Speech
by Mr Nicolas Sarkozy
President of the Republic of France

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Alzheimer’s and related diseases plan

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Sophia Antipolis

Friday 1st February 2008
Ministers, Ladies and Gentlemen,

I am both honoured and happy to be here with you today to launch the Alzheimer’s Plan. It’s a moment we’ve all been waiting for and I understand the impatience you have expressed.

And why shouldn’t you be impatient? When the distress of a loved one impacts on the entire family, I understand that it’s difficult to wait and that every day counts.

Now there will be the five-year Alzheimer’s Plan. This is a lasting commitment on behalf of the state in the fight against this disease. This is a personal commitment.

I am particularly happy to be in Sophia-Antipolis, a centre of excellence for education and research in our country, in a département, dear Christian ESTROSI, that didn’t wait for the Alzheimer’s Plan to lead the fight against this disease. Faced with suffering and a certain form of fatality, exceptional actions exist, treasures of humanity exist, and devotion to our most fragile seniors exists. But that isn’t enough. The Alzheimer’s Plan pays homage to the action led by everybody, but must increase the efforts made by France against this disease.

Last September, I set up the Commission chaired by Professor Joël MENARD, whose work and presence I acknowledge. The members of the Commission and the technical groups worked swiftly over a two month period, and, on 8th November, Professor MENARD submitted his report to me; it is a remarkable piece of work and Roselyne BACHELOT will agree with me. The report of the Commission is exceptionally rich and precise. It has perfectly grasped the necessity for global care for the patient and his/her carers. It has shown that the care system must be organised around the sufferer and his/her family. Alas, the opposite is often true: the patient and his/her loved ones struggle and grope their way along and all the while the disease continues its path of destruction.

The Alzheimer’s Plan that we are presenting has been largely inspired by the report of the Commission chaired by Professor MENARD. As soon as the report was submitted, the administrations concerned went to work on defining the Plan. I would like to thank Roselyne BACHELOT, Valérie PECRESSE and Valérie LETARD who also worked relentlessly. We have made a full analysis of the MENARD report and have discussed it thoroughly. It would have been easy to announce a hurried Plan, without figures or a schedule, but I like it when I’m criticized six days out of seven for going too fast and on the last day for not going fast enough. So I’ve tried to go at the right speed to announce a credible plan. I wanted this Alzheimer’s Plan to be methodical. The work on defining the Plan is now complete.

This is where it all starts. The time for action has come. I have decided that an interministerial policy officer will lead and coordinate implementation of the Plan. I would like to thank Florence LUSTMAN, Inspector General of Finances, who has accepted this task. It is an essential one.

She will be the guarantor of the execution of measures set down in the Alzheimer’s Plan that I am going to present to you. She will be the guarantor of the results. She will be the relay between the different Ministers. She will have a driving role in relation to the administrations and key players. With the Ministers, you will be the standard bearer of the fight against Alzheimer’s, in
particular during the French presidency of the European Union, because our intention, Roselyne, is to make the fight against this disease a European challenge. All countries are affected; we cannot content ourselves with entrenching ourselves behind our borders, ignoring the progresses or difficulties of other countries.

It will be your responsibility to make sure that this plan improves the life of sufferers and their loved ones. You will also be responsible for the Plan gaining in strength until 2012. This is a five-year plan. We will put the indicators in place to enable us to follow the Plan step by step. We will assess the Plan starting in 2011. I am fully aware that a lot of hope is being placed in the action of the ministers, in your action, and in mine.

We are confronted with a disease that is far more than a dysfunction. Alzheimer’s and related diseases are a rupture in human existence.

A rupture because Alzheimer’s is alterity that we do not want to see for what it is. It is more comfortable to live in a state of individualism, ignoring others. Alzheimer’s disease demands solidarity and not resignation.

A rupture because Alzheimer’s disease plays with time. It makes the past unbearable for the sufferer and the present unbearable for carers. When will this illness get the better of my wife, my husband, my mother, my father? Every family asks itself this question every day.

A rupture because Alzheimer’s disease seems to resist our dream of being all-powerful. This disease plays hide-and-seek with researchers. The most promising avenues today could be dead-ends tomorrow.

What is the mind frame of the Alzheimer’s Plan faced with these difficulties?

We first wanted it to be a combination of preparing for the future, of diagnosis and treatment, and caring for people suffering from the disease, of which there are more each day. The challenge is twofold: more and more people need to be cared for now, and more and more resources need to be released for there to be less and less sufferers in the future. We are experiencing the scissor effect. We must not and cannot neglect the present under the pretext that we need to prepare for the future. France has to maintain its rank in diagnoses and therapeutic innovation. France must contribute to making Alzheimer’s, within 10 or 15 years, an illness whose evolution it is possible to stabilise. I hope that, within a few years, we will not be suffering like today – perhaps we won’t even be dying – from Alzheimer’s disease.

The trademark of the Alzheimer’s plan is to integrate research, Valérie, health, Roselyne, and solidarity, the other Valérie. It is a meeting point of the action of several ministers who must work together. This is how the Alzheimer’s Plan has been designed. Research must improve treatments and support. Treatments must be organised coherently, with home-help services or in establishments, Christian. Helping the patient is a whole; it is not a series of successive technical acts.

The Alzheimer’s Plan focuses on the human being. We wanted to put the patient at the heart of the Plan. It is the honour of a civilisation to help and protect those who have become “locked” within themselves. It is the honour of a civilisation to relentlessly tie links between generations. On seeing sufferers, I said to myself: that could be us one day; that could be me. That’s why I decided, and I accept full responsibility for it, to create medical levies. It wasn’t an easy decision. But, to all those who ask me for more resources, I would like to say: I ask you for more solidarity to understand that I cannot produce resources if I don’t take bold decisions. The medical levies are the expression of responsibility and solidarity: responsibility because it’s never easy to release new margins for manoeuvre. Where can we find the money? Solidarity because these margins for manoeuvre will make it possible to finance the new requirements generated by longer life expectancy. We are going to need more resources. And I don’t see how we can present a plan without presenting the resources. To all those who are not brave enough to accept the choices we have made, I say: go and tell the French population, seeing as you don’t want this extra income, how you’re going to find the money. That’s the credibility of the Plan too.
I would also like to thank the members of parliament who voted in this measure. It's so easy to ask to spend even more money: but here, everybody is responsible – and already there isn’t enough money and the health insurance system is in deficit. Without extra resources, what can we do? Thanks to what is maybe not the easiest decision to accept, we have 300 million euros for the Alzheimer’s Plan, available as of 2008. This will be 500 million euros in 2012. In total, one billion six hundred million euros will be spent to fight Alzheimer's disease. Who can say that it isn’t necessary? Without the levies, there would have been even greater deficit. That’s the truth. We need to look it in the face and, I weigh my words: I wanted this priority.

This is a considerable sum: one billion six hundred million euros. It’s a huge financial commitment that must not be to the detriment of the health insurance accounts, which are already in deficit. Can we keep on spending more, without providing for the extra resources? This is why the medical levies took effect from 1st January 2008. So, why am I talking about the levies? I’m talking about the levies because I wanted extra income, and I fully accept that, to be able to present further spending to you in a credible way. How could I come and present further spending without the necessary resources? I know, my friends said to me: "don’t talk too much about the levies, talk instead about the expenditure". But here I am, talking about the levies! Because, if anyone doesn’t want these levies, then they should come and tell the French population how we’re going to pay the extra expense. The debate cannot be ignored. I didn’t want to leave families alone to face this drama. I didn’t want to say to research: "do what you can with the resources you have", because you know full well that that isn’t possible.

In addition to Alzheimer’s, we are also financing other health priorities: the fight against cancer, because we are not going to abandon the fight against cancer because we’re fighting against Alzheimer’s, and something that touches me right in the heart, and Roselyne knows this well, is the development of palliative care. I cannot accept the idea that seriously ill compatriots cannot die with a minimum of respect and dignity.

There are not enough palliative care centres; we need more.

I will have the opportunity to specify the orientations that I intend to give to the Government’s action in these two fields: cancer and palliative care. My priority will be the same as that for Alzheimer’s disease: more than resources, techniques, structures and numbers, there are people suffering who can’t take it any more and that we have to put at the heart of these different plans.

On 21st September 2007, for World Alzheimer’s Day, I met the France Alzheimer association, whose president, Mrs Arlette MEYRIEUX, I would like to salute. On this occasion, I had traced the main orientations to fight against the disease. Today, I have to specify the content through the four objectives of the Alzheimer’s Plan.

The first objective is to be better informed of this disease, because if we don’t know more about it, then we cannot act. France is going to make an effort without parallel in terms of research. I am perfectly aware that we have to play catch-up. France’s share of scientific publications on Alzheimer’s disease is barely above 3%, whereas France’s share in biomedical research on a global level is 6%. We are going to make up for this shortfall.

A foundation for scientific cooperation will be created to boost research into Alzheimer’s disease. Leaning on INSERM, the aim of this foundation will be to attract the best French and foreign researchers and to give support to the best teams. It will have to develop partnerships with private actors. Initial contact shows that the perspectives for public-private cooperation are promising. I am delighted.

In view of the size of the challenge, we cannot work behind closed doors. The foundation will finance costly equipment needed to make advances in research. It will strengthen ties between fundamental research and clinical research, following the same integration logic that forms the basis of the Alzheimer’s plan. It will be one of the first achievements of the policy of excellence that I hope for research in our country. Between 2008 and 2012, 200 million euros of the Alzheimer’s budget will be devoted to research. I expect the foundation to allow us to reach the objective that I have set in founding the Commission chaired
by Professor MENARD: the discovery or validation of a diagnosis and treatment in France. That’s the goal. I expect the foundation to exploit synergies between research bodies, universities, hospitals and the corporate world. If we all get together to find, then find we will. The Alzheimer’s plan will boost research in social sciences. All care methods, be they medical or social, need to be pushed forwards and assessed.

The action of the Foundation for scientific cooperation must always follow the principle of respect for the patient. I would like patients and their families to be associated with defining research policy orientations. Patients’ consent to take part in clinical studies must be given special attention in view of the state of awareness of the patients.

Second objective: better care for patients and their families when the disease arises. I want the Plan to help patients and their families to absorb the shock when the disease is declared. Structures for diagnosis will be developed. 38 memory and 3 memory resource and research centres will be created by 2012. The Alzheimer’s plan must shorten timeframes for diagnostic appointments.

In addition, a system to announce the disease will be set up. This announcement must not be crushing. It must not be a short sharp shock of the kind: “Madam, Sir, you have Alzheimer’s”. To enable better understanding and out of simple humanity, time must be granted. The announcement is a long-term process, which requires dialogue between professionals. The announcement must be accompanied with precise information on the different care options for the patient. It is essential not to leave the patient alone to face his/her diagnosis and to avoid confusing diagnosis with prognosis. What I am saying is valid for Alzheimer’s disease, cancer and all the rest. Faced with a disease for which there is often no real treatment, it is a duty to explain, reassure and guide the patient and his/her loved ones.

The announcement must lead to support. Once again, the Alzheimer’s Plan wants to integrate the approaches. The announcement must go hand in hand with informing the patient about available support. This is why we will be creating Centres for the Autonomy and Integration of Alzheimer's Patients. They will be a single point of contact for families as part of the care system. They will be based on experience acquired by the départements. The aim of the Alzheimer’s Plan is to build, based on the know-how of the départements, a place providing information for patients and coordinating their care. In practice, families will be able to meet doctors and social workers for advice and guidance. These Centres for the Autonomy and Integration of Alzheimer's Patients will not be a further administrative layer. They will promote what works well on the ground thanks to the départements and the National Fund for the Independence of Elderly and Disabled People. These centres will be an anchor point for families. Départements and their partners will need to communicate on this system. The first trials will be carried out in 2008. We don’t have time to lose.

I hope that the first trials will be combined with the implementation of a national telephone number to inform families and guide them towards Centres for the Autonomy and Integration of Alzheimer's Patients.

We need a national telephone number that guides families to the structures that exist. Informing and guiding must be integrated to improve the quality of life of patients and carers.

Special support will be given when announcing the illness. A national reference centre for young sufferers, based on the model of centres for rare illnesses, will be created. It should enable early detection of the illness to avoid uncertainty that only aggravates the illness. Everything shows that the earlier the diagnosis is made, the more chance there is of the patient remaining autonomous. We owe young sufferers a specific care system. For these patients, we have to evolve from the chaos they are experiencing today towards an organised care offer. I am perfectly aware that the challenge is huge. I want to rise to it. Being 60 and ill is not the same as being in your eighties.
The third objective of the Plan is to improve the long-term quality of life of patients and carers after the diagnosis. I know that this is the area where expectations are highest. I consider that the needs are immeasurable. These unlimited needs require a human and organised solution. The priority is to adapt the home or establishment to the specific requirements of Alzheimer’s patients. The Plan will favour the intervention of ergotherapists and phsycomotricians to equip the home. A maximum must be done to enable sufferers to live at home, because that’s what they want. In centres, extra personnel will be brought in, to the tune of creating 30,000 extra places, in order to offer patients suitable care and activities. The individual cases of patients who have wandering or disturbing behaviour need to be better taken into account. Suitable care would reduce their behavioural problems and the need for medication. Knocking them out with drugs is not a solution either. It’s a matter of quality of life. The solution is most certainly not containment or isolation. The solution is suitable and intelligent care.

Crises can arise that require more specialised care. Within Alzheimer’s disease, there are a number of different situations, and therein lays the difficulty of the plan: we need to be able to handle all of these different situations.

Today, where do people with Alzheimer’s who have a fit end up? In the hospital casualty department. This is unacceptable. Unacceptable for them and unacceptable for the hospital, which is already overworked. We are going to make means for this. The Plan provides for the creation of specialised Alzheimer units in mid-term establishments to better manage interruptions to care.

These increased resources will not be enough; we all know that already. We could plan for ten times more. Some people, and maybe rightly so, estimate that even that wouldn’t be enough. But I want and have to get out of this “always more” logic. A Plan is not about “always more”. I want the Alzheimer’s plan to make what already exists more efficient, I want it to promote what has been achieved. The extra resources will only be enough – 1 billion 600 million euros – if they are used coherently. One of the first problems raised by the commission chaired by Professor MENARD is the absence of coherency. Coherency is necessary for the good of the patient. One of the main innovations will be establishing the profession of coordinators. This person will conduct overall care for the patient. He/She will have to organise the intervention of doctors and medico-social professionals. This measure is innovative because it puts the different professions at the service of the person suffering. Once again, the system has to be adapted to the individual and not the other way round. Départements that want to will be able to establish the first coordinators this year.

To help sufferers in the long-term at home, carers need to be supported. The development of respite structures will go together with solving the issue of transporting the patient to these institutions.

In addition, the doctor in charge of the patient suffering from Alzheimer’s will need to pay special attention to carers’ capacity for endurance. The strength of a chain depends on its weakest link. It is senseless to care for the sufferer if the carer’s capacity to resist erodes in silence. The global approach must always take precedence.

The Alzheimer’s plan: the fourth objective: the ethical consideration. Ethical considerations and the respect due to the patient must be omnipresent in both the practice of professionals and in the places where sufferers live. I want ethical thought to exist and to be spread. Specific resources will be dedicated to this.

A number of legal questions will emerge from the ethical issue. The Alzheimer’s plan must provide pertinent answers to the very delicate question of consent of the person suffering from
Alzheimer’s, particularly at the time he/she is admitted to an institution. We cannot hope to put the person at the heart of the action if we avoid this essential question. We have the unique opportunity to deal with this question together.

Other measures feature in the Alzheimer’s Plan. I do not want to mention them all here. But I think that the few actions I have mentioned are emblematic of our will.

Does Alzheimer’s disease offend our human dignity? Then let’s reply collectively with a burst of humanity.

Does Alzheimer’s resist science? Then let’s fight and help researchers to combat this disease.

Alzheimer’s disease is a devastating illness. And like many other scourges, we are going to fight this one. Let the Alzheimer’s Plan give us energy and give our seniors justice and dignity. I add that, every six months, I will chair a meeting with the ministers concerned to evaluate the results of the Alzheimer’s Plan. If we are wrong, then we will change. If we haven’t done enough, then we’ll do more. If there are things to modify, then we’ll modify them. But I want France to be exemplary in its research into this disease and in its care for sufferers of this disease.

Ladies and Gentlemen, I am perfectly aware that this is a challenge unique in its kind; a health challenge rarely seen in a country like ours. I would like to add that, within the framework of the necessary reorganisation of the hospital map, with Roselyne BACHELOT we will tie this reorganisation in with the Alzheimer’s plan. A certain number of hospitals will evolve towards medium and long-term stays. And as part of medium stays, we want to develop units to take care of Alzheimer’s patients. The matter is coherent, and from this point of view, I know exactly that more places are expected of us. So, I have tried to present, with the ministers, a global plan that does not oppose patients and carers, the present and the future, research and support, but that mobilises everyone around one single objective: find the means to stop this disease. Make sure that those suffering from this disease today live as comfortably as possible, without neglecting anybody, without leaving anybody alone, whether carer or sufferer.

You understand, Madam, the task that waits you is not an easy one, but you will be supported by Roselyne BACHELOT, Valérie PECRESSE, Valérie LETARD and, if you so wish, myself of course. I know that you will achieve the results.

Ladies and Gentlemen, I think I have demonstrated that France is aware of the size of the challenge that awaits us. I know that the combat is just beginning and I would like to say to researchers, doctors, to all those in France who have understood that the situation is serious, very serious, that we are going to support them with an unrivalled research effort. You have also understood that I take it to heart to bring you these answers. I have the feeling that your impatience has been real. Objectively, having mobilised what we have mobilised, having found the logic of a coherent plan despite the challenges of this disease being multiple because each situation is different, all within eight months, you can rest assured that your country is mobilised to help you, and that not one of you will be alone. Once again, I believe in this plan, but I will not hesitate to change it if the assessment shows that we have forgotten such and such an element necessary for the efficiency of the health action that we are leading. Believe me; my objective is that in five years time, we can say that considerable progress has been made in research and support.

Thank you.