

Presentation by Marcel Brasey (Geneva/Switzerland) at Congress “The Alzheimer’s disease: a social challenge” on June 5, 2009 in Paris/France
(Translated from French by Mitchell Slutzky)

Ladies and gentlemen, Hello!

My name is Marcel Brasey. I am 65 years old and I am Swiss-German. For the past 10 years, I have lived with the diagnosis of probable dementia of the Alzheimer’s type. Before that, I first worked in scientific research, and then in marketing and development of pharmaceuticals. It was my great passion and also the essence of my identity for more than 30 years.

It all began during a regular work meeting...

As usual, I directed the meeting. But, this morning there, I was unable to speak and write my presentation on the board, nor to listen to and take notes at the same time. Nobody noticed anything. But to me, I recall it as if it were September 11. That was the beginning of my difficulties. Later, it would be explained to me that it was my working memory which had broken down... for ever!

It became increasingly difficult for me to talk on the telephone. When I did, I needed to write down on paper word for word, all that I wished to say to the person on the other end. But, very quickly, I usually ended up with too many cards, which became impossible to manage. In addition, I became afraid of being made fun of; these notes had to be hidden away with all the others. I did not make any further efforts to hide or to compensate after this, because to compensate was synonymous with denial of disability. All was to remain visible. There was chaos everywhere, in my head and on the desk!

My functioning became very unpredictable often in opposition to my previous predictable personality. Gradually, I slipped from precise to generalities, from staying focused to becoming fuzzy, from remaining active to becoming idle. To escape from the calls and the unforeseen, I gave up on my usual responsibilities. All the excuses were good, either to avoid unpleasant situations or to save time... much of time.

And the months pass... but nothing changes!

One really enters another world, purely linear but constricted, in which one advances baby step by baby step. I could no longer multi-task. I especially tried to avoid questions and answers. Because all too often, I would have to answer with “I do not know any more”, “I forgot” and “I do not understand”. To protect myself a little, I started to avoid people who were too curious, too talkative, and all those whom I suspected of not having much empathy.

One tries to speak to the doctors about it. But we do not find the words that are necessary. And very often, they do not hear our pleas. Our symptoms appear too mundane, too subtle, not taken seriously!

It all falls on deaf ears. With a cancer or advanced Alzheimer, one would undoubtedly be more quickly recognized and helped. Instead there are rounds of appointments, questions, a few unhelpful explanations, but never any precise answers.

Inevitably there comes a time when one must stop working, along with a loss of self-esteem. The family either gives empty reassurances, or they deny the seriousness: "You work too much; it is just from being overworked!" I lived with months of uncertainty and extreme, internal and external stress.

Finally, after much from persistence and with a little luck, I fell upon a well-informed doctor who directed me towards the Center for Memory Evaluation. There, I found what I sought: listening and understanding of my situation, arrival at the proper diagnosis, and the guidance and help to improve my functioning through cognitive rehabilitation.

The diagnosis changed everything.

My professional career, my hobbies and plans for retirement, especially my life expectancy. Initially, it led to panic, and I believed that this must be the end. At 54 years old, I have major memory loss... Alzheimer's... it is incomprehensible, it is alarming! Despite everything, at least for the immediate future, I feel relieved.

In the end, I need to know as much as I can about this adversary. And this condition evokes many questions: "What will be the reaction of my close relations? Where will I be in five years, ten years, and what state of awareness? Who will assume responsibility for me? Who will pay for my care?"

But the question which returns to me unceasingly, to my spirit, is the following, a very simple one: How long do I have left to live? Medicine gives us 8 years on average. The expectancy range can be from 2 to 20 years. For once I choose to prefer the uncertainty!

Then, is it necessary that one either accept or deny the diagnosis? To deny, it is to worsen the situation. To accept, it is certainly better! But that sounds a little too unstoppable, too fatalistic and too final for my taste.

The possibility of very early detection of the disease, of being able to profit from a neuropsychological follow-up and the arrival of the first drugs really changed the equation. These options enabled me to remain hopeful, to stabilize my losses and to organize my life with the disease. Sometimes, I also think that the early diagnosis enabled me to avert the worst. It might actually enable me:

- to keep me from feeling alone, without treatment or support
- to prevent me from lapsing into a serious depression and being dosed with psychotropic drugs for years
- to prevent me from being unjustly professionally disqualified

- and perhaps this diagnosis would prevent me from driving the highway into oncoming traffic, thereby preventing me from causing a serious accident.

Yes, it is necessary to diagnose as soon as possible, especially given improving accuracy and new treatment options. That gives us a true chance of rehabilitation and social utility! From my point of view, the result would be a win-win! For us, patients and close relations, for you the professionals and for the public in general. And yet to this very day, in Switzerland, and perhaps also in France, two patients out of three do not get diagnosed, and even fewer of these who are diagnosed ever receive treatment and an appropriate follow-up.

What great difficulty it is to live with an invisible evil

At the beginning, the only concrete signs were in the medical report. But by definition, these must remain confidential. It is well, but the secrecy also exposes me to the insensitivity of others, with their difficulty understanding that I have this type of disease. How do I begin to tell them that it is not a simple depression or a professional burn-out? That it is about being in the early stages of Alzheimer's disease!

Of course, seen from the outside, one sees a healthy mind in a healthy body.

No symptoms... or at least not of disease!

Nothing significant or wrong stands out! Wrongly or rightly, I take that like a reproach.

Then I try to explain... and sometimes to even justify my diagnosis. Usually I expect it to be a waste of time and effort! But what can I say or what evidence can I give to support my case?

And how can I handle the frustration when I feel badly inside and when others say: "But you see, you are doing well", or better still "Me too, I have problems of memory, it is normal!" They may be trying to be sympathetic or supportive, but how should I respond?

Finally, it does not matter the name of the disease. It is all the same, because it is all so terrifying... Alzheimer's, Pick's, Lewy Body or Vascular Dementia: for me, no matter the diagnosis it is necessary to obtain the right to treatment and an assumption of capacity to make my own decisions, albeit appropriately modified to my pattern of strengths and weaknesses. But very quickly, I was confronted with another obstacle, that of the label "dementia of the Alzheimer type" and of a determination: stage 1, 2, or 3...

But I am not crazy!

For the large majority of people, having dementia is synonymous with madness (ed. In French the two words are the same: demence for both dementia and insanity). And that is how it becomes a problem, this gap that exists between the knowledge of the specialists and those of the population in general. It is especially true when others hear the term dementia. But in normal use people speak about this to refer to criminal actions and not about disease! Then the conclusion is readily drawn: dementia = insane = Alzheimer's! This connection is damaging; the label surprises families so much that they try to hide us,

out of fear, pity and shame. Do they do this to protect us, or to protect themselves? Certainly, there is a little of both. It is legitimate, but that does not fix anything... for anybody.

Stigmatization is everywhere!

One works hard at keeping up a good image. That way complicated situations are avoided. Some of us end up transforming our deficits into grand gestures. In those instances, one becomes very creative, sometimes like a gifted actor. But at what price? Why, do I continue to play this exhausting game of hide-and-seek in relation to others? And what is worse, this is a cheating of myself. Who is the culprit? It is the fear of stigmatization in words and in pictures. Those fears become synonymous with the disease. It is an explosive cocktail of stereotypes, false ideas and negative stereotypes of the last century. But, is this my problem alone, or is it also yours? I think that it concerns everyone. Mine if I am satisfied with the passive role of victim. It is the problem of my close relations, if they want everything to remain as it used to be. It is the doctor's problem also, if this delays the diagnosis and if the results are not communicated openly to his patient. Of course, it is often assumed that ignorance is bliss, that it is better to hear no evil, say no evil speak no evil...

But am I still competent?

The worst is that I myself used to think that once a person developed Alzheimer's he was fatally incompetent and hopelessly dependent. Fortunately, in my contacts with other patients at my memory clinic, I could see just the opposite. I now know that we can do a lot to develop our preserved capacities. If one seeks them out, one can find signs of them, while bringing them into focus, separating them from the forces contributing to our weakness. There is now an emerging profile of patients. There are now a group of more actively engaged patients who assert the right to knowledge about the diagnosis and present level of functioning and who remain an essential actor in their therapeutic and social follow-up.

And will my personal freedom vanish?

The exercise of autonomy is a basic right, especially for a person with memory loss. But inside I want to declare my "independence". If it is about the capacity to drive a car, I cannot do it any more. Often, even when well-rested, I have the sensation of going on "in a blur". On the motorway, I passed too close to the safety rails. Sometimes I came very close to having an accident. To give up my freedoms was terribly difficult, but the results on the tests of attention were too poor to ignore. And so "independence" wants to say, "I am capable of knowing what is good for me, I can remain like this for a very a long time. Because even if I can hardly explain my reasons, I can still decide! And even if I do not manage to justify my choices, I can still choose!" When weighing the responsibility of this autonomy, I weigh two opposing forces: "Should I respect my current values or those that I had before the disease?"

My answer is clear: nobody must be unaware of my current perspective. It evolved a lot since the the disease was first diagnosed and it has become a part of me. Here, I like to quote Gandhi who said: “What you do for me, but without me, you do it against me!”

But how can I cope with the catastrophic reactions of others once I reveal my diagnosis?

I found the answer within other patients living with this disease. Those diagnosed around fifty become advocates, sometimes even militantly so. It may appear to be an atypical attitude, but it is one that seems appropriate to me and it helps advance my cause. These people all previously held positions of responsibility and all belong to the post-Aricept-Exelon generation that started at the end of the 1990’s.

In Australia, Christine got her license, remarried and presented at conferences. Claude in France, wrote an autobiography and paints paintings. Marilyn joined the board of directors of Alzheimer’s Association of Canada and regular public talks about living with dementia. But at the same time, all of us with dementia at times forget to turn off the gas stove, we get lost on familiar streets and at times cannot repeat a simple sentence...

Facing the disease leads to a change of perspective.

Somebody once said “One cannot stop the waves, but one can learn to surf”. Admittedly, that will not be easy. But by looking more closely at the difficulty, perhaps one will get there! It is a way of adapting, and of being unable to separate the good parts from the bad. Sometimes I conclude:

- Wait a minute! This is not that serious, I do not feel physical pains
- And besides, I have finally time for myself. I can choose to pursue activities which really please me
- At these times, I realize that I can do things I no longer thought I could do.

I rely upon my computer

Because the real world passes by too quickly, I rely upon my computer and the Internet. There, I can fully accept myself with the disease. I can read and write at my own speed. The computer allows me the necessary time. It never scolds me “Hey you’ve forgotten something!”, or “I already told you that!” Even when I make it repeat things ten times it remains calm and never becomes annoyed. It accepts me as I am. It’s like a friend it’s almost human, and at any rate it has become indispensable in helping me to live with the disease!

And, I face a demanding task

The forced abandonment of my profession came as an enormous shock. How can one fill this void? The English example, where young patients in early stages started to talk about their challenges of living with dementia on the Internet (ed. DASNInternational.org),

encouraged me to create my own French site. There, I write my about various aspects of my situation which I share with other people who are in the same situation. This space enables me to connect with others who are living with the same challenges, enables me to feel me useful and to emphasize the capacities which remain preserved within me. I also use my site to remain connected with my family and friends. It has become another way of helping them understand and appreciate my handicaps and hopes.

I also try to reduce the stress and the negative emotions

What really enabled me to survive, has been the psychological support from which I benefited during the past year plus. Within the daily fog, I can once again find my way, comfortably myself...

I discovered a technique and a philosophy of stress reduction: mindfulness meditation, as developed by Dr. Jon Kabat-Zinn. As a result of this practice, one learns how to release oneself from negative ruminations, to accept setbacks, to let go of distortions, to see things as they really are, even during times of great personal challenge, interpersonal conflict and grave disease.

Over the past year, I was fortunately to be able to take part in the first organized Mindful Based Stress Reduction (MBSR) group organized under the auspices of the memory center at the University hospitals of Geneva.

I especially embrace a new life philosophy

My intellectual decline forced me to live life differently; to drastically simplify my life compared to before. More than the disease itself, I had to stop reacting to it catastrophically. In regards to the existential crisis that I faced since the beginning, I let myself be influenced a little by Sénèque, a little by Nietzsche and especially by Jollien! For those who do not know him, Alexandre Jollien is a young Swiss philosopher, born with a birth defect. He wrote about what it is like to be “abnormal” as a reference for all those which wish to better understand and appreciate what it is like to live with a handicap. Its title: “Le métier d’homme” (publisher Du Seuil, Paris 2002) (rough translation “*The occupation of man*”)...It is a masterpiece!

Agreed: none of this will cure me. The disease will be always there. But having this outlook provides great relief and changes my perspective!

Although it may be too late to cure me, it may not be too late to become a better friend to myself! I try to address what I used to ignore, to go places I used to avoid, to re-examine and reconsider things I never saw or never heard before! This has become a way for me to regain myself, of arriving home again. This small “philosophical therapy” enabled me to widen my connections to the world and has allowed me to take a more positive approach to my disease.

**My life with the disease rests on three pillars:
The first, is maintaining close relationships, for daily connection and for basic needs**

André Gide wrote in his newspaper in 1930: “I believe that diseases are keys that can enable us to open certain doors. I believe that these particular doors, only disease can open.” I think that this is especially true of Alzheimer’s disease. As much it can destroy the family, it can also erect a new structure.

The hardest challenge is to redefine one’s role and how to develop within the redistribution of abilities. “That which becomes weaker, accept it; that which becomes stronger leave it be”.

So that’s how it goes, it is necessary that the patient and close relations well understand and embrace this readjustment; it is not a catastrophe to keep hidden from others...

But, it is also imperative that the patient maintain the role of the responsible patient. Besides helping oneself to safely survive, it will also help others become more understanding and supportive.

The 2nd pillar, seek the help of memory center professionals to help with comprehension, motivation and rehabilitation

They can be the most solid allies in helping to preserve a certain degree of autonomy and self-esteem. A professional there helped me to relearn how to do simple things that I had forgotten. For example, how to use vending machines, to withdraw money from the ATM, or how to organize a diary, all of these skills taught particularly to my needs. I especially found that this training provided me with the support and the motivation necessary to initiate and carry out new projects.

And for the afflicted ourselves, my fellow travelers, here is the 3rd pillar

Of course, I am conscious of belonging to a very small minority of patients who are people with early-onset Alzheimer’s disease who are still at the early stages. I also know that the majority among us do not find our place within the current community supports. Too many young people end up being admitted into a geriatric institution, because they are too disabled to continue in normal life.

Become involved in your Alzheimer’s Associations. Keep in mind that their mission has traditionally been to help family members and other close relations. Join together with other diagnosed young people, even beyond your borders; with the advent of the Internet this has become possible! I myself realized that only those who live an identical situation can really fully understand. Between us, the communication is immediately easier.

In 2000, the first support and advocacy network for the rights of people with dementia, formed just this way -- through connections made on the Internet -- was created in the United States by patients themselves (ed Dementia Support and Advocacy International - - DASNI). Some Europeans have also joined the movement, including Mrs Claude Couturier in France (who is the author of the book *Puzzle, Journal d'une Alzheimer*" Publisher Josette Lyon 1999; translation: "Puzzle, Diary of someone with Alzheimer's",) and myself.

We firmly believe that if we know what to anticipate in the future, we will be better prepared to delay the progression of our disorders. And, it is only through membership in a group of people with dementia, even if only virtual, that we can counteract the urge to become socially withdrawn and isolated. Contrary to the generally accepted ideas, a good number among us could stabilize our condition, even make a lasting improvement in their neuropsychological scores, despite a confirmed diagnosis of Alzheimer's or a related dementia.

The international specialist in cognitive rehabilitation, Dr. Linda Clare of London, has become particularly interested in us. She has just published a two-year study on the positive gains in social identity that are made by participating in this group.

Finally, what really gives me strength is the feeling that I am not alone, that I remain useful to myself and to other people touched by or interested understanding more about the disease. I have the firm belief that it is to better accept the premature decline, to take more control over the course of my life, and to more easily adapt to the losses, even when they pile up...

Before concluding, I would like to recognize and to thank the team for the neuropsychologists of the memory center of Geneva and in particular, Mrs. Anne-Claude Juillerat Van der Linden, who during more than ten years guided me, motivated me and gave me the courage to face my challenges.

In my account, I voluntarily emphasized the good things that can arise more than the bad, for that approach has always been my nature. But, and you know this perhaps better than me, the misfortune that is Alzheimer's disease remains a force to be reckoned with. The fear of stages yet to come never leaves me. What remains unbearable for me today is not losing my memory for day-to-day events or conversations, but the idea that one day my gaze may be vacant and that I will gradually lose all my education and acquired knowledge about the world, without any possibility of getting it back.

Today, 10 years after my initial diagnosis, I no longer feel ashamed about being a person diagnosed with Alzheimer's. While I no longer believe everything will be fine in the future, I trust that there remains much to learn from, to grow from and to appreciate, no matter the challenges ahead.

I thank you for your attention.