

## Alzheimer's: Demands and Complaints of Caregivers in Latino America

**Federico Ortíz-Moreno\***

*Social Psychologist, Monterrey, México*

**\*Corresponding Author:** Federico Ortíz-Moreno, Social Psychologist, Monterrey, México

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In this article, I would like to review some of the demands and complaints of families and caregivers when facing Alzheimer's, how to cope with the problem and the person who has dementia. But before talking about the demands and complaints of families and caregivers, let us take a quick look about what is Alzheimer's disease in a broad sense.

As it is already well known by for almost every people, Alzheimer's is one of the most terrible diseases we can face, as it destroys not only the person who has this condition, but also to the same family who suffers the consequences. However, we must not forget the positive side of it as it makes us more sensitive, to know a little more human suffering, helps us appreciate what we are and what have.

The work here is in part the result of a survey carried out for more than five years to families of people with some form of dementia, mainly Alzheimer's. The people surveyed, most were from Mexico (80%), but there were also of Argentina, Colombia, Uruguay, Chile and Spain (the remaining 20%). The sample was of 2,400 people.

The aim or intention was to know what demands and critics raised from family members and caregivers regarding to the disease itself, the people with dementia, the family members, doctors, nurses, nursing homes or day-care centres, as well as associations.

### The study

This study has been presented in Mexico, Colombia, Argentina, Uruguay, Chile, United States, England, and part of this same study, in France. While this study has caused controversy in some places because of the data shown and it is said here, the only country in which caused "sting" was in Mexico, perhaps because here, in our country we are not used that to tell us the things clearly, face to face, as we are not used to listen to criticism, or because, in this case the

most affected or pointed out, have been doctors, most of them with very little culture and very little sensitivity, that in a certain way they cannot be touch even with a petal of a rose.

Countries such as Argentina, commented that this work contained a harsh criticism, especially doctors, but there was a large group of relatives who came to congratulate me, telling me that: "Finally someone out came here and spoke with the truth!".

In Argentina, the work was presented in several cities. In other countries such as Colombia, Uruguay and Chile, there was no problem; While in England or France, this was taken as a constructive criticism, but it must be clarified that the culture in Europe, is far away that the poor culture we have in Mexico.

For almost all of us it is inescapable that the problem of dementia is growing every day at no speed limit. And worse yet, no one can stop it. The problem becomes more serious when looking at it in a more objective way the problem multiplies, not by one, but by two, three or more people. And this is because it is not only the person suffering from the disease, but the same family who suffers the consequences.

So this the main reason that in our countries, our authorities should consider this issue as a matter of priority national, although so far they have done nothing.

### Talking about Alzheimer's

Alzheimer's disease is characterized by the decrease of intellectual functions, with a consequent loss of memory, deterioration and inability to think properly. The person affected with Alzheimer's suffers a drastic change of personality, with a tendency to be depressed or irritable. They can no longer follow instructions, are confused and disoriented in relationship to time and space. They also can get lost in places well-known to them. There are alterations in their judgment, such as, mistaking family members and in many cases they do not remember who they are.

These are some of the questions more frequently asked in relation to Alzheimer's disease.

### What is Alzheimer's?

Alzheimer is a progressive disease and causes degeneration of the brain, provoking loss of memory, the ability to organize ones thoughts and a change of behaviour in the person. Also, it produces a decrease in the intellectual functions of the person, enough to interfere with the capacity to carry out daily activities of ordinary life.

Alzheimer's disease is the most common of all dementias: scientifically it is defined as such. Its name comes from a german doctor, Alois Alzheimer, who for the first time in 1907 described the disease. It is irreversible and there is no cure for it up to the moment. This disease is known to destroy little by little the neurons of the brain, obstructing the free passage of information between cells and finally loosing contact with the world.

### What are the most common symptoms of Alzheimer's?

Many of the first symptoms are not easily noticed because they look like natural signs of aging: forgetfulness, loss of concentration, difficulty in coordinating movements and speech. The most common symptoms are:

- Progressive loss of memory.
- Confused and disoriented in to time and space.
- Lose, leave or hide things in unusual places.
- Shows signs of agitation, anxiety or nervousness.
- Wanting to leave the house, arguing that it is not his/hers.
- Getting lost, even in his/her own neighbourhood
- Not recognizing close relatives: husband, wife, children.
- Looks tired, quiet, sad or depressed.
- Is tense, restless, irritable or aggressive.
- Paranoid, i.e: suspects of everyone around them.
- Hallucinates, seeing things that are not there or hearing noises that do not exist.

### What causes Alzheimer's disease?

The cause of Alzheimer's is not known yet. Recent studies held by scientists, doctors and investigators show a growing evidence of multiple factors in the origin of the disease. There are also more growing evidences showing that Alzheimer's disease it is due or has a component or genetic character. The investigators have found that some genes in one way or another can cause the disease. These genes are located in the chromosomes 1, 12, 14, 19 and 21 and, perhaps, some others.

Of course, you cannot let other factors go unchecked, such as a virus, toxic agents, environmental agents, metals, electromagnetic-

ic fields, inflammatory reactions or blows on the head that could possibly provoke a general dysfunction of the organism and the behaviour of the person in a combined or isolated form. Also, by experience, it is known that there are other factors that exist and in a certain manner can cause an earlier appearance of the disease.

These factors can be seen earlier for different reasons:

- Death of a spouse, child or a close family member.
- Change of residence.
- Car accident, even if they do not have suffered injury.
- Some types of surgery or a reaction to anaesthetic.
- Suffering a fall or a blow on the head.
- Retirement or being discharged from work.
- Have been assaulted or attacked.
- Tension or emotional stress.

### Who can suffer from or is liable to have Alzheimer's?

Anyone can have Alzheimer's. It does not distinguish nationality, race ethnic group or social level. It affects equally both: men and women, but there are more cases of women with Alzheimer's considering the fact that they live longer. Generally speaking, it is found in persons between 65 and 70 years of age, but there are cases of people 50 or even younger (40) that have been diagnosed with Alzheimer's.

### What do we know in Mexico about Alzheimer's?

It is the fourth principal cause of death in people up to the age of 65, after heart disease, cancer and diabetes. It is estimated that there are almost one million people affected with dementia, 60% with Alzheimer's. And, what investigations never say is: what about the family and care givers? Because we have to say they are also affected by this problem. On other issue, the relationship of those who have dementia is 60% women against 40% men.

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### How can a good diagnosis of Alzheimer's disease be carried out?

Before a good diagnosis of Alzheimer's is considered, it is necessary the evaluation of four important aspects:

- A good medical record that includes symptoms and observed changes.
- A complete physical check-up with blood and urine exams.
- A neurological exam, including X-Rays, CT Scan, EEG (electroencephalogram) and a Magnetic Resonance Imaging (MRI).
- A mental or psychological exam of the state of mind of the person or the more commonly known minimal exam (MMSE).

### Is there any cure for Alzheimer's disease today?

At this moment there is no known cure in order to combat or to stop Alzheimer's; however, scientists, doctors and investigators in all parts of the world are working on it. The medications most common employed here are Aricept (donepezilo), also known as Eranz. A second medication is Exelon, also known as Rivastigmina.

Other new drug is Galantamina (Reminyl), which has demonstrated not only an improvement on cognitive symptoms, but also on behaviour, like apathy, agitation and psychosis. Now, Memantine or Namenda is one of the new medicaments more used. This drug works on the nervous system in the sending of messages. It seems that the progress of Alzheimer decreases in the last stage. Akatinol (Merz) and Ebixa (Lundbeck) are the commercial names in Mexico.

It is important to understand that all these maledictions are not precisely used in order to cure, but to help the person to be a little bit more lucid and calmer. Also, one must mention that these medications work only in the first and part of the second stage of the disease, not in an advanced stage. Finally, we have to mention

that some of these maledictions may cause side effects and not necessarily one work better than the other.

For the moment, the best alternative is to give them the best of us, the best quality of life possible, treating them with tenderness, love, affection, understanding and respect.

### Three stages of Alzheimer's Disease

For a better understanding of how his disease develops, Alzheimer's Disease is divided in three stages:

We all know how difficult is to live and to be a witness of the development of this disease that is slowly running out largely to ourselves and our loved ones. There is no order or time accurate to the facts presented here, but somehow this is a small summary of what we are already experiencing and which sooner or later will face.

The course of Alzheimer's disease varies from one person to another. There is no order in how is going to appear or how long each one of the stages are going to last, The time of life of the people is also difficult to predict, since this depends on many factors, including the degree of impairment that is as well as the care provided to the patient.

#### First stage

This first stage lasts approximately 2 to 5 years in which we can observe a gradual deterioration in memory. In the early stage of Alzheimer's, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, he or she may not remember that he already ate or forget the conversation that had with his son just minutes before.

#### Second stage

At this second stage, all aspects of memory gradually begin to fail. This stage lasts approximately 2 to 10 years, in which important alterations of brain function happen with most worrying symptoms occur or that attract our attention. They start to encounter problems of dysphasia, apraxia and agnosia.

- Aphasia means difficulty in language, difficulty to talk or maintain a conversation, saying one word for other.
- Apraxia relates to the difficulties that the patient has to carry out learned functions. For example, the person does not know how to get dress
- Agnosia is a loss of the ability to recognize people live with that. And, although this loss is not complete, the person with Alzheimer's gets to the point when he does not

recognize family members or even he does not recognize his own face in the mirror.

It is important to point out that although the onset of Alzheimer's disease cannot yet be stopped or reversed, an early diagnosis can allow a person the opportunity to live well with the disease for as long as possible and plan for the future.

### Causes

At this time, we do not yet know what causes Alzheimer's disease or how to stop its progression.

Researchers have discovered that Alzheimer's disease:

- It is not a part of normal aging
- It affects both men and women
- It is more common in people as they age: most people with the disease are over 65
- It is not caused by hardening of the arteries
- It is not caused by stress

Meanwhile scientists are looking at three other important areas;

### Family history

For a few families, there is a definite connection between family history and Alzheimer's disease. While for others, a family history of Alzheimer's disease puts them at greater risk than someone with no family history. Though knowledge in this area is growing, the connection to heredity is not fully understood.

### The external environment

The cause of Alzheimer's disease may be in our environment -- perhaps something in the water, soil or air.

### The internal environment

Alzheimer's disease may be caused by something within the body. It could be a slow virus, an imbalance of chemicals or a problem with the immune system. Researchers today believe there is no single cause of Alzheimer's disease. Instead, they believe it is caused by a combination of factors. There is still much that we don't know about the disease, but researchers continue to look for causes.

### Risk factors

Getting to know what is the risk or probability to get Alzheimer's is one of the questions many people ask. On the basis of comparisons of large groups of people with Alzheimer's disease with others who have not been affected, researchers suggest that there are a number of risk factors. This means that some people are more

likely to suffer from the disease than others. However, it is unlikely that the disease could be traced to a single cause. Main causes have been related to age, sex and some other factors.

This means that some people are more likely to suffer from the disease than others. However, it is unlikely that the disease could be traced to a single cause. It is more likely that a combination of factors lead to its development, with the importance of particular factors differing from one person to another. Main causes have been related to age, sex and some other factors.

### Age

About one person out of twenty over the age of 65 suffers from Alzheimer's disease and less than one person in a thousand under the age of 65. However, it is important to note that although people do tend to become forgetful as times goes on, the vast majority of people over 80 stay mentally alert. This means that although the likelihood of suffering from Alzheimer's disease increases with age, old age does not itself cause the disease. Nevertheless, recent evidence suggests that age related problems such as arteriosclerosis may be important contributing factors. Also, as people are now living longer than in the past, the number of people with Alzheimer's disease and other forms of dementia will most probably increase.

### Sex

Some studies have suggested that more women are affected by the disease than men at any one time. However, this can be misleading because women as a group live longer than men. This means that if men were to live as long as women and did not die of other illnesses, the number suffering from Alzheimer's disease would be about the same as that for women.

### Genetic factors (Heredity)

In an extremely limited number of families Alzheimer's disease is a dominant genetic disorder. Members of such families inherit from one of their parents the part of the DNA (the genetic make-up), which causes the disease. On average, half the children of an affected parent will develop the disease. For the members of such families who develop Alzheimer's disease, the age of onset tends to be relatively low, usually between 35 and 60. The onset is fairly constant within the family. A link between chromosome 21 and Alzheimer's disease has been discovered. As Down's syndrome is caused by an anomaly in this chromosome, many children with Down's syndrome will develop Alzheimer's disease if they reach middle age, although they may not display the full range of symptoms.

### Head injury

There is evidence to suggest that a person who has received a severe blow to the head may be at risk of developing Alzheimer's disease. This risk is higher if at the time of the injury the person is over 50, has a specific gene (apoE4) and lost consciousness just after the accident.

### Other factors

There is no conclusive evidence to suggest that any particular group of people is more or less likely to develop Alzheimer's disease. Race, profession, geographical and socio-economic situation are not determinants of the disease. However, there is mounting evidence to suggest that people with a higher level of education are at less risk than those with a lower level of education.

### Alzheimer's and its impact in the family

Alzheimer's is one of the more terrible diseases we can have, because it not only destroys the person who suffers it, but also the same family who undergoes the consequences. Having to take care of a patient who does not understand the things and that at the same time we do not even know ourselves to understand them make that our life changes completely. People do not understand us, the family goes away.

This means that people think that all that that we say that it happens to us, are pure inventions of ours, that the person is well, that is due to things of his or her age, that we do not have to worry... The reality is other... There is no support, there is no understanding; there is only loneliness, sadness, anger, desperation, fear to the future, fear to remain alone, fear to lose everything...!

### Coping with Alzheimer's

Those who have lived tragedy to care of a patient with Alzheimer like we do, we know how difficult that is to face the day to day new situations, most of the times exasperating, that it comes to the point that everything becomes cloudy to us, everything comes down. Then, we ask for help and this never comes. People do not understand us; they do not live the 24 hours of the day with in the patient...! And we as family members and as caregivers we feel lonelier.

The problems are many to undergo, there are many the problems that we faced. We felt fear, anger, distresses, desperation, loneliness... We felt so many things that it comes to the point that we explode or simply our world comes down without being able to continue helping our love one, the patient.

And as you will know to have a relative with Alzheimer, it is hard and devastating. You and me who have live this, who has seen it; we know that it is quite difficult to face a situation like, that this disease practically destroys all the family. Unfortunately there is no cure at the moment Investigations continue, but there is still too much to do.

### A hard disease

The Alzheimer is a frankly devastating disease, because he is not only the patient who suffers it, but also the own family who undergoes it. One would want that the patient could understand us and we talk to them in a logical way, as if this logic he or she will understand. We do not realize that, unfortunately, his or her brain has been destroyed, that it is not his fault of what is happening to him and that his behaviour, often aggressive are product of its own disease.

There is no better way if we want to stablish a good relationship with the person who has dementia is to speak to them slowly with calm, seeing to him or to here to the eyes, taking him from the hand, loving him, touching him with tenderness and respecting him as an adult helps a lot in these cases. It is obvious that we get desperate and hopeless when they do not understand us, they become anxious, repeat and repeated the same question, they want wanted to go from home, they do not recognize the people, etcetera....

But such is the life and we must accept the things so as they are. And although the disease is terrible and the process that the family live, specially the main caregiver, is tremendous, also we must learn to see the positive aspect; then, we, who have had the experience to have lived all this, we have also learn to know the meaning of life, to know what we are, and the important roll that we played in taking care of the ill person

If you want support, help and understanding, or you feel desperate, perhaps you can share your experiences with another people. They can also learn from you, Go to the nearest Alzheimer Association where you are. Sure they will help you.

### 10 warning signs

Alzheimer's disease is a progressive, degenerative disease. Symptoms include loss of memory, difficulty with day-to-day tasks, and changes in mood and behaviour. People may think these symptoms are part of normal aging but they are not. It is a sigh that something is happening and that we have to do something. So, if this occurs, it is important to see a doctor or to go to your nearest local Alzheimer Association so they can help.

## 10 warning signs

1. **Memory loss that affects day-to-day function:** It's normal to occasionally forget appointments, colleagues' names or a friend's phone number and remember them later. A person with Alzheimer's disease may forget things more often and not remember them later, especially things that have happened more recently.
2. **Difficulty performing familiar tasks:** Busy people get distracted from time to time. For example, you might leave something on the stove too long or not remember to serve part of a meal. People with Alzheimer's might prepare a meal and not only forget to serve it but also forget they made it. This means that a person with Alzheimer's disease may have trouble with tasks that have been familiar to them all their lives, such as preparing a meal.
3. **Problems with language:** Everyone has trouble finding the right word sometimes, but a person with Alzheimer's disease may forget simple words or substitute words, making her sentences difficult to understand. When talking, people cannot really do it. They misplace words, they begin to stutter, say one thing for another; they get annoyed or irritated
4. **Disorientation to time and place:** It's normal to momentarily forget the day of the week or the way to get to the store. But people with Alzheimer's disease can become lost on their own street, not knowing where they are, how they got there, or how to get back home.
5. **Poor or decreased judgment:** People may sometimes put off going to a doctor if they have an infection, but eventually seek medical attention. A person with Alzheimer's disease may have decreased judgment not recognizing a medical problem that needs attention or may dress inappropriately, for example, wearing heavy clothing on a hot day.
6. **Problems with abstract thinking:** From time to time, people may have difficulty with tasks that require abstract thinking, such as balancing a cheque book. Someone with Alzheimer's disease may have significant difficulties with such tasks, recognizing numbers or performing basic calculation may be impossible as they do not recognize what the numbers in the cheque book mean.
7. **Misplacing things:** Anyone can temporarily misplace a wallet or keys from time to time. A person with Alzheimer's disease may put these and other items in inappropriate places — such as an iron in the freezer or a wristwatch in the sugar bowl — and then not recall how they got there.
8. **Changes in mood or behaviour:** Everyone experiences a broad range of emotions — it's part of being human. People with Alzheimer's tend to exhibit more rapid mood

swings, for example, from calm to tears to anger, for no apparent reason.

9. **Changes in personality:** People's personalities can change somewhat with age. But a person with Alzheimer's can change dramatically, either suddenly or over a period of time. A person with Alzheimer's disease can become confused, suspicious or withdrawn. Someone who is generally easygoing may become angry, suspicious, or fearful.
10. **Loss of initiative:** It's normal to tire of housework, business activities or social obligations, but most people regain their initiative. A person with Alzheimer's disease may become very passive and require cues and prompting to become involved.

## New studies

Now days, studies show new approaches. Scientists seem to agree that there are two proteins in the brain that are heavily involved. One is beta-amyloid, usually just called amyloid, which reaches abnormal levels in the brain of someone with Alzheimer's and forms plaques that collect between neurons and disrupt cell function. The other is called tau. This also reaches abnormal levels, and forms neurofibrillary tangles inside neurons which block the neuron's transport system.

What scientists don't know is exactly how these proteins relate to each other, or what causes them to build to such damaging levels. It is said that Tau is more like fire in the brain, as opposed to amyloid, which is probably a toxic chemical.

It can be compared like if you think you are in a big house or a mansion, and you're spraying this whole toxic chemical around it, it's going to damage things. But really, what causes the huge damage is when you light the match. And this is a challenge that those dedicated to investigation must uncover. And if we try to find what gets the fire start or going, we must continue studying it.

For the moment, it is believed that there is probably some balance between resilience factors and your own vulnerability factors. Some people, somehow, are able to put out that kindling and suppress it. They almost have a better fire extinguishing system in the brain than the rest of us. Up to the moment, we do not know it.

One more theory, deals with what they called metabolic factors that play a part in this roll. The "toxic chemical" of amyloid, that is probably going to be sort of cooked up by a number of things that are metabolic that all of us will suffer from as we age; for example, our ability to metabolise cholesterol and glucose, plus inflammation, oxidative stress and "the garbage collection system" of the brain that are not working well. In addition to this, all of those

things, that help push the amyloid accumulation, which then probably causes damage to the synapses, which causes tau aggregation, which is really what starts the fire.

### More challenges

In the past 20 to 30 years, scientists have argued about which protein plays a bigger part in the development of the disease. Now scientists started once again talking about plaques entangled in the brain even before symptoms occur. So both of those are contributors, but the question is: what was the real cause? Well, it is a neurodegenerative that goes to this point and has to be considered.

As we already know there are many other proteins involved in Alzheimer's disease. The challenge now is to understand that it's very complicated and we may be looking at a heterogeneous activity of ageing that's associated with this pathological protein that goes awry and calling that Alzheimer's disease... If we are really going to make strides in this disease, we're not going to just be affecting plaques, like we thought before, or tau and tangles.

Now the challenge to the clinicians is to think about how do we clinically define dementia. Is this really the most productive way to think about these disorders, by looking to the end stage and saying that's the disease? We're going to have to be looking for a combination approach.

We need, in other words, to understand brain function at an earlier stage. He thinks the microglia, cells that act as an immune defence in the central nervous system, are an important part of the picture. We need to see how different cells "talk to each other" and how neurons work together and cause disorder. And we need also to think about the role of immunology which is probably very important, as in cancer, and the vascular system, and the gut, and maybe even the bacteria in the gut. It's an "integrated system", but progress in science is based on tackling one proposition at a time.

### Dementia: a big problem

Dementia is a human problem and so, of course, it's a global problem. The number of cases is huge. Our estimates about what scientists call "prevalence", or the proportion of people getting it, are getting better, but they are still not nearly good enough. The number of people who have dementia is rising rapidly in low- and middle-income countries, as people live longer. Estimates of prevalence in these countries have been revised upwards as we get better at identifying and diagnosing the people who have it.

But there is something that we must be considered, as it looks something different may be happening in high-income countries. "There is some emerging evidence that in high income countries

the incidence rate, but since there are more older people, numbers affected continue to rise will be consistent with what we know about the risk factors for dementia and the improvements in cardiovascular health, nutrition and education in high income countries.

Research shows that most people currently living with dementia have not received a formal diagnosis. In high income countries, only 20-50% of dementia cases are recognised and documented in primary care. This 'treatment gap' is certainly much greater in low and middle income countries, with one study in India suggesting 90% remain undiagnosed. If these statistics are extrapolated to other countries worldwide, it suggests that approximately three quarters of people with dementia have not received a diagnosis, and therefore do not have access to treatment, care and organised support that getting a formal diagnosis can provide.

### Numbers of people with dementia

- Someone in the world develops dementia every 3 seconds.
- There were an estimated 46.8 million people worldwide living with dementia in 2015 and this number is believed to be close to 50 million people in 2017.
- This number will almost double every 20 years, reaching 75 million in 2030 and 131.5 million in 2050.
- Much of the increase will be in developing countries.
- Already 58% of people with dementia live in low and middle income countries, but by 2050 this will rise to 68%.
- The fastest growth in the elderly population is taking place in China, India, and their south Asian and western Pacific neighbours.
- Dementia became a trillion-dollar disease in 2018
- Dementia is the 7<sup>th</sup> leading cause of death worldwide

### More data

- Many countries have no dementia diagnostic tools, no access to clinical trials and, few specialised doctors and researchers
- Demographic ageing is a worldwide process that shows the successes of improved health care over the last century. Many are now living longer and healthier lives and so the world population has a greater proportion of older people. Dementia mainly affects older people, although there is a growing awareness of cases that start before the age of 65.

### Economic impact of dementia

- The total estimated worldwide cost of dementia is US\$818 billion in 2015, which represents 1.09% of global

GDP. By 2018, the global cost of dementia will rise above a US\$ trillion.

- This figure includes costs attributed to informal care (unpaid care provided by family and others), direct costs of social care (provided by community care professionals, and in residential home settings) and the direct costs of medical care (the costs of treating dementia and other conditions in primary and secondary care).
- Direct medical care costs account for roughly 20% of global dementia costs, while direct social sector costs and informal care costs each account for roughly 40%. The relative contribution of informal care is greatest in the African regions and lowest in North America, Western Europe and some South American regions, while the reverse is true for social sector costs.
- This means that if global dementia care were a country, it would be the 18th largest economy in the world. The annual costs exceed the market values of companies such as Apple (US \$742 billion) and Google (US \$368 billion).

### Alzheimer's is a big problem worldwide

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Alzheimer's disease is the most common cause of dementia and accounts for 60-70% of all cases. Alzheimer's disease and other dementias are progressive, degenerative illnesses that attack the brain. They affect people's abilities, impacting on all aspects of their life and upon others in their lives, particularly those who care for them day by day. And no country is adequately prepared to deal with a crisis of this magnitude.

Lack of awareness and understanding has resulted in insufficient resources to address this crisis. Worldwide, attention to this rapidly growing problem is so small that most of those affected continue to suffer without help, or hope. This must change! The quality of life of people with Alzheimer's disease and other dementias can be transformed. Too often, they, their families and carers lack the support that they need and deserve.

ADI (Alzheimer's Disease International) an organization representing near 100 associations around the world, urgently call upon all governments and stakeholders to act now.

### Action plan

Within the limits of the resources available to different countries, an eleven-point action plan consistent with the Kyoto and Paris Declarations should be implemented as follows:

1. Provide public information about the symptoms, treatment and course of the disease.
2. Reduce stigma by promoting understanding and awareness.
3. Provide training and tools to healthcare professionals (including social workers) and family caregivers, to encourage early assessment, diagnosis, appropriate care, and access to optimal treatment.
4. Provide access to primary and secondary health care services, responsive to the needs of people with dementia.
5. Promote access to a range of options for long-term care that prioritize maintenance of independence, home and community-based care and support for family carers
6. Make all care environments, including (acute) hospitals and long term care institutions, safe places for people with the disease.
7. Encourage the fullest possible participation of those living with the disease, in the life of their communities and in decisions about their care
8. Ensure a standard of living adequate for health and well-being, including food, clothing, housing and medical care for people with the disease
9. Provide a legislative framework to regulate and protect the rights of those people with dementia who lack the capacity to manage their everyday lives

10. Fund awareness programs to promote greater understanding that the risk of the disease can be reduced
11. Prioritize research into Alzheimer's disease and other dementias.

Alzheimer's disease and other forms of dementia are not a natural part of ageing. Prevention is possible. Care can improve quality of life for the person with dementia and their families. Medical research will continue to improve upon existing effective treatments. Be positive and adopt the solutions that will help millions of people today and tomorrow

### Charter of principles

Alzheimer's Disease International (ADI) the umbrella organisation of Alzheimer associations throughout the world. ADI's purpose is to build and strengthen the organisational capacity of its member associations and to raise global awareness of dementia – stronger Alzheimer associations are better able to meet the needs of people with dementia and their carers.

For the care of people with dementia and their carers, the principles stated below should be seen as basic, core principles. Many national associations may choose to elaborate on these, especially if their country is at a more advanced stage of economic development.

### Statement of principles

Alzheimer's Disease International (ADI) recognises the following principles as fundamental to the provision of care for people with dementia and for the support of their family members and carers:

- Alzheimer's disease and related dementias are progressive, incapacitating diseases of the brain that have a profound impact on people with dementia and members of their family.
- A person with dementia is a person of worth and dignity, deserving the same respect as any other human being.
- People with dementia need a physically safe living environment and protection from exploitation and abuse of person and property.
- People with dementia require up-to-date information and access to coordinated medical, psychological, rehabilitative and welfare services. Anyone thought to have dementia needs prompt medical assessment and those with dementia require ongoing care and treatment orientated to maximising their quality of life.
- People with dementia should as far as possible participate in decisions affecting their daily lives and future care.

- The family carers of a person with dementia should have their needs assessed and provided for and should be enabled to take an active role in this process.
- Adequate resources should be available and promoted to support people with dementia and their carers throughout the course of dementia.
- Understanding the experience of living with dementia, especially from the perspectives of people with dementia and their carers, is vital to providing effective advocacy, quality care, and meaningful rehabilitation. Information, education and training on dementia, its effects and how to provide care must be available to all those involved in the assistance of people with dementia.

Alzheimer's disease and other forms of dementia are not a natural part of ageing. Prevention is possible. Care can improve quality of life for the person with dementia and their families. Medical research will continue to improve upon existing effective treatments. Be positive and adopt the solutions that will help millions of people today and tomorrow

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For the care of people with dementia and their carers, the principles stated below should be seen as basic, core principles. Many national associations may choose to elaborate on these, especially if their country is at a more advanced stage of economic development.

### Dementia is not a normal part of ageing

- There are 7.7 million new cases of dementia each year, implying that there is a new case of dementia somewhere in the world every four seconds. The accelerating rates of dementia are cause for immediate action, especially in low- and middle-income countries where resources are few.
- The huge cost of the disease will challenge health systems to deal with the predicted future increase of prevalence. The costs are estimated at US\$604 billion per year at present and are set to increase even more quickly than the prevalence.
- People live for many years after the onset of symptoms of dementia. With appropriate support, many can and should be enabled to continue to engage and contribute within society and have a good quality of life.

- Dementia is overwhelming for the caregivers and adequate support is required for them from the health, social, financial and legal systems.
- Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders - at international, national, regional and local levels.

People with dementia and their caregivers often have unique insights to their condition and life. They should be involved in formulating the policies, plans, laws and services that relate to them.

The time to act is now by:

- Promoting a dementia-friendly society globally;
- Making dementia a national public health and social care priority worldwide;
- Improving public and professional attitudes to, and understanding of, dementia;
- Investing in health and social systems to improve care and services for people with dementia and their caregivers;
- Increasing the priority given to dementia in the public health research agenda.

### What to do?

#### Recommendations

For some care partners the family is the greatest source of help. For others the family is the biggest source of distress. It is important to accept help from other members of the family if they are available and not to provide care on your own. If you are feeling distressed because your family members are not helping, or are perhaps even critical of you as the primary care partner, it may be helpful to call a family meeting to discuss the care of the person. Such behaviour may be due to a lack of understanding about dementia.

#### Share your problems

You need to share your feelings about your caring experiences with others. If you keep them to yourself, it may be more difficult for you to look after the person with dementia. If you can realise that what you are experiencing is a natural response to your situation, it will be easier for you to cope. Try to accept support when it is offered by others, even if you feel you are troubling them. Try to think ahead and have someone to turn to in an emergency.

#### Make time for yourself

It is essential that you make time for yourself. This will allow you to spend time with others, enjoy your favourite hobbies and, most importantly, enjoy yourself. If you need a longer amount of time away, try to find someone to take over the caring for you so that you can have a rest.

#### Know your limits

How much can you take before it becomes too much? Most people will come to realise how much they can take before they reach the point where the caring becomes too demanding. If your situation is too much to bear, take action by calling for help to prevent and avoid a crisis

#### Don't blame yourself

Do not blame yourself or the person with dementia for the problems you encounter. Remember, the disease is the cause. If you feel your relationships with friends and family are dwindling away, don't blame them or yourself. Try to find what is causing the breakdown and discuss it with them. Remember that relationships with others can be a valuable source of support for you. This can prove to be an asset for both you and the person with dementia.

#### Take and seek advice

It will help you to seek advice concerning your changing role and the changes that occur in the person with dementia.

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#### Take and seek advice

It will help you to seek advice concerning your changing role and the changes that occur in the person with dementia.

#### Remember you are important

You are important to yourself and important in the life of the person with dementia. Without you, the person would be lost. This is another reason why it is so essential to take care of yourself.

## Some other things to take in consideration

### Learn to accept help

Learning to accept help may be new to you. However, as is often the case, members of your family, friends or neighbours may want to do something to help you and the person with dementia. But they may not know what might be helpful for you. A word or suggestion from you and perhaps some guidance will give them an opportunity to help. This may help someone else feel useful, help the person with dementia, and provide you with some welcome relief as well.

### Self-help or support groups

A self-help group (a group for care partners) can be another source of help for you. A self-help group (also called a support group) provides an opportunity for care partners to come together, share their problems and solutions, and support each other. In a growing number of countries there are Alzheimer associations that can help you find such a support group. If no such association exists, you could consider establishing one.

### Costs

- The total estimated worldwide costs of dementia are US\$604 billion in 2010.
- About 70% of the costs occur in Western Europe and North America.
- Costs were attributed to informal care (unpaid care provided by family and others), direct costs of social care (provided by community care professionals, and in residential home settings) and the direct costs of medical care (the costs of treating dementia and other conditions in primary and secondary care).
- Costs of informal care and the direct costs of social care generally contribute similar proportions of total costs, while the direct medical costs are much lower. However, in low and middle income countries informal care accounts for the majority of total costs and direct social care costs are negligible.

### Background

- Dementia is a syndrome that can be caused by a number of progressive disorders that affect memory, thinking, behaviour and the ability to perform everyday activities. Alzheimer's disease is the most common type of dementia. Other types include vascular dementia, dementia with Lewy bodies and frontotemporal dementia.
- Dementia mainly affects older people, although there is a growing awareness of cases that start before the age

of 65. After age 65, the likelihood of developing dementia roughly doubles every five years.

## Demands and complaints

### Alzheimer's...

One can say that Alzheimer's is that this disease is difficult to deal with; but it is time to change this concept, to change the melody, the same old song and focus not only the negative aspect or negative side. While it might be exhausting, must not forget the positive side of it, at least for families and caregivers, as this helps us to make us more sensitive to know a little more human suffering, helps us to appreciate what we are and what we have.

### The numbers

The numbers really impact and are impressive. Increasingly there are more people with dementia, and the question jumps at point-blank range: who will care for them or who or who take care of us?, are we really prepared?, does the Government have funds to take care of this people?

### What we see in Latin American countries

What we see in Latin American countries, is the same what it happens in other countries worldwide. The family living experience the same every place you go to. No matter if it is Mexico, Argentina, Brazil, Colombia, United States, France, Spain, England, Germany, Australia, Netherlands, India, Japan and China. In each and every country the drama that the families live is the same. We live in a world that is collapsing with us and we do not know how to stop this. We are still poor countries with no enough economic resources like other countries have in order to pay and give attention regarding to health problems.

At the same time, we have to say that there is no financial support and the few Day Care Centers that we have there have no specific programs to provide adequate stimulation for people with dementia, especially Alzheimer's. And although we have several support groups for the families, there are still too much to do, like to implement a national program that brings attention to this big problem we have in our countries. It seems for me like our governments have already Alzheimer's and they have forgotten to do their job.

### Complaints we face.../Complaints against...

While facing this problem where tears, physical, economic, social and emotional factors are involved, family demands and complaints arise every day and everywhere. Here are some of their demands... Complaints against:

### Demands and complaints...

Before this physical, economic, social, and emotional problem that the family is suffering raises the demands and complaints of care giver and family members being these the main issues to point out

- Complaints against the person with dementia.
- Complaints against the same family.
- Complaints against doctors.
- Complaints against nurses.
- Complaints against nursing homes and day-care centres.
- Complaints against the associations.

### Complaints against people with AZ

- Do not understand us.
- Do not help.
- They pretend there are ill.
- Blackmail us.
- Time consuming.
- They kill us.
- They piss us off.

### Complaints against family

- Family disintegration.
- No physical and no economical support.
- Family interests.
- Financial and economic interests.
- Forgetting the person.
- Person is abused.
- Caregiver is abused.

### Complaints against doctors

- Do not understand.
- Do not listen.
- Do not look at the eyes.
- Think they know more than anyone else.
- Too much medication.
- Know nothing.
- Ignorants.
- Pushy.
- No sensibility at all.
- They charge more than they have to...
- They fall sleeping while consulting.

From those expressed complaints, the most recurrent ones are expressed against the doctors. This happens everywhere, especially in Mexico, as well as in Latin America, Spain and United States. While, on the other hand, both in Europe and Australia could say they are better and have a much better preparation and higher de-

gree of sensitivity. The countries with the best image are England, Scotland, Australia and New Zealand.

Mexico is not the best. And it is not me who say this not, hundreds and thousands of families with whom I have had contact say this. Arrogance or believing they are the grate thing, or to be un-touchable like gods, is part of their personality. But their lack of culture and, especially, his lack of sensitivity, betrays them.

The coldest professional are neurologists who do not even see to the person's eyes when going to consult, nor even to the eyes of relatives. Rrely they touch them or shake hands. In Mexico the problem of doctors is given more than in other neighboring countries, where there is sensitivity; but not I the way that should be, being more humans.

I know people in very different parts of the country, medical neurologists and geriatricians, where their only interest is money, and they have not a bit of humanitarian aid. I'm not saying that they do not have to charge, but... when you see in their eyes just the reflection of money it is sad to see this, like they were saying a new "unwary client" is coming.

Those famous protocols or studies to which invite people to enter, it is a terrible thing. They are taken as "guinea pigs", causing distrust in the families. This what I have lived in experience itself and seen with my own eyes, to join relatives, to go to the doctor you go to query; doctor who, unfortunately, jumps the sign of pesos, dollars, euros or whatever in their eyes and many times, in cuff-link, hand to hand with the president of the Association, making big business.

In nearly more than thirty years that I have been in this world of Alzheimer's, this suddenly seems to become like a circus I have seen everything: from recognized physicians being taken handcuffed from hospitals where they work, accused of illegal acts, up to doctors with very little ethics, trying to do business with families by sending them to do studies that do not need, or to nursing homes, where they receive commissions for each person they refer. And those medical doctors are responsible for the education and ethics committees!

### Complaints against nurses

- Do not how to treat the person.
- They are not prepared.
- Conflictives among them.
- Tend to lie.
- They fall sleeping while in duty.

The problem with nurses - with all the respect that they deserve - is the lack of preparation they receive, also the image that they have themselves created to provide its services in each place and that was not the most suitable. The problem is precisely of them, because there are very good nurses, who are dedicated and have vocation and spirit of service. What happens is that sometimes it is the organization for which they work. In addition to not receiving a good salary, a classical example could be agencies of nurses, who send home an element that does not always fit with the family environment, and emerging problems.

The case may get worsen when this nurse must repeat shift when the substitute element does not arrive, and when the nurse on shift must remain at that home.

### Complaints against Day Care Centres

- Do not how to treat.
- They are not properly Day Care Centers.
- They are dirty or unclean.
- Do not have activities at all.
- People are overmedicated.
- People are abused.
- Too expensive for what they do.
- It is more a business than a help or a social service.

The theme of the day centers, nursing homes and geriatric is another of the complaints by family members. The most frequent complaints is that there is no good spaces. Although they are announced as the best, nursing homes, they do not have staff prepared or trained. People there works receive no good salary, centers pay them the minimum wage, in case they get paid; they do not have specific planned activities and all that they do is to watch TV, play lottery, and nothing more.

It also should be noted that taking advantage of the situation, "caring" for hours or for a day or a week, becomes a great business, something that will not rigged with what is offered; i.e., that charge is far superior to the services actually offered.

In our country - Mexico - there are some good centers. They may not have all the necessary infrastructure which reckoned a Center, because they are suitable places, but they are, at least, places where you can breathe peace and harmony, where all are treated with respect and love. I could name other rooms, which have good facilities. However, some people I referred to certain centers as elitist.

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they have to have as Center, but they are suitable places, places where you can breathe peace and harmony, where all are treated with respect and love. I could name other places, which have good facilities. However, some people I referred to certain centers as elitist.

### Complaints against the associations

- Do not god attention.
- Do not have an office.
- Do not answer phones or e-mails.
- Respond to other interests.
- Focused on other layers or social classes.
- They have not support groups.
- Coordinated by physicians, not by family members.
- They seem to be ghosts associations.

It is sad to see that many of the associations that appear as "existing" associations, the truth does not work as such; they do not attend people and do not respond to needs of those who need help. It seems that some of them are simply there, thickening a list where it seems that there are many groups or associations, when they don't really exist or do not work as such.

### The need for a commitment

To establish an association or to build or establish day centre is not so simple, it takes courage and commitment, pointing that it is not always money which will give success to a project.

You need people committed to values, with commitment, with a spirit of service and love. And, while these fundamental values are not taken, it will be very little that can be done. It is not only having money; the money, in this case it is not everything. You need to have vision; sensitivity is needed to find out what the needs of the people.

### Three questions to ask...

Before these demands of wat family and caregiver are living in this society, it would be convenient that we all ask ourselves these questions:

- What do we want to do?
- What can we do?
- Where do we want to go?

The answers may not be a simple answer, the main needs are commitment, responsibility, work and spirit of service; above all, demanding rights for the sake of the elderly.

**Dementia: global priority**

Within the demands and requirements we must not forget the following:

- Promote sensitivity and knowledge of the disease
- Respect the human rights of people who suffer from it
- Recognize the fundamental role of the family and caregivers
- Provide access to the social system and health
- Highlight the importance of early treatment
- Take measures to prevent the disease, through improvements in public health policy

And once again: The Government and the authorities do not pay attention or care very little for health. In Mexico authorities speak of plans, plans that are just part of the political discourse to which we are accustomed and where nothing is done. Like Shakespeare said: "Words, words and only words".

**Where is our real commitment?**

And the Government...?

The medical committees...?

Scientific committees...?

Committees of education...?

Ethics committees...?

Are they only decorative?

Who handle them?

What their purposes?

Or they are part of the decoration of a Roman circus?

**And that's what happens with these committees:**

- Do not report, they are closed.
- Respond to other interests.
- No real interest in people with Alzheimer's nor their families.
- Low sensitivity, unethical.
- Null or very little commitment

**What people with dementia want**

Finally, I would like to highlight, although this was not part of the study, what are the demands - not of the family - but of the people with dementia. We have forgotten them, as if they already did not have voice, as if they did not exist, but we have to underline they are still people. And, what do they ask for? They ask for:

- To be taken into account as a person, not as sick body.
- Take into account skills and abilities they still have, not those who have lost.
- Focus on their feelings... not in their deficiencies.
- Let them participate in everything what they can still do.
- Spaces to talk and express their feelings.
- Do not forget them, as they are still part of this world.

**Testimonies**

To take a close look of how families and caregivers feel and think about this problem, here are four testimonies of people who have lived in this world. Two of them with dementia, fighting for their own rights; the other two are families members.

**Testimony number 1****The time to say goodbye**

Federico Ortiz-Moreno,  
Monterrey, Mexico.

Living with an Alzheimer's patient is not easy, but we should not make this more difficult. Certainly, the burden is heavy because there are many factors that influence all this, such as the physical, emotional, financial, social, environmental, that make you feel bad, but it is a great lesson to remind us: the value of life.

On a personal level, it helped me in a lot of things. To learn and understand that there are many needed people for whom we can do something. It allowed me to form an association that has led to several support groups in my hometown, several other associations in my country and even abroad, but more than that, it helped to appreciate what life is, what we are, what we do, both, for our loved ones, for ourselves and others.

To me, the three stages considered for the Alzheimer's disease are all important, and each brings us to a special situation in our lives.

The first stage is the one-off forgetting where we are and just learning what is memory or the lack of it. A stage where we notice "something" happens without realizing fully what it is really happening, that memory is being lost by a degenerative disease and that these symptoms are not simple carelessness, distraction or simply a person's character.

Then, there comes a second stage, which is hard to bear because the person is anxious, angry, want to leave home alone, does not

understand, and much less understand it, and every day the situation gets us to the brink of despair.

We want the person to understand us, while it should be the other way around: We need to understand that he or she no longer lives in the world we live. Despite this, men and women are still individual beings and they deserve all the respect and affection that we can provide.

Finally, it comes a stage that I think is very sad and painful, when we know that everything is ending, when we feel completely powerless, helpless, not being able to do something for someone who we saw with great force and energy and now is being lost in the world of silence and forgetfulness.

What can we do about this? Well, many things! It is not just to pray and ask God that everything is being resolved. No, we must also need to prepare us for his departure and to know how to say goodbye to them. Knowing that sooner or later they will go and what we did for them, here and now is really important. "Do it in life, brother; do it in life".

You have to give love now and do not remember them with sadness later on, when they are dead, when there is nothing to be done. Of course, many families are reluctant, and I know that sometimes it is very difficult to let them go, but we must. Just as at first it is difficult to accept the disease and in fact many of the families do not accept... The same is true when it comes to accept that they eventually have to go.

It is easy to say I have lived 45 years having my father with Alzheimer's Disease and other members of my family with the same problem. It is easy to say, but it is also very hard to face it as a son and as a family member.

I have had the experience of living every stage of the illness with my father, who died in June 1998. I personally think it's been a hard and at the same time a wonderful experience to provide care. He and his illness allowed me to appreciate what life is about, knowing that, despite the bad days and the bad times, the endless hours of anguish, anger and anxiety, there was always something to learn from that beloved person even that he had lost his cognitive abilities.

As a final message I would say to all families and caregivers, and staff in the health area, the following:

- There is still too much to be done. Although they are no longer the same as before, there is still too much to do, especially if they are in the first stage.
- Enjoy them right now while you have them. Yes, because

despite they suddenly appear not be with us or become aggressive, they're still human beings and need love, affection and security. We are the only ones we can give it to them.

- Learn to say goodbye to them. The disease is very hard and the farewell can be hard. We also need to learn to say goodbye. Sooner or later, they will no longer be with us. That in case we have not yet depart before.
- In life, brother, in life! Love him, love them. Enjoy them. Tell them this right now, do not wait until they are six feet underground to say you loved them.
- You're not alone. Perhaps there will some moments you will be alone or feel very lonely, but there's always someone who can understand you and appreciate you, understand your feelings and be with you. The disease is hard, I know, but is harder to forget and forget them.

Federico Ortiz-Moreno,

Monterrey, Mexico.

Social psychologist

Founder of the Alzheimer's Association of Monterrey, Mexico)

His father and six other relatives had Alzheimer

#### Felicity, a girl from South Africa

Felicity De Lange,

Pretoria, South Africa,

My name is Felicity and I live in South Africa. I never got married and took care of my parents for many years. It was my choice as I had the most loving and caring parents and enjoyed a beautiful childhood.

My Dad was a good man. He loved his family dearly, loved to participate in sport as a young man, excelled in tennis and cricket. He enjoyed a very healthy lifestyle and never smoked or drank alcohol.

My Dad was a workaholic and worked for the same Company, for 45 years. When he retired, my parents looked forward to travelling around our beautiful country.

I am the third sibling of four children and my Dad adored me all his life. I think the reason was that they almost lost me at birth - I was born prematurely at seven months.

He used to joke with me in my early twenties by suggesting that I should take care of him and Mom when they grow old. I promised him that I would.

For two years after his retirement, I chauffeured my parents, around the country, on various vacations. He became very nervous of driving soon after his retirement and I used to do most of the driving especially on long trips.

My parents lived close to me in their own home. My Mom would insist that I have dinner with them every evening after work before retiring to my own home.

I noticed that my Dad started distancing himself and became a bit of a "loner" – he never had any hobbies and I think he became very bored. He started doing strange things like making a cup of tea, then placing the fresh milk in the grocery cupboard and the sugar basin in the freezer or even mixing coffee and tea together!

My parents lived close to me in their own home. My Mom would insist that I have dinner with them every evening after work before retiring to my own home.

My Mom started complaining about his driving. He would stop at a green traffic light and drive when the traffic light turns red. Fortunately it happened in a quiet suburb - there was not much traffic. He became very forgetful and became very aggressive towards my Mom.

I realized that my Mom was taking strain and I invited them to move in with me permanently.

I live in a duplex apartment – living area downstairs and the bedrooms upstairs and in the early hours of one morning, Dad woke up to go to the bathroom. Instead of turning left, he turned right and fell down a flight of 16 stairs.

He was bleeding profusely from a cut above his eye. After treating the bleeding by applying pressure on the wound and stabilizing him, we took him to the closest hospital where he was admitted. Various tests were done and he was diagnosed with Dementia. This is where a journey started with this disease called Alzheimer's.

For sixteen years my Mom and I went through the different stages of the disease. We took care of him and smothered him with love. Every Alzheimer's patient has his own unique personality.

I always adored my Dad's personality and it made it so easy to take care of him. He eventually stopped talking and became our big baby. We had to think for him. When he wanted to go to the toilet, he would hit on his leg to draw our attention. If he was hungry, he would ever so gently put his fingers to his mouth, we knew he wanted to eat. If he was thirsty, he would tilt his head back as if he was drinking something.

I worked during the day and my Mom took care of him during the day. Mom hardly left his side during the day and I took over from her in the evenings. We really became so "in tune" with his needs and "body language". It was difficult at times and the worst part was the lack of sleep.

Mom and I used to take turns in sleeping in my Dad's room, just to ensure that every second night, we got a good night's rest. At times I became very emotional at work but that was because of the lack of sleep. Fortunately I had a very understanding Manager at the time and he would send me home early on many occasions. Dad enjoyed it.

Dad enjoyed a lot of pampering from us. He got so used to it, when he opened his eyes after his nap; he would lift his feet waiting for his daily foot massage that he so adored!

Saturdays were very special days. We would bath him and groom him I used to cut his hair myself if he needed a haircut.

After his bath and grooming session, I used to place him in a comfortable chair, dim the lights and he would listen to the Big Band stand music on Radio 702. The music was "oldies: from the 1940's and 1950's.

He would smile and clap his hands. He loved listening to music, whenever he clapped his hands; we knew that he was happy and contented.

Unfortunately, he developed pneumonia and was in hospital for 21 days. He was too weak to return home and he was transferred by ambulance from the hospital to a nursing home.

He was unable to eat on his own and the doctor inserted a feeding pipe through his nose. He died 18 months later. I regret having agreed to the insertion of the feeding pipe as it prolonged his suffering and he eventually had no quality of life. Unfortunately emotions got in the way and all that I wanted was to keep my Dad alive.

Thinking back now, the part that I disliked the most was the fact that we became very isolated and housebound. My siblings were all married with their own families and lived far away and only came to visit occasionally. Fortunately my Mom and I were great friends, who helped a lot – we were totally committed to one another and made an excellent team. We also found time to pamper one another either with foot massages, facials and pedicures.

My Dad passed away in 2005 and my Mom in 2010. I still miss my parents very much but yet I feel very honoured and proud that I took care of them as well as they took care of me as a child.

Felicity de Langue, she is originally from South Africa and lives in Pretoria. I had the first contact with her in June 1997, when by Internet she was looking for information on Alzheimer's.

We remained in contact, and later on, at the end of 1998, she wrote to me asking if I was going to attend the ADI Conference

which would take place the following year in South Africa. I said yes. I had the pleasure of meeting her in Johannesburg in 1999, being in her house with his parents, her mom and her dad. We both remember with excitement and joy when trying to talk to his father – who already did not speak at all - and tell him that I knew that he had been a great tennis player. When talking about how great he was on tennis, his eyes lit up and he tried to talk. (FOM)

### The voice of people with dementia

Give voice, give a space to people with dementia is something that has to be done in Conference of this type. They are really the people who know more than us about this topic. And they want to be considered not as someone who is ill, but as someone who is like us: a person like any other. Here are some testimonies of people with dementia who have participated in international conferences about dementia and Alzheimer's.

#### Helga Rohra

A personal experience living with dementia. "A letter to you, my friends and to all of you who have been touched by dementia", Helga Rohra.

Almost 4 years have passed since I got that diagnosis: "You have got a quite seldom form of dementia. It is called Lewy-Body dementia". Today I realise that life with such a diagnosis is a challenge. It is a daily challenge for myself and all those around me.

Imagine... I was a person in a highly demanding profession. A translator, who spoke five foreign languages. Someone who was very active in her early 50 ties.

I took care of my son and my two cats.

I was very involved in social activities. I dedicated my time to helping refugees, especially youngsters seeking asylum in Germany and handicapped people.

I enjoyed life. I was respected and admired. My neighbours knew I could always give an answer. I was a very open-minded person.

Almost 4 years have passed since I got that diagnosis: "You have got a quite seldom form of dementia. It is called Lewy-Body dementia". Today I realise that life with such a diagnosis is a challenge. It is a daily challenge for myself and all those around me.

My life was okay. And all of a sudden everything changed... everything became different. I forgot my vocabulary, even in my mother tongue. I got lost. My visual hallucination became my best friend. My fatigue permanently present.

My son is my assistant. My cats are my best companions. Social activities are a burden.

Dementia is something others are afraid of. They know just a bit about Alzheimer's disease. They avoid me. They feel embarrassed. What can they talk about with someone like me? They think I do not understand.

They have in their mind a certain picture of people affected by dementia. The press is, in part, to be blamed. It was a long way. A journey to my new self. I know that a dementia is more or less a clinical diagnosis. The way I deal with this "handicap" is to fight.

I started a special programme. A New way of diet, of daily physical exercise, mental training. I am actively speaking up on behalf of all of us affected by dementia. We are in the very beginning.

Medicine/tablets are important, but even more important is the way you deal with your handicap. Believe it or not you can make the best of it. Life is beautiful even with dementia!

I attend German and European conferences. I tell them to forget what books say about cognitive impairment and to instead please realise the still existing abilities people with dementia have and promote them!

I tell doctors, carers, authors to talk to us, to listen to us, to involve us in their decisions about new programmes for people with dementia. We know best what we need, what burden our family carries day by day. I speak up for us all: Involve us, believe in us.

Living with dementia is a new life. It is a challenge for you all and also the chance to face dementia together.

#### Helga Rohra.

Munich, Germany.

March, 2011.

#### What is it like to have Alzheimer's?

I have been diagnosed with Alzheimer's Disease "Alzheimer's from the Inside out".

Richard Taylor,

Houston, Texas. U.S.A.

#### What is it like to drive your car from Houston to Anchorage?

The answer depends on many things: the type of car you will drive, the age of the car, how well you maintained it, where you are in your trip, if others are helping you with the drive, if you have enough gas or access to a gas credit card, if you have accepted the fact you must drive to Anchorage, whether or not you are afraid of arriving in Anchorage.

#### What is it like to have Alzheimer's?

This, too, depends on many things: Do you have an existing group of individuals who are committed to your wellbeing? Are you

a proactive or a reactive person when it comes to dealing with doctors, your health insurance company, and yourself?

Where do you live: Houston, Texas, or Houston, Nigeria? Do you have insurance? Especially long-term care insurance? Does your culture and economic class encourage and promote younger generations taking responsibility and care of their family's older generations. There are dozens of important factors outside of yourself that will directly and significantly influence you and your inner experiences with the disease.

After meeting, speaking, and corresponding with hundreds of people who have Alzheimer's, I am convinced there is no universal answer to the question, "What is it like to have Alzheimer's?"

Since the disease process unpredictably and seemingly randomly destroys various cognitive processes and undermines the basis of most all understanding and memory, each person has a unique and personal way of dealing with the rate, the degree, and the various components of the syndromes we attribute to Alzheimer's disease.

Neurologists who tell us they understand the disease because they see 4 or 40, or 400, individuals with Alzheimer's does not mean they understand me or you. Just as there really is no single "average" person, there is no meaningful "average" Alzheimer's disease experience.

I was diagnosed with dementia of the Alzheimer's type two years before I wrote this piece. I imagined, maybe hoped, that some day I would wake up and a heavy velvet curtain would have fallen during the night. I would wake up to a world where I could see shapes but not enough details to know what or who they were, sort of like Plato's flickering shadows on the wall produced by the fire.

From time to time, a gentle wind blows the curtains and changes the patterns through which I see the world. There are large knots in the curtains and I cannot see through them. There is a web of lace connecting the knots to each other, around which I can sometimes see.

However, this entire filter keeps shifting unpredictably in the wind. Sometimes I am clear in my vision and my memory, sometimes I am disconnected but aware of memories, and other times I am completely unaware of what lies on the other side of the knots. As the wind blows, it is increasingly frustrating to understand all that is going on around me, because access to the pieces and remembering what they mean keeps flickering on and off.

Thanks in large part to my family caregivers, I am still fun firmly.

Whenever you have first-hand experience with something, you are sensitized to it in your surroundings. Break your arm and you will be amazed at how many people you know who have broken their arms. Buy a new home and lots and lots of people will tell you their homebuyers' stories. Discover you have cancer and almost everyone you know will know someone who had or has cancer and has a story to tell.

What happens when you tell people you have Alzheimer's disease? My experience has been that the announcement is initially met with silence. People then express their sorrow, mention something about an article they read about new advances in the fight against the disease, and then change the subject. The next time we meet, they apologize for not "saying more," and then with watery eyes they tell me their experience with the disease in a relative, friend, or neighbour.

I believe Alzheimer's has replaced cancer as the most feared disease people can imagine. Like cancer, there is really little we can do to avoid it. (Come on now, please, let's get real: "Eat more broccoli"?). There is no cure for Alzheimer's, and it asserts total control of your mind and eventually your body. The disease does what it wants with us and to us, and we are reduced to being observers of the demise of our own minds.

I admit, I don't have a more appropriate or supportive way of responding to the announcement of friends or family members who announce that they have been diagnosed with Alzheimer's disease. It was a shock to me when I first heard it, as it will be a shock to you when you hear it from someone else. We don't know much about it.

Much of what we do "know" is not true or is only partly true. If we don't have it, we don't want to know much about it. We don't want to admit to ourselves that we need to know much about it. Out of sight, out of mind. It's the way I was living. It's the way I would still like to live.

Taken from its book: "Alzheimer's from the Inside out".  
Chapter: What is like to have Alzheimer's Disease?  
With the permission of Dr. Richard Taylor.

Editorial: Health  
Professions Press.

#### Message from Richard Taylor to people with dementia...

I have lived lots of life since I was diagnosed. You are not alone in this journey unless you chose not to reach out to seek out others who share similar disabilities with you. You now have an obligation to stand up and speak out about what it is like to live with the symptoms of dementia. If you don't, how will others who don't live with them figure out what it means and how it feels?

### Organizations working in the field of dementia

Besides the WHO, the World Health Organization, there are two big important groups that have been involved in this battle against

- You are not fading away, you are changing. But, of course, we all are changing all the time. Just because you are changing somewhat faster, perhaps in ways others are not, does not mean you are any different as a human being than all other human beings.
- Live your life to its fullest. Don't try to live without or around your symptoms. Live with them, they are a part of you.
- There are lots of folks in your boat, or at least in boats close enough to speak with and spend time together.
- Seek them out and start conversations and possible friendships.
- We still need each other in order to feel good about ourselves in a deeper sense.
- Stand up and speak out.
- You own it to yourself and others.
- If we don't tell others what it is really like to live with the symptoms of dementia how will they ever know?

dementia: Alzheimer's Disease International (ADI) and Dementia Alliance International (DAI).

### Alzheimer's Disease International (ADI)

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations around the world, in official relations with the World Health Organisation. Each member is the national Alzheimer association in their country who support people with dementia and their families. Our vision is prevention, care and inclusion today, and cure tomorrow.

We have a huge challenge ahead of us, and people are invited to join his movement to speak out and say we need changes; we need to act right now to help people with dementia and their families.

We need to as an persuade our governments to do something, it is their job and their duty. We must act now I national plans that will take time to develop and set in place and are essential in achieving tangible actions for the benefit of people with dementia and their families and care partners who don't have time to wait.

Alzheimer's Disease International (ADI), that is like an umbrella of all the national associations in the world has published every

year global prevalence data on dementia in the World. Here is some data:

- 58% of those affected lived in low and middle income countries, underlining the high impact of the condition in those regions, where awareness is low, health and social care are poorly developed.
- Social protection is limited.
- Population ageing is the main driver of projected increases.
- We assumed that age-specific prevalence would remain constant. This assumption is challenged by recent evidence suggesting a modest recent decline in dementia prevalence in some higher income countries (HIC), but an increase in prevalence in China, likely linked to recent changes in population health, particularly exposure to cardiovascular risk factors.
- Since population ageing is occurring at an unprecedentedly fast rate in middle income countries, the bulk of the increase in numbers through to 2050 will occur in those regions.
- By 2050 71% of those with dementia would be living in what are currently lower and middle-income countries (LMIC).

### Some other issues to point out

#### About diagnosis

- Early diagnosis means I can live well for longer.
- As few as one in every ten individuals living with dementia in low and middle income countries receive a diagnosis. World Alzheimer's Month is about remembering those affected by dementia, including many who may be worried about developing dementia themselves.
- A diagnosis of dementia that is made early in the course of the condition enables people with dementia and their families to be better equipped to cope with the progression of the condition, and to have the opportunity to live more meaningful and productive lives. Individuals who are diagnosed early also have a unique opportunity to take part in dementia research, which may identify new treatments, help to find a cure or improve care.

#### An ethical framework for dementia

#### A belief about the nature of dementia

- Dementia is caused by damage to the brain.
- Dementia is harmful to the individual because it leads to a decline in mental ability.

### A belief about quality of life with dementia

- With good care and support, people with dementia can expect to have a good quality of life throughout the course of their illness.

### Recognising personhood, identity and value

- The person with dementia remains the same, equally valued, person throughout the course of their illness.
- This is regardless of the extent of the changes in their mental abilities and other functions.

### Promoting the interests of everyone involved

- Our well-being, and our freedom to make our own choices or follow our own interests, are important aspects of life.
- These can be promoted in people with dementia by encouraging relationships with family and friends and by helping them to express their personal values
- The separate interests of carers must also be recognised and promoted.

### People with dementia are fellow citizens

- We are all dependent to some extent on one another (a concept often referred to as 'solidarity').
- We therefore have a responsibility to support people with dementia, with in families and within society as a whole.

### A 'case by case' approach to decision making

- Ethical decisions can be approached in 3 stages:
- Identify the facts (e.g. What is the real problem? How much distress is it causing? What are the alternatives?)
- Apply ethical values (e.g. well-being, avoidance of harm, freedom to make own decisions), to the facts identified
- Compare the situation with other similar situations to find relevant similarities or differences.

Source: Nuffield Council on Bioethics.

### Recommendations for people with dementia

#### If you are living with dementia

Remember that you don't have to be alone. It is possible to live better with dementia than the public perception of it by seeking support from your family and friends, health and social workers, from the Alzheimer association in your country and by joining Dementia Alliance International (DAI). You have a right to feel empowered, included and to be treated as an individual.

#### If you are worried about developing dementia

Speak to your doctor about any concerns. Alzheimer associations in many countries provide support with seeking a diagnosis and living with dementia, as well as information on risk reduction and help to find support groups. When people with dementia and their families are well supported, feelings of shock can be balanced by a sense of reassurance.

#### If you are a care partner

Remember that caring for someone with dementia can be challenging. Don't be afraid to ask for help or to join the Alzheimer association or subscribe to DAI in your country to advocate for change. It is important to take care of your own physical and mental health needs. This will make a big difference to the wellbeing of yourself and the person you are caring for.

#### As a society

The stigma that surrounds dementia remains a global problem. Early diagnosis can be encouraged through greater awareness and by recognising the symptoms of dementia. Dementia Friendly Communities are being established all over the world to educate people about dementia and to provide community-based support networks for those affected.

#### As a government

Developing a national dementia plan will help your country to deal with the growing impact of dementia. Earlier detection of dementia will also help lower the financial impact of dementia on the healthcare system. Implementing a plan helps to increase national awareness and education about dementia and can improve access to diagnosis, treatment and care, promoting a better quality of life for people living with dementia.

#### Dementia Alliance International (DAI)

Dementia Alliance International (DAI) is a worldwide, non-profit, association of people with dementia at all ages. It aims to represent, support, and educate people living with all forms of dementia and provides a unified voice of advocacy, empowerment and support to their individual autonomy and an improved quality of life.

Dementia Alliance International is the peak body globally for people living with a dementia and the global voice of people with dementia. DAI is an independent self-advocacy organisation of people with dementia, in partnership with Alzheimer's Disease In-

ternational and whenever mutual collaboration is possible, with all national Alzheimer's organisations.

This global non-lucrative organisation works hand to hand with people with dementia trying to work on awareness about this big problem this group hopes to support other people to live well with dementia. We also aim to give an authentic voice to people with dementia, and to support and advocate not only for them, but to teach that living well is possible, and by providing an advocacy and support group, of by and for people with dementia.

It is important to note here that DAI is not competing in any way with other advocacy organisations but rather contributing a unique voice, unique services and a focused advocacy and support service specifically of, by and for people with dementia.

### Why not include people with dementia?

Increasing awareness about dementia and the development of treatments has led to earlier diagnosis. As a result, people with dementia are contacting Alzheimer associations asking to be included because there is a better understanding of their needs as expressed directly by them.

It is important to acknowledge that people with dementia have abilities that need maximising so they can remain active participants in life. People with dementia can contribute their direct experiences to the development of programmes and services and help Alzheimer associations develop a greater understanding about the experience of living with dementia. This can help reduce stigma, inequality and discrimination and enable a person with dementia to feel valued and included.

It is essential to ask people with dementia exactly what it is that they want and need before considering setting up any of the following services.

### Providing Information

Specifically for people with dementia on topics such as:

- o What is dementia?
- o Treatment
- o Support and resources available
- o Practical tips for coping
- o Planning for the future

Factsheets, booklets, videos and websites may all be useful ways of providing information. Consult and involve people with dementia in the development of information materials for them. Remember that people with dementia are not all the same. Those

affected at an early time in their life will have different needs to older people.

### Support groups

Like carers, people with dementia may need someone to turn to for support or just to talk. Other people with dementia are the only people who know first hand what a person with dementia is experiencing. Setting up support groups for people with dementia is an important way of providing support but does require careful planning and groups should be led by supervised, trained facilitators.

### Link to other resources

Other organisations in your country may provide support for people with dementia, such as those concerned with mental health generally or the welfare of older people. There may already be support or advocacy groups available. It is important to find out what support other organisations are providing so that you can refer people with dementia to them.

Dementia Advocacy and Support Network International (DAS-NI) is a network of people with dementia throughout the world who support each other mainly via online chat rooms and email.

### Educational programmes

Many Alzheimer associations provide educational programmes such as seminars, workshops and courses for carers. Consider organising sessions for people with dementia either on their own or with their carers. Relevant topics may include:

- o How a diagnosis is made
- o The different causes of dementia and their effect on behaviour
- o How to plan for the future – using powers of attorney, making wills, living wills
- o Coping with a diagnosis
- o How to simplify and organise your home and life
- o Support from new technology

### General principles for people with dementia

- o Respect for dignity, autonomy, freedom to make choices, independence
- o Non-discrimination (disability, gender, ethnicity, age)
- o Full participation and inclusion in society
- o Respect for difference; acceptance of disability as part of human diversity
- o Equality of opportunity
- o Accessibility
- o Equality between men and women

It is quite important to provide a detailed guidance on the relevance of these principles to important areas of everyday life on the same basis as others. These include:

- Right to Life.
- Accessibility at all levels.
- Equal Recognition before the Law.
- Freedom from torture, cruel, inhuman or degrading treatment, exploitation, violence and abuse.
- Living independently and participation in the community.
- Respect for home and family.
- Health.
- Rehabilitation.
- Employment.
- Adequate standard of living and social protection.
- Participation in political and public life, cultural life, recreation, leisure and sport.
- Lobbying and advocacy to ensure that these policies and plans can be accomplished.

#### Alternative solutions...

There are many things that can be done, but more to do only proposals are necessary actions. We must need to take action and demand.

- Raise awareness of the problem through information campaigns
- Inclusion of the diagnosis and treatment of dementia in primary care
- Creation of support groups
- The creation of day-care centres
- Promoting research and funding sources
- Development of human resources and multidisciplinary issues.

#### Dementia: As a global priority

Within the demands and requirements we must not forget the following:

- Promote sensitivity and awareness of the disease.
- Respect the human rights of people who suffer from it.
- Recognize the fundamental role of the family and caregivers.
- Provide access to the social system and health.
- Highlight the importance of optimal treatment after established diagnosis.
- Take measures to prevent the disease, through improvements in public health.

#### Don't forget...

Don't forget that beyond words, space and time, there is the ability to give love that ultimately it is what keeps us alive in this world that is for all. They may have forgotten who they are, but we don't. Let's do something for them, let's do something for us [1-10].

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