug-related iatrogenic accidents are thus considerable.

To deal with behavioural problems, sedative medication, although raising many questions, can nevertheless prove indispensable in certain specific cases. However, there are no data in the literature that would enable a particular class of medication to be recommended for these patients. The risk of iatrogenic accidents and of accelerating the disease's development with certain psychotropic drugs can make the use of such medication difficult.

2. Objective

To improve the quality of practice and the use of psychotropic drugs in this disease

3. Measure

Description of the measure

Drafting clinical practice recommendations about sedation for dealing with behavioural problems in difficult situations and how to handle behavioural problems.

Drafting and circulating programmes to evaluate and improve professional practice in the effective use of medication, including psychotropic drugs, in elderly patients including those suffering from Alzheimer's disease.

Implementation details

Setting up a working group responsible for drafting recommendations.

4. Actors

Supervision HAS

Partners DGS, learned societies, organisations approved for the evaluation of professional practice, the Order of Pharmacists (Ordre des pharmaciens)

5. Schedule

2008 - Drafting recommendations and an evaluation programme

2009 - Implementation

6. Funding

Not applicable

7. Evaluation

Degree of participation by professionals in training and improvement in their practice

Reduction in consumption of psychotropic drugs (regular monitoring of indicators).

Objective 5

Improving residential care for better quality of life for Alzheimer's disease sufferers

Care for an elderly person suffering from Alzheimer's disease within a family poses specific problems which may prove insurmountable as the disease develops. The appearance of behavioural problems, the need for a permanent presence and the impact on the carer's health can cause arrangements for care at home to fail, regardless of the improvements made for care at home and of how devoted the family is, not to mention all the cases where there is no family carer. An institution offering accommodation for dependent elderly people (EHPAD) then becomes the only structure that can house patients in the more advanced stages of the disease.

Currently, on the basis of a survey of registered institutions, 6,100 receive Alzheimer's patients, and 1,135 declare that they have a specialist unit (representing a capacity of more than 18,000), although many impose restrictions on accepting people with behavioural problems.

In order to deal with the length of waiting times for EHPAD places, and the lack of capacity in these establishments to offer differentiated, evolving care according to the seriousness of the patient's condition, two challenges must be faced: continuing to create places, reducing disparities between regions, and the need to adapt the ways in which EHPADs are organised to deal with the specific needs of Alzheimer's sufferers, as this is the only way to avoid repeated hospitalisation.

Specific units must therefore be identified for patients suffering from behavioural problems, that can offer them suitable activities and the attention of specially trained professionals in sufficient numbers. On the basis of data about behavioural problems and the needs of patients, the measure proposes two types of units:

- **suitable care and activity units operating during the day**, designed for people with Alzheimer's or a related disease with moderate behavioural problems; such a unit functions during the day, with residents returning to their usual residential units at the end of the day; the unit relies on the provision of specially designated rooms (activity rooms, washrooms etc.) and a walking area, and care provided by trained personnel (specific care and rehabilitation) in sufficient numbers;
- **"reinforced" residential units with 10 to 15 places offering space for activities and accommodation** for people with significant behavioural problems.

These units with reinforced staffing will be created as part of the medicalisation of establishments, with a gradual increase in levels of supervision.

The Plan includes an extremely ambitious programme for the architectural adjustment of EHPADs. This is an essential element in patients' quality of life, and it will be strongly supported in investment programmes. A special prize will be set up to reward EHPADs for making the most suitable architectural and interior layout choices for the specific care of patients suffering from Alzheimer's disease.

The Plan also provides for specific measures for young Alzheimer's patients, filling a major gap between care at home and hospitalisation.

Creating or identifying specific units for patients suffering from behavioural problems within EHPADs

In particular, this measure includes increasing the number of professionals working with patients and reinforcing their skills.

1. Context

As Alzheimer's disease evolves, psychological and behavioural symptoms or behavioural problems often appear. These may include apathy or aggressiveness, wandering behaviour or agitation. These are very important issues in Alzheimer's disease, as they have a considerable impact on patients and on patients' families. They also constitute the main difficulty encountered by EHPAD professionals.

For example, 80% of residents with Alzheimer's or a related disease present behavioural problems at some stage in the evolution of the disease. Of these 80%, 25% have moderate behavioural problems (measured on an internationally validated scale) and 10% have major problems (aggressiveness etc.). These problems must be measured more effectively and the diagnosis of the disease must be made clearly for EHPAD residents affected by it.

2. Objective

Many EHPADs have already created dedicated units. The Plan provides for **the creation of specific units to be generalised, distinguishing between two types of units** according to the degree of behavioural problem of the people concerned.

The objective is to achieve **30,000 places in EHPADs with specific projects, adapted to the seriousness of the behavioural problems.**

12,000 places to be created,

18,000 places to be reinforced.

These units will be reinforced in terms of staffing, with a high level of supervision, the intervention of professionals specially trained in the disease, and training for all staff in these establishments in the specific nature of the care required. They will also be adapted with regard to their architecture and internal layout.

3. Measures

(1) Specially adapted treatment and activity units will be created to offer residents with productive behavioural problems, social and therapeutic activities during the day in a specially adapted living area in a calm environment with space to walk around.

They will be led by specially trained professionals, which requires that the professional skills made available to patients be widened. This will include **creating the role of "gerontological assistant"**, a new skills profile described in measure 20.

It will also be necessary to reinforce teams with new skills in this area, such as psychomotor and occupational therapy. Speech therapists may also intervene on the basis of a medical prescription.

Finally, psychiatrists will be involved with the operation of these units, either working with the psychiatric team or in a partnership with independent psychiatrists. Daily care for the disease regularly requires recourse to psychiatrists: EHPAD staff acknowledge that they are sometimes helpless to deal with certain facets of the disease.

The creation of these specific units will require extra staffing, enabling the establishments to be more medicalised. Pricing for these units must also be re-evaluated, in order to incorporate these professionals, such as gerontological assistants, psychomotor therapists and occupational therapists, into the establishments' teams. In addition, all the institutions' staff must be trained to deal with the specific nature of care for Alzheimer's patients.

The presence of a living unit of this type within an EHPAD, occupying people with behavioural problems during the day, will enable other residents to benefit from more

traditional social activities, offering all residents times apart and times together without having to move residents experiencing behavioural problems at a particular point in the history of their disease from one bedroom to another.

These activities and care are very important because they can reduce behavioural problems by 20% and cut down on use of sedative psychotropic drugs and restraint. They may involve structured activities (physical activity, sensory activity, nutritional aspects) designed specifically to improve behavioural problems. Similarly, spatial orientation rehabilitation, cognitive validation groups, behavioural approaches and psychosocial treatment in general can improve quality of life and reduce the incidence of behavioural problems, even if such interventions still need to be better evaluated.

2) For patients with very considerable behavioural problems, reinforced structures 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.

3) These specialist units must also be adapted in their layout and even architecture to host Alzheimer's patients.

The Plan thus provides for the launch of a major investment programme, subsidised through modernisation credits from the CNSA, in order to avoid the development work undertaken for specific Alzheimer's units weighing too heavily on the price for accommodation paid by patients and their families.

Initially, the modernisation plan will enable 15,000 places to be adapted or constructed in 2008.

This work will be carried out according to **specifications established by the Ministry for Social Affairs, the ANESM, the HAS and the CNSA together with foundations such as the Fondation Médéric Alzheimer and professionals who have worked on these architectural issues.**

Adherence to these specifications will be a decisive factor in the CNSA's allocation of support, and expertise in this area must be continuously available to establishments.

An "Alzheimer's architecture prize" will be created to reward the most innovative EHPADs. The prize will emphasise the advantages of thinking about architectural quality in caring for Alzheimer's patients.

4. Actors

CNSA, DGAS and DGS in partnership with the ANESM, the HAS and the DSS.

5. Schedule

2008: re-evaluating pricing to enable new professionals to be incorporated

2008: validating the definition of specific care and activity units and reinforced accommodation units for patients with behavioural problems (consensus group)

2008: refining the tool for finding out *département* needs: Regional Health and Social Affairs Department (Direction régionale des affaires sanitaires et sociales, DRASS) and CNSA

2008-2012: recruiting professionals to put these special units together

2008-2012: orienting the CNSA's investment support programmes towards the architectural adaptation of these units

6. Funding

Adapting units and creating adapted units by reinforcing personnel

The additional funding for the **12,000 new places** (staff reinforcement) amounts to **€180 million** throughout the term of the plan.

The funding for **adapting the 18,000 existing places** (staff reinforcement) amounts to

€378 million throughout the term of the plan.

Work on the layout of units

€180 million in CNSA investment credits in 2008.

This objective will be pursued. Part of the CNSA funding allocated to investment in 2009-2012 will be devoted to supporting investment in these specific units dedicated to caring for Alzheimer's patients.

7. Evaluation

Process indicators

Production of specifications for both types of units

Creation of an architecture prize

Results indicators

Number of places created in specific care and activity units

Number of places created in reinforced Alzheimer's units

Number of units developed according to specifications

Measurement of behavioural problems

measure 17

Creating specialized units within health care rehabilitation and follow-up (SSR) departments for Alzheimer's patients

1. Context and issues

Ensuring continuity of care by facilitating access to hospital treatment in cases when hospitalisation is necessary

As Alzheimer's disease develops crisis periods of multifactorial origin may arise (carer fatigue, acute diseases, interruptions to care etc.), which often result in the appearance or exacerbation of behavioural problems. In this situation, recourse to hospitalisation may be necessary and often constitutes the only possible response.

After an appropriate medical assessment (short stay in geriatrics for elderly people, other acute services for young patients), there is a need for **appropriate follow-up care and rehabilitation (Soins de Suite et de Réadaptation, SSR)**, offering cognitive remediation programmes that can improve the patient's ability to perform the actions of daily life.

This provision takes its inspiration from what has already been achieved in certain "psychogeriatrics" units.

2. Objective

To separate out cognitive/behavioural units within follow-up care and rehabilitation (SSR) departments

Identifying such units (of 10 to 12 beds) within either generalist or geriatric SSR departments should offer specific care for both young and elderly patients, whether they live at home or in an institution. The aim is to enable them to return to their usual place of residence.

With appropriate architecture and dedicated, specific care and support staff, and on the basis of a medical and psychosocial assessment, these units aim to stabilise behavioural problems using individual cognitive and behavioural rehabilitation programmes and to provide the care given before the crisis situation arose, in the absence of an indication of a short stay in a specialist organ or reanimation unit.

This cognitive/behavioural specialisation in the treatment given to patients with Alzheimer's and related diseases within authorised SSR structures requires the intervention within these units of specific personnel (psychomotor therapist, psychologist, occupational therapist, gerontological assistant etc.) and access to psychiatric sessions. These individualised units must be included in the medical project and the long-term contract covering objectives and resources for establishments authorised to provide SSR activities.

3. Measure

Identifying cognitive/behavioural units within existing SSR services.

In addition to **reinforcing the staff of these units**, the aim is also to enable the **necessary work** to adapt the premises in which the Alzheimer's units are identified to the requirements of the pathology.

4. Actors

Supervision: DHOS

Partners: DGS for cognitive/behavioural rehabilitation, mission T2A

5. Schedule

From 2008, the resources allocated can be used to carry out the first work required and to recruit specific personnel. The increase in capacity will continue throughout the term of the plan in terms of both investment and reinforcing the staff.

6. Funding

Funding amount

The funding of these units within SSRs is set at **€24 million** in new measures renewable over the term of the plan (for 120 structures) for staff reinforcement and **€24 million** in investment for adapting the premises

Sources of funding

Health insurance funding (ONDAM).

Initially the identification of units will be accompanied by specific funding, and then lasting finance will come from a specific valuation within the SSR's pricing per activity.

7. Evaluation

Numbers of units and beds identified from 2008.

Percentage of patients who return home from these units compared with other care solutions.

1. Context

At later stages of evolution, young patients suffering from a loss of autonomy making it impossible to remain at home yet cannot be admitted to the usual health care facilities.

2. Objective

The first necessity is to take advantage of the study organised as part of the launch of the national centre for young Alzheimer's patients to find out the numbers and accommodation needs of these young patients.

The second necessity is then to design better facilities and accommodation for young patients.

3. Measure

Professionals in day care and temporary accommodation need to be made aware of the specific nature of the situation of younger patients. In addition, the objective is to lift the regulatory barriers to enable patients to be accepted in the most appropriate structure for their individual situation, whether this is an EHPAD or a specialist care centre (Maison d'Accueil Spécialisée, MAS), the institutional plan of which must include a specific section on how to receive them.

According to the results of the survey, units dedicated specifically to young patients will be created within reference institutions.

4. Actors

DGAS, DHOS, DGS in partnership with the national centre for young Alzheimer's patients (Centre national pour les malades Alzheimer jeunes)

5. Schedule

Study launched in 2008

Adaptation of institutional plan to include accommodating young patients: 2009

6. Funding

Study in collaboration with the national centre for young Alzheimer's patients to identify patients likely to enter an institution, and drafting specifications for institutions - **€0.2 million**

7. Evaluation

Process indicators

Conducting the survey

Drafting specific institutional plans for accommodating young patients

Results indicators

Number of young Alzheimer's patients cared for in these establishments in relation to the needs expressed

Satisfaction of patients and their families

1. Context and issues

The prevalence of early-onset Alzheimer's disease in France is little known. According to data supplied by the state health insurance provider, about 8000 people under 60 have "long-term medical condition" (ALD) status for Alzheimer's disease. Of these patients, only a small proportion (1 to 2% of all Alzheimer's patients), have monogenic inherited forms with an autosomal dominant transmission mechanism.

Aside from these specific forms, the age at which the disease appears does not constitute a criterion for defining a specific nosological entity. However, problems specific to Alzheimer's disease in younger patients can be identified:

- Two out of three times, early-onset Alzheimer's disease is diagnosed late, as the illness is often considered by the general public to be a disease of the elderly. The often insidious signs that appear at the beginning of the disease are not always recognised by carers or are wrongly seen as psychological symptoms in the absence of diagnostic tools suited to first-line professionals (general practitioners, occupational doctors etc.).
- The disease is responsible for major difficulties in employment and family life, which deteriorate gradually and lead to serious consequences in the absence of appropriate early care.
- In this context, the despair and social isolation felt by patients and family members is particularly acute and requires specific support that takes account of the disturbance to the family dynamic.
- At later stages of evolution, patients suffering from a loss of autonomy that makes it impossible to remain at home cannot be admitted to the usual care facilities and dedicated medicalised units are not available for this population of younger patients.

Improving the early identification of sufferers is essential to reduce diagnostic uncertainty and limit the evolution of the disease and its impact on the social lives of patients and carers. The earliest possible access to innovative therapies, setting up specific structures for cognitive and behavioural rehabilitation and the creation of accommodation and respite units are essential priorities in improving care for patients.

2. Objective

To improve access to the diagnosis, the quality and the co-ordination of treatment for young patients by putting in place a care strategy that takes account of all the health problems affecting patients and aims to:

- develop **knowledge**, particularly in epidemiology and the social sciences,
- reinforce **research**, as the disease in young subjects constitutes an observation and analysis model enabling its genetic and physiopathological mechanisms to be better identified and innovative therapeutic methods to be imagined,
- produce and distribute **standards for good practice and shared tools** to guarantee quality of care and to coordinate treatment across the whole territory.

3. Measure

a- Description of the measure

Identifying one or two national reference centres for young Alzheimer's patients among the CMRRs:

Its mission will be to develop knowledge and organise care in the field of early-onset Alzheimer's disease, and in particular to:

- optimise the diagnosis and provision of care for patients in the territory, in relation with existing care and treatment structures (memory centres, hospitals, EHPADs, independent medical professionals, occupational doctors etc.),
- define standards for good practice and tools for organising the diagnosis and the provision of care at national level,
- set up epidemiological monitoring by creating patient cohorts that can also serve as a basis for research projects,
- initiate and promote research, particularly genetic, metabolic and therapeutic research, in relation with existing national and international teams working on the same or similar themes (rare diseases, neuroscience etc.),
- develop information for patients, their families and health and social professionals,
- train the health professionals and social partners involved,
- forge national partnerships with existing diagnosis and care centres and with associations and institutions and create synergies with research teams abroad,
- ensure immediate voluntary access to any new therapy that might act on the evolution of a patient's disease and level of comfort,

This structure, consisting of several thematic centres that may be geographically distinct (research, epidemiology, good practice, shared files, professional training, public information etc.) in order to carry out all its missions, will be united by a health professional with an international reputation in the field.

b- Implementation details

- Specifications for the missions of the national centre to be drafted by a working group supervised by the DGS and the DHOS and bringing together representatives of health professionals, researchers, learned societies, patients' associations and the institutions concerned (HAS, the National Health and Medical Research Institute (Institut National de la Santé et de la Recherche Médicale, INSERM), CNRS),
- Launch of a DGS/DHOS call for bids procedure based on a set of specifications,
- Applications examined by a jury including independent national and international experts giving a consultative opinion to the Ministry of Health,
- Nomination of the centre by ministerial order for a period of five years, renewable according to the results of the evaluation.

4. Actors

a- Supervision: DHOS, DGS

b- Partners:

5. Schedule

- Drafting the specifications: 2008
- Launching the call for bids: November 2008

6. Funding

amount **€0.6 million**

sources **Health insurance system (ONDAM - health establishments - MIGAC)**

7. Evaluation

External evaluation during the centre's fifth year of operation on the basis of the specifications and results.

Objective 6

Recognising skills and developing training for health

Valuing the work and the skills of people who work with dependent elderly people, and particularly patients suffering from Alzheimer's disease, is a priority.

Two observations suggest that existing roles are not entirely suited to the specific nature of Alzheimer's disease:

- A mismatch between requirements and staff training:

Caring for highly dependent people with behavioural problems and states of agitation is a difficult task for young professionals, who have little training to prepare them for these situations. The "baptism of fire" often determines whether a care professional chooses to continue in this career. Dealing with crisis situations requires training in care and care techniques but also a degree of psychological and social knowledge that is still lacking, particularly in the environment of care for the elderly. In the absence of interdisciplinary training across the various qualifications in cognitive and behavioural problems, the response to requirements is inadequate.

- A lack of sufficiently developed career pathways between health and medico-social care and too few prospects for development.

Faced with the challenge this disease poses to managers and care staff operating in the area of high dependency and cognitive problems, staff training should be rapidly implemented targeting overall health care, support and treatment for elderly people .

The government will shortly be presenting a global plan for careers in the medico-social sector, developing the attractiveness of these roles and organising real career pathways for professionals.

measure 20
**A specific career and skills development plan for
Alzheimer's disease**

As part of a global plan for medico-social careers to be presented shortly by the government, specific measures will be dedicated to caring for patients suffering from Alzheimer's disease.

1) creation of *qualifying training for coordinators*.

On the basis of "case manager" trials, a coordinator's training programme will be created to achieve the target of 1000 trained objectives by 2012.

2) improving care for patients by providing new professional skills

a) identification and competence description of the role of "**assistant gerontologist**" ;
The gerontological assistant will contribute to caring for patients with a high degree of dependence or cognitive deficit: he or she will be responsible for following the care, help and support plan proposed by the medical team and the coordinating nurse.

Help with daily living, specific care techniques and providing support and assistance care are at the heart of this role.

b) provision of *staff specialising in cognitive and behavioural rehabilitation*:

- The initial training for occupational and psychomotor therapists will include a training module focusing on neuroscience and caring for Alzheimer's patients.
- The objectives of improving care for patients involve the provision of initial training for **2000 extra psychomotor and occupational therapists**: planning of this training should be the subject of consultation with the Association of the Regions of France as part of the Careers plan. The new staff will work in institutions or for SSR or SSIAD services.

3) specific training plan for all staff working in adapted units in EHPADs.

Section II. Knowledge for action

Objective 7

Making unprecedented efforts in research

Setting up a national structure to coordinate research in the form of a Foundation for Scientific Cooperation (Fondation de Coopération Scientifique, FCS).

1. Context and issues

Coordinating and developing research activities into Alzheimer's and related diseases

French research into Alzheimer's and related diseases is neither sufficiently developed nor sufficiently coordinated to be able to punch its weight at global level.

The creation of a national structure to coordinate research into Alzheimer's and related diseases, which would have enough of a critical mass to face the international competition, would be a way of ensuring a continuity from fundamental research to clinical research to innovative treatments, to the advantage of medical progress.

2. Objective

To set up a national network of excellence in research and treatment in Alzheimer's and related diseases in the form of a Foundation for Scientific Cooperation.

To supervise, stimulate, coordinate and lead the essential research activities into Alzheimer's and related diseases, a national network of excellence will be put together.

The network will unite all the French research teams with international reputations, whether they are public or private, in order to bring fundamental and clinical research and social sciences together with the focus on patients.

The network, a real "brain for Alzheimer's", will constitute a flexible, effective structure that respects existing organisations.

This coordination and scientific leadership structure will have the status of a foundation for scientific cooperation (articles L.344-11 to L.344-16 of the Research Code), which should provide positive support for possible developments in the general organisation of health research in France. The Foundation will ultimately be able to receive public and private funding (including gifts and sponsorship from donors such as manufacturers).

Supported by the national research council (INSERM) and the School of Higher Studies in Public Health (Ecole des hautes études en santé publique, EHESP), the foundation will be a way of putting into effect several of the measures in the plan (such as measures 24, 25 to 31 and 33), coordinating the actors and forging close bonds with private research.

3. Measure

Setting up a foundation for scientific cooperation (FCS), for which initial funding will come in state credits, before 30 June 2008 under the supervision of the Ministry of Higher Education and Research and the Ministry of Health, Youth Affairs and Sports.

4. Actors

Supervision: *Ministry of Higher Education and Research.*

Partners: *Ministry of Health*

5. Schedule

Foundation to be created by 30 June 2008

6. Funding

Cost of operating the foundation:

2008: €0.26 million

Total cost 2008-2012: **€1.5 million**

The foundation will also receive initial capital funding in 2008 of **€10 million** from the CNSA support fund and **€4.4 million** from the Ministry of Higher Education and Research.

Alongside the foundation and the measures it will fund, research with organisations and via calls for projects will be increased: €10 million in 2008 then €15 million extra per year from 2009, amounting to **€70 million over the term of the plan**.

7. Evaluation

The actual set-up of the foundation for scientific cooperation.

measure 22

**Developing clinical research of Alzheimer's disease and improving
evaluation of non-drug therapies**

1. Context and issues

Clinical research into Alzheimer's disease, whose mechanisms are still only partially known, must be amplified considerably.

2. Objective

To support the research activities of hospital teams by significantly increasing resources for the hospital clinical research programme (PHRC).

Every year, through a call for tender, the PHRC develops clinical research on priority subjects in health establishments. The development of the research effort into Alzheimer's and related diseases, and particularly the clinical research effort, is crucial to the success of the plan. Increasing the PHRC budget will support clinical research in hospitals into the disease.

The projects presented by hospital teams for the PHRC may cover subjects such as adapting diagnostic and therapeutic strategies in the treatment of Alzheimer's and related diseases or the quality of care and the quality of life of patients and carers.

The projects must also involve non-drug therapies, which must be better known and better evaluated.

3. Measure

Description of the measure

Placing Alzheimer's disease (and related diseases) at the heart of the PHRC's priorities from 2008 to 2012 inclusive, with a significant increase in the programme's budget.

Implementation details

The PHRC call for projects is issued every year in a ministerial circular.

After a selection process involving the foundation for scientific cooperation, the health establishments concerned are informed of the research projects chosen by the health ministry and the credits to be allocated for their funding.

4. Actors

Supervision: Ministry of Health, HAS for the evaluation of non-drug therapies

5. Schedule

From the 2008 financial year.

6. Funding

Funding amount

€3 million per year in new funding, for a total of **€15 million**

Sources of funding

Health insurance system (ONDAM - health establishments - MIGAC)

7. Evaluation

Number of clinical research projects on Alzheimer's and related diseases funded between 2008 and 2012 inclusive

Number of publications arising from these research programmes

1. Context and issues

The aim of this measure is to reinforce the potential for research into Alzheimer's disease by attracting young researchers to the subject. The funding of 20 doctoral students and 10 post-doctoral students per year during the term of the Alzheimer's Plan is proposed. This measure is necessary to develop research projects.

2. Implementation details

These young researchers will come to support research projects that have been selected in response to calls for tender. The salaries of post-doctoral students can be allocated when a research project is selected by the ANR or launched by the structure responsible for overseeing the research section of the Alzheimer's Plan.

With regard to doctoral students, grants can be allocated from the ministerial quota for priority subjects.

3. Implementation schedule

Funding for projects in the call for projects and associated recruitment: the first project selection will be made for summer 2008 via the ANR and thereafter according to the calendar of calls for projects.

"Strategic" ministerial doctoral grants: from June 2008

4. Cost

€1.1 million per year from 2008, amounting to €5.5 million in total for the period 2008-2012.

5. Funding

Post-doctoral research will be funded from the budget of the foundation for scientific cooperation or the ANR, and doctoral grants will come from ministerial funding.

New assistant surgeon and hospital teaching assistant positions

1. Context and issues

French research teams are not sufficiently mobilised on this subject, and there is an urgent need to provide incentives for young researchers to develop their careers in the long term around this problem, where competition is strong and training times are long.

2. Objective

It is difficult to fulfil the care, training and research functions associated with these posts simultaneously. They require a protected role, which can only be guaranteed in the already very structured university hospital environment. A variety of disciplines may be involved: neurology, geriatrics, imaging, neuropathology but also epidemiology, biochemistry, immunology, cellular biology. Careful organisation of the work of these young doctors, pharmacists or scientists could enable them to play a moderate but effective role in treatment and in teaching, while preserving the dominant objective of clinical research in all its forms. In three years it would be possible to prepare them for a university hospital career or a private or public research career, once they have acquired a university doctorate, and doubtless gained complementary experience abroad.

3. Measure

a- Description of the measure

Announcing ten new posts for university hospital Assistant Surgeons (Chefs de Clinique des universités-Assistants des hôpitaux) or Hospital Teaching Assistants (Assistants Hospitaliers Universitaires)

In the fields of gerontology, neurology, radiology and psychiatry.

b- Implementation details

As part of the annual interministerial review of university hospital staffing

4. Actors

Supervision	Ministry of Higher Education and Research - Ministry of Health
Partners	university hospitals/ARH/medical faculties/universities

5. Schedule

Funding for clinical programmes and associated recruitment: the first projects can be selected in 2008.

6. Funding

Annual funding of €0.84 million from 2009, i.e. a total of €3.4 million over the period, shared between the Ministry of Health (ONDAM - MIGAC health establishments) and the Ministry of Higher Education and Research.

7. Evaluation

- Creation and allocation of these posts
- Number of publications and citations of the teams that have benefited from this reinforcement and these ten new posts.

1. Opportunity

The contribution of the human and social sciences to understanding the various aspects of Alzheimer's disease (AD) is well recognised: neuropsychology, together with fundamental research in cognitive psychology, has allowed considerable progress in recent decades in our knowledge of cognitive function, cognitive problems and how to exploit remaining capacity. The social sciences offer analyses of health systems, family solidarity and attitudes to patients which can be mobilised and adapted to the specific issues of AD. However, this area of research is currently underdeveloped in France. It is therefore necessary to promote these disciplines within a global approach to the disease. Measure 9 is also motivated by this logic.

2. Implementation details

Several types of measure are proposed to attract more researchers in the human and social sciences to this field:

- public scientific and technological institutions (établissements publics à caractère scientifique et technologique, EPST) and universities targeting posts dedicated to the problem;
- funding research programmes, particularly multidisciplinary research, through calls for projects or with support from the EPSTs and universities for the laboratories involved;
- funding for doctoral and post-doctoral students to support selected projects

3. Implementation schedule

Medium term, because the aim is to attract researchers in the human and social sciences to areas that have not yet been much explored by the national community. It will therefore no doubt be necessary to plan preparatory activities organised by the foundation for scientific cooperation. However, a first call for projects could be adjudicated in early 2009. Recruitment will be carried out once the teams are in place.

4. Cost

€2 million per year from 2009, for a total over the period of €8.3 million.

5. Funding

Projects funded by the foundation for scientific cooperation.
Funding for doctorates and post-docs: foundation budget supported by the INSERM. Statutory researchers' posts from EPST/university budgets.

measure 26

Support for research groups working on innovative approaches

1. Opportunity

The aim is to encourage groups to come together to research original aspects of Alzheimer's disease that so far have been explored little or not at all. The development of new directions for research, sharing skills and complementary approaches and filling current gaps, is essential for the plan to succeed.

2. Implementation details

These teams and their projects will be selected by the Foundation for Scientific Cooperation.
An existing INSERM procedure, such as Avenir (future) positions, could be used to attract new groups by announcing posts focusing on Alzheimer's-related subjects.

3. Implementation schedule

First groups in place in 2009, continuing throughout the term of the plan.

4. Cost

€1.4 million per year from 2009, for a total of €5.6 million over the period

0. Funding

From the budget of the Foundation for Scientific Cooperation, which could be completed by the INSERM's Avenir budget and salary funding from the EPSTs/universities.

measure 27

Support for methodological research groups in human and social sciences

1. Opportunity

This measure aims to encourage the creation of a research group in clinical research methodology, bringing together researchers, patients and manufacturers, and a themed network with a human and social sciences research programme.

2. Implementation details

The team and the network will be selected on the basis of their projects by the foundation for scientific cooperation.

3. Implementation schedule

Group set up and network formalised during 2009.

4. Cost

€1.2 million per year from 2009, for a total over the term of the plan of €4.9 million.

5. Funding

From the budget of the foundation for scientific cooperation with participation by EPSTs/universities.

1. Context

The contribution of imaging, and particularly MRI, to research into neurodegenerative diseases is beyond dispute as a way of finding out more about how they evolve. France currently has only one very high field MRI facility (≥ 7 tesla), which has just been installed at the NeuroSpin centre in Saclay.

2. Objective

To create an **automated image processing research centre**, including a process for extracting knowledge that can be exploited on the basis of large volumes of data, with **the installation of two new very high field MRI systems** (≥ 7 tesla).

3. Measure

The proposed research centre and the sites of the two planned MRI systems will be selected by the Foundation for Scientific Cooperation on the basis of international scientific expertise and a precise evaluation of requirements.

4. Implementation schedule

Identification of the centre: end of 2008, followed by one or two years of development depending on the chosen site.

Installation of MRI equipment:

- first system: 2009;
- second system: 2011

5. Cost

Initial investment in the centre: **€3 million** (excluding imaging equipment)

Centre operation (from 2010): **€2 million per year** for a team of 20 people MRI ≥ 7 tesla:

€5 million/device for the investment; **€1 million/year** for the operation of each device

Total effort over the term of the plan, from 2009: **€23 million**

6. Funding

Foundation for Scientific Cooperation.

Studying large patient populations (cohorts) with long-term monitoring

1. Opportunity

These studies complement therapeutic trials. In general they require collections of biological samples to be constituted or exploited.

The use of cohorts will enable genotyping studies to be put into effect (Measure 30). They will also serve as a basis for other biological studies aiming to achieve a better characterisation of the mechanisms behind Alzheimer's disease.

2. Measure

Creating two cohorts for monitoring, whose precise characteristics will be defined by the Foundation for Scientific Cooperation on the basis of a call for bids.

3. Implementation schedule

Mid-2008, with planned funding over 10 years.

4. Cost

2008: **€1.15 million**; 2009 and after: €2.7 million. Total cost 2008-2012: **€12 million**

5. Funding

Foundation for Scientific Cooperation.

1. Opportunity

The high-speed genotyping of patients and controls should enable genetic traits of vulnerability to Alzheimer's disease to be identified. A project has already been launched in the UK, which should reach completion in summer 2008. A large-scale project should be launched in France to exploit existing work, in particular projects in Lille and Rouen, which could also be completed by the summer. A feature and strength of French research is that we have a large number of cases (2500) and controls (10000).

This subject is particularly important for research into young patients.

2. Implementation details

This major genotyping project, using a genome-scan approach, can only be conducted quickly with the help of the National Genotyping Centre (Centre national de génotypage).

3. Implementation schedule

From 2008.

4. Cost

2008: ~~€~~**3.2 million**; 2009: €2.15 million. Total commitment over the period of €5.4 million

5. Funding proposals

Foundation for Scientific Cooperation.

measure 31
Exploiting the genome sequencing of the microcebe

1. Opportunity

The microcebe is a small primate (lemur) in which 20 to 30% of individuals spontaneously develop a disorder comparable to Alzheimer's disease. It could therefore be very useful, particularly in examining any genetic components of the disease and especially in young patients, to compare the microcebe genome with the data collected from the high-speed genotyping in measure 30.

2. Implementation details

Once the scientific objectives have been defined, the genome will be sequenced by the National Sequencing Centre (Centre national de séquençage).

3. Implementation schedule

Exploitation from 2009.

4. Cost

Commitment from 2009: **€1.2 million**. Total cost 2008-2012: **€3.9 million**

5. Funding proposals

Foundation for Scientific Cooperation.

1. Context and issues

The diagnosis of Alzheimer's disease and diagnoses in geriatrics and neurology in general are complex. The evolving nature of diagnostic tests and the information provided by studies and research make continuous training efforts a necessity. To develop research and involve a larger number of doctors in either including patients in protocols or conducting studies, they must be offered training using different incentives from those of observational medicine, developing a methodological effort and a vision of public health.

Training in clinical epidemiology, reading the medical literature critically and analysing the variability of practice will be offered to doctors in specialist units.

2. Objective

To improve the quality of medical practice by training doctors in clinical epidemiology. To increase the number of doctors taking part in research protocols.

3. Measure

Description of the measure

Training all CMRR and CM doctors and independent neurologists (1,500) over five years.

Implementation details

- The measure concerns hospital practitioners and independent specialists, mainly neurologists but also psychiatrists, working in the field of neurodegenerative diseases.
- The funding will enable the launch of a call for bids from approved organisations, including those approved for evaluating professional practice.

4. Actors

a-Supervision: DHOS/DGS

b-Partners: learned societies, approved training organisations

5. Schedule

Training in 2008 and 2009

6. Funding

Annual cost: €0.44 million; cost over the period: €2.2 million

Source of funding

Independent professionals: social security funding law (LFSS) - contractual action fund (Fonds des actions conventionnelles)

Hospital professionals: state budget - Ministry of Health 2009

7. Evaluation

- Number of professionals trained
- Number of doctors taking part in research protocols

Developing links between public research and industry

1. Objective

To improve mutual knowledge between public and private research in the context of a particularly complex pathology in which therapeutic advances are still in their early stages. We propose the creation of training to inform medical students about the world of the pharmaceutical industry, and particularly the conditions under which new drugs or diagnostic tests are developed.

2. Implementation details

Creation within two universities of visiting professorships from the pharmaceutical industry. This measure will be implemented jointly with the French pharmaceutical companies' association, the LEEM (Les Entreprises du Médicament).

Raising academic awareness of industrial issues through CIFRE grants (Convention Industrielle de Formation par la Recherche, fixed-term research contracts in industry) or interface grants (contrats d'interface) with the university to finance scientific researchers and doctors.

3. Implementation schedule

September 2009.

4. Cost

€160,000 per year from 2009, for a total of €640,000

5. Funding proposals

Funding by the university and the Foundation for Scientific Cooperation.

Objective 8
***Organising epidemiological
surveillance and follow up***

measure 34

Setting up epidemiological surveillance and follow up

Setting up a system for collecting activity data and for epidemiological surveillance and follow up within specialized units.

1. Context and issues

It is important for each region to have activity data (number of patients examined, number of new patients), data about patient characteristics (diagnosis given, seriousness of the disease, type of support available to the patient) and care quality indicators. Three regions already have shared computerised files (Calliope).

2. Objective

To enable specialist memory care provision be adapted through regional care organisation schemes and the quality of their operation be evaluated. To obtain epidemiological data and activity data for specialist centres.

3. Measure

a- Description of the measure

Production of specifications defining the data to be collected. Computerising memory units and volunteer independent neurologists.

b- Implementation details

Drafting of the content by a working group. Call for tender open to existing CMRRs to implement this measure and create a national database.

4. Actors

Supervision

DHOS: for collecting data on centres' activity

DGS for defining the information to collect.

Foundation for scientific cooperation for exploiting the data, especially the epidemiological data

Partners

Federation of CMRRs, Nice university hospital, independent neurologists

5. Schedule

Content to be drafted by March 2008. Call for projects in June 2008

6. Funding

Funding amount

Creating and rolling out the system, training doctors, purchasing software **€0.8 million**

Managing the database: **€0.3 million/year**

Sources of funding

Health insurance system (ONDAM - health establishments - MIGAC)

7. Evaluation

- Computerised case management in 50% of centres by 2009, 100% by 2010 - Activity data and epidemiological data

Section III. Mobilising around a social issue

Objective 9

providing information for general public awareness

Families facing Alzheimer's disease need **local information and guidance** in order to be able to contact the professionals who are nearest and best able to help them in the diagnosis and care of the disease. Being guided towards these professionals in both the medical and social sectors depends on the constitution of a well identified network.

Local features (population affected, support structures, local services, involvement of local communities etc.) require concrete information specific to the district concerned to respond to the needs of the public. This information is currently difficult to find, which does not promote the optimum use of the care and services available.

measure 35
**Setting up a telephone helpline and a website for
information and local advice**

1. Context

On 21 September 2007, the France Alzheimer association set up a national helpline on the number **0 811 112 112**. This number gives access to all the associations in the France Alzheimer network, the only national network of families and patients. It enables anyone to contact the local association or the France Alzheimer head office for information, advice, support or a listening ear. **This number represents major progress, and will be supported throughout the term of the Plan** by the public authorities.

In addition, the progressive creation of a **unique local centre** for patients and carers and the **appointment of a coordinator should be accompanied by the establishment of a single national number for contacting the nearest MAIA** and enabling carers to enter the coordination system.

2. Objective

The object is twofold: firstly to guarantee support and a listening ear for carers, the purpose fulfilled by the number put in place by France Alzheimer with the support of the public authorities, and secondly to provide information on care, support at home and respite options in a given district.

The multiplication in telephone numbers devoted to Alzheimer's disease leads to additional complexity. The objective in 2012 is to have a single number which, depending on the nature of the request, connects callers to the system put in place by France Alzheimer or, locally, to the single point of contact, where services and care for the patient and carer are coordinated.

The aim is thus to offer a swift, local response to the needs of patients and their families. The connection to the nearest MAIA and the case coordinator will enable the various questions and requests of patients and their families relating to care to be answered.

A website with information at *département* level would operate alongside this system.

3. Measure

1/ Accentuating support for the France Alzheimer association in its training for helpline operators, developing the tools for responding to people affected.

2/ Developing a single telephone number connecting to either the structure put in place by France Alzheimer or to the local coordination centres.

This number will be designed for patients and their families who are already within the coordination system.

3/ Creation of "e-seniors" Internet portals to the websites of *département* councils.

As part of its mission to develop digital services throughout the country, the public financial institution the Caisse des dépôts et consignations (CDC), together with the DGAS, is currently running trials in three districts of new "e-seniors" web portals giving access to the websites of the local authorities (the Manche, Oise and Dunkirk councils).

These portals provide a great deal of information for elderly people and carers about their rights and places providing support, with a directory including geographical locations, etc. The portal includes an intranet for professionals.

The portals will be made available nationally in parallel with the creation of coordination structures in each *département* in order to offer local information on-line.

4. Actors

Ministry of Health, Ministry of Social Affairs, France Alzheimer, ADF, CNSA, CDC

5. Schedule

2008-2012	support for the system put in place by France Alzheimer
2010	creation of a single telephone number and organisation of connections to local MAIAs
2009-2010	generalisation of "e-seniors" web portals to the websites of <i>département</i> councils, integrated with the web portals of the MAIAs

6. Funding

€0.2 million per year to support France Alzheimer

€0.7 million per year for the operation of the single number from 2010

€0.5 million in 2008 and 2009 in CDC design and engineering credits for the generalisation of the "e-seniors" portals

7. Evaluation

Process indicators

Establishment of the e-seniors portals

Establishment of the single number with local connection

Results indicators

A single number by 2012, connecting to information and a listening ear for carers or the local coordination centre

Holding regional conferences to support the implementation of the plan

1. Context and issues

Local features (population affected, support structures, local services, involvement of local communities etc.) require concrete information specific to the district concerned to respond to the needs of the public. This information is currently difficult to find, which does not promote the optimum use of the care and services available.

2. Objectives

Organising regional conferences will be a way of supporting the implementation of the Alzheimer's plan at regional level and of:

- communicating local information about the disease and its care including local support facilities and resource centres,
- promoting the establishment of and access to a network of care and services,
- creating space for communication between the various parties involved (professionals, representatives of patients' and carers' associations, institutions, politicians etc.) about the issues raised by the disease: care, ethics, the life of patients,
- contributing to modifying representations and perceptions of the disease and ways of dealing with it.

3. Measure

Description of the measure

Organising and promoting regional conferences for the various parties involved, including the general public, through local meetings.

Implementation details

The conferences will be organised by government services. They could be given a strong start via the national conference organised by the ministry as part of the French presidency of the EU, scheduled for 27 and 28 October 2008. The conferences will then be held through 2009.

4. Actors

Supervision Ministry of Health, Youth Affairs and Sports (DGS, DHOS, INPES, Information and Communication Delegation (Délégation à l'information et à la communication, DICOM)) working with the DGAS.

Partners ADF

5. Schedule

- Defining the organisation and preparing tools and documentation in 2008
- National launch: end of October 2008
- Conferences held in 2009

6. Funding

Funding amount **€2.3 million**

Source of funding state - Ministry of Health

7. Evaluation

- Quantitative indicators - number of meetings, participants, profile of the conferences and the Alzheimer's theme
- Qualitative indicators - quality and results of discussions
- global evaluation of the process - number of regions that have included Alzheimer's in their regional public health plan (Plan régional de santé publique, PRSP).

measure 37

Studying disease knowledge and attitudes

1. Context and issues

Alzheimer's disease creates fear, and the public's view of the disease and the people suffering from it isolates patients and their families even more. The public's awareness of the patients' cause and that of their families must be reinforced, in collaboration with the patients' and health professionals' associations, which are already working hard in this direction.

Social solidarity must be developed further by publicising the efforts of those who assist and support patients: carers, health and medico-social professionals and patients' associations.

2. Objective

To raise the public's awareness of Alzheimer's disease, the patients' cause and that of their families, in collaboration with the patients' associations.

3. Measure

- Carrying out a qualitative survey to **understand non-specialists' degree of knowledge and the attitudes of the general public and of health professionals to the disease.**

- Measuring and monitoring the development of the population's attitudes and knowledge about Alzheimer's disease by representative surveys (including questions in the INPES health survey, the Baromètre santé).

4. Actors

a- Supervision: INPES

b- Partners: DGS, France Alzheimer, learned societies (SFN, SFGG)

5. Schedule

- Qualitative study: preparation 1st quarter 2008, fieldwork 2nd quarter 2008. Population surveyed: general public, not family carers, first-line health professionals. Use of the INPES framework contract for studies.

- Construction of a module of questions to monitor the public's knowledge and attitudes about Alzheimer's diseases, the patients suffering from it and the best ways of dealing with it (need for a diagnosis as early as possible) based on the results of the qualitative study. Pilot study to test the module: 2nd half of 2008

- Incorporation of the module into the 2009-2010 INPES health survey.

6. Funding

a- Funding amount: **€0.1 million** (€70,000 for the qualitative study, €30,000 for the "Alzheimer's" module test)

b- Sources of funding: **State - Ministry of Health - INPES**

7. Evaluation

- Publicising the results of the qualitative study (press coverage, tie-in with possible regional conferences)

- Improvement in public knowledge and acceptance of Alzheimer's disease monitored by indicators taken from surveys of the general population

- Increase in early diagnosis/decrease in late diagnosis (indicator to be prepared).

Objective 10

Promoting ethical thoughts and an ethical approach

1. Context and issues

In Alzheimer's disease, ethical considerations are present throughout the duration of the condition, from diagnosis to death. Ethical support means asserting the permanent state of the human being in all circumstances, even the most degraded. Many initiatives have already been taken in this area through the actions of the French-Speaking Association of Rights for the Elderly (association francophone des droits de l'homme âgé), the CMRRs and ethics units. What is missing is a centre of documentary resources and stimulation for this ethical thought that can provide tools, documentation and a list of contacts on the subject of Alzheimer's disease for any team that wants them and produce a summary of ethical considerations for circulation.

Regional ethics units are currently being set up. The CMRR will also subsequently fit into this system.

2. Objective

To create a **reference space** within a memory resource and research centre (CMRR) or an existing regional ethics unit, with the task of stimulating reflection, looking in detail at specific questions relating to Alzheimer's disease, create momentum and serve as an educational and documentary resource centre. The centre will subsequently fit into the system of regional ethics units.

3. Measure

Description of the measure

Funding a CMRR or an ethics unit to enhance ethical reflection, liaising with the existing regional ethics units. Its other objectives will be to:

- act as an educational and documentary resource centre,
- serve existing units and create momentum,
- summarise discussions,
- establish formal working links with ethics units and the National Ethics Consultative Committee (Comité Consultatif National d'Ethique, CCNE) so that the issues raised by Alzheimer's disease remain linked with society's attitudes,
- amplify previous reflection on the ethical questions raised by Alzheimer's and related diseases and ensuring this work is published,
- lead meetings in 2008 to discuss issues including advance directives, trusted persons, voluntary participation in diagnostic, prognostic and therapeutic trials, new technologies such as restraint bracelets,
- be ready to lead an urgent study group to discuss ethical controversies likely to arise in the coming years in France or abroad,
- develop the specific features of Alzheimer's disease in teaching ethics,
- to set up psychosocial research into the best conditions for obtaining the patient's opinion

Implementation details

DHOS/DGS call for projects on the basis of a set of specifications

4. Actors

- a-Supervision DGS
- b-Partners DHOS, federation of CMRRs

5. Schedule

Call for bids in February 2008

6. Funding

- a- funding amount **€0.4 million/year**
- b- sources of funding **LFSS - ONDAM - health establishments (MIGAC)**

7. Evaluation

Number of meetings organised, creation of a database, organisation of a conference every year, organisation of training.

measure 39
Launching a discussion about the legal status of Alzheimer's patients in institutions

1. Context and issues

As early as 2004, the consensus group on freedom of movement described with precision the context in which a dependent person finds himself or herself cared for and on occasion accommodated against his or her will. Indeed, the impossibility of obtaining informed consent makes his or her agreement debatable even when it is expressed.

Moreover, in the patient's own interests, caring for the patient may involve using techniques that seriously restrict his or her freedom (closed units, magnetic bracelets, restraint belts). Without questioning medical protocol and the reality of these methods being indicated, it must be admitted that the consequent deprivation of liberty must be legally supervised. This question is well known in the field of psychiatry. **But the legal provisions in force in this area do not apply to medico-social establishments. The result is a legal vacuum that needs to be filled.**

In addition, the law of 5 March 2007 reforming legal protection for adults now provides the possibility of organising one's own protection in advance: anyone can now draw up a future protection mandate, entrusting responsibility for looking after them and their affairs when they can no longer do it themselves to a person of their choice. The appointed person may be given the role of legal representative or trusted person. This is a kind of living will that enables one's own dependence to be anticipated. However, this legal tool cannot be applied to people who are already affected by Alzheimer's disease.

Finally, while the new provisions of the 5 March 2007 law respond to situations of accommodation against the patient's will or without their consent, including elderly people directed into medical retirement homes, by requiring a decision from a guardianship judge (juge des tutelles), these texts only apply to people subject to judicial or legal protection. No provisions exist outside these procedures.

2. Objective

The objective is to end the legal confusion relating to the difficulty of acquiring the consent of a person suffering from Alzheimer's disease and to clarify the roles of the various people around the patient: trusted person, guardian, carer.

3. Measure

Given the complexity of the issue, **a working group has been set up to look at the subject:** it consists of representatives of the ministries concerned and representation from the CCNE, the Alzheimer's Collective and patients' families.

Before 30 June, the group will propose concrete solutions for settling this delicate question, which raises the issue of fundamental freedoms and the rights of the most vulnerable citizens.

measure 40

Organising regular meetings focusing on the autonomy of people suffering from Alzheimer's disease

1. Context and issues

The law on bioethics provided for the creation of spaces for ethical reflection at regional or interregional level. These units give detailed, multidisciplinary consideration of public importance to advance directives, the conditions for informed consent and participation in research protocols and clinical trials. But the term "consent", in the sense of the expression of complete autonomy, is perhaps inappropriate in the context of this disease. What needs to be sought is a profound assent, an agreement to participation based on an incomplete comprehension, through signs representing confidence.

The second subject concerns the use of tracking bracelets for the purpose of protection. The advantages and issues of such devices require discussion.

2. Objectives

- To enable debate and reflection about patient representation (how to reconcile trusted person, guardian, main carer and family, leaving room for the patient?).
 - To open a public debate on the use of GPS bracelets.

3. Measure

Description of the measure

Organising two conferences bringing together the general public, professionals, experts and representatives of associations, (one about patient representation and the other about the use of GPS bracelets).

Elaboration and publication of the proceedings of these conferences.

Implementation details

Setting up a working group responsible for preparing for these conferences, including specifying the questions and debates to undertake.

Organising the conferences with the Information and Communication Mission (Mission de l'information et de la communication, MICOM) and DICOM.

Drafting and publishing a summary of the discussions that took place.

4. Actors

- a. Supervision DGS/MICOM/DICOM
- b. Partners DGAS, reference CMRR

5. Schedule

June 2008

March

2009

6. Funding

- Funding amount: **€0.03 million per year**
- Sources of funding: **State - Ministry of Health**

7. Evaluation

- Level of participation in conferences
- Drafting and circulation of documents to support discussions
- Evolution of regulation in force to take account of any conclusions reached.

measure 41

**Informing patients and their families about trials
implemented in France**

1. Context and issues

Patients and their families who wish to take part in clinical trials do not have access to the information that would enable them to apply.
Experimental centres find it difficult to recruit people to take part in research protocols.

2. Objective

In order to ensure that patients are informed about research protocols and have equal access to them, we propose that information about all the research currently under way in France be published on the National Observatory for Alzheimer's Disease Research (Observatoire national de la recherche sur la maladie d'Alzheimer, ONRA) website, in association with the France Alzheimer site. Work on assistance in understanding the protocols and on the terms of patient consent to these trials must also be carried out. This work will make it easier to include patients who wish it in research protocols.

3. Measure

a- Description of the measure

Creating a section on the ONRA website accessible to the general public that presents current research in France, conditions for taking part and the issues raised by these research protocols.

- Implementation details modifying the specifications of the ONRA site to add this mission.

4. Actors

- a. Supervision DGS
- b. Partners ONRA, Toulouse university hospital, Foundation for Scientific Cooperation

5. Schedule

- DGS-ONRA agreement in the first quarter of 2008
- Placing new information on-line in October 2008

6. Funding

- Funding amount: ~~€~~**0.05 million**
- Sources of funding: **State - Ministry of Health**

7. Evaluation

- Comprehensiveness of the information on line.
- Number of people visiting the site.
- Number of people included in research protocols in France.

Objective 11

Making Alzheimer's disease a European priority

measure 42

Making the fight against Alzheimer's disease a priority for the European Union during the French presidency

1. Context and issues

At European level, Alzheimer's and related diseases have never been given much political visibility. The future French presidency of the European Union is an opportunity to carry this public health issue higher up on the European agenda, and to share French discussions and progress in the area with our European partners.

2. Objective

To improve European cooperation in the fight against Alzheimer's disease.

3. Measure

a- Making Alzheimer's disease a European Union priority.

b- Implementation details: adopting the conclusions of the EU Council inviting member states and the European Commission to share national and local experience in the areas of improving diagnosis, medico-social care, integrating care and services, drug strategies and the quality of life of patients and carers. Making use of the conclusions of completed research work and strengthened cooperation between research teams should also be encouraged.

4. Actors

a- Supervision: DGS and the Delegation for European and International Affairs (Délégation aux affaires européennes et internationales, DAEI)/DICOM

b- Partners: Directorate-General for Health and Consumers; French and European NGOs

5. Schedule:

2nd half of 2008

6. Funding: not applicable

7. Indicators

Adoption of conclusions on the fight against Alzheimer's disease by the EPSCO Council (Employment, Social Policy, Health and Consumers)

measure 43
Publicizing and promoting research across Europe

1. Opportunity

The French presidency should be an opportunity to promote and make use of research into Alzheimer's and related diseases.

2. Implementation details

- Organising a conference describing the measures put in place and the results of French teams.
- Setting up an ERA-NET: to organise scientific collaboration at a European level, an ERA-NET, coordinating national programmes, could be proposed to the European Commission by France for launch under the French presidency. This measure is not proposed in the report.

3. Implementation schedule

Conference: 2nd half of 2008.

Next ERA-NET work programme: closing date 2 August 2008.

4. Cost

Conference: €0.3 million

5. Funding proposals

Foundation for Scientific Cooperation.

1. Context and issues

At European level, Alzheimer's and related diseases have never been given much political visibility. The future French presidency of the European Union is an opportunity to raise this public health issue higher up the European agenda, sharing French discussions and progress in the area with our European partners.

2. Objective

To improve European cooperation in the fight against Alzheimer's disease.

3. Measure

Organising a European conference to give concrete form to the sharing of national and local experience in the areas of improving diagnosis, medico-social care, integrating care and services, drug strategies and the quality of life of patients and carers.

Implementation details

- Organising the conference
- Publishing proceedings

4. Actors

Supervision

DGS and the Delegation for European and International Affairs (Délégation aux affaires européennes et internationales, DAEI)/DICOM

Partners

Directorate-General for Health and Consumers; member states; European Parliament; French and European NGOs

5. Schedule

30 and 31 October 2008

6. Funding

amount: **€0.3 million**

sources of funding: state - Ministry of Health

7. Indicator

number of participants at the conference
publishing and circulating the proceedings