

**General population survey of the perceptions, knowledge and opinions of Alzheimer’s disease**

**Background**

The French government’s Alzheimer Plan 2008-2012 has put the spotlight on Alzheimer’s disease – a disease that affects 800,000 people in France and the incidence and prevalence of it are on the increase. This Plan and the reports that came before it have helped bring out the specific aspects of this disease in comparison with other chronic diseases. What is talked about most is the extent to which the disease is under-diagnosed, along with – as in other diseases – the difficulty doctors have pronouncing the diagnosis. The reasons advanced to explain this situation often include social representations, and these are seen as potentially so negative and stressful that doctors, patients and family are tempted to put off to the last possible moment pronouncing a disease that “confirms everybody’s worst fears about ageing” (Gallez, 2005, p.22). Which is why the Gallez report (2005) and the more recent Ménard report (2007) both emphasised the need to “change attitudes to the disease”, emphasising the disease’s extremely negative social image and the consequences this has on its management.

For this reason, one of the measures of the Alzheimer Plan 2008-2012 is more specifically concerned with “knowing how the disease is seen”. This measure, entrusted to the French Institute for Prevention and Health Education, is broken down into three stages:
- review of the literature on how Alzheimer’s disease, the subject of this overview, has been portrayed in society;
- qualitative study of the perceptions, knowledge and attitudes relating to the disease among the public at large, health professionals and family carers;
- quantitative survey among the general population on the same topics.

**Aims of the survey**

Provided for by Measure 37 and reinforced by Measure S1 of the Alzheimer’s Plan, the main aim of this quantitative survey carried out among the public at large is to measure peoples’ perception, understanding and opinions about Alzheimer’s disease. More specifically, the survey should help:
- provide an initial assessment of certain follow-up indicators in the Alzheimer’s Plan;
- supplement the information coming out of the literature review and the qualitative study concerning the knowledge, attitudes and opinions of the general population with regards to Alzheimer’s disease carried out in the summer of 2008;
- test a questionnaire prior to its introduction in the 2010 Health Barometer.

**Method**

The survey was carried out by the BVA Institute among a representative sample of the French population of 2013 persons aged 18 years and over. The sample was constructed using the quota method in terms of the sex, age, socio-professional category of the head of the family, after stratification by region and by housing conditions. People were questioned by telephone between 9 and 25 October 2008. They answered a 20-minute questionnaire worked out by INPES in collaboration with a group of experts made up of institutional representatives (DGS – the Directorate-General for Health, CNSA – the National Solidarity Fund for Autonomy, InVS – the French Health Protection Institute), representatives of France Alzheimer, the Médéric Alzheimer Foundation, the Foundation for Scientific Cooperation, ISPED – the Institute of Public Health, Epidemiology and Development, in Bordeaux, ANLLF – the association of French-speaking independent neurologists, as well as geriatricians and psychologists.

**Results**

1. **Feeling of being informed about and fear of Alzheimer’s disease**

A. **Cancer, AIDS and Alzheimer’s: trio of the most serious diseases**

Alzheimer’s disease is spontaneously regarded as one of the three most serious diseases, mentioned by a quarter (27%) of those questioned. However, it comes a long way behind cancer and AIDS, judged to be the most serious diseases (according to 93% and 53% of respondents, respectively), but far ahead of heart disease (mentioned by 17% of people questioned), cardiovascular disease (15%) and diabetes (8%). The elderly make up the largest proportion of people to consider Alzheimer’s disease to be one of the three most serious diseases. This perception is also more frequently found among people who know a sufferer in their family circle.
B. Alzheimer’s disease, the disease third most feared by those questioned

Cancer is the disease that arouses the greatest personal fear: 76% of the people questioned said they were afraid of it for themselves. Alzheimer’s disease is the third most frequently mentioned disease: 59% of the people questioned said they were afraid of it for themselves, of whom 22% very much so. This fear is more usually expressed by elderly people and people regularly caring for a relative with Alzheimer’s disease.

C. A feeling of being less well-informed about Alzheimer’s disease

Although those questioned regarded themselves to be widely informed about topics such as smoking (94%), drinking (89%) or diseases such as cancer (82%), they are less than unanimous in expressing the same feeling with regard to Alzheimer’s disease (62%).

The feeling of being well informed about Alzheimer’s disease shows a strong correlation with the fear expressed about this condition: people who say they are well informed about Alzheimer’s disease are also those who say they are afraid of it. This relationship is more marked in elderly subjects.

In addition, 79% of the people asked believe that television, the newspapers and magazines should have more to say about Alzheimer’s disease.

D. A disease of the memory and of dependence

Asked about the three words that come to their mind when speaking about “Alzheimer’s disease”, a very large proportion of the people included in the survey mention words or expressions to do with loss of memory (69% of the people questioned mentioned a term or idea of this kind). Dependence is the second idea spontaneously raised (53%), before loss of intellectual capacities (34%) and notions of “loss of identity” or “decline” (22%).

The images painted of Alzheimer’s disease differ depending on the age of the person questioned: while with young people Alzheimer’s disease is virtually synonymous with memory loss, it embraces more dimensions in older subjects, who mention terms or ideas associated as much with loss of memory as of dependence. On the other hand, no differences are found in representations between people faced with Alzheimer’s disease (who have an Alzheimer’s patient in their family circle) and those who have not been exposed to the disease.

2. Personal attitudes and proximity to Alzheimer’s disease

A. Uneasiness in the presence of a patient expressed by a third of those questioned

While a large majority of the people questioned say that they do not or would not feel any uneasiness in the presence of an Alzheimer’s patient, one third nevertheless did express such an uneasiness. It is expressed more often by the over-65s, as well as by those fearful of Alzheimer’s disease for themselves.

B. Unanimous desire to know one’s own diagnosis
91% of the people questioned would like to know their own diagnosis if they had any signs suggestive of Alzheimer’s disease.

C. Proximity to Alzheimer’s disease

Four people in ten (38%) say they have or have had one or more persons with Alzheimer's disease in their family circle. In most cases this means a family member (72% of people said they knew at least one person with Alzheimer’s disease), more rarely a member of the larger family circle.

One person in ten (9%) of all the people questioned regularly provide care (at least once a week) to a person with Alzheimer’s disease. Regular caring is to some extent split along age lines, older people being faced with this situation more often than young ones.

3. Knowledge about the disease

A. Perception of signs suggestive of the disease

Overall, those questioned know the signs suggestive of the disease: a large majority of them correctly picked out the three characteristic signs from a list of six items and correctly identified the false assertions.

However, there remains a certain vagueness where specific memory disorders are concerned: while a majority (60%) does not regard the inability to recall on demand the name of some well-known personality, four people out of ten do see it as a symptom of the beginnings of the disease.

Similarly, the link between old age and memory loss is firmly rooted in people’s minds: 74% of those questioned take the view that it is normal to suffer from memory loss as you grow older.

B. Knowledge of factors preventing the disease

The knowledge about the factors preventing the disease among those questioned reflects the uncertainty that exists as to the role that various factors play in the onset of Alzheimer’s disease. Stimulating the brain with crosswords or memory games is the only factor on which everyone was agreed: indeed, 80% of them thought that this helped prevent Alzheimer’s disease. On the other hand, opinions are very much more divided as to the role of environmental factors: 39% of the people questioned feel that not smoking reduces the risks of developing Alzheimer’s disease, while 44% see environmental pollution as a risk factor for the disease.

C. Main problems at the start of the disease

For nine out of ten people, having Alzheimer’s disease, including in the early stages, is synonymous with difficulties in everyday life, whether this means difficulties in dealing with paperwork (96%), in performing everyday tasks (93%), in driving a car (89%) or in relations with those around you (91%).

4. General opinions about Alzheimer’s disease and about treatments
Opinions are relatively consistent as regards the extent of the disease and its consequences: 93% of the people questioned believe therefore that “Alzheimer’s disease can have devastating consequences for the family of the patient” and 83% that “these days more and more people are suffering from Alzheimer’s disease”. Similarly, eight out of ten French people think that “a 40-year-old person can have Alzheimer’s disease”. On the other hand, the origins of the disease still divide opinion, with 59% of the people questioned disagreeing with the assertion that “Alzheimer’s disease is often hereditary”. The incurability of the disease is accepted by six people out of ten: 65% of those questioned believe that “today, there is nothing that can be done to cure a person with Alzheimer’s disease” and 64% do not think that “there are any effective treatments for Alzheimer’s disease”. By contrast, there are 84% of people who think that “treatments do exist to improve the wellbeing of patients”. And 65% of the people questioned also believe that “a treatment for Alzheimer’s disease will be found during [their] lifetime”.

5. Opinions about the Alzheimer Plan

Around half of the people questioned (56%) said they had confidence in the measures public authorities were taking to combat Alzheimer’s disease. 16% of those questioned said they had heard about the Alzheimer Plan and knew what it was about and 38% had heard it mentioned without knowing exactly what it contained; overall, 54% of the people questioned had heard of the Alzheimer Plan. The level of knowledge about the Plan is greater among people declaring a higher income, upper management and graduates, as well as among those who had an Alzheimer’s patient in their family circle.

According to the people questioned, the Government’s three main objectives in their campaign against Alzheimer’s disease should be the search for new treatments (65% of mentions), respite relief for families caring for a person with the disease (60%) and the establishment of specialist care homes (52%); only 39% of those questioned mentioned keeping Alzheimer’s patients at home as a priority objective.

When told the content of the Alzheimer Plan, 87% of the people questioned think that the plan is going to improve the situation with Alzheimer’s disease in France (33% considerably; 54% quite considerably).

The areas in which people would most like to receive information are, in the order mentioned: progress in research (64% of mentions), advances in the care provision for patients and their families (41%), advances in diagnosis (37%). To a lesser extent, the information could also relate to how the plan is being implemented locally (17%), the level of funding to have actually been received by the players in the field (15%), European initiatives (9%).
Conclusions and discussion

This survey, carried out in a representative sample of the French population over 18 years of age, confirms the results of the qualitative study conducted in the summer of 2008 as well as the literature review of the social representations of Alzheimer’s disease; these highlighted in particular the extremely negative representations associated with this disease, which was seen as a real “curse”. In this survey, Alzheimer’s disease stands among the three diseases that people fear most, after cancer and traffic accidents. More than eight people in ten have the feeling that it is affecting more and more people. The disease is spontaneously and very widely associated with memory loss, corroborating the way in which in collective representations Alzheimer’s disease is seen as a “disease of the memory”. In addition, the people questioned are well aware of the social consequences linked to Alzheimer’s disease: dependence is the second factor to be mentioned associated with this disease; a very large majority of those questioned connect Alzheimer’s disease, even at an early stage, with problems in performing activities of daily living and recognise also the devastating effects that the disease can have on those around the patients. The incurability of Alzheimer’s disease is largely accepted as a fact, even if it is frequently hoped that a treatment for Alzheimer’s disease will be found in the coming years. Besides confirming this negative representation of Alzheimer’s disease, the survey provided an indication of the place the Alzheimer’s disease occupies in the concerns of the population at large and what their expectations are from the public authorities. According to the judgment of those questioned, Alzheimer’s disease is not the most serious disease; it is mentioned only in third place, by a quarter of the population, after cancer and AIDS. This perception is strongly linked to proximity with Alzheimer’s disease. People with someone near to them who has Alzheimer’s disease, who represent 38% of the population, are more inclined to cite this disease as the most serious. Despite that, the people questioned recognised the place given by the public authorities to the campaign against Alzheimer’s disease: just over half (54%) are familiar with the Alzheimer Plan and 39% think that Alzheimer’s disease is a priority for the public authorities. The expectations of the people questioned related for the most part to research, giving families respite relief and establishing care homes. Research is also the subject that people would like to know more about as the Alzheimer Plan progresses.