

Policy Forum

French lessons: Leadership in Alzheimer's disease

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Be Heard Here First

1. Inauguration Day – Two Translations

It is impossible to forecast anything at the beginning of 2009 about health policy in general, or Alzheimer's disease (AD) specifically, that is not both optimistic and cautionary. Our new President, Barack Obama, who spent the campaign energizing the nation about prospects for change, is hunkered down with advisors tackling our financial and economic crises and remapping the nation's foreign affairs. But if the multiple plans for health insurance reform that have started appearing from Congress are any indication, we may well be in store for serious and sustained leadership on this front in the near term.

However there is something very troubling about this new start on healthcare: it's all become about paying for it. Somewhere over the past few months, it has become impossible – or at least it seems irresponsible – to think about healthcare in anything but monetary terms. How will we save Medicare and Medicaid? How will we fight profiteering within the insurance and managed care industries and move to reimbursement that covers more (all) of us? How will business owners, large and small, stay afloat while subsidizing employee health costs? How will American families manage our own stretched healthcare budgets?

These are important, fundamental questions to be sure, especially given our domestic and global economic crises, and the burst of governmental spending to manage them. But shouldn't we also be having a simultaneous discussion about *prevention* of illness and how to *provide* the actual care – how, in fact, to make the fruits of world leadership in medical research available to more Americans in the form of compassionate care? Before we close the patient file and move on to reimbursement exclusively, are there not other equally fundamental questions about our *duty* to care?

Any consideration of this complex question—beyond one or two slogans in policy speeches—is now seen as frivolous

and not pertinent. In fact, I think these questions are *im-pertinent*, in the best possible sense. And in the lingo of the day, we can no longer *afford* not to ask them.

For a study in contrasts, consider another January 2009 Presidential inauguration—that of the President of the Czech Republic, Vaclav Klaus, as rotating President of the European Union. Outgoing EU President, France's Nicolas Sarkozy, will collaborate with Klaus closely on priority issues, as is the custom of the essentially shared European Presidency. And among the EU's top priorities, alongside banking industry reform, will be the first disease-specific pan-EU plan ever – to fight AD.

How AD has risen to the top of European awareness is largely a tribute to President Sarkozy, who tirelessly lobbied for a pan-EU version of what he has accomplished at the national French level: a comprehensive “French Alzheimer's Plan” that integrates brave new initiatives in research, caregiving, and medical and public education in a plan that is already funded by the French government and widely embraced by most of the nation.

Granted, Sarkozy's pan-EU AD proposal still faces a polyglot of political challenges from a loose alliance of diverse nations that, individually, do not share France's passion for a fight against AD. Granted, some steps have already been taken on AD efforts by other individual member nations: Germany has made enormous advances in clinical research; the United Kingdom is developing more supportive care giving and social support services; while Italy, Norway and Finland are also beginning to respond to the coming epidemic. Still, it may be hard to sell France's much more comprehensive approach on the larger European stage. But this just added fire to Sarkozy's passionate argument for a pan-EU plan at a special Presidential meeting of EU legislators and AD leaders from around the world who met in Paris on October 30, 2008.

What emerged at the Paris meeting in detailed reports on the French plan and speculation on a pan-EU version was precisely what we do not hear from any of the healthcare discourse in the US today: Sarkozy's AD plan is about the goal of patient-centered, preventive care, not just the business of funding it. It is also a deeply personal commitment from a national leader about moral duty first and foremost. Stunning.

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As Sarkozy explained when he first announced the initial French plan in February, 2008:

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 deadends tomorrow.¹

But to his credit as a politician, this personal immediacy has been transformed into a compelling political imperative:

It seems that Europe must fully commit itself to the fight against Alzheimer's disease because its values are at stake.

The Charter of Fundamental Rights of the European Union recalls our duty to preserve the dignity of infirm persons. Respecting the dignity of human beings is at the heart of European democratic values. After the horrors which traversed our continent for the duration of the twentieth century, respect of the dignity of the person is an absolute imperative for us all at the dawn of the twenty-first century.

Solidarity is another founding value of Europe. Despite their differences in terms of organisation, our systems of solidarity all rely on the State, on social partners, businesses and individual responsibility. In all European countries there is a system which protects individuals from the vagaries of life. It is a profoundly European value to leave no one behind. The systems of solidarity must evolve in order to be more efficient and to motivate work. But they must be preserved in their ultimate objective. We cannot renounce that which constitutes our fundamental nature as Europeans.²

In an American moment when we too have a new President with enormous personal commitment, what we need is this degree of clarity about *why* we must change healthcare, not just how we will pay for it.

2. A Master Plan – Unifying the Science

The French Alzheimer's Plan—administered by Sarkozy appointees: Florence Lustman, Inspector General of Finances for France; Philippe Amouyel, Professor of Public Health at the University of Lille; and Raphaël Radanne, special health advisor to President Sarkozy—has authorized 1.6 billion Euros

(or a little over \$2 billion US) over 5 years, including 200 million Euros for research, 200 million for patient care and 1.2 billion for social and family support.³ Tellingly, it is difficult to compare this figure with a similar grand total for US AD spending primarily because no one is keeping coordinated records on the various efforts, and no one is thinking five years ahead. But clearly the most important piece of the US AD puzzle is the approved 2008 National Institutes of Health commitment of \$644 million for research – the lowest NIH spend since 2005.⁴ We can count on millions more in private research and development, but still what remains absent are the other components of a coordinated plan to address an epidemic in the minds of a nation – an understanding of the patient, care giver support, education, a vision of what will happen if we do nothing, and a commitment to preventing it. Certainly some efforts are being made to address these issues, but not by a centralized force – governmental, private or public – and not with any national priority.

In contrast, the French plan will support 44 specific objectives divided around 10 key measures. Seen as a whole, the plan seeks to provide better treatment and support for patients and caregivers through a single source of contact, and speed up research by creating a Foundation for Scientific Cooperation.⁵ According to Sarkozy,

The trademark of the French Alzheimer's Plan is to integrate research, treatment and support. Our aim is not only to intensify our effort in each of these separate areas. Our aim is also to develop synergies between each of them in order to improve the quality of life of afflicted persons and their families.⁶

In an interview with *Alzheimer's & Dementia*, Sarkozy's principal implementer for the French Alzheimer's plan, Florence Lustman, suggests that this integrative approach will make good use of scientific advances now and in years to come:

Both the United States and Europe can learn from each other. The USA has been a leader in Alzheimer's research since 1978...while the French Alzheimer's plan is the... first one to deal with research. Its originality is to integrate all aspects of the fight against the disease in order to serve better the patients and family carers. In the medium term, research will enable us to delay or treat the disease but in the short term, patients must be helped to cope with an

³ "The reasons for a conference like this – Reminder of the 2008-2012 Alzheimer's Plan", prepared for the French Presidency of the Council of the European Union: Europe against Alzheimer and related diseases, Thursday 30th and Friday 31st October 2008, Bibliothèque nationale de France, Paris. French Ministry of health, youth affairs, sport and associations; Ministry of higher education and research; and Secretary of State in charge of solidarity

⁴ Congressional Budget Office, 2008.

⁵ "The reasons for a conference like this – Reminder of the 2008-2012 Alzheimer's Plan"

⁶ Speech by The President Of The French Republic, European Conference on the fight against Alzheimer's and related diseases, Bibliothèque Nationale de France, Friday October 31st 2008

¹ Speech by the President of the French Republic, "Alzheimer's and related diseases plan", Sophia Antipolis, France. February 1, 2008.

² Ibid.

early and supported diagnosis, and their quality of life must be improved with non-pharmacological therapies that can help them stay at home longer.⁷

The chief architect of the French plan is leading cardiologist Dr. Joël Ménard, and as a man of science, his first focus was coordinating the best that France already has to offer on a diversity of clinical fronts, seeding new leaders and lines of research, and integrating it all so that it best serves France, the European Union, and beyond. Highlights of the scientific initiative include:

- Reinforcing current strengths by facilitating the work of multi-disciplinary centers with strong previous scientific production and exploiting population cohorts, participation in genome-scan studies, better use of experimental models already developed in France, such as the microcebe.
- Attracting new teams from experts connected with existing teams, and opening new fields, such as cellular biology, systems biology, vascular biology, immunology.
- Attracting forty young researchers per year through a national program and training 10 more PhD and post-doctoral researchers per year.
- Training 1500 additional professionals in clinical epidemiology, etiology, diagnosis, prognostic, therapeutic trials, and meta-analysis.
- Recruiting Associate Professors from the pharmaceutical and diagnostics industries to teach the new generation of AD professionals.⁸

Already there are new French scientific working groups in controlled clinical trials and prospective studies, neuropsychology and clinical investigation, neuro-imaging, biomarkers, genetics, animal models, cell biology and neuropathology.⁹ In an interview with *Alzheimer's & Dementia*, Dr. Ménard explained that these efforts will systematically explore and integrate insights on new technologies as diverse as:

*Experimental and cellular models, to the possibilities of performing more sophisticated neuropsychological, biochemical and functional imaging studies in humans... Also, a national Center for Genetic Alzheimer diseases will be created, on the model of what is done for other diseases, such as mucoviscidose, myopathies, and others.*¹⁰

And to assure that the new advances are efficiently shared to expedite clinical application, Dr. Ménard has planned:

...a global information system to have the most comprehensive database on issues like Alzheimer's-related hospitalization causes and duration of hospital stays, practices for attributing mortality to Alzheimer's on death certificates, population and incidence studies, prediction

*models on prevalence and incidence special cohort studies, best practices on structure for standardized and computerized medical dossiers, surveys of awareness and perceptions of AD among the general population, research applications, and synthesis of research results*¹¹

3. La Condition humaine

Just as systematic as its scientific infrastructure is France's commitment to refocusing care on the patient throughout the process. The planned systems of psycho-social support start at point of diagnosis and respect the wide range of needs implicit in AD care through the entire disease cycle. Under the French Plan, family interventions begin at diagnosis and every effort is being made to make those assessments earlier and earlier. Primary care physicians are actively engaged in diagnosis as well as long term supervision of care. According to Sarkozy:

*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 [diagnosis] 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. These centres will be an anchor point for families.*¹²

The value of this approach to a care continuum will be clear to anyone running the care giving gauntlet in the US. Here, a patient and family are given a diagnosis, usually two years after onset, and then left to find their way through loosely linked social service networks that hand off patient and family in an uncoordinated fashion that often ends up compromising both patient and caregiver, leaving essential issues unresolved.

And finally, growing from the same understanding of the central role of the patient and family, Sarkozy has called for a Europe-wide reevaluation of the "ethics of Alzheimer's," by which he means the rights of the patient, the family and the nation: legal status of AD patients in institutions, informed consent around end-of-life decisions, treatments, and clinical trials. Sarkozy asks:

How should we obtain the consent of a person to enter a nursing home? How can we reconcile the respect of the patient's autonomy and their security? What attitude is appropriate with regard to a person who has lost all their usual means of communicating? How can we adapt treatment to a person's preferences? What role can carers play to assist the patient in expressing their choice?

These are all concrete questions for which we must find ethical answers. Faced with such questions, we cannot settle for purely technical replies, nor is it possible either to confine ourselves to a purely compassionate register. Legislation must help in clarifying certain situations. However, it is the behaviour of each one of us faced with suffering and the gradual disappearance of the afflicted person's autonomy that takes precedence.

⁷ Interview with Florence Lustman, Inspector General of Finances. November 20, 2008

⁸ Interview with Joël Ménard, Professor of Public Health, Paris. October 30, 2008.

⁹ Ibid.

¹⁰ Ibid.

¹¹ Ibid.

¹² Speech by the President of The French Republic, "Alzheimer's and related diseases plan", Sophia Antipolis, France. February 1, 2008.

*Well-informed behaviour, based in every circumstance on the respect for the dignity of the person, is essential. There are no universal rules in this area. While the principle of the respect of dignity is universal, its concrete application depends on the situation of the afflicted person, their family and their environment.*¹³

4. Toward a Global AD Plan

Sarkozy and his team are already looking beyond a pan-EU AD plan in some of the world's first realistic overtures toward a global approach. At the moment, these are overtures to learn from the different ways AD is managed in different cultures. Sarkozy's special health advisor, Raphaël Radanne, talked with us about some of the more apparent opportunities:

*A fruitful collaboration could certainly engage between Europe and the USA concerning research (for instance on the subjects currently being identified for European cooperation such as large intervention studies, studies on young onset dementia patients, genome wide association studies...) but also exchange of good practices or definition of standards for care or ethics*¹⁴

Marc Wortmann, Executive Director of Alzheimer's Disease International, addressed the Paris conference and cited a new global dementia incidence figure of 30 million, but he also suggests that we must quantify the economic scale of the epidemic if we are to rally worldwide attention:

*At the moment, most people have no idea at all of the economic impact. So we have to tell this over and over again. You need a solid, research based report to really convince the media and policy makers. That's how it went in Australia, UK and Netherlands for instance. After publication of the reports, governments started to act – they could not neglect the problem anymore. The report is essential, but not enough. We also need a global awareness campaign.*¹⁵

George Vradenburg, President of the Vradenburg Foundation and leading AD advocate in the US, argues for a broad-based collaboration on global AD:

*With the global incidence of Alzheimer's now approaching or exceeding that of HIV/AIDS, the global community must marshal the same unrelenting focus and large-scale resources as the HIV/AIDS community in order to prevent the social and economic agony of what is quickly becoming a global Alzheimer's pandemic.*¹⁶

Vradenburg traveled to Sarkozy's Paris summit in October at the behest of the Alzheimer's Study Group (ASG), which is

¹³ Speech by The President of the French Republic, European Conference on the fight against Alzheimer's and related diseases, Bibliothèque Nationale de France, Paris. October 31, 2008.

¹⁴ Interview with Raphaël Radanne, Special health advisor. November 20, 2008.

¹⁵ Interview with Marc Wortmann, Executive Director of Alzheimer's Disease International. November 1, 2008.

¹⁶ Interview with George Vradenburg, President of the Vradenburg Foundation. November 5, 2008.

currently mounting, in consultation with Leon Thal Symposium scientists, and disease-specific advocacy organizations, one of the only efforts toward a consolidated US response to Alzheimer's. ASG is also now considering specific ways to collaborate with the French government on global efforts.

5. The Ugly American?

France's efforts at home, on the EU stage, and even globally are significant, but there are obviously a few extenuating circumstances for any comparative study of French and US leadership styles. First, France and much of the rest of the EU are socialized healthcare systems, driven less by what the health delivery, pharmaceutical, managed care, and reimbursement markets will support than by what the government will. As we never tire of reminding ourselves, most real innovation behind current AD therapies and the next generation of disease-modifying drugs has been driven by US corporate leadership, not a government health system.

Because of this market driven reality, much of the organizational infrastructure that France now rallies to develop has existed here in some form for a while.

We already have NIH-coordinated research, for instance, and some efforts are underway to dovetail the best of it with that going on across the Atlantic and elsewhere. Our information technology industries like Microsoft have already begun to support globalization of data in ways that may better support research and caregiving. The FDA is already working with industry and the AD community to address regulatory roadblocks to better treatments, in some limited respects collaborating with the EU's EMEA in the process. (It is worth noting, though, that Dr. Ménard and a growing part of the international AD community argue that greater coordination is needed between governments and regulatory bodies, including Japan and Australia.)

Meanwhile, there are already some efforts within the US non-governmental sector to integrate a scientific, political and caregiving national plan against AD. And it could even be argued that we have already come to see the need for greater caregiving support, as the French are now addressing. We talk that talk, at least. In short, many of the pieces of an integrated plan are already to be found in the US. They are just not in place yet.

But the most significant issue differentiating France and the US is probably what we started with: the overwhelming cost of revamping our mismanaged healthcare system to accommodate a disease like AD at a time of historic economic crisis. Alzheimer's Disease International estimates that by 2010 there will be 864,000 people in France affected by all forms of dementia, with a subset of that representing the total French AD population by the end of the decade.¹⁷ This compares with an estimated five million AD cases in the US today.¹⁸ So ours is a significantly larger public health

¹⁷ Numbers of People with Dementia, Fact Sheet prepared by Alzheimer's Disease International, 2008.

¹⁸ Alzheimer's Association Fact Sheet, 2008.

challenge, especially as our healthcare expenditures continue to skyrocket at a rate that Victor R. Fuchs, Ph.D. professor emeritus of economics at Stanford University, recently estimated could “absorb 30% of the gross domestic product — a proportion that exceeds that of current government spending for all purposes combined” in 30 years.¹⁹

This system-wide financial pressure makes it perhaps more difficult than ever before to fund an ongoing effort to fight AD, especially since we fight yearly incremental budgeting by the legislature that makes the kind of long-term package-deal budget behind the French Plan impossible here. Without doubt, funding of an American Alzheimer’s Plan is uniquely challenging.

The French and Europeans also admit that the global economic crisis will inject a degree of uncertainty into their AD plan. But even before the crisis had defined itself, Sarkozy had taken the extraordinary measure of instituting healthcare levies against French workers, who previously enjoyed strictly state-funded healthcare. With blunt common sense, Sarkozy justified the unparalleled move up front, even as he announced the AD plan in February:

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.

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.²⁰

The price tag may be much larger here in the US, but the need to fight what will become the most costly disease of the next generation is exactly the same. As we focus on our own fiscal reality, with billions and even trillions tossed around every day, we would do well to learn from the French resolve.

As the leaders of two very different nations meet for the first French/American *tete-a-tete* this year, the AD community must insist that President Obama be mindful not only of the more straightforward matters of trans-Atlantic collaborations such as shared clinical trial data, drug patent extensions, and truly global studies on the impact of AD. Likewise, we must insist that he bring plans for something more than reimbursement. As our new leader, it falls to him to rediscover *an American duty to care* in the face of the epidemic that will define a generation. President Sarkozy has much to say on that matter and it behooves us all to learn a bit of French.

¹⁹ “Three ‘Inconvenient Truths’ about Health Care”, *New England Journal of Medicine*, volume 359, number 17. : October 23, 2008. Original calculations from “The long-term outlook for health care spending.” Washington, DC: Congressional Budget Office, November 2007.

²⁰ Speech by the President of the French Republic, “Alzheimer’s and related diseases plan”, Sophia Antipolis, France. February 1, 2008.