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Alzheimerâ??s scares. Why? Because it is an illness that no one can cure

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JoÃ«l Jaouen, president of France Alzheimer, provides important insights into the role and objectives of the patient association. He explains why France Alzheimer together with other learned societies filed a case with the State Council against the French Minister of Health & Solidarity.

Could you give us an introduction to France Alzheimer and yourself to our international audience?

France Alzheimer was created in 1985; thus having 33 years of existence. It was born out of the need of health professionals and of families who had to cope with enormous difficulties on a daily basis. At the very beginning, it was a federation â?? not a union or association â?? that since spread the idea into all French regions. Today, France Alzheimer is a national network of 99 associations present on the entire French territory, including the overseas French Indies (Ile de la RÃ©union, Martinique, Guyana, Guadeloupe, New Caledonia and most recently Mayotte). All departments are organized via an association that has an independent management but is part of the national network that we manage from our Paris-based headquarters. France Alzheimer has four main missions. First**,** when we receive a family, we propose an interview with a psychologist, and of course group sessions. Then, we have something we call â??memory coffeesâ?• (les cafÃ©s mÃ©moires). The idea is that families affected by Alzheimerâ??s have a good time and â??live as they used to beforeâ?•. Families mustnâ??t isolate themselves from society. They need to come back to where life takes place and where society is present. It is so important to maintain the social bonds through our interactions. When isolating ourselves, we will lose the fight.

Second, we have this kind of â??Step-in at any timeâ?• locations (Halte Relais), which are focusing on the three parties concerned by Alzheimerâ??s: the caregiver such as for example a family member (not the professional medical caregiver), the patient himself, and lastly the â??couple patient-caregiverâ?• since the first two cannot be separated because they are interlinked with each other. So we have activities focused on the caregivers, the patient and the associated duo affected by the condition. In these â??Step-in at any timeâ?• locations, we propose activities to the patient, as to allow the caregiver to get away or meet a psychologist if he wants to.

Our social mission includes something very important, namely to allow caregivers to have a break. They need rest because caring of an Alzheimerâ??s patient is very intense and can easily lead to burn out. We, for example, offer holidays for Alzheimerâ??s affected families. We do as a commercial agency does; we have a catalogue to be used by the entire France Alzheimer network, where families can choose among 18 different holiday destinations. They can travel with the patient because once arrived, well-trained teams welcome the families and the patient for a 10 day-long journey. This is something that is very close to the heart of France Alzheimerâ??s social mission.

We try to adjust our activities to the needs of Alzheimerâ??s patients. Even though we are not caregivers, we do have an expertise and can propose concrete activities to the patient, such as for example cognitive stimulation workshops. Like many associations, we have psychologists that are employed either by the associations themselves or called upon demand. For the cognitive stimulation workshops, we have volunteers too. Imagine, during a roundtable, the psychologist will ask the patients to find a word starting with the letter A. The volunteer will be behind and support the patient when in difficulty. This needs a lot of commitment and important logistics to cope with.

We want to be innovative and are now into art therapy. And we get great results. Itâ??s like an old hard drive on which things have been left. If you do not stimulate it, you will not know. This is what we are doing, we seek this stimulation.

We are also thinking about how to reach out to the younger generations to bring them on board, with a so-called inter-generation approach. I will give a concrete example: for the International Day of Alzheimerâ??s which took place on September 21st, we reached out to the youth to raise awareness on ageing populations, and got them to engage in fundraising activities, as people tend to donate more to younger people.

Thatâ??s like the English model, where charities send younger people out with a box to collect money for different causes.

Yes, but Alzheimerâ??s is difficult to describe, and even more, we are scared about it. Alzheimerâ??s scares. Why? Because it is an illness that no one can cure. Psychologically, itâ??s very, very hard because people affected by Alzheimerâ??s little by little degrade physically and intellectually. And that scares. Everybody tells me how great they find the engagement of France Alzheimer, but at the same time, how scared they feel. It is an ultimate paradoxical situation.

I end up on social missions with dance therapy. And now Iâ??m going to make you laugh because I have tested in my own department â??Laugh Therapyâ?•. Making people laugh brings a lot of good feelings. We feel well after and it costs us nothing.

The second key pillar of France Alzheimerâ??s activities is capacity-building and training. We are focusing on two target groups: volunteers and family caregivers. The National Solidarity and Autonomy Fund (Caisse nationale de solidaritÃ© dâ??autonomie) serves as the state treasurer. The way it works is that the Government will put money in the fund and calls for funding proposals. We have been able to make the case for the training of family caregivers. A well- trained caregiver will be more efficient. We give him a toolbox through a 14 hours training session. Over the past four years, we have trained more than 21,000 people in France. We have obtained such good feedback that our training initiative has been renewed by the National Solidarity and Autonomy Fund. And soon, we are very pleased to say that we will have our memory coffees financed too.

In May 2018, the Ministry of Health & Solidarity announced that it would stop reimbursing four Alzheimerâ??s medications. Moreover, several pharmaceutical companies have either faced setbacks in or pulled out of clinical trials for dementia treatments. How has this impacted the Alzheimerâ??s community in France to date, and how will you counter the apparent decrease in the effort to produce Alzheimerâ??s medicines?

A decision was indeed made by the Ministry of Health & Solidarity to stop the reimbursement of drugs, and thus less medical appointments. This has multi-layered consequences. Let me tell you how I experienced my own fatherâ??s illness. Once a month, we both went to see the doctor. What for? Well, to renew his prescription. But this medical appointment, was it only for my father? Of course not. It is for the caregiver too, and this is what I call a collateral damage.

There is a big risk related to what I just mentioned. The patient and his family will no longer visit regularly the doctor because the latter will anyway not renew the prescription. There is a huge risk of losing the continued connection to the doctor, who, if the case, can act as a safety guard because he can react immediately to new difficulties. This risk exists, and we cannot ignore it.

The second negative impact is that today when you go to the pharmacy you can buy these drugs because they are still on the market. However, since they are not reimbursed any longer, you need to pay them out of your pocket. Those who will be able to buy them as those who can afford them. In fact, the French system functions as follows: there is a 2% tax on drugs that are reimbursed but it goes up to 10% when they are no longer refunded. There is a direct financial impact, and those who cannot afford to pay are the ones that are penalized. This is what France Alzheimer considers as a social discrimination.

What activities is France Alzheimer undertaking to counter this decision?

We are well-connected with key opinion leaders and various societies such as for example the Gerontological Society, the Society of French Neurologists and several others. We are actually seven organizations that joined forces to make a state appeal against the decision of the Ministry of Health & Solidarity. We are now seizing the Council of State.

In France, we have the Haute AuthoritÃ© de Sante (HAS) which has the power to make decisions based on the recommendation of a scientific commission that provides justification of whether a drug is efficient or not. So, the original decision comes from the HAS. The commission itself is called the Transparency Commission, but we knew that is was made of people who were against us. Is this what you call transparency? The most important opponent is Prof. Olivier St. Jean, who is the head of the Transparency Commission. He made the fight against the reimbursement of Alzheimer the fight of his life and enjoys using the media for his purpose. The day the Minister of Health announced the end of reimbursement of Alzheimerâ??s drugs, he went to the French radios with help of a journalist from the French journal â??LibÃ©rationâ?• to announce the outcome of his book entitledâ??Alzheimer, le grand leurreâ?• â?• (Is Alzheimerâ??s disease an illusion?). He argues that our brain goes into degeneration but itâ??s a normal process. Our recourse against the Ministry of Health is not lost because we have strong arguments based on scientific evidence. Of course, we are on good terms with the Ministry of Health, but we have our own convictions that differ. We do not mix the two.

How do you see the future, and what are your strategic priorities looking forward?

There are several trajectories. Since 2017, we are working on the adjustment of France Alzheimerâ??s statute and hope to have it done by 2019. A concrete example is the change of notion â??to be present in each French departmentâ?•. We have modified that notion into a â??presence over the entire French territoryâ?•, because who tells us that we still have departments in the near future. So, it is better to anticipate possible changes and to project the future of France Alzheimer by preparing ourselves for possibly upcoming administrative changes.

Most recently, the CNSA (National Fund for Solidarity and Autonomy) has invited us to join them to work on the issue of a more inclusive society. It is about how to transform our current society into an inclusive one. We have already worked on that issue in 2017 when we run a national campaign on how to change the way we look at the patient (Â« changement de regards sur le malade Â»). It is about changing the gaze of society but also of the one of the caregiver. If not trained properly, the immediate family caregiver has an important lack of knowledge and comprehension of Alzheimerâ??s. There are a lot of things one doesnâ??t know and understand.

Finally, we need to get more involved at the European level. Soon we will be travelling to Barcelona for the Annual Conference organized by Alzheimerâ??s Europe. Two years ago, I went to Copenhagen and I realized that we have a deficit of presence. We are not present, we are not visible. When the problem of reimbursement came up, Alzheimerâ??s Europe stood next to us and supported us with a press release. With Albania and Latvia, we are one of the three European countries that deleted reimbursements. None of the big five has done it: neither Germany nor Italy nor Spain.

I also want our Alzheimerâ??s associations to work more on proposals for the patient. We always stay behind because we left it to the professionals; yet we know how to do things, we have the expertise and the experience. We are currently testing a new initiative: therapeutic education of the Alzheimerâ??s patient. Therapeutic education is well known for patients with diabetes but not for those affected for example by Parkinsonâ??s. We have never asked a Parkinsonâ??s patient to participate. For Alzheimerâ??s, it is even more complicated, but we are working on this issue. Our ultimate goal is to make the patient participate and change the way we look at patients. Last year, we sent proposals to the Government explaining how the society could better accompany the caregivers. For me, there are two different categories of caregivers: one is the family caregiver for the home-based patient, and the other is the professional caregiver. This is when you are in a joint relationship, in which you have to manage two problems.

How can we do better to integrate and propose solutions for the patient? We will need to bring this question up to the European level. There is also the question of young patients. How old are they? Around fifty. And there are those living with the Down Syndrome. In France they live in special care centres, yet we managed to improve their lives. We call them today the ageing handicap. Once reach the fifty-year cap, many of them develop Alzheimerâ??s and we donâ??t know how to cope with it.

There is much more still to do, and our association will do its very best to advance all the challenges pertaining to patients and families living with this very difficult condition.

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