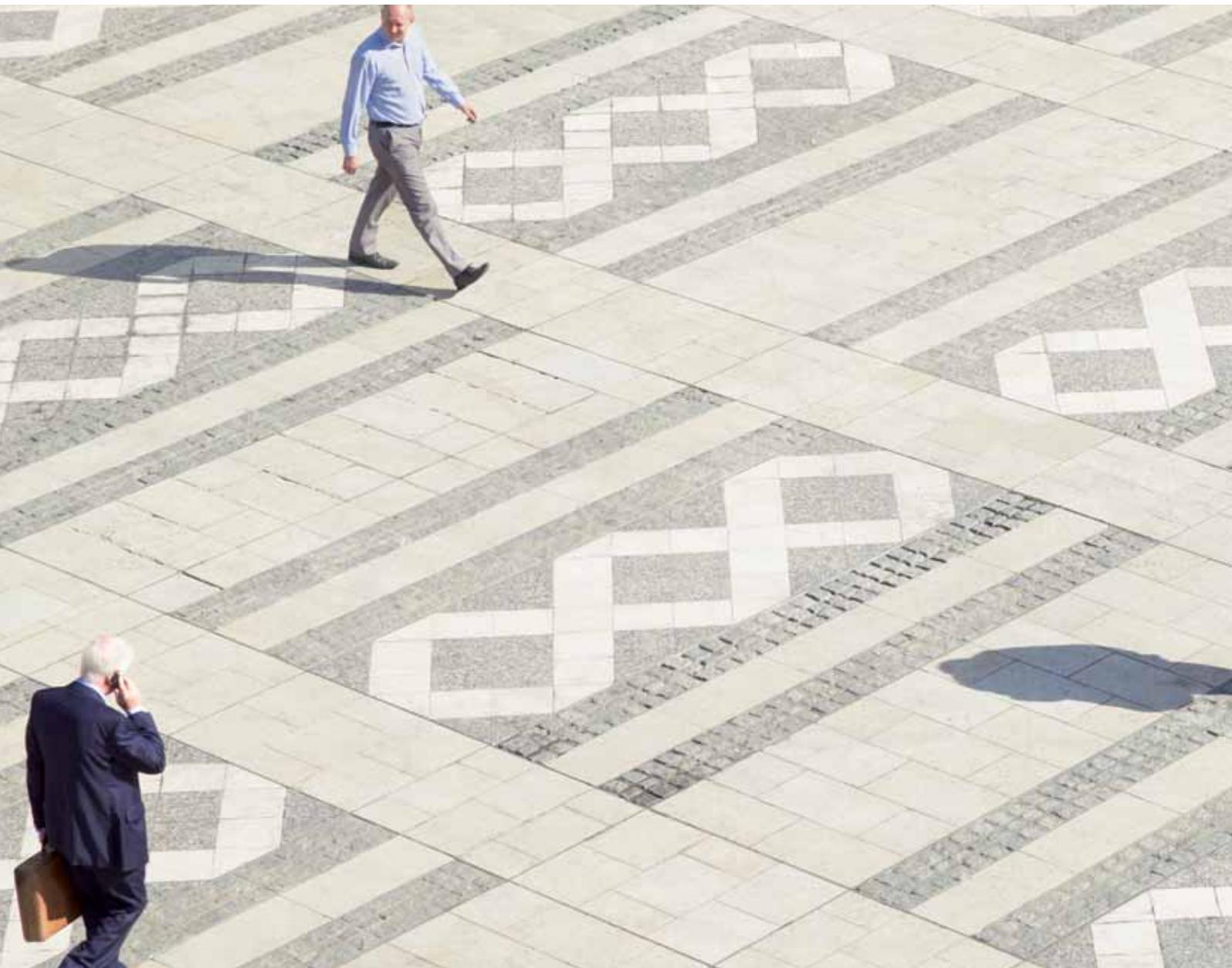




Alzheimer's Disease: A practical guide for families





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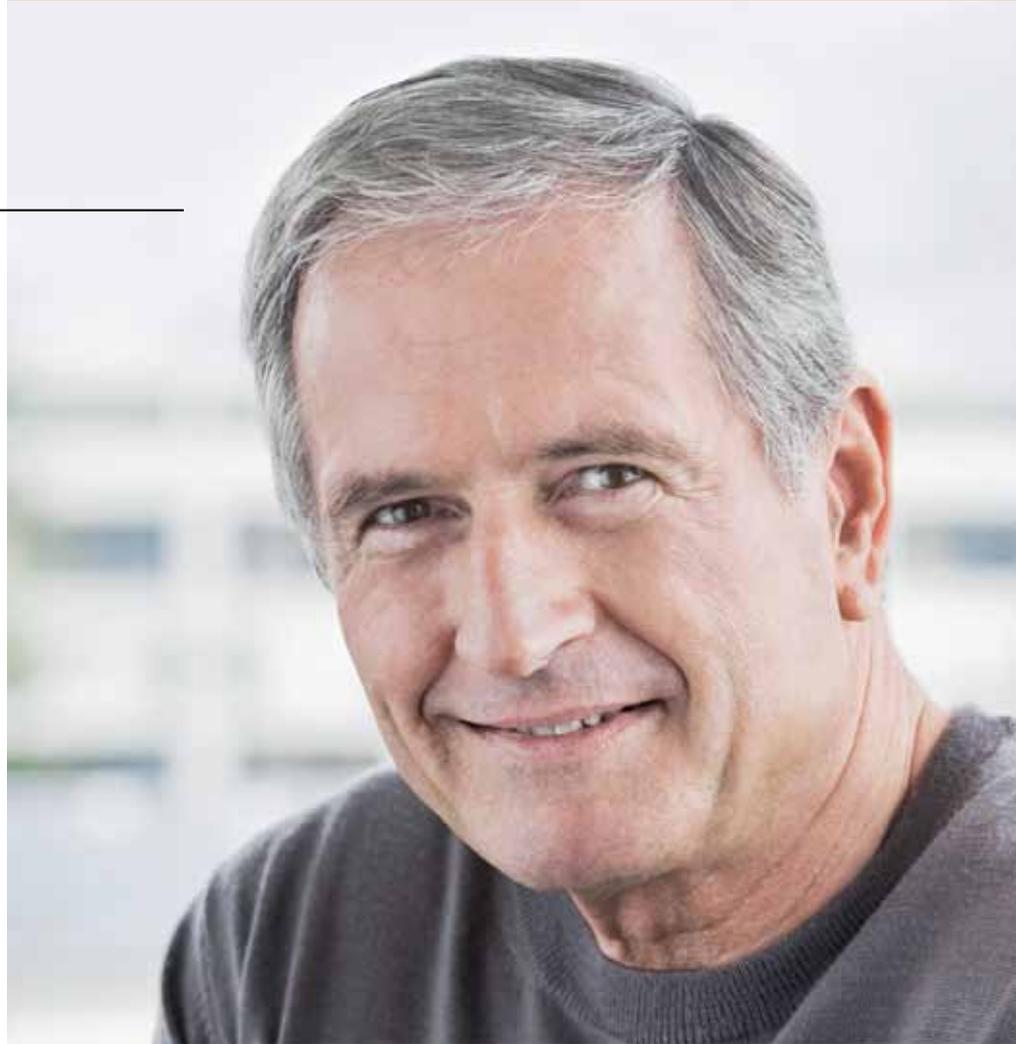
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Chapter 1

¿Why does memory fail us?

Víctor Isidro Carretero.
Neuropsychologist



1.1. Ageing means change

Ageing is a process of change and adapting to new situations. Occasionally these changes are triggered by social variables such as retirement or the loss of loved ones but it is evident that the passage of time also impacts people physically and psychologically. Ageing is therefore the set of morphological, functional and psychological changes that time irreversibly brings about in people.

Julio is 66 and had been the stationmaster at his village station all his life until he retired one year. He has recently been arguing more often with his wife Blanca. They have been spending more and more time together in the last year. Blanca complains that he is always in the way and does not let her get on with the housework as she should. He gets annoyed as he feels that he does not fit in anywhere, not even in his own home, he is always in the way and not even his wife is happy to have him around.



Adaptation to change is one of the definitions of human intelligence. Some of us might find it more difficult, some of us less, but we all have trouble changing our daily routine and need willpower to do so. Whether it's a routine that we have chosen or that has been imposed upon us by circumstances, we normally feel more comfortable when faced with the predictable than with the uncertain.

But apart from all these changes which are there for all of us to see, there are others where the clues are not so easy to spot. Over time our brain also changes.

Our brain fashions our personality and controls our behaviour. Thanks to its activity, we can make sense of all the information we receive through our senses and relate it to the other information and experience that we have gained throughout our lives.

An older person's brain differs from a younger person's. The brain's weight and volume decrease with age and there are vascular and neural metabolic changes. Apart from these changes associated with ageing, there can also appear the characteristics of diseases known as "dementias" which we will see below.

We can classify the elderly into two groups on the basis of brain function:

- Those who age healthily, with all the changes and alterations associated with the passage of time but without any added illnesses.
- Those whose ageing will be accompanied by a pathology that will affect their brain function.

1.2. Changes in cognitive functioning in the elderly

a) Attention

We can define attention as the selective process of filtering what we choose to attend to and what we choose to disregard. In other words, it works as a funnel or sieve, removing the information which is not important for us at any given time.

We observe that the elderly find it difficult to divide and switch attention, where the person has to attend to more than one task.

Cruz has always enjoyed knitting while she listened to the radio or watched what she called talk shows on television. At times she was even able to go on knitting while she discussed the news with her neighbour Mati. In two months' time she will be a grandmother again and this time it will be a girl at last. That's why she wants to knit some nice clothes for when she's born and leaves hospital. Nonetheless, despite all her efforts, she notices that she is only able to do it when she turns down her television or turns it off. Otherwise, she drops a stitch and has to undo the whole thing.

b) Reaction time

This is the period from the time information is received to the time it triggers a response.

Reaction time is one of the cognitive functions that most changes in the elderly, their response to the stimuli around them slowing.

c) Intelligence

The concept of intelligence is rather broad but we can talk of two types.

- **Fluid intelligence:** This is understood as the capacity to solve problems by reasoning and creating novel concepts and solutions. It is an ability that declines with age.

- **Crystallised intelligence:** It is built up through life experience. A clear example of this type of intelligence is the accumulation of knowledge in terms of vocabulary. It is a cognitive ability that is strengthened through experience and therefore by ageing.

d) Memory

Memory is the cognitive process through which we register all the data, facts and experiences which are important to us.

Our memory can have the most diverse content. The time we need to memorise something for can also change. We store such important memories as our wedding day or the birth of our children. These are memories that we treasure as special and wish to remember all our lives. However, we also recall other less important things for less time such as the shopping list that we draw up after having a quick look at our fridge and before going down to the supermarket. Depending on how important the event, we will pay more or less attention and register it for more or less time.

Memory works very much like a camera. Sometimes when we set off on a trip to some new place, we want to keep nice memories of that experience and we therefore pack a camera. The moment I see a beautiful landscape I ask my family to stand there for me to take a picture of that context. It is the moment of "registration", when our attention focuses on capturing information of that important instant. It is a particularly important moment (in both the example of the camera and the memory process that we explained) because if we do not centre properly or choose the right light, the photo will not come out right. During the memory process, if we do not focus our attention properly during this stage, we will not register the facts correctly

and we will then realise that there is information missing.

Once we have accumulated dozens of pictures in our camera, we need to continue working to ensure that the photos are not lost.

I have to develop the photos and place them in an album (or a CD if they are in a digital format), in the best chronological order and even including comments about each place and event. Similarly, in order to consolidate a memory, I need to carry out the second phase of the process, "retention" or "consolidation", in which I link such memories to my previous experience and knowledge. If I place the photos of my trip to Paris and mix them up with those of my holidays in Barcelona which took place many years earlier, my classification will be a mess.

Lastly, the third phase of the memory process is "recall". I want to find the photos that I took a few years ago with a friend. I think of where I took them, I look for them in the relevant album. If they were all mixed up, it would be a difficult task but if they are in order, it will be much easier. This happens with memories. The more they are set in a significant context and the more attention I paid at the time they registered, the better I will recall the significant event or information.

The memory process is therefore made up of three phases (registration, retention and recall) where problems can arise which then make it difficult for us to remember something.

As we age, we may experience memory problems related to sensory limitations (a

loss of hearing, vision problems, etc.), changes in attention and emotional problems (depression, anxiety etc.), in addition to other problems directly connected with dementias.

1.3. Quality of life in old age

We know that there are two possible ways to age (we can be healthy or ill) and we can then ask ourselves the following question: what can we do to improve the quality of this last part of our lives?

Encouraging physical and cognitive activities is key to developing subjective well-being; increasing social relations and active social involvement and participation improves our self-image and enables the improved use and therefore the greater stimulation of our mental functions.

Prevention is one of the basic areas of all dependency care programmes due to the hardship and limitations brought about by events associated with ageing such as retirement or the

death of a spouse. The search to adapt to these new realities that the individual has to live through is the basis of these programmes.

In addition to the physical and cognitive aspects, we therefore need to encourage everything that concerns emotional wellbeing and motivation in ageing. The search for new interests, involvement in a peer group or relations with inter-generational groups (encouraging the tutoring of younger people, making the elderly feel that they belong and are important in our society) will strengthen people's emotional and affectionate state during the active ageing process.

Content

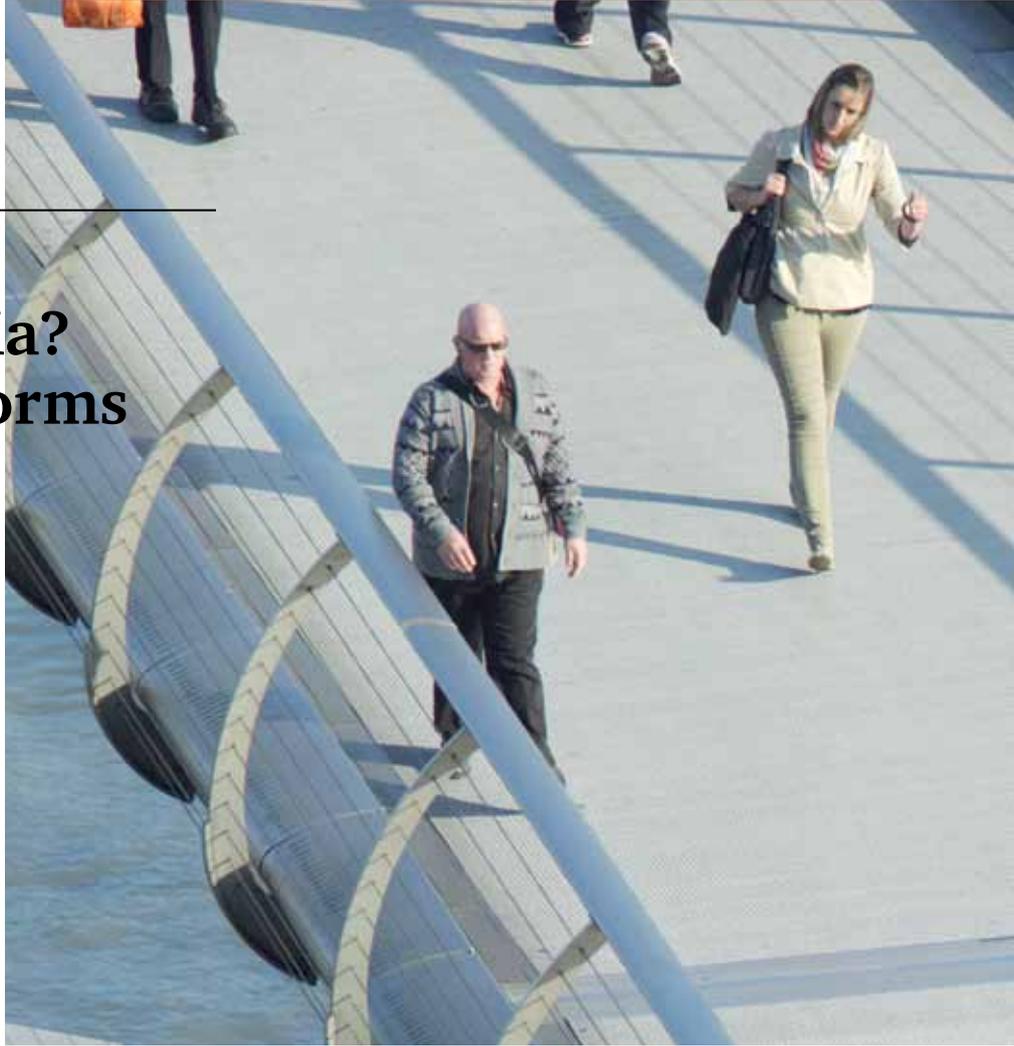
2.1. Mild Cognitive impairment

2.2. Types of dementia

Chapter 2

What is dementia? Most frequent forms

Víctor Isidro Carretero.
Neuropsychologist



Dementia is a syndrome, in other words, a group of symptoms that usually appear together and trigger a series of consequences in the person affected.

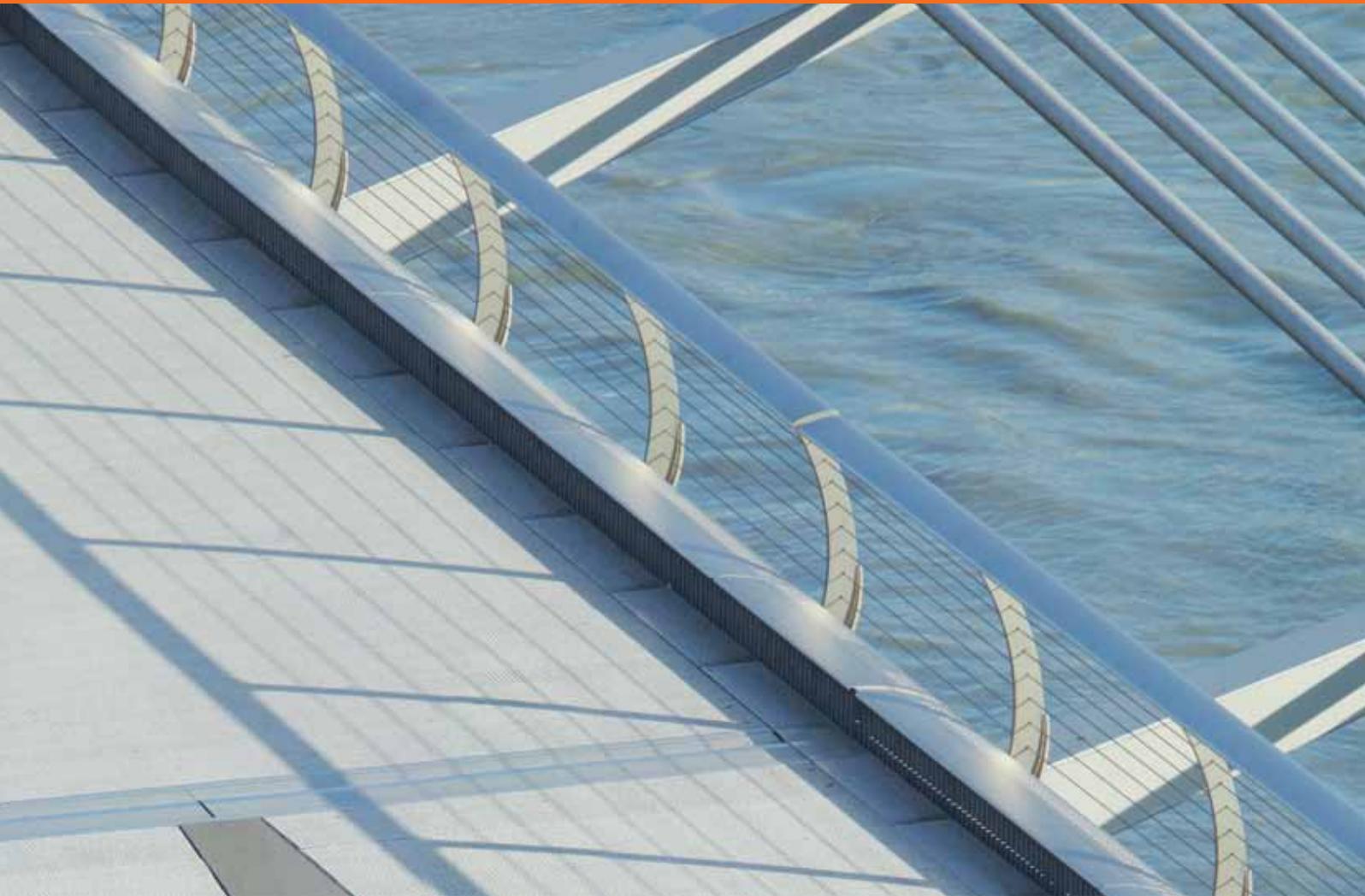
We can classify the symptoms in three large groups that we will address throughout this document:

- Cognitive systems.
- Psychological and behavioural symptoms.
- Functional disorders.

Cognitive symptoms affect our mental or intellectual abilities, such as memory, attention, orientation or language.

Although they are usually the first warning signs, they occasionally go unnoticed in the family as they may be confused with simple changes associated with ageing or sensory difficulties. Even today we have inaccurate stereotypes of what is and what is not normal in old age meaning that the actual symptomatology of dementia goes unnoticed.

Anyone who develops dementia will have lots of problems coping with work or household responsibilities, dealing with the people around them and even organising their free time.



When should we take note?

There is no doubt that it can be difficult for someone without specific training in dementia to know when they should seek a professional opinion on the “mental lapses” of a close relative. It may at times feel as if our loved one’s personality is changing because they seem to be acting out of sorts. If we get to the stage where we say “I really don’t know what’s go into my mother lately” or “my father has really changed in the past few months”, we should not hesitate to ask for a professional opinion on those changes.

The diagnosis of dementia disorders is a differential diagnosis in which we have to discard possible diagnoses until we reach the right one and can therefore take time. It is therefore important that we visit the specialist as soon as possible. The first step should be to discuss these small (or big) changes with your GP.

Here is an example:

Manolo used to go out for a walk every morning whatever the weather in order to keep in shape. He liked to walk at a healthy pace around his neighbourhood and

although in the evening he also liked to go out for a stroll with his wife, it was during his morning walks that he felt that he was keeping his muscles and joints in shape. However, for the past two months he has stopped going out for his morning walk and confines himself to his afternoon stroll, arm in arm with his wife. Neither his wife nor children understand this change. They insist that he should go on with his routine as it's not good for him to spend his mornings sitting in an armchair, but he refuses outright and only wants to go out if he goes with his wife

Another frequent case:

Felisa is a very sociable lady. Throughout her life, she has enjoyed her afternoon coffee and trips to the cinema or theatre with her friends. Her decision not to marry when she was young and live her life as she wanted was a fully conscience decision although not normal practice at the time. Felisa has always defined herself as a "modern" woman for her time, delighted to live in a large city and enjoy a wide ranging cultural life. This was how it was until last year. Now her friends have to insist and almost force

her to go out with them, she has lost all initiative and seems not to enjoy all those things that used to excite and amuse her.

Important changes are taking place in Manolo and Felisa's interests, motivations and lives in general. Cognitive changes may trigger changes in personality, make people behave differently from how they used to before those symptoms appeared.

One of the reasons for the change in Manolo's routine may be that he is experiencing episodes of disorientation that make it difficult for him to move around independently in those places where he used to walk and this explains why he tends to go out only when he is accompanied by another person, in this case his wife.

Felisa's friends were hugely surprised to see their friend so demotivated and apathetic and did not understand that the reason could be a series of alterations in attention that made it difficult for her to enjoy these lively gatherings with her lifelong friends and colleagues.

2.1. Mild Cognitive Impairment (MCI)

There are cases where, despite the deficits in a person's cognitive or mental functioning, there are no limitations to the individual's functional capacity.

People with MCI have memory problems or other subjective complaints concerning cognitive

performance that are assessed by neuropsychologists but do not seem to exhibit the consequences or only do so during highly complex activities that do not form part of their daily lives

How MCI develops varies. Some MCI patients may remain stable, reverse

or go on to develop a dementia disorder. Around 15% of patients diagnosed with MCI go on to develop dementia every year. It is therefore essential to monitor these patients over time.

2.2. Types of dementia

There are more than one hundred diseases the consequences of which are associated with dementia. Initially we can divide them into primary neuro-degenerative dementia, secondary dementia and mixed dementia.

In the case of primary neuro-degenerative dementia disorders, the cells forming our central nervous system, neurons, are affected with no directly known cause or the multifactorial influence of several causes at the same time. The most common form of primary neurodegenerative dementia is Alzheimer's disease.

In the case of secondary dementia, the main cause is a known disease which is unrelated to the central nervous system. The most frequent is vascular dementia.

Mixed dementias include those cases where there is more than one disease at the same time that cause dementia. The most numerous cases are those in which we find Alzheimer's with an associated cerebro-vascular disease.

Primary neuro-degenerative dementia disorders:

- Alzheimer's disease.
- Dementia with Lewy bodies.
- Frontotemporal dementia.
- Other.

Secondary dementia:

- Vascular dementia.
- Dementia caused by brain tumours.
- Normotensive hydrocephalus.
- Infections.
- Other.

Mixed dementias:

- Associated Alzheimer's disease and cerebrovascular disease.
- Other.

Alzheimer's disease

Alzheimer's disease is the most frequent form of dementia (accounting for around 50-70% of all dementia disorders) and its initial and characteristic symptom is the difficulty in remembering recent events while remote memories such as memories of our childhood and youth are preserved for longer.

As the disease progresses, problems start to appear with language, attention, recognition, comprehension and the performance of actions. The type and frequency of behaviour changes vary as the disease progresses and develops.

During the more advanced stages of the disease, the cognitive decline is accompanied by physical impairment and disability which may leave the patient bedridden. Nonetheless, the progression and development of the disease varies markedly from one patient to the next and life expectancy can vary from five to 15 years or more.

Throughout our lives, we create a wide network of knowledge and memories by accumulating experiences and understanding. Our neurons are responsible for creating that network of communication (synapses). This is precisely the target attacked by Alzheimer's disease. The disease destroys the network and kills neurons directly and makes communication between those that are still alive difficult. It does it through the accumulation of a specific protein inside and outside neurons. Inside the neuron what is known as neurofibrillary tangles form that end up killing it while amyloid or senile plaques accumulate between nerve cells, cutting off neuron communication

Alzheimer's disease causes the degeneration and atrophy of the cerebral cortex, which is the part of the brain responsible for the superior cognitive functions that most distinguish us from animals. Atrophy starts at the temporal lobes (with an early and severe impact on the hippocampus, a key area for learning new information and emotional control and response) and subsequently extends to the parietal lobe, causing a considerable reduction in brain mass and weight

Our entire personality, all our emotions and in general all our mental activity is regulated by this complex organ, the brain. Therefore if the brain changes, our personality and mental activity will also change to a greater or lesser degree. If

we are related to someone with Alzheimer's disease we should always bear in mind that our loved one's conduct and behaviour are caused by their brain activity and if this changes, their behaviour will too.

More than a century has passed since the first documented case of Alzheimer's disease. It was the "case of Auguste D." a German woman who in about 1900, when she was around 50, started showing personality changes, accompanied by strange behaviour and curious memory problems which mainly affected her memories of the most recent events and situations. Auguste lived with her husband in Frankfurt, and it was precisely her husband who noticed that there was something wrong with his wife. She always seemed to be distrustful of the people around her (including her husband) and had paranoid thoughts where she thought that people wanted to hurt her or were out to get her. When she had these thoughts, she tended to behave aggressively without restraint. Particularly noteworthy was the trouble she had in remembering her daily life and recent events. As a result, in November 1901 Auguste was admitted to the Psychiatric Hospital in Frankfurt, where she was seen by the doctor, Alois Alzheimer. She was admitted because of her personality changes and memory problems. Her clinical records describe how her symptoms started with persistent delusions of jealousy (Auguste accused her husband of being unfaithful), a rapid and gradual loss of memory, temporal-spatial disorientation, serious language impairment (in both comprehension and speech), paranoia, hallucinations and associated behaviour disorders. Alois Alzheimer treated and studied the case and conducted a histopathological analysis of Auguste's brain after her death in order to describe the pathological

process that had caused all the symptoms described. He found an atrophic brain, plagued with neurofibrillary tangles and amyloid plaques, characteristic of the clinical manifestation of what years later Kraepelin would term “Alzheimer’s disease”.

Dementia with Lewy bodies

Dementia where the main histopathological finding is the presence of Lewy bodies, created by the alteration of the alpha synuclein protein in the neurons of the cortex and also in subcortical areas (diencephalon and neural tube).

It is characterised by major fluctuations in cognitive symptoms (in other words, there are days when patients seem to have fewer cognitive problems), there are periods of lethargy and drowsiness, motor ability and balance problems and psychotic type symptoms such as delusions and hallucinations.

It is a pathology highly related to Parkinson type dementia that has the same symptoms, preceded by all the characteristics associated with Parkinson’s.

Frontotemporal dementia

This is a form of dementia that usually affects younger people.

It normally appears when the person is around 45 to 60. In this case, the atrophy mainly affects the frontal lobe and the temporal lobes. These areas are key in controlling social conduct. They enable us to know what we can do in public and what we can’t; they tailor our acts to the situation we are living at any given time.

With the onset of the disease, there are no deficits in cognitive capacities. Memory, calculation ability and other aspects are not

affected. What is really affected in people with the disease is relational behaviour as they may act strangely or outside what is considered to be socially acceptable. There are two possible forms: one marked by disinhibition and another characterised by apathy.

Desinhibited patients may fully ignore social forms all together and become excessively sociable with strangers, fail to wait for their turn in conversation and be easily distracted, acting impulsively and showing behaviours that are stereotyped and persistent. The apathetic form is characterised by a lack of energy and interest in social conduct and relationships and personal cleanliness and hygiene and all related activities are stopped.

Cognitive symptoms such as language and reasoning problems may not appear until years later and symptoms are therefore often confused with purely psychiatric problems.

Vascular dementia

This is the dementia disorder caused by vascular lesions of the brain of both ischemic (cerebral infarction) and haemorrhaging (cerebral haemorrhages) etiology in the cortical and subcortical area. When the cortex is affected, symptoms such as trouble with language, inability to make gestures and recognise objects will prevail. Its onset is sudden and its progression gradual. If the subcortical area is affected, the onset will be more sudden and the symptoms will include apathy, motor and mental retardation and memory problems.

Other forms of dementia

There are other diseases that cause dementia such as endocrine metabolic disorders, vitamin deficiencies, brain tumours, infections of the central nervous system, problems in the circulation of cerebrospinal fluid, cranio-encephalic traumatism, etc.

Content

3.1. Memory

3.2. Language

3.3. Disorientation

3.4. Attention

3.5. Agnosia

3.6. Apraxia

3.7. Calculation

3.8. Body schema

Chapter 3 Cognitive symptoms. Much more than normal forgetfulness

Cynthia Pérez Muñano.
Occupational Therapy



From the time it becomes evident that someone has Alzheimer's, their cognitive capacities will start to decline gradually over time. In other words, the change is not sudden or abrupt, but will take place gradually. Symptoms appear that will progress in different stages where other new symptoms will develop.

We can distinguish different cognitive symptoms in Alzheimer's disease.



3.1. Memory

Memory loss is the main and most characteristic symptom of Alzheimer's disease. When someone is initially diagnosed with Alzheimer's, the concept or idea that the family and actual patient may have (if they have no previous knowledge) is what they have seen, read or heard in the media. Sometimes memory is stressed, leaving other symptoms to one side. We will later see that Alzheimer's disease is not only a loss of memory but also encompasses many other symptoms.

We can distinguish several types of memory that are affected in the course of this disease. If we classify them by time, we would differentiate:

- **Immediate memory.** Immediate memory is what we use to retain important or necessary information for a specific timeperiod (it lasts only a few seconds) in order to subsequently act or carry out the defined operation. In this case, data storage is limited to a few objects.

- **Recent or short-term memory.** Together with our immediate memory, it is the first to be affected and can therefore set off alarm bells in the patient's immediate surroundings. In this case, more chunks of information are stored and for longer, from a few days to several weeks. The loss or impairment of this type of memory means that our loved one will be unable to remember recent events. They will initially forget events that took place a few days ago. That period will slowly get shorter until in the advanced stages, they will no longer remember what they did a few hours or minutes ago.

Juana is 87 and was diagnosed with the disease five years ago. She follows the same routine every day: she gets up at 9 am, has breakfast, takes a shower and with her caregiver's help, starts her daily stimulation, ranging from gym exercises to various memory, language, orientation exercises etc. Before lunch, she relaxes in the lounge and watches television. When Lidia, her daughter, arrives at 2pm, they have lunch. Lidia asks her mother what she has done during the morning but Juana is unable to remember. She sometimes says that she does not know while at other times she gets it wrong.

This is a very common situation. The person becomes increasingly disoriented in time and space and behaves inappropriately at certain times. For example, in the case above, Juana tells her daughter at midday that she has to have breakfast because she does not remember that she already had it.

These changes that are observed in Alzheimer sufferers are due to the

physiological and morphological changes taking part in their brain. The neurons responsible for processing the information that we receive externally are dying resulting in fewer inter-connections.

The part of the brain responsible for memory and learning is called the hippocampus. If we compare an image of a healthy brain with another brain with Alzheimer, we would note that due to the loss of neurons, the brain has shrunk. We would also distinguish numerous "empty", "hollow" areas in the brain because of this. And if we look at the hippocampus, which, as we have said is directly related to memory, we would see that with time it almost completely disappears.

We therefore have to avoid thoughts such as "he doesn't remember because he doesn't want to" or "he doesn't do what I ask to annoy me" because the patient may not remember or may not be able to do anything else, probably because they cannot as that part of their brain has stopped working. It is not that they don't want to, as we may sometimes think.

- **Remote or long-term memory.** This type of memory is able to store large chunks of auto-biographical information, from several weeks before and even recall distant events, who we are, what we have done and how we have lived.

In an Alzheimer patient, this memory lasts longer while short-term memory is lost and more recent events are forgotten first.

By looking at the type of content stored, we can differentiate other types of memory:

- **Working memory.** This is our day to day memory which we use to carry out our daily tasks. There is a correlation between working memory and immediate memory.

For example, this is the memory we use when we want to remember the numbers in the telephone directory. We will use this memory to store this information but next time that we want to use, it we will have to look it up again.

Alzheimer sufferers will be able to retain their working memory in the very early stages but as the disease progresses, they will lose it or it will become impaired. They will therefore be unable to remember a telephone number or the shopping list unless they have it written down etc.

- **Episodic memory.** This type of memory refers to remembering specific dates and events, where and when they took place. Thanks to it, we can organise the events in our lives correctly.

People with Alzheimer's will have trouble when remembering and organising the events in their lives. Initially, distant memories will remain intact while memories of more recent events will be lost early on.

Fernando has Alzheimer and has lived with his wife Elvira in Madrid for 10 years. He no longer remembers being married and it has become difficult to live with him. He wakes up at night and shouts, asks who she is and throws her out of the bed. They now sleep in separate beds. At other times, he confuses his wife with his mother and he relates to her as such. In addition, he is disoriented and thinks he lives in the village in Jaen where he was brought up.

At times the patient remembers their past life as if it were a present event and can therefore forget that they have grandchildren or children. They may even feel that they are still living in their home town.

If we prepare a line showing an elderly person's life with their memories, it would look something like this:



As we have said, Alzheimer sufferers will forget more recent events before more distant ones. Therefore if we look at that life line, the first thing they would forget would be retirement. The person forgets that they have retired and therefore may behave in a way connected with when they were working.

Francisco is 79 and lives with his wife. Every morning when he gets up, he asks her to prepare breakfast quickly because he has to go to work.

If we follow the graph, he would then forget his children. This is perhaps one of the hardest and most complicated symptoms for a family to cope with, to have a parent forget who their children are. But in the patient's life, that child is a subsequent memory and in relation to other memories, one of the last.

In addition to not remembering this information, Alzheimer sufferers live

through this stage as if they were younger and were, for example, newlywed. They therefore frequently confuse their spouse with their father or mother and their children with their spouse and behave inappropriately with them.

They will gradually lose their most recent memories until they get to their parents. Our parents are one of our last memories which we generally do not forget, basically because of the bond between parents and children from the time they are born.

- **Categorical or semantic memory.** This refers to the archiving of conceptual knowledge. Thanks to this memory, we have knowledge about the world, the names of things, their meaning and any other abstract knowledge. In addition, it enables us to relate certain information to other information.

This information does not vary (eg. the provinces of Castilla y León).

This type of memory starts being affected during the early stage of the disease although it is not until later, during the moderate stage, that its impairment becomes apparent.

Semantic memory is the ability to associate a pear and banana as fruit, create a list of words in the same category, for example, animal names or do comprehensive reading.

- **Procedural memory**. This relates to the learning of the skills and abilities to carry out daily activities (getting dressed, riding a bike, cooking etc). These procedures are automated and are often carried out without conscience awareness.

By repeating such activities and creating routines, Alzheimer sufferers can retain this type of memory to a certain extent although in the moderate stage, they start to have trouble particularly in relation to the activities of daily living.

3.2. Language

Problems with language, which becomes less rich and fluent, is another of the characteristic symptoms of Alzheimer's disease. Communication with our loved one thus becomes increasingly complex.

They will start having trouble following a conversation with more than one person at the same time and difficulties in naming objects or finding the right words.

Roberto lives with his mother who has recently been diagnosed with Alzheimer. He says that he finds her increasingly distracted and conversation has declined considerably. When he attempts to ask her something, he gets a no or rejection for an answer. For example, when he gets home from work in the evenings, he asks his mother what she has been doing while he was at work and she answers: "Do you really think I'm going to tell you? I don't want to talk to you."

Initially, the absence of communication on the part of the patient may be due to fear or embarrassment at having others recognise their mistakes. They will

isolate themselves to avoid having the people around them recognise their difficulties. It is important to take this into account and avoid reacting negatively to answers and building a bad relationship between the patient and caregiver. We have to continue trying to communicate, showing respect and building trust, encouraging them to take part in conversations.

Con el paso del tiempo, además de la expresión, la comprensión del lenguaje también se ve afectada, al igual que se ve mermada la capacidad para la lectura y la escritura.

With time, in addition to expression, understanding will also become affected while the ability to read and write will become impaired.

Finally, sufferers enter a stage where they barely utter a word or just mumble.

We can therefore distinguish several problems connected with language:

Verbal language

a) Expressive

- **Denomination.** As we have already mentioned, Alzheimer sufferers will begin to have trouble finding the right words in conversation. They are usually able to understand the words but they find it particularly difficult to access their phonological form. For example, they will create phrases of the kind: *Bring me that, give me that thing used to write, this is a...a...comb.*

This is commonly known as the “tip of the tongue” syndrome. The patient may be able to initially hold a smooth conversation but it will become impaired or slow because of this difficulty. They may become frustrated because of “wanting to and being unable to” and because during this initial stage, they are aware of their loss and mistakes.

- **Smooth spontaneous language.** With time, language will become less rich and broken. Conversations will gradually become less dynamic and less expressive and intonation will decline.

Similarly, in the more advanced stages, patients will find it difficult to recount, relate, describe and define situations and objects although if asked, they will be able to reply correctly.

For example, if we ask: *What’s your home town like*”, they will reply *My village...Yes, well, it’s really pretty...* but will provide no further information. Conversely they will be able to reply to questions that we ask on the subject: *Was it a big or small village? Did it have a church? What was it like? etc.*

Replies will become increasingly simple, generally yes and no.

In addition, the words they use to talk to others will also be simpler and more repetitive.

- **Repetition.** They will start having difficulty repeating words we say out loud as they will change the words for others that sound similar (this also happens with spontaneous language).

For example, when we ask them to repeat the word “*prophet*”, an Alzheimer’s sufferer will pronounce “*moppet*” or when trying to say *I have 5 pence left* they will become confused and say “*tense*” or “*intense*”.

In the last stages of the disease, a phenomenon called echolalia may appear. Echolalia is the repetition by Alzheimer’s sufferers of the last phrase, word or syllable pronounced by another person in their presence. As the name itself indicates, there is a kind of echo.

Pedro is no longer able to hold a logical conversation due to his deterioration and can barely understand simple orders. But he is constantly repeating everything he hears around him. If someone near him says, for example, the word brush, he will answer brush, brush, rush, ush, ush ush...

b) Understanding

Alzheimer’s sufferers will find it difficult to understand what we want to convey. Initially, it will take an effort or it will even be impossible to understand long phrases and complex orders that include other more simple orders. Moreover, the fact that they do not understand certain words or confuse them with other words with a similar sound or with a similar phoneme (as we have seen in repetitive language) makes communication even harder.

However, non-verbal comprehension remains. A friendly gesture, a kiss, speaking in a respectful and affectionate manner etc is perceived as something pleasant and positive while shouting or abruptness is perceived as something negative and may receive a the relevant reply (crying, anger, aggressiveness etc).

When we get to this last stage, the patient is practically silent. They do not utter a word or any type of logical discourse and only mumble some sounds or unintelligible words or they hum and only say “mummy” and “daddy”.

Reading and writing

a) Reading

Gradually they lose the ability to understand what they are reading and even to read. They will understand short and simple phrases better and those words they are most used to seeing.

The ability to recognise letters will also be affected, particularly, those letters that are very similar and which only change position, such as bs, ps or ds.

Just as with words, where they replace one word with another similar sounding word, when reading they will change words which are written in a similar manner. For example, they will read “quickly” instead of “quietly”.

Finally, in the advanced stages, Alzheimer patients lose all ability to read although in some cases they may retain the ability to read some individual words or letters (rather because they know that word or it sounds similar than because they know how to read) but will not understand their meaning.

b) Writing

During the mild stages, problems start to appear in writing words or phrases. They are no longer able to write them correctly (subject, verb and object).

During the moderate stages, they have difficulty with dictation, although they are able to copy words. Their handwriting becomes more irregular, unintelligible or there are misspellings (some letters are repeated, others are left out etc). They are able to write their name and surname and in some cases, sign their names.

In the final stages, they lose the ability to write altogether even at automated level and are unable to sign, write their name and surname and address, etc.

3.3. Disorientation

Another very characteristic symptom of Alzheimer's disease is disorientation at three levels: temporal, spatial and personal. Not knowing what day of the week it is, what year, where they live or whom they live with, is common among these people. These three types of orientation are lost pretty early on, making life with Alzheimer sufferers difficult.

We will provide an overview of each of the three types of orientation:

Temporal orientation

Alzheimer patients will start to lose all notion of time, not recognising the exact date, month and year but they do know what day of the week it is. As the disease progresses, they will become more disoriented about the date (and even confuse the year) and day of the week and subsequently will not recognise any of these, not even knowing what time of day it is.

It is good for Alzheimer sufferers to have an organised daily routine; getting up and going to bed at the same time, doing the same thing, having lunch at the same time etc. However, this may increase their temporal disorientation as doing the same thing everyday makes it difficult to know what day of the week it is (eg their routine will not change because it is the weekend).

Because of this temporal disorientation, the patient may make mistakes in certain activities of their daily living such as when they get dressed. They may not know what time of year it is and may wear summer clothes when it is winter and viscera. In addition, they will not know if they have to eat, if they have already eaten or exactly how long ago they had a shower.

Spatial orientation

They start to become disoriented when they are driving or when they are walking in places which are not very familiar or well known and they get lost. For example, they get lost when going to pick up their grandchildren at school, they get the school or house wrong, etc. Although they have already visited these places before, they have not spent much time there and as their ability to remember declines, they are unable to recall this very new memory.

They will subsequently get lost in places which are better known like in their own neighbourhood or nearby neighbourhoods, with which they are more familiar. They do not know where the stores are to do the shopping or the park where they spent the afternoon with friends.

Because of this loss, Alzheimer sufferers stop going out of the house alone because the patient is afraid and refuses to and the family decides they are no longer capable. The patient will only leave the house when they are accompanied by family or a close friend. Physical activity will decline and physical problems may appear earlier unless there is appropriate stimulation.

Finally, they become disoriented within their own homes and do not know where the rooms are (bedroom, bathroom, kitchen etc).

Miguel is in a moderate stage of the disease and lives with his niece Rosa. She explains that although he has lived in the house for five years, whenever her uncle needs to go to the bathroom he asks her where it is and she has to take him.

In addition to the above, they do not

know where they are, in what town, in what house. Many talk about the town where they were born or spent most of their lives or childhood and not the city where they currently live.

M^a Teresa lives in Madrid with her husband who has Alzheimer's. She says that almost every week, Luis gets upset because he wants to go home. When she tries to explain that this is his home, he becomes distressed and starts to cry. The house he remembers as his own is where he used to live when he was young.

Personal orientation

Already in the moderate stages of the disease, Alzheimer sufferers stop knowing who they are.

They do not remember or recognise their tastes and likings, where they have worked or who their family and friends are. They forget they have grandchildren, children, a spouse etc. And they are unable to assign a role to the people they come into contact with (they do not know who the doctor is, the neighbour, their daughter etc).

76 year old Juan has Alzheimer's in a moderate stage. When we ask him what he does every day and what his life is like, he replies as if he were much younger, single and his wife were still his girlfriend. He makes no mention of his children or grandchildren.

3.4. Attention

Attention is the capacity to voluntarily apply understanding to an objective and take it into account or consideration. We can also define it as a quality of perception that works as a kind of filter of environmental stimuli, assessing those that are most relevant and prioritizing them for detailed processing.

This cognitive function is impaired in people with Alzheimer's. They suffer from what is known as aprosexia which may be defined as an individual's inability to sustain attention, owing to a senso-neural or mental disorder.

José visits his grandmother frequently at the care home where she was admitted a few months after she was diagnosed with Alzheimer's. Whenever he is with her, he tries to stimulate her through games, music, cards etc but his grandmother is unable to go on with the same exercise for more than 5 minutes. As soon as Jose becomes distracted, she gets up and starts doing something else or loses concentration by looking at the people moving around her.

This loss of the ability to fix attention for a certain length of time will mean that the person is unable to carry out a specific activity or is unable to complete it since as soon as they start it, they will become distracted.

Although Alzheimer's disease triggers this loss, there are factors that help sustain attention during an activity or task.

These include both external and internal factors.

External factors

- **Strength of the stimulus.** The stronger the stimulus, the greater the attention that we pay (strong and bright colours, loud or cheerful songs, activities involving movement etc).
- **Size.** As in the case of strength, the larger the stimulus, the more it will get our attention. Using large balls, letters or boards may be an option.
- **Repetition.** A weak stimulus repeated several times over may have a significant impact, eg., repeating movements in gym exercises (raising arms, legs ten times etc.).
- **Contrast.** When a stimulus contrasts with surrounding stimuli, it calls more attention.
- **Moving the stimulus.**

Internal factors

- **Emotion.** Those stimuli that trigger emotion call our attention much more. A clear example of this is the use of music to stimulate Alzheimer patients.
- **Interests.** Tasks related to our interests and motivation will call our attention more and increase the benefits. Getting some to carry out activities voluntarily, with that internal motivation, is very important.
- **Social suggestion.** Seeing others doing the same thing, invites the patient to get involved.

M^a Jesús goes to an Alzheimer's Day Centre every day. She objects to participating in activities and when she does so, she spends no more than 10 to 15 minutes in the room with her colleagues; she says she's tired and does something else. However, when they have their sewing workshops (she was a dressmaker), she can spend hours in the room without a break or becoming distracted.

3.5. Agnosia

Agnosia is defined as the inability to recognise the world around us through our senses (sight, smell, touch, taste and hearing) without them being damaged or altered. It is the failure to recognise faces (including in the more advanced stages, our own), colours, tastes, objects etc and what they do.

Today is Nieves' birthday and her two grandchildren have bought her a framed photograph of the three of them together. When she receives the photograph, Nieves doesn't recognise herself and even exclaims excitedly "Just look, it's my mother"!

Apart from not being able to initially recognise people patients are less familiar with and subsequently those they are more familiar with, it also means that they are unable to recognise the food they are eating, they are unable to adapt to spaces they do not know as they do not adequately recognise the layout (they may trip or knock against something and fall), they may not recognise the different parts of their body as theirs or their feelings about their bodies, they may not know that what there is in the bathtub is a sponge and soap and what they are used for, meaning that they may not wash properly or just not wash at all.

Visual agnosia

Alzheimer sufferers will be unable to recognise graphic images (daily objects, photographs, letters and numbers, associate images and words etc), faces (of the people around them, family or well-known characters), forms (large, small, square, round), colours (light-dark, the colour of an object or what an object or colour is called) and will also find it difficult to organise space, time and perception.

Tactile agnosia

Problems appear in recognising embossed figures, distinguishing textures (rough, smooth), the hardness of objects or identifying daily utensils through touch.

Auditory agnosia

Difficulties arise in differentiating sounds, recognising each of them and evoking others (animals, instruments etc) or imitating them.

Agnosia affecting the sense of smell and taste

Difficulty or impossibility of differentiating and recognising smells (cologne, water etc), if something smells good, bad or does not smell and also in tasting food (salty, sweet) and knowing what they are eating.

3.6. Apraxia

Apraxia is the loss of the ability to carry out voluntarily purposeful gestures or movements. As in the case of agnosia, the person retains the strength, sensitivity and coordination needed to carry out the action and their desire to perform it.

We can differentiate various types of apraxia:

Ideomotor apraxia

Ideomotor apraxia is characterised by the inability to carry out simple spontaneous gestures by either following orders or imitation, eg, waving good-bye, making the sign of the cross, imitating brushing one's hair, etc.

Sara works in a home for the elderly where most residence have Alzheimer's. Every day when she leaves she says goodbye and asks them to wave her good-bye. She sometimes waves to remind them. Most residents are unable to perform this action.

Ideational apraxia

The person is unable to carry out a sequence of interrelated movements or gestures and may be unable to make adequate use of daily objects, eg. take books out of a box and place them on a shelf or take the key out of a box, put it in a lock and turn it.

Before having Alzheimer's, Ana worked all her life as a secretary for the family business. Her work was to tidy paper., She was responsible for the mail and she handled phone calls. When we now ask her to put a letter in an envelope, she cannot do so correctly. She takes the paper and tries to put it in the envelop without folding it (she is unable to open the envelop and at the same time put the letter in it).

Constructional apraxia

Constructional apraxia is the inability to build in space, such as an inability to write, draw, do puzzles etc.

This symptom makes people very dependent when it comes to their daily living activities as they will be unable to dress themselves, take a shower, wash or eat by themselves. They will be unable to carry out the necessary movements to complete those actions.

In the final stages, it may mean that they are unable to open and close their mouths, swallow correctly etc.

3.7. Calculation

Alzheimer sufferers' ability to carry out calculations will also become impaired. First of all, they will lose the ability to perform the most complex processes such as problem solving and later, the simpler processes such as the ability to carry out simple arithmetic (additions, subtractions, multiplications and divisions). They will also be unable to provide a numerical estimate of things since numbers lose their symbolic value.

All this means that they are unable to do the shopping since they do not know how much things cost and do not understand how much they have to pay or the change they need. They will be unable to add, subtract, count forward or back, order numbers from largest to smallest etc.

3.8. Body image

Our body image is how each of us views our own body, be it at rest or in movement. It is also the knowledge that we have of our body in relation to its different parts and to space, objects and the people around us.

This conception of the body, its position and its different parts becomes impaired in Alzheimer patients. Concepts such as left, right, in front, behind, close to or far from will lose all meaning.

The person will start having trouble moving in space, finding their position with respect to others and objects (and therefore runs the risk of falling or not reaching what they need).

In addition, they will lose the notion of the different parts of their bodies and the feelings that they generate. The person may therefore put clothes on wrong or not wash properly.

In the more advanced stages, it is usual to see these people also lose control over their posture and they walk, sit or lie in an ungainly manner. For example, when they are sitting in an armchair, their bodies may be leaning completely to one side or they may be hunched forward.

Summary of the cognitive symptoms of Alzheimer's disease

Síntomas cognitivos

Memory loss	Loss of most recent memories, retaining more distant memories
Loss of ability to communicate	Difficulty finding the right words, holding a smooth conversation, understanding orders, reading and writing
Disorientation	Three types: spatial, temporal and personal
Aprosexia	Inability to fix attention
Agnosia	Difficulty in recognising external stimuli received through the senses without their being damaged
Apraxia	Inability to carry out purposeful movement. Three types: Ideomotor, Ideational and Constructional Apraxia
Loss of ability to carry out calculations.	First of all, inability to solve complex problems and handle money and subsequently to carry out simple arithmetic operations
Pérdida del esquema corporal	Loss of own body image, different parts and positions on the body with respect to other parts

Content

4.1. Working on memory

4.2. Working on language

4.3. Working on orientation

4.4. Working on attention

4.5. Working on agnosia

4.6. Working on praxis

4.7. Working on the ability to calculate

4.8. Working on body image

Chapter 4

Working at home to strengthen the mind

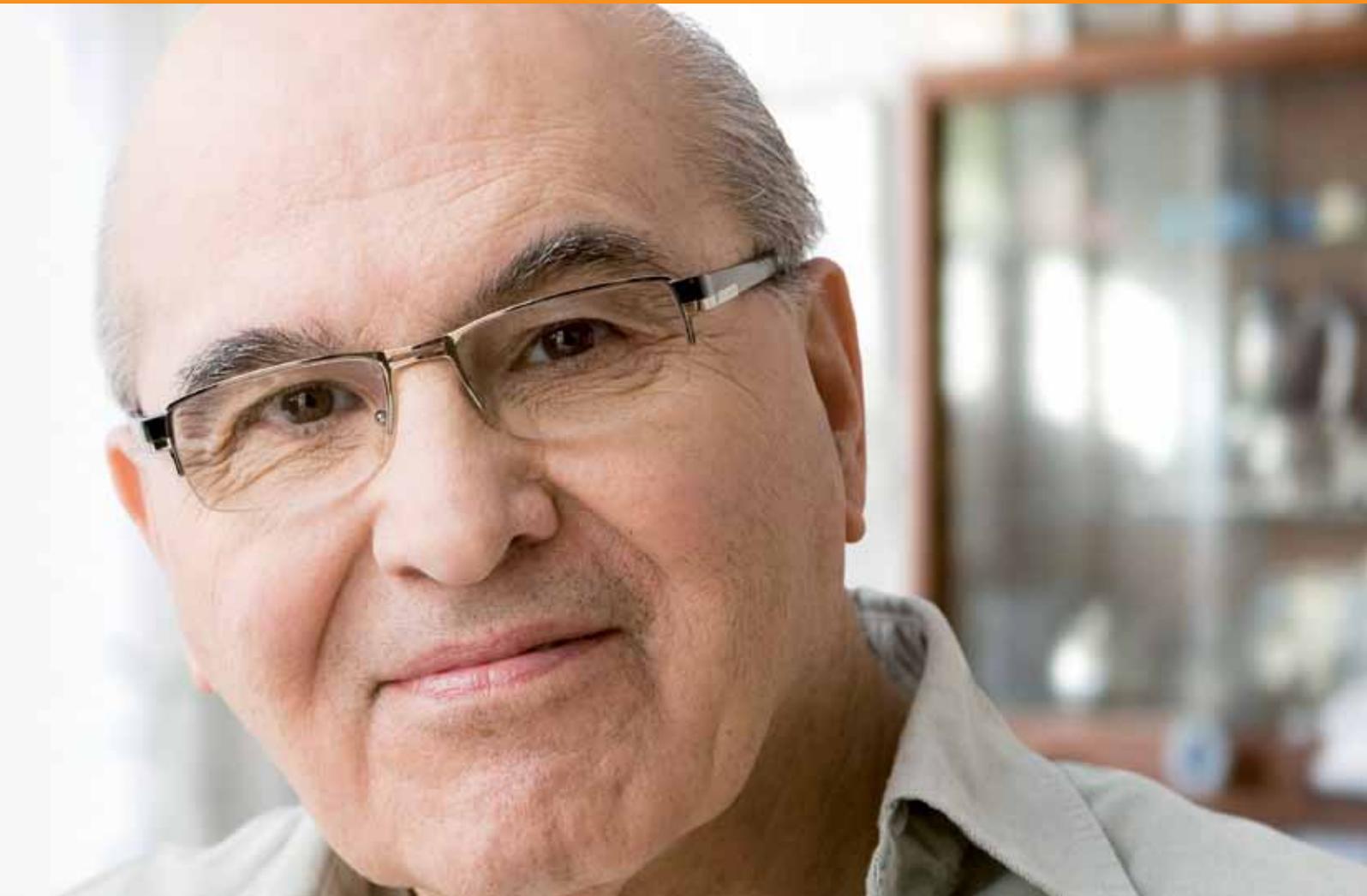
Cynthia Pérez Muñano.
Occupational therapist

After having described the symptoms that appear in Alzheimer's disease, we need to treat them. We have to control them, insofar as it is possible in order to slow the progression of the disease.

There are currently different drugs aimed at controlling or improving these symptoms. However, there is evidence of the good results of combining them with non-pharmacological therapy. Physical and cognitive stimulation is advisable to slow the progression of the disease and also help control behavioural disorders and mood changes.

The objectives pursued are:

- Slowing the progress of the disease by stimulating the cognitive abilities which the patient still has.
- Keeping the cognitive abilities that are already impaired in order to slow their loss.
- Maintaining the maximum functional level and independence possible when it comes to daily activities.
- Encouraging physical mobility to a maximum (arms and legs, wandering around, transfers etc).
- Improving/ maintaining the correct posture.
- Avoiding falls.



- Reducing pain.
- Encouraging social and leisure skills.
- Giving the patient something to do and making them feel useful.
- Improving their state of mind.

Generally speaking, the aim is to ensure that the person has the best quality of life possible.

Before starting, there is something that has to be made clear: in Alzheimer's disease, the cognitive loss will be gradual and there is currently no cure. Therefore, with respect to the cognitive symptoms which we have talked about

and often when it comes to the functional and physical symptoms, the aim will be to slow the progression of the disease. We cannot, however, aim to recover those functions which are lost.

There are certain exceptional cases where patients' lives will be improved such as for example when they have spent time in hospital or in bed as in such cases, their day to day stimulation is less and many of their daily activities are carried out by someone else for them.

Having said this, it should also be noted that it is often the actual family, professionals or people close to patients who make them more dependent than they really are. Someone who is suddenly diagnosed with Alzheimer stops being a person and becomes a patient and often what the person wants, needs or can do is no longer taken into account. Other people around them, moved by feelings of sadness, affection or fear may become overprotective and refuse to let the patient do things they can still do for themselves.

Nuria goes to her grandmother's every day to help her with the housework. At lunch time, her grandmother no longer knows how to cut her food with a knife and fork. Nuria, who can see how her grandmother is getting weaker and weaker, in order to save time and stop her food getting cold, cuts her meat up and at the same time feeds her.

What we have to do is to try to ensure that our loved one continues to do everything possible for themselves and helps us or is involved as much as possible in those activities they can no longer handle alone. We can ask them to help us cut, peel or prepare different foods which we need for lunch, to fold the clothes that we have ironed or simple items such as towels, to separate whites from coloureds for the washing machine, to help us make the shopping list and keep the accounts or to lay the table or make the beds with or without our supervision.

In short, the patient needs to be kept busy and made to feel useful. This will in turn provide physical and cognitive stimulation.

If we take it symptom by symptom, we can stimulate our loved one with different types of activities. Although we are going to look at different kinds of exercises, it should be noted that one same exercise may work various cognitive functions at the same time and not only memory or attention, for example.

4.1. Working on memory

As we have already seen, memories in Alzheimer sufferers will be lost in a somewhat peculiar fashion. We will have more trouble recalling our most recent memories than those distant events related to our past lives, work, youth, childhood etc.

When stimulating memory, we can differentiate activities aimed at working on remote or long-term memory or recent or short-term memory and immediate memory. It is important to work on the first type of memory in particular as we have to try to preserve those distant memories for as long as possible, delaying their loss as the disease progresses.

We suggest different activities for these two types of memory:

Immediate memory

- Repeating lists of words.
- Repeating what is said on television or in the paper.

Short-term memory

- Games such as "Memory", where you need to look for image pairs. The game will have to be increasingly simplified and cards will have to be removed or the rules changed (instead of looking for pairs with the cards face down, looking for pairs with the cards face up and trying to remember where they are when they are turned face down).
- Reading news in the newspaper, watching the news and telling a story and after a while, recalling the news or asking questions about it.
- Showing the patient photographs, pictures from magazines, drawings and after a while, asking them to remember as many things as possible.
- Remembering daily events (previous

day's dinner, weekend activities, people they have seen during the week etc).

Long-term memory

- Gathering personal details (name, surname, address, telephone number etc).
- Biographical memories. Remembering and placing the most important memories of their past life. Preparing a diary (name, date and place of birth, family members etc).
- Remembering places or people from the past through photographs or videos.
- Talking about work, where they lived, school, games they played when they were children etc.
- Remembering the past through objects (clothes, pictures, games, kitchen tools etc.).

4.2. Working on language

In order to help our loved one hold on to their language ability, particularly spontaneous language and comprehension, we have to take advantage of daily activities, the times we spend with them and the stimulation activities we perform, talking them through them and thus attempt to avoid the loss of language.

There are different exercises to stimulate this function.

Verbal language

a) Automatic language

- Saying the months of the year, seasons or days of the week.
- Calling up numerical series (counting from 0 to 10, from 10 to 0, etc.).

b) Denomination and evocation

- Naming the objects that appear in photographs.
- Defining words (both those to be defined by the patient and those they have to guess).
- Saying words that begin with a particular letter or syllable (words beginning with a C or CA).
- Incomplete words.
- Classifying words (names of fish, flowers, people or objects that we can find in a kitchen, bedroom etc).
- Synonyms and antonyms (the opposite of clear is...)
- Associating words (sock – foot, summer – heat, apple - fruit.).

c) Spontaneous language

- Holding conversations on subjects of interest to the patient and which make them want to talk.
- Showing them photographs or pictures or drawings and asking them to tell us what they see, to describe it.

d) Repetition

In the more advanced stages, when previous language has been lost, we stimulate its production through repetition, adapting each exercise to the patient's deterioration:

- Repeating phrases.
- Repeating words.
- Repeating syllables.
- Repeating letters and numbers.

e) Comprehension

- Giving simple orders and have them carry them out.
- Using non-verbal language to understand such orders (when we go to the dining room, saying what we are going to have to eat and making the gesture with our hand).

Reading and writing

a) Reading

- Reading exercises (paragraphs, syllables or letters).
- Reading comprehension. Writing orders and having them carry them out when they read them (eg, raising their hands).

b) Writing

- Writing exercises (writing, dictation, copying phrases or words, handwriting exercises, writing names and surnames). It will be important to stimulate the patient to sign just in case they need to sign an official document.

In addition to all the above, there are certain guidelines to encourage appropriate communication such as on the use of non-verbal language, repeating orders to the patient or waiting for a prudent period of time for them to reply. We will provide further details later.

4.3. Working on orientation

Temporal, spatial and personal orientation will become impaired very early on in Alzheimer sufferers. As mentioned earlier, recovery of lost functions will be complicated (not to say impossible) and therefore stimulation in this respect should be carried out in a passive manner.

For example, if we look at temporal orientation, there is no point in asking the patient for an hour what day of the week it is, the date etc as they will be unable to remember. In the same way, there is no point in repeating today's date for that hour. We should provide them with the information without having to tell them constantly.

Temporal orientation

- Placing a calendar in the room where the patient spends most time, indicating the day of the week, the date, month and year so that they can see it without having to ask. We can also show them the season.
- Decorating our surroundings to reflect the season, spring, summer, autumn or winter.
- Association work: in summer we wear light clothing, in winter, we wear coats, in autumn, the leaves fall, in spring, flowers grow etc.
- Arranging parties, meetings or meals related to the time of year. At Christmas, we sing Christmas carols, at Easter, we eat Easter eggs, etc.

Spatial orientation

- We can use the aforementioned calendar or another specific calendar to help the patient remember the town where we live, address etc.
- Using signs (with words or drawings)

for the different rooms of the house to make it easier to find them.

- Using signs in rooms to help them pick up and adequately store objects (identifying each drawer in the cupboard, indicating where the cutlery or glasses are in the kitchen etc).
- At night leaving the bathroom light on, helping them to find the bathroom alone.

Personal orientation

- As with long-term memory, creating a diary, showing their name and surname, place of birth, school and friends, youth, work, spouse, children etc. It may be accompanied by photographs to help them recognise things or subsequently people..
- Preparing a family tree with photographs.

We will take advantage of situations to encourage the Alzheimer patient to participate and help their orientation (calendar, diary, photograph cut-outs etc). We will also help the patient to exercise physically, we will work on praxias and attention by using scissors to do the cut-outs and we will help keep the patient busy, doing something for a reason, helping them feel more motivated and cheerful.

4.4. Working on attention

As mentioned, the ability to sustain the attention of Alzheimer patients is severely impaired by the disease. If we work in a group, we should look to carrying out one-hour sessions since stimulation is smoother. Conversely, if we work individually, 10 or 20 minutes will be more than sufficient time for stimulation as otherwise the person will get tired. We will have to leave time for a break and subsequently start another activity, without overloading them.

While they are concentrating on an activity, Alzheimer patients are stimulating their attention. However, there are some more specific exercises if we want to work this cognitive function

- Searching for specific items from a group of varying items. For example, searching for all the suns on a page with different pictures (suns, stars, moon, clouds etc). Different items can be used depending on the patient's level of impairment or education, including a list of letters (circling all As on the page), numbers, colours, forms, objects etc.

- Carrying out the above activities verbally since the elderly also have sight problems and will have trouble identifying images on paper. For example, saying a list of letters and clapping whenever they hear a B. This type of activity can also be performed using daily objects such as television (they can tell us whenever there is an advert), the radio (clapping whenever they hear the word I or you) etc.
- Searching for a specific object in a photograph or drawing. For example, looking for a picture where there is a dog or bird).
- Looking for differences between two images.
- Solving a maze.

4.5. Working on agnosia

We will work on recognising faces, objectives and their properties (form, colour, texture, smell etc) through our five senses. The aim will be to show the patient how to identify the objects and then use them. To help them know what the objects are for, we show them, for example:

Sight

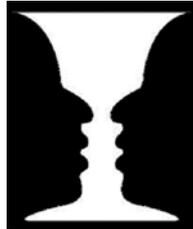
- Recognising graphic images. Photographs or drawings of fruits, utensils, clothes, household furnishings, monuments, etc.
- Recognising images from shadows or outlines.
- Recognising letters and numbers.
- Discriminating figures-background. For example, differentiating the faces

of two people who are face to face and the goblet they form.

- Recognising colours from a list. For example, asking them to identify red.
- Asking what colour the image or object we are showing them is.
- Separating images or objects



according to colour, form or size. For example, separating kitchen utensils as long or round, separating chickpeas by size, separating objects that are the same colour, etc.



- Searching for similarities or differences in a picture. For example, in a list of drawings, selecting those that are the same.
- Recognising the faces of well-known people. Saying their names or describing some characteristic that identifies them (whether they are actors, sportsmen etc).
- Recognising the faces of the people around them through photographs.
- Recognising facial expressions (sadness, joy, surprise).

Sense of touch

- Recognising daily objects (spoon, pencil, glasses etc) through touch. mediante el tacto.
- Recognising embossed numbers and letters.
- Differentiating the texture of objects (smooth, rough, sharp).

Hearing

- Recognising sounds, whether cows mooing, sheep bleating, bells ringing, a car, coins etc.
- Evocating and imitating sounds, imitating the mooing of a cow, the barking of a dog, imitating the sound of a motor bike or a car accelerating, for example.
- Recognising songs.

Smell and taste

- Recognising food by its smell or taste.
- Differentiating salty, sweet, bitter, acid etc.
- Recognising smells (flowers, cologne, and air-freshener).

When working on recognition, differentiation or evocation, it would be advisable to use those objects, images, sounds, foods or smells that are most present in the patient's day to day life, helping them to arrive at and hold on to their awareness for as long as possible.

4.6. Working on apraxia

Alzheimer sufferers will have trouble carrying out purposeful movement in their daily activities, i.e., they will suffer apraxia. They will need help from those around them to carry out such simple tasks as brushing their teeth, getting dressed or using the phone.

Our loved ones will gradually become slightly more dependent and will need our help with these activities in some way. However, our helping them does not mean that we do things for them. We have to offer them the minimum assistance that they need for them to complete the task alone.

Although we will go into the subject of the assistance we can provide later, an example is the use of technical aid or adaptations or reminding them from time to time of what they have to do or start the movement and let them finish it afterwards.

Josefa can feed herself but after three or four spoonfuls she stops for a rather long while. Her daughter says she gets stuck. The situation is solved by reminding her that she has to eat and has to put the spoon in her mouth.

At other times, Bea (her daughter) takes her hand with the spoon and takes it to her mouth and Josefa goes on eating. There is no need for anyone to feed her.

In these cases, the kind of exercises are “do as if...”, and they have to do it. Better if we give them the necessary tools to carry out the action or we take them to the room where the activity is normally conducted. If we tell them to do as if they were putting the washing out on the line, we should provide the pegs or, if possible, take them to the clothesline.

Ideomotor apraxia

- Asking them to perform simple movements such as brushing their teeth, combing their hair, buttoning their shirt, waving hello. We will take every opportunity to carry out daily activities and help them do them for longer.
- Imitating simple gestures.

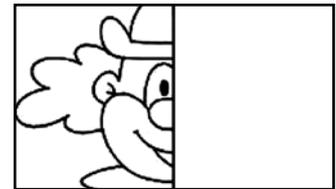
Ideational apraxia

- Asking them to carry out an entire sequence of movements. For example, washing their face (turning the tap on, wetting their hands, taking soap, stroking their face, rinsing their hands, collecting water in their hands and lifting it to their mouth, turning the tap off and drying themselves with a towel).

Constructional apraxia

- Doing puzzles.
- Copying drawings or figures.
- Completing an unfinished picture.

- Drawing pictures or simple figures (a square, circle, tree, watch, etc.).



- Copying parts of drawings: symmetrical shapes.

With these stimulation exercises (and this recommendation can be extended to other activities), we should carry out those activities that most motivate our loved one. Exercises connected with their work, hobbies and leisure activities may well be very beneficial. We can carry out sewing, cooking, carpentry, craft work, modelling activities etc.

4.7. Working on the ability to calculate

The loss of the ability to make calculations will mean that the Alzheimer patient quickly loses the concept of numerical value. Their ability to perform functions such as doing the shopping, using transport or carry out any other activities that entail handling money, will therefore become impaired and they will be unable to carry them out alone.

The stimulation activities that we can carry out are:

- Solving mathematical problems. The difficulty should be adapted to the patient's deterioration. For example, "We have all this fruit at home: 3 pears, 4 apples, 2 kiwis and 5 oranges. There are two of us living at home. We are going to share out the fruit in such a way that we both have the same". Or to put it more simply, "We have a box of 20 oranges. Your younger daughter wants 2 and I want 4. How many oranges are left?"
- Simulating or carrying out calculations at home before going shopping. Seeing how much money they have and using advertisements, choosing what to buy and what not to buy, how much change they will receive etc.
- Carrying out simple sums: additions, subtractions, multiplications and divisions.
- Ordering numbers according to their numerical value (the largest to the smallest for example).
- Recognising even and odd numbers.
- Counting by twos or threes or subtracting.
- Counting from 1 to 10 or 10 to 1.
- Using games such as bingo or tiddlywinks, where they have to count.

4.8. Working on body image

We will try to make the person aware of the different parts of their body and the sensations deriving from them in order to improve postural control.

For the parts of the body and their distribution, we can do the following exercises:

- Identifying the part of the body where each item of clothing goes.
 - Reminding them of the different parts of the body through massages, movement or when we are showering them: "We are washing your right arm, this is your right arm. And now your right hand. These are your fingers, we move them".
- In order to help control posture, initially we can use a mirror to help. We can sit the patient in an armchair or chair in front of the mirror and ask them to adopt the correct posture, straight, without falling sideways.
- Once they have the right posture (with or without our help), we will ask them to concentrate on the sensations, the weight on their buttocks which should be similar
- in each half of the body, the support of their legs, the position of their shoulders etc. This will help them to sit properly by remembering the feeling.
- This process is really complex and our loved one will soon adopt incorrect postures. It is up to us, their families, friends or professionals, to help them sit up straight and not slouch, using cushions, towels etc which we will place around them.
- Asking them to touch different parts of their body: ears, nose, mouth, tummy etc.
 - Issuing instructions to move parts of the body: raising their right hand, touching their left ear with their right hand, picking up the piece of paper in front of them or to their left with their right hand etc.
 - Showing them a drawing of a human figure and asking them to point to different parts of the body.

4.9. Sensory stimulation

During the advanced stages of the disease, it becomes more difficult to carry out the cognitive exercises that we have seen up to now. Our loved one does not respond to any of the stimuli mentioned above, is unable to carry out any actions or communicate with those around them.

At this stage we propose sensory stimulation. It is not a matter of their recognising the sounds, objects, colours etc as in agnosia but rather to “awaken” their senses. We can do this by:

Sight

- Presenting bright stimuli, both directly or indirectly (eg by shining a light on the wall)).
- Presenting objects, images or brightly coloured lights.
- Presenting moving objects, images or lights.
- Presenting moving objects or lights for them to follow with their eyes.

Hearing

- Presenting sounds (a bell, for example) outside the patient’s field of vision. We can change the intensity, duration of the sound or how close we ring it.
- If they can still walk alone, we can hide and call them by name to see if they recognise where we are and can follow us.
- Presenting sounds both basic (bells, drums, animals etc) and different more complex sounds, such as music and tunes.

Music can help stimulate or relax the patient and is an important tool when

working on their state of mind. We generally associate music with leisure activities. The elderly will remember village parties, fetes etc and will not feel that we are evaluating them. Moreover, with music we not only work on sensory stimulation since other aspects such as memory, language or physical mobility also benefit.

We will have to adapt to our loved one’s tastes and use songs that they like. We can draw up a list of their favourite songs or music together with them and the people close to them, although in the advanced stages where the person is no longer able to answer, we can work with the songs or music of their time.

Sense of touch

We can pass objects over our loved one’s arms, back, legs, face etc. We can use:

- Objects with different textures: rough, smooth, bumpy, etc.
- Objects, liquids or meals at varying temperatures.
- Large objects with a rougher feel (giving a massage with a rubber ball) or small objects for a finer touch (the tip of a pen or two of our fingers).

Taste

We can give them different food, fruit, drinks etc. Different flavours: bitter, sweet, acid and salty. It is important to give them the softer flavours first and end with the strongest in order to avoid disguising the softer flavours and give them water to drink to avoid mixing flavours.

Smell

Presenting different smells (under both nostrils together or each nostril separately). We can use meals and food, as we have described above, cologne, plants at home or which we find when we go out for a walk and introduce smells related to the past, such as the cologne that they used to use, smells related to their work (wood, painting, books), etc.

Again we should leave the strongest smells to the end.

4.10. Physical stimulation

In addition to cognitive stimulation, it will be important to stimulate our loved one's physical ability. Although initially the changes take place in the brain and cognitive functions are affected, they will subsequently have problems walking properly or moving different parts of their body. We will therefore have to work with them to avoid these abilities being lost early on.

Walking

It is important that patients are able to walk alone for as long as possible. We should take frequent walks with the patient and try to avoid them having a sedentary existence. We should pay special attention to their knees as they will lift them less and start dragging their feet, increasing the risk of falls.

At some time in the progression of the disease, they will need the help of a walking stick, a walking frame or finally a wheelchair. We should try to delay the possible use of these devices for as long as possible and they should always be used under professional supervision. Nonetheless, we should try to make them walk alone or with someone's help at different times. For example, there are people who will need a wheelchair to go out as they cannot walk far. We can use a wheelchair to take them out but at home they should be encouraged to walk (from the lounge to the kitchen, from the kitchen to the bedroom, from the bedroom to the lounge etc) without a wheelchair.

Active movements

We should also stimulate the movement of all parts of the body to ensure that joints are as flexible as possible as this will help our loved one to be more independent day to day for longer.

As we have already mentioned above, we should let them help us around the house and we can also plan gym sessions. During gym sessions, we can work on moving all body segments. Generally this is done while the patient is sitting and each movement is repeated 10 or 15 times, starting with the head.

- Head /neck: Moving their head up and down (saying yes), to the sides (saying no), touching their shoulder with their ears and making a complete turn
- Shoulders: moving shoulders back and forward, putting arms up and down, opening and closing their arms, making circles with their arms.
- Elbows: Folding elbows (touching shoulders with hands).
- Hand/ wrist: turning wrists, palms up and down, opening and closing hands, separating figures.
- Torso: lateral movements (inclining the body to the left and right), turning the torso to both sides.
- Hip: lifting both knees at the same time or separating and crossing their legs at the same time.
- Knees: bringing their feet up and down.
- Feet/ankle: turning ankles inward and outward, bringing feet up and down or stretching them and moving toes.

At the end, we can suggest that they stand up and sit down 5 or 10 times.

Passive movements

In the advanced stages where the person is no longer able to move alone, it will be us who we will need to move their limbs, following the direction of each joint. This will help the patient remain physically mobile and avoid them pain and the atrophy of their limbs.

Movements should be slow and consistent and initially small in order to let the body adapt and warm up. Once we reach the limit, the movement should be repeated before we pass on to the following joint.

Movements should stop if there is pain. The aim is not to force the patient but to help movement.

During the exercises, we could name each part of the body that we are manipulating to make the patient more aware of the sensations deriving from it.

Massages

Similarly, it will be important to massage patients in the more advanced stages of the disease. As they are unable to move, circulation problems or stiffness may appear and limbs may retract. Massages should always be gentle, in one direction and superficial. We should use moisturizing cream for our hands to move smoothly and avoid causing pain.

In addition to improve that they bring about, massages also have a relaxing effect and are a manner of stimulation through touch and of communication between the caregiver and patient, strengthening the bond between them.

All this stimulation (both cognitive and physical) should be carried out regularly although it is also important to let the patient rest. A routine

should be created and the same type of activities should be carried out every day, always in the mornings or afternoons, as with other day-to-day activities.

The symptoms of the disease will appear slowly but we can keep our loved one stable for some time and delay their onset as the disease advances.

Content

5.1. Difficulties in our relationship with our relative

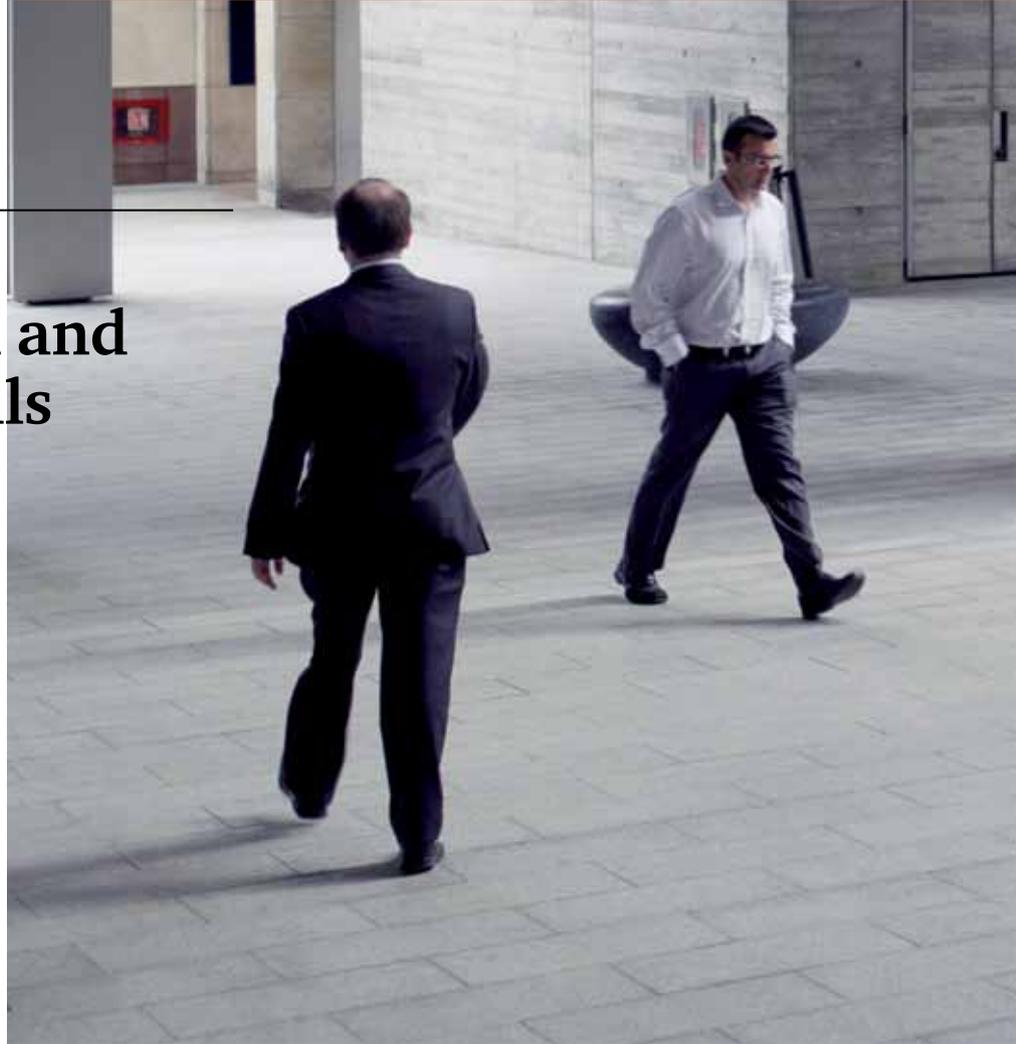
5.2. What to do in order to build a good relationship and communication

5.3. What not to do in order to build a good relationship and communication

5.4. Other matters to be taken into account in body communication

Chapter 5 Communication and relationship skills

Cynthia Pérez Muñano.
Occupational therapist



We have already seen how Alzheimer patients will have problems in communicating with others and are often aware of this difficulty. Conversation will become harder and they will lose the initiative to communicate with us, often in order to conceal their own disability. In addition, because of this difficulty in expressing or understanding orders, patients may become distressed or approach us with some degree of anxiety. We have to be prudent when we communicate since, if our attitude is too disciplinary, cutting or

alarming we can increase their feeling of anxiety.

It is necessary to take these issues into account in order to attempt to stop them and build a good relationship between the patient and their family as this will be the basis of the work we will do after. If there is a good relationship, the chances that our loved one will be willing to collaborate with us will increase and we will find it easier to achieve the objectives pursued.



If we establish this relationship correctly, we will not only improve the care of our loved one but also avoid any negative feelings that could arise (anxiety, irritation, anger etc). We will avoid their isolation and allow the m to go on receiving recognition and the affection of others and let them feel that they belong.

In this respect, we will need to be aware of the problems that may arise in the relationship, the positions we

should adopt and just as importantly, know the attitudes we should avoid when we approach them.

5.1. *Difficulties in our relationship with our relative*

Everyone is different and patients will suffer different disorders and symptoms will appear at different stages during the disease. It is important to be aware of some of these difficulties so that we see them as part of the disease and do not take them personally. As we have already said, we have to get thoughts such as “*he does it to annoy me*” or “*he doesn’t like me*” out of our heads and build a good relationship with our relative, avoiding negative feelings about them.

The difficulties that may affect Alzheimer sufferers include:

- Unwillingness/ reluctance to talk.
- They are unable to find the right words in the middle of a conversation and therefore the conversation is regularly interrupted.
- They are unable to hold a logical conversation or build meaningful phrases.

- They lose the thread of the conversation. They constantly jump from one subject to another without any sense.
- They do not sustain attention.
- They repeat things several times over.
- They become noticeably distressed when they hold a conversation or try to communicate. Feelings such as impotence may make someone more irritable.
- They lose the ability to understand. They no longer understand even simple orders such as “*let’s get up*”.
- They do not reply to what I’m asking.
- They say nothing.
- They do not allow anyone to get close to them and touch them.
- They appear irritable whenever anyone goes near them.

5.2. *What to do in order to build a good relationship and communication*

As we have just said, everyone is different depending on their personality and life experience. Therefore, there will be no one way in which sufferers handle their disorder and how we should approach them. Instead, we will have to understand them personally and know how to approach them. Slowly we will discover small tricks in order to relate to our loved one and respond to different situations.

But there are several measures that we should adopt in order to help both parties to communicate.

a) Approaching the patient

- Warning of our arrival or entering the room by knocking at the door, saying hello, calling out their name or introducing ourselves.
- Approaching the patient slowly and not too abruptly to avoid a negative response, surprise or giving them a fright.
- Establishing visual contact, placing ourselves before them. If they do not look at us, we can move their heads slowly in order to exchange looks. If they continue not to look at us, they probably do not want to

look at us or are not receptive to communicating with us.

- We can use physical contact as we approach in order to increase the sense of security and trust although not everyone likes it. Therefore, if we perceive any gesture of rejection, we should stop the physical contact and go more slowly.
- Explaining what we are going to do at each stage.

b) Verbal communication with the patient

- We will need to pay attention to how the patient talks, if they increasingly use shorter phrases and simpler words since this is how we will have to communicate with them.
- Starting conversations on subjects that the patient likes in order to encourage them to talk.
- Offering simple instructions, breaking an order down into several simpler orders. For example, instead of “*lay the table*”, saying “take the tablecloth”, “now place the glasses” “now place the plates” etc.
- Repeat things as often as necessary for them to understand and remember.
- Prepare direct questions which are to the point and which call for a yes / no answer. We will avoid them wandering off the subject and help them to answer. For example, if we see that they are restless, we can ask “*would you like to go to the bathroom?*” *does anything hurt?* instead of “*What’s wrong?*”.
- If they are unable to find the right words, we can try to help them by offering them synonyms or asking them to describe the characteristics, what it’s like, what’s it for, what colour is it, point it out etc.
- Give them time to reply. When processing information, their brains work more slowly than other

people’s and we will therefore have to wait for a prudent period of time for them to reply. If there is still no reply, we can rephrase the question more simply for them to understand.

- Vocalizing correctly, speaking clearly and slowly.
- Using a pleasant, relaxed and affectionate tone of voice. They may not know exactly what we are saying but just as babies can catch the intonation of “where’s the most beautiful baby in the world?” they will catch the intonation and affection.

c) Non-verbal communication with the patient

- Accompanying conversations with simple gestures. Body language is also important for them to understand. For example, if we say “*please sit here, we’re going to have lunch*”, we can understand but if we accompany it with gestures “come” (moving our hand towards ourselves, asking them to come), “*sit here*” (pointing at the chair), “*we’re going to have lunch*” (we raise our hand to our mouth as if we were eating), we make it easier for patients who have increasingly more trouble because of the deterioration in their health to understand.
- Accompanying the questions we ask with samples of what they should choose. For example, if we ask them “would you prefer a banana or an apple?” showing them both a banana and an apple, we make it easier for them to choose.
- Knowing how to listen and expressing assent when they talk to us.
- Paying attention to their body language to see what’s happening. For example, if the patient is restless, opening doors and touching the lower part of their bodies, they may want to go to the bathroom.

- Showing affection by taking their hand, stroking their face, backs, giving them a kiss etc.
- Being receptive to expressions of affection. In the advanced stages, we cannot communicate verbally with the patient or hold a meaningful conversation or work with them, but we can still enjoy their company through shows of affection. When they touch our face or kiss us, they are also communicating.
- Facial expression: being expressive when we communicate in order to better express emotions such as joy, surprise, sadness, fear etc.

5.3. What not to do in order to build a good relationship and communication

When approaching the patient and establishing communication with them and in order to improve our relationship, we should avoid certain actions as they could generate anxiety or negative feelings. The better our relationship with the patient, the more we will achieve and the more they will communicate and participate.

We should therefore::

- Not argue in their presence or raise our voice since they will in all likelihood become more agitated.
 - Not talk to them in a childish manner as if they were small children. Although the person may be highly dependent in their daily activities and occasionally we can think that they are like children, they are not. We should remember that they are adults and should be treated as such.
 - Not talk to them in a negative manner but using positive statements. Tell them what they can do and how they can help us instead of what they can't do.
 - Avoid having them feel that they are being evaluated since if they perceive that, they will collaborate less with us. This is very common in cases where the Alzheimer sufferer lives at home and we want them to carry out stimulation activities. If the person attends a workshop, day centre or care home, they will probably be more willing to participate as there will be someone in authority telling them what to do. But at home, it is different. It is their relative who tells them what to do or asks them and the patient is not receptive. We should therefore try to attract them to the activity through conversations or work they like.
- For example, if we ask them to read the paper and we ask them specific questions on what they have read they may refuse to answer. We can start a "casual" conversation of the kind "*imagine, I read this in the paper this morning*", to see if they will collaborate.
 - Avoid asking for things and planning activities which are far beyond their ability as we will be asking them to make a major effort, they will not achieve the objective and they will end up feeling frustrated.
 - Avoid expressions of the type "*do you remember..?*", "*who's that person?*", "*look who's come to see you?*".
 - Avoid conversations with the patient and other people.
 - Not force communication when the patient is not receptive.

5.4. Other matters to be taken into account in communication

In addition to the above, there are other measures which may help communication and which we should take into account when we approach the patient in order to have the best relationship possible.

These are:

- First of all, we should check that the person sees and hears correctly and that their difficulty in communicating is not attributable to a sensory processing disorder
- Respecting the patient's silences and times of rest. Like us, they will not always feel like communicating.
- Feeling empathy. It is important that we know how to put ourselves in their shoes to see what they are feeling or why they are behaving as they are.
- Avoiding distractions in the room where we are working or talking with our relative.
- Getting their attention by calling them by name.
- Giving positive feedback when they do something well or give the right answer. Saying "*very well done*", "*go on*" or nodding in agreement.
- Respecting their small everyday things and customs.
- Being patient. As the disease progresses, it will no longer be possible to apply logic and reasoning.
- Be tolerant and do not embarrass them.
- Be flexible.

As we have seen, Alzheimer sufferers will slowly lose their abilities and the activities that we can do or relationships that we can build will slowly decline. We have to be aware of this and learn to enjoy our loved one in each stage. Even in the final stages when it seems difficult to communicate with the patient, we can still do something, supported by non-verbal language and stressing the person's human side, letting them enjoy the contact and affection of the people around them.

Summary of what to do and what to avoid

What we should do	What we should avoid
Announce our arrival and say what we are going to do	Argue or shout in front of the patient
Give simple instructions and repeat things	Talk in a childish manner
Give them time	Speak to them in negative sentences. Better to say what they can do rather than what they can't.
Vocalize and use a gentle tone of voice	Expressions such as "do you remember...?"
Establish visual contact	Force the person to communicate
Physical contact if the person allows	Making them feel evaluated
Important non-verbal language and gestures	
Show affection and be receptive	

Content

6.1. Depression

6.2. Apathy and oppositional defiance

6.3. Anxiety

6.4. Psychomotor agitation

6.5. Erratic wandering

(and risk of escape)

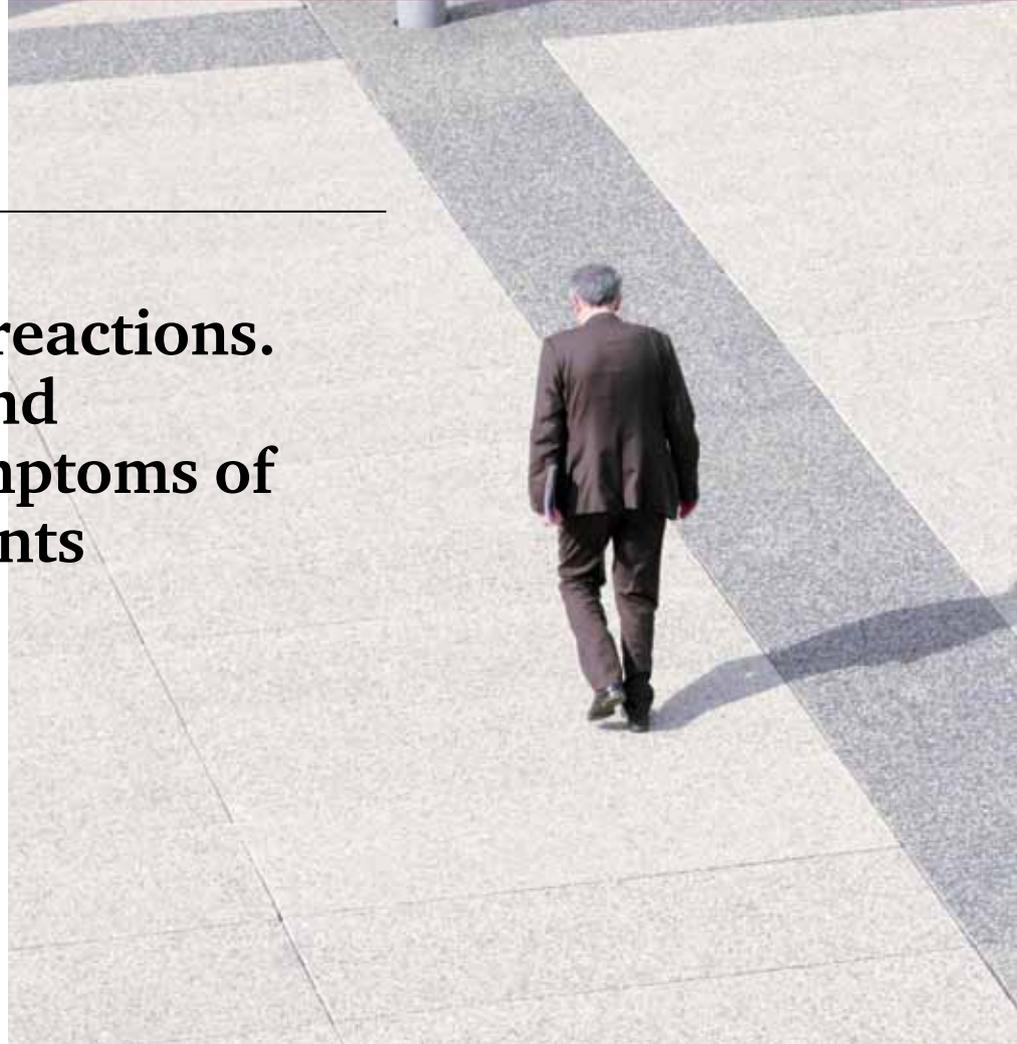
6.6. Aggressiveness

6.7. Delusions

Chapter 6

Understanding reactions. Psychological and behavioural symptoms of Alzheimer patients

Víctor Isidro Carretero.
Neuropsychologist



Perhaps the symptoms that may seem the strangest to the people living around and with the patient are those known as the psychological and behavioural symptoms of dementia (BOSD). It is easier to perceive the cognitive loss or inability seen so far (disorientation, loss of memory, agnosia etc) as signs or symptoms of the disease than the psychological or behavioural problems which it entails.

Behavioural problems are therefore the symptoms which are most difficult to cope with. Occasionally, they can be handled catastrophically by the family, triggering major conflicts within the

group and increasing the burden of the main caregiver or caregivers.

A few years after Paqui was diagnosed with dementia, during which time her children and husband had got used to her not remembering where she put things or being disoriented and having to tell her where each room was, other symptoms started to appear which they all found more difficult to get used to. The first thing that caught the attention of her daughter Esperanza was the day when she arrived at her parent's, like every evening, and found her mother crying bitterly in her room. She had argued with Guillermo, Esperanza's father and Paqui's

6.8. Hallucinations

6.9. Desinhibition

6.10. Euphoria

6.11. Sleep disorders

6.12. Eating disorders



husband. Esperanza was truly speechless when she heard her mother explain how she had seen Guillermo having a fling with the downstairs neighbour. After listening to her for a while and trying to calm her down, she left her alone in her room for a minute and went to talk to her father. Her mother had been so adamant that no matter how much Esperanza trusted her father, she harboured a doubt. Seeing how his daughter believed her mother's story, Guillermo felt offended. He was having the same friendly relationship with the fourth floor neighbour that he had had for the 50 years they had been living in the block of flats. But how could his daughter ever

imagine that he was going to deceive her mother who had been the love of his life?

While they got angry and subsequently apologised for not trusting each other, Paqui came into the lounge and asked them with a big smile what the problem was. Paqui had forgotten what had happened a few minutes earlier and the jealousy delusion had disappeared completely. Esperanza and Guillermo consulted the neurologist and he explained that delusions or irrational ideas are one of the behavioural symptoms of dementia

A behavioural disorder is all behaviour that because of its intensity, duration and / or frequency has a negative effect on the individual's life or social relationships with those around them.

It most often appears in the moderate stage of the disease although some symptoms may appear in the early stages (such as depression, which is more characteristic in the initial stages) or remain until the severe stage. Around 80% to 90% of people with dementia show some behavioural symptoms although there are many differences with respect to their presentation, recurrence and recovery.

The onset of cognitive symptoms that have not been properly treated may lead to the appearance of behavioural problems. For example, someone who is disoriented in space, does not know where they are and does not receive an answer to their request for information or help, may end up wandering erratically, a behavioural problem, in their attempt to satisfy their need to know where they are.

In addition to being related to cognitive impairment, behavioural disorders are also interrelated and the appearance of one disorder may point to the onset of others. As an example, we could say that hallucinations involving aversion or dislike of a person normally end up in catastrophic and aggressive reactions.

It is important to always remember that the person's behavioural problems are due to their illness, which makes them live in a parallel world, where certain events are interpreted differently and where their response has nothing to do with social forms or conventions. They are not deliberately misbehaving, no matter how much they may sometimes appear to be, but rather they are behaving as the disease lets them behave.

Psychological and behavioural symptoms of dementia (PBSD)

Depression	Delusion
Apathy / Oppositional defiance	Hallucinations
Anxiety	Desinhibition
Psychomotor agitation	Euphoria
Erratic wandering/escape	Sleep disorders
Aggressiveness (verbal / physical)	Eating disorders

6.1. Depression

Depression is a state of mind where we feel down and sad. We experience suffering and feel empty useless and out of place. Depression is more frequent in the initial stages of the disease, when the person is still in some way aware of what is happening to them. It is true that few patients are aware that they are ill and even fewer who understand what dementia is. However, most do have what we call an awareness of loss. The person with dementia is aware that they are no longer able (or are no longer allowed) to do certain things which previously filled their lives.

Simple things such as strolling around the neighbourhood, taking care of the grandchildren or cooking for the family give us reasons to live. The elderly are the population group with the most free time, which they have to fill with enjoyable activities or hobbies. We only need to visit an elderly care home to see the number of activities in which these people participate. However, with the onset of dementia, all this starts to change.

As the relatives of a dementia patient, we have to take care not to limit our loved ones too much. With the best of intentions and “in order to avoid greater harm”, we tend to overprotect them, which is not at all positive for the patient. We should remember that they will tend to be able to do all those activities which they are trained to perform and are repeated for longer while all abilities that are no longer exercised will tend to disappear faster with dementia.

But not only should we respect the patient's utmost independence in order

to preserve their abilities but we should also encourage a positive state of mind. Someone who feels useful and integrated within their family environment and friends is normally in a better state of mind than someone who feels that they do not belong and with a minor role in the group.

Felipe was very frightened the day he went into the kitchen and found his wife trying to fry the meat pasties for dinner with liquid detergent. About a year earlier, his wife had been diagnosed with Alzheimer's, and he knew he could not let her out alone as she soon became disoriented and distressed but until now she had been fine at home. She had always been a good housewife. But what she most enjoyed was being in the kitchen and she was a really good cook. Felipe could not understand how she could have done something as outrageous as frying with detergent. Felipe lost his nerve and told her she could not longer go into the kitchen. From now on he would do the cooking although he was rather clueless.

Besides the negative effect on what they had to eat, as Felipe did not know how to cook anything other than fried eggs, steaks and salads, he noticed a change in his wife's mood. It is true that since he had stopped her from going into the kitchen, she had at no time tried to oppose him or object to his decision. But he had noticed that since then she was sad and he saw how his wife spent hours in front of the television without understanding what the programme she was watching was about.

Two weeks after having taken the decision, Felipe found his wife crying while she was laying the table (which she

still did every day) for them to have what he had prepared for dinner. He asked her what the matter was and she could not explain. She did not know what was wrong and only cried inconsolably.

That night while he was thinking about it in bed, he decided he couldn't bear to see his wife so sad. She had always really enjoyed spending time in her little kitchen as she called it, and he had to do something for her to go on enjoying it. He decided that as from the next day he would let her back into the kitchen but they would cook together and always under his attentive supervision to know what ingredients his wife was using. Slowly as she felt useful again, her state of mind started to improve and they were able to go on sharing those happy moments where she did the cooking and he was her assistant for another year. The disease's progression continued and eventually she was unable to do anything in the kitchen. But that was many months after this first incident and in the meantime they were able to enjoy those movements together in their little kitchen

The search to enhance a person's self-esteem through the approval of their behaviour and the validation of their personality as the adult they are should be a constant in our relationship with the patient.

6.2. Apathy and oppositional defiance

We understand by apathy the absence of energy and motivation to initiate actions and / or take an interest in activities that the person previously found interesting. It is a state of indifference which in Alzheimer patients entails a significant level of inactivity and the associated decline.

It is important that we suggest to the patient that they carry out activities that at least in the past they found interesting and enjoyable. Apathy may even extend to favourite hobbies or activities, which, often due to the loss of abilities, they now find difficult to carry out. We then need to find the way to simplify these activities so that they can still do them, using the resources that are still available. For example, perhaps someone has been a dressmaker all her life. At some stage of the disease, she is no longer able to make a dress but she can still sew a button on or carry out other activities with fabric and thread.

Once apathy sets in, it will take much more of an effort to get the patient to collaborate in simple tasks such as personal hygiene, feeding and in general, in all the activities of their daily life. They will show defiance, understood as a negative response to every proposal from caregivers and / or family.

It is standard practice to check what the closest person, the main caregiver, who most often has to deal with the patient's defiance, is like.

They are precisely the person who has to make the most effort to sustain the

patient's attention, who most time has to devote to the patient, who has to cope with their defiance and objection to do what they are asked.

Susana very much felt that no one understood her when every weekend her brother Raul told her that she made a mountain out of a mole hill and their mother wasn't so difficult to handle. From Monday to Saturday Susana was responsible for looking after their mother who had Alzheimer in a moderate stage. She devoted most of the day to looking after the house and her mother.

With the onset of the disease, they agreed that she (who did not have a job) would look after their mother from Monday to Saturday and Raul, their brother, would come on Sundays for her to have a break. Since her childhood, she had had a close and trusting relationship with her mother. But with the onset of the disease, this began to change.

From the time she got up in the mornings Susana had to battle against her mother's constant opposition: when she got up from bed, took off her nightdress and washed, waiting for meal times etc. No matter how minimal what she asked her mother to do, she had to plead and insist in order to get her to collaborate.

Her mother was still rather independent when it came to some of her daily activities since on Sundays when it was her brother who was responsible for carrying them out, her mother coped rather well. Susana did not understand why her brother, who had always had a far more distant relationship with their

mother, now knew how to handle her so well.

Susana felt that her brother did not understand when he told her that on most days it took her more than one hour to get their mother out of bed or that most days she refused outright to step into the bathroom. On Sundays, however, her mother was all smiles. She blamed herself for not doing things properly, not being able to satisfy her needs and easily losing patience. No matter her efforts to observe how her brother did things and attempt to imitate him, her mother's behaviour did not change.

The disease progressed slowly and as it progressed, her mother's deterioration and dependence increased and at the same time, the level of her opposition gave way. Her mother was no longer able to carry out those daily activities but she did not object to Susana doing them.

6.3. *Anxiet*

Anxiety is a state where there is an accumulation of energy, exaggerated activation and nervousness. It is an unpleasant emotion of distress which arises when we are faced with situations that are beyond us or threaten us. In addition to the emotion in itself, we also consider anxiety to include the physiological, motor and cognitive responses that we produce as a result of that emotion.

The situations or events that may cause anxiety may be incredibly varied, from having to carry out a presentation in public in a large auditorium to being left locked in a lift. But we all agree that anxiety is uncomfortable and when we feel it, we try to find the way to avoid it and make it disappear. There are people who, in order to avoid anxiety, become members of a gym in an attempt to burn adrenaline, others prefer to meditate in the search for a state of relaxation or simply go to the cinema in order to empty their minds and forget their worries for a while. We all look for ways to avoid a state of anxiety, that is all of us except for Alzheimer patients.

Let's imagine for a second what someone with dementia feels, a person who is disoriented in time and space, i.e, who does not really know where they are or what time of day (or night) it is. In addition, their memory problems mean that they are unable to remember what they have done to get here or what they have to do after (if there is anything for them to do). In addition, their language difficulties mean that they are limited when asking the people around them for help or information. The scenario can become even more complex if we add other types of symptoms such as delusions and hallucinations (which we will explain later). In this context, it is easy to imagine the emotions and reactions of anxiety that Alzheimer patients can suffer.

A lot of what we can do for the patient when it comes to anxiety has to do with allowing them to express that inner distress by sharing, listening and understanding.

6.4. Psychomotor agitation

We understand by psychomotor agitation any purposeless movement or associated behaviour which tends to be repeated over time. It is normally a response associated with an inner anxiety that because the person is unable to express that accumulated energy or channel it in more productive or positive ways, ends up as psychomotor agitation.

The disorganised and disproportionate increase in motor functions is usually also accompanied by vegetative activation which may produce tachycardia, excess perspiration, etc.

As their family, we have to assess our loved one's general condition when these behavioural disorders arise, as they are often the only way that they express a subjective unease: pain, fever, constipation, a urinary tract infection or any other circumstance that produces discomfort.

Some examples of psychomotor agitation in people with dementia are:

- Rocking the body back and forth.
- Repetitive movements of the legs and / or arms.
- Repetitive movements of the head.
- Stretching and pulling of clothing.
- Tendency to remove clothing.
- Repetitive movements associated with their previous work (For example, simulating using a sewing machine).
- Simple stereotypes (rubbing, scratching etc.).
- Complete stereotypes (running their fingers through their hair playing with an object, etc.).

This type of uncontrolled activation of movement, if it takes place too regularly, can become a major source of stress for the people around the patient. Having to

cope with these stereotypes can occasionally cause the family a significant accumulation of stress that makes relations and interaction with the patient difficult.

In order to avoid reaching such a point, it may be helpful to give that repetitive movement a sense of usefulness. For example, if our loved one is constantly moving their hands as if they were winding and unwinding a ball of yarn, we can give them a real ball of yarn. Or if what they are doing seems to be combing their hair, we can give a comb for them to really comb their hair. This can help us avoid seeing such repetitive behaviour as “weird” and to feel less uncomfortable when we are near Alzheimer sufferers while they repeat the same movement over and over again.

Also important in controlling this type of behaviour is to eliminate all kinds of stimulating drinks (coffee, tea, cola drinks etc) and alcohol no matter how long they have been drinking them and irrespective of whether they have never made them nervous before.

6.5. Erratic wandering (and risk of escape)

While the Alzheimer sufferer is still able to walk alone, has the ability to balance and is able to get up from a chair or bed, a possible way of expressing the inner anxiety mentioned above is through erratic wandering or drifting.

This consists of the person purposelessly walking around, from one place to another with no fixed destination. If they do so in their own home, we will see them go from one room to another, opening doors, cupboards and drawers. If they do it outside, there is the added problem that they may escape and get lost.

When faced with this problem, there are two key things that we should consider:

- Eliminating the possible risks in the area where they are wandering.
- Controlling the risk of escape.

We currently know that it is not advisable to use mechanical restraints (belts, bibs, etc.) in agitated patients who are wandering as they have been seen to increase the patient's level of anxiety and therefore agitation. What we have to do is create a risk free environment where the patient can wander. In other words, an area where the person can move around and express themselves freely without endangering their physical integrity or that of others. Letting the patient wander freely in an appropriate context will allow part of that energy accumulated in the form of anxiety to be channelled and probably allow both the patient and therefore ourselves to rest for longer and better at night.

Possible risks are stairs, slopes, cutting utensils, kitchen appliances etc. We will therefore have to

examine all areas that are easy to access and if any area can be dangerous, we will need to find a way to prevent them from going there.

We can take drastic measures such as putting locks on dangerous areas or such simple measures as disguising the door handle by placing a jacket over it so that the patient does not recognise it. As is so often the case, when living with and in our relationship with the Alzheimer patient, we will have to use our imagination and work to find the way to limit their life and therefore ours as little as possible while also minimising the risks.

Sometimes, in addition to wandering around the house, the patient tries to get out alone and it can give us quite a fright if we cannot find them. We will have to limit the possibility of escape by locking the door, putting a bell on the door so that it rings whenever it opens or by disguising it by putting a coat stand or umbrella stand in front of it (once again, the need to use our imagination prevails).

Something else that can influence the patient's wandering is that the place may be over-stimulating, i.e, it contains too many objects or things that call their attention. We have to differentiate between an environment which is rich in stimuli for the patient from one which is over-stimulating and which may stress them out.

We need to take care of the lighting (it is not advisable to have too much lighting or too little) and the room should not be painted in colours that are too bright and stimulating. If our loved one is inclined to look through drawers and cupboards, it would be better to lock those where we store

important things or things that they should not touch. At certain times of the day, television or the radio may help them relax but we should not have them on all the time as there may be programmes, scenes or sounds that they do not understand and which cause them more distress. Evidently we should never have more than one apparatus on at a time.

6.6. Aggression

Perhaps the most feared of all behavioural disorders of dementia sufferers is aggression, understood as a set of behavioural patterns the aim of which is to hurt someone near them or themselves.

We can divide aggressive behaviour into three forms:

- Verbal aggression.
- Attempted physical aggression.
- Physical aggression.

Aggression may be activated by internal or external factors, depending on whether it is an external event that provokes it or an internal psychological process which is activated irrespective of the context.

Aggression is often provoked by a failure to correctly understand one's environment. Alzheimer patients live their own reality, where the stimuli that surround them may be misinterpreted and threatening.

One of the moments that most lends itself to shows of aggression is when the patient is washed or showered by someone else. At this time, the patient may feel vulnerable and uncomfortable because they are naked, insecure and afraid of the water and intimidated by our presence. In the section below we will see how we may be able to reduce those moments of aggression.

6.7. Delusions

We understand by delusion any irrational ideal or thought that comes to the mind of a dementia sufferer, distancing them from the real understanding and perception of their environment. They are beliefs that, as they are firmly ingrained in the patient's mind, they will defend with all their might and utmost vigour and no matter how much we attempt to show them that they are wrong, they will refuse to admit it.

The plot is generally rather intricate and they may even create a series of bizarre stories, worthy of the best mystery films. We should not encourage the plot to increasingly thicken and spread.

Delusions form part of what we call psychotic symptoms and they represent

a total rupture between the real world and the world of the patient who creates their own reality in parallel to that of others. As they live a different reality, their behaviour is also altered and reactions may appear stemming from fear when confronted with ideas of harm to reactions of joy in the face of beliefs which are excessively positive for them.

We classify delusions according to their subject matter. The most frequent in dementia are:

- **Theft:** the person believes that personal objects and / or money are disappearing and normally blame someone around them (often the main caregiver) of this theft. This type of delusion is very frequent in people with dementia and is aggravated by the memory losses that also result

from the disease. The dementia sufferer leaves things in places they cannot later remember and when they go to look for them, cannot find them. This prepares the ground for subsequent delusions of theft.

It is also frequent for them to come up with strange stories concerning their belongings or savings, even accusing their spouse, children or other family members of having taken them.

- **Persecution:** the person who suffers it assures that someone is spying on them, is following them and is watchful of everything they do or say.
- **Harm:** this refers to any concern or fear of danger or harm that someone may want to inflict. Subjects such as poisoning, conspiracies etc are common.
- **Grandeur:** the person asserts that they have an important position in society or is a well known personality such as the president of the government, the owner of the care home where they live or the person in charge of everyone around them. As such, they act in an authoritarian and dictatorial manner with the people around them.
- **Erotomaniac:** this consists of believing that someone is madly in love with them and does things to win their affection. The alleged lover may be someone close to them or even a public or famous figure.
- **Capgras:** this is the belief that someone (a son / daughter, spouse etc) has been changed for a double who has taken their place and is pretending to be them.

As we can see, delusions can have a negative meaning for the patient and cause them suffering, anguish and stress (such as in the case of delusions of theft

or harm) or cause none of these negative feelings (as in the case of delusions of grandeur or erotomania). As delusions are relatively complex to handle in dementia, we should never encourage them but if they do not cause the person important suffering the best thing is not to become obsessed with the weird stories the patient tells, since as we said, there will be cases where episodes of delusion will not have negative consequences for them.

There may be times when the person with dementia insists so much on a specific subject and offers so many explanations for us to believe their version that we are really led to doubt the veracity of the facts. As a close family member, we should remember that delusions are one of the most frequent symptoms of dementia and should bear in mind that they can affect any subject or person involved in their lives. We should be particularly careful when the person starts with a delusion of theft and makes us doubt of the veracity of the events. Dementia sufferers frequently accuse the person closest to them of these thefts, be they family or professional caregivers. Whenever this type of claim arises or any other complaint that someone is making them feel uneasy, we have to be very careful and discern whether it is for real or a delusion. In other words, we cannot take for granted that these issues are always the result of a delusion nor conversely, believe outright what they tell us about their daily lives and the person caring for them.

6.8. Hallucinations

Hallucinations consist of false perceptions that can affect any of the senses although in dementia, the most frequent are visual hallucinations (seeing things that do not exist) and auditory hallucinations (hearing non-existent sounds or voices).

Hallucinations are one step further from delusions. Not only does the person think that they perceive certain things that are not true as in delusions but they perceive things that do not exist. The reactions of dementia patients are therefore more striking when they suffer hallucinations than delusions. It is easy to understand that it is more distressful for them to “see” and “hear” how someone is going into their room to steal (hallucination) than to believe someone has gone in to steal (delusion) but without perceiving it directly.

Because a hallucination is a false perception and delusion, a belief about something that has taken place, we could say that the distress created by a hallucination is more present while the distress created by a delusion concerns something that has happened or passed.

We offer at least one example of each type of hallucination:

Visual

Laura is 80 years old and has lived in a care home specially for dementia sufferers since her husband Arturo died six years ago. Her dementia is in the moderate stage and for the past few months she has been complaining to the home's assistants because they do not put a plate on the table for her husband at meal times. The assistants reply as gently as possible that her husband Arturo died a few years ago. Laura replies that she is angry and perplexed that they should say such a horrid thing with Arturo sitting there next to her.

Auditory

For the past few weeks Paco has been complaining to his children when they come to visit of the noise his neighbours are making at night. He can hear how they argue, shout and even hears banging and he cannot sleep until the noise dies down. His caregiver, who lives with him and looks after him, does not hear anything like that and claims that he is surprised because as far as she knows, there is an elderly lady living on her own in the flat upstairs. Paco's eldest son decides to check for himself and goes up to speak to the upstairs neighbour. The door is indeed opened by a lady of more or less the same age as Paco and when he explains the issue of the noise, she replies that she is really sorry but she does not make any noise since she is actually used to going to bed pretty early.

Olfactor

Araceli has frightened her daughter and son-in-law on various occasions by going into their room first thing in the morning shouting and distressed because she can smell smoke and fire and has asked them to get up fast because there must be something burning in the house.

Gustatory

The care home assistants normally have problems feeding Julian since he claims that his food has a strange taste. Initially they thought that he simply did not eat well because he did not like any of the dishes served at the care home. But as they have come to know Julian they have realised that he enjoys a dish one day and another day says that it tastes of metal or that it has gone off.

Tactile

Grandmother Noelia was diagnosed with dementia several years ago and was sometimes startled and jumped in her seat while the whole family was relaxing watching the television. When they asked her what was wrong, she said that she felt that someone had touched her from behind or pinched her.

Somoesthesis

People assert that they have different feelings about their own body, such as feeling empty, hollow, petrified etc.

As in the case of delusions, with hallucinations, no matter how much we assure the patient that what they are seeing, hearing or feeling is not real, we will not convince them and we can even increase their distress by forcing them to firmly defend what they are “witnessing” or making them think that we want to mislead or upset them.

6.9. *Desinhibition*

Dementia sufferers lose (cognitively speaking) the ability to know what they can do in a group and what they can't. They forget what the social norms are and do not understand how someone should behave when in the company of others. In other words, they have trouble knowing what behaviours are right or wrong at a specific time and in light of the circumstances.

Because of all these limitations, things such as decorum, discretion and in general, activity involving processes of inhibition and certain behaviours are altered and disturbed.

This may be one of the symptoms that most distress the families or other people living close to the patient. As explained above, practically everyone understands that someone with Alzheimer's forgets things, but for most people, it is harder to understand that that they have no qualms about undressing in public or quite openly start talking about their sex lives.

A clear example of this type of disorder is the fact that if the patient feels hot or the clothes they are wearing are uncomfortable, they will not hesitate for a second to take them off irrespective of who is around. We need to ensure that the clothes they wear are not uncomfortable, they are not too tight or hurt them. If, however, our loved one tends to undress constantly, we should try to use clothing that they find more difficult to take off. Lastly, in this respect, it is important that the clothes they wear suit the temperature of where they are as this makes it less likely that they will try to undress because they are too hot.

Another frequent behaviour owing to disinhibition is the appearance of uncontrolled sexual conduct. The absence of control may refer to the place where the patient performs sexual practices or the people at whom they are directed. We can find several situations. The first is masturbation. Masturbation will only be a problem if it is carried out in an inappropriate setting, around people or in a compulsive manner. In the privacy of their own room, it is not a problem for the dementia patient and may even be a way of channelling the excess energy produced by anxiety. If masturbation takes place in an inappropriate setting, we will need to re-direct that activity to an adequate setting, i.e., to the privacy of their own room or bathroom. We should always do this gently and delicately, avoiding ridicule or making them feel guilty.

It is also possible that they direct their sexual drive towards someone close to them, a member of the family, friend or professional caregiver. Like with masturbation, we have to try to make them understand naturally that it is not an appropriate behaviour, without judging, understanding that it is a symptom of the disease they are suffering.

6.10. Euphoria

The emotional state of dementia sufferers is characterised by what we call “lability. This concept relates to a state of instability and the dissociation of the emotion/situation.

Cognitively healthy people who are emotionally stable are characterised by their ability to tailor their emotions to the context or situation they are living at any particular time. For example, if we are in a very important work meeting, we understand that we have

to be serious and calm, if we at our child’s birthday party, we try to be happy and if we are at a funeral, we understand sadness, crying and even despair as normal emotional responses.

The emotional lability process suffered by dementia sufferers breaks this relationship of coherence between the situation lived and the emotional response produced.

Dementia sufferers can go from the most euphoric laughter to tragic crying in just a few seconds, without the situation they are living having apparently changed at all.

Euphoria or an emotional state of excessive happiness may become a behavioural disorder if it jeopardises or endangers the well-being of the patient or those around him.

6.11. Sleep disorders

The rhythm and duration of dementia sufferers’ sleep and rest is also altered.

There are two possible sleep disorders:

- **Insomnia:** difficulty in getting to sleep.
- **Hypersomnia:** excess sleepiness or drowsiness.

What happens in Alzheimer patients is a combination of both. They suffer insomnia and agitation at night and hypersomnia during the day as a result of the lack of rest at night.

Why does this happen? We know that the patient is disoriented in time (i.e. they do not know what time of the day it is), and also in space (they do not clearly recognise where they are) with

the concern and worry that this entails. There may be cases where there are also symptoms such as delusions and hallucinations. Within this context it is natural for the person to sleep more during the day, when there is light and they can see where they are (even if they cannot quite recognise it) and the people around them. It is at night when disorientation, confusion and even fear (which they sometimes feel) are at their worst.

Generally speaking, older people need less sleep than younger people. If we take into account that during the day they may spend several hours “nodding off”, the number of hours sleep at night may be significantly reduced.

Someone who spends long hours awake at night will make it difficult for those living with them to sleep. In turn, that lack of sleep may be a further risk factor with caregivers feeling overburdened, unable to recover from the exhaustion of looking after the patient during the day.

Therefore an altered sleep pattern (drowsiness during the day-wakefulness at night) is not positive for the patient or their family. These habits need to be watched over and care must be taken not to allow more than one nap (after lunch) during the day which should not be too long so that the patient spends a more restful night in bed.

6.12. Eating disorders

Appetite and eating are another area where disorders may appear that make daily living with the dementia patient difficult:

- Anorexia.
- Bulimia.
- Disorderly eating.

Behaviours may range from the refusal to eat to gluttony, eating without stopping. The most common, however, is for the patient to eat in a disorderly manner in terms of variety and times.

Symptoms such as agnosia may affect the loss of recognition of tastes, which may lead to the refusal to eat certain foods whose flavour the patient does not recognise. Generally, the patient stops recognising salty flavours before sweet flavours.

Problems with swallowing and the risk of choking may add further complications to the subject of feeding.

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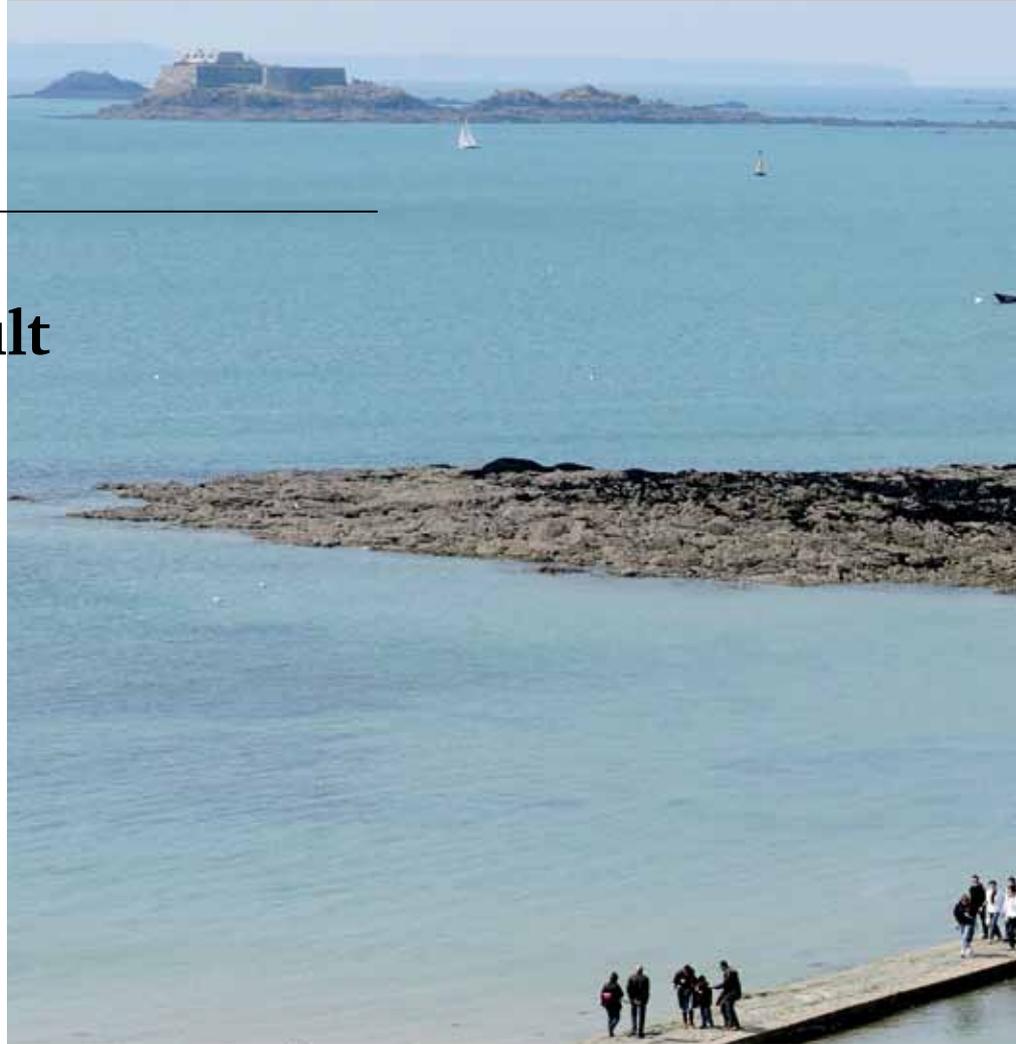
7.4. Hallucinations and delusions

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Chapter 7

Handling difficult situations

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In this document we try to set out how although living with someone with Alzheimer or some other kind of neurodegenerative dementia may at times be complicated, there are ways of approaching the situation and relationship that make daily life easier.

When we talk about difficult situations, we normally refer to the word “handling” since in this field there is no really magical solution that we can use with all patients. Individual differences between people will determine what will be effective or not in a particular situation and at a specific time. However, the progression of the disease

will also dictate the differences over the years we live with the patient. What may be really useful in the initial stage of the disease may even be counterproductive in its moderate or severe stages. What we need is common sense and if something does not work or gives us more problems, we should not be afraid of looking for new alternative solutions to that particular problem.

The first thing we should resort to when handling any of these difficult situations is empathy, i.e., we should develop our understanding of the circumstances that have led the person to do what they have done. Empathy allows us to put



ourselves in the shoes of others without compromising our objectivity. If we discover the cause (in most cases, it exists) of certain difficult behaviour, we can do more to try and handle it.

Difficult behaviour may occasionally be caused by physical discomfort such as a urinary tract infection, a toothache or a simple headache. At other times, there may be something in the patients' surroundings that produces psychological distress or anxiety such as a television which is too high, repetitive noises that they do not recognise, presence of people whom they are afraid of.

Thought and perception disorders are likely to be accompanied by episodes of agitation.

Below we set out a list of the guidelines or advice to be applied depending on the difficult situation that arises.

7.1. Repetitive questions

- Don't lose patience. Whenever they repeat a question, it is like the first time they ask us. They will therefore not understand why we are despairing at their questions.
- Encourage the patient to express any doubts, stimulating language and communication.
- Most repetitive questions by dementia sufferers concern problems of temporal-spatial orientation. We should therefore place objects that help them with orientation around them (clocks, calendars, activity timelines etc).
- When they ask us the question, try to have them find the answer themselves. For example: if they ask us the time, we should tell them to look at the clock on the wall (pointing it out to them) or if they ask us what time we have lunch, we should tell them to look at the activity timeline.
- We should encourage routines through timetables setting out important activities for them and ways to carry them out. Routines always make it easier for people to remember what they have to do at that time and avoid having to ask us.

7.2. Repetitive behaviour

- We should find a way of affording meaning to that repetitive behaviour. For example, we can get the patient to fold napkins or plastic bags.
- When this behaviour is transformed into something useful, as in our example, we should positively reinforce it. We can thank the patient and let them know that they have been really helpful.
- There are occasions when such behaviour is motivated by pure boredom and if we suggest other pleasant activities that they may carry out instead, they will have no difficulty in abandoning it.
- In the more severe stages, automatic movements may appear such as rocking of the body or movement of limbs. In such cases, we can do nothing and it will be better to allow their expression than attempt to find ways to limit such movement. It will then be up to us to find ways of ignoring such behaviour.

7.3. Aggression

- It should be noted that the patient is not voluntarily aggressive. Aggression is a further consequence of the disease.
- Look for the cause and attempt to track (on paper or mentally) the situation, what happened before, who was targeted, etc.
- Try to reduce tension as far as possible.
- Talk to them in a calm voice; avoid shouting or gesticulating too much.
- Ask for help to restrain them if we see that we cannot cope alone.
- If it is necessary to restrain the patient, do so with care and avoid struggles.
- Call attention to stimuli that relax them or help them escape.
- Call them by name and remind them of whom we are and what we are doing there.
- Learning to foresee any increase in aggression before they become physically aggressive. We start to notice them become tense, congested, threatening or verbally aggressive.
- At no time respond in a physically or verbally aggressive manner.

7.4. Hallucinations and delusions

- For the people suffering them, they are totally real perceptions and ideas (although for us they may be unreal and completely false). We should not try to contradict them or attempt to prove them wrong.
- Avoid saying “*relax, there’s nothing wrong*”. For these patients there is something wrong and they have every right to show distress or anxiety.
- Transmit assurance by keeping calm.
- Never leave them alone in such times of anguish.
- Sit at their side and express an interest in what is happening to them.
- Listen to them (not agreeing or rejecting what they tell us).
- After initially listening and understanding them, their level of alertness normally decreases. We will then attempt to divert their attention to stimuli that are completely real.
- Some people may calm down with physical contact (caresses, touching their shoulders etc).
- We should avoid encouraging delusions or hallucinations by participating in them even if they are positive. No matter how happy a person may be because they are hallucinating, for example, seeing their children when they were young, we should never encourage it, with comments such as “*what lovely children*” or making them believe that we also see them.

7.5. Defiant opposition

- Allow alternative behaviour or choices as far as possible. For example, when suggesting what clothes to wear, do not force them to wear a particular jumper. Instead, offer possible alternatives for them to choose.
- If we do not get the patient to do something the first time round, leave them and revisit the subject later.
- Respect their slowness (at both cognitive and motor level). Often it is not a question of their refusing to do something but rather of their refusing to do it too quickly.
- Treating them as the adults they are and not as children.
- Look for motivation rather than obligation.
- Try to ensure that the rhythm and style of their daily life are as similar as possible to what they had before falling ill. In other words, if someone has not enjoyed going out for long walks, we should not ask them to do so now. Or if someone has never read before, we should not ask them to do so now simply as a way of doing mental exercises.
- Make them feel useful during the day, asking them to help us in certain tasks and congratulating them when they strive to do things well.
- Be flexible and accept the progression of the disease as the patient becomes increasingly dependent.

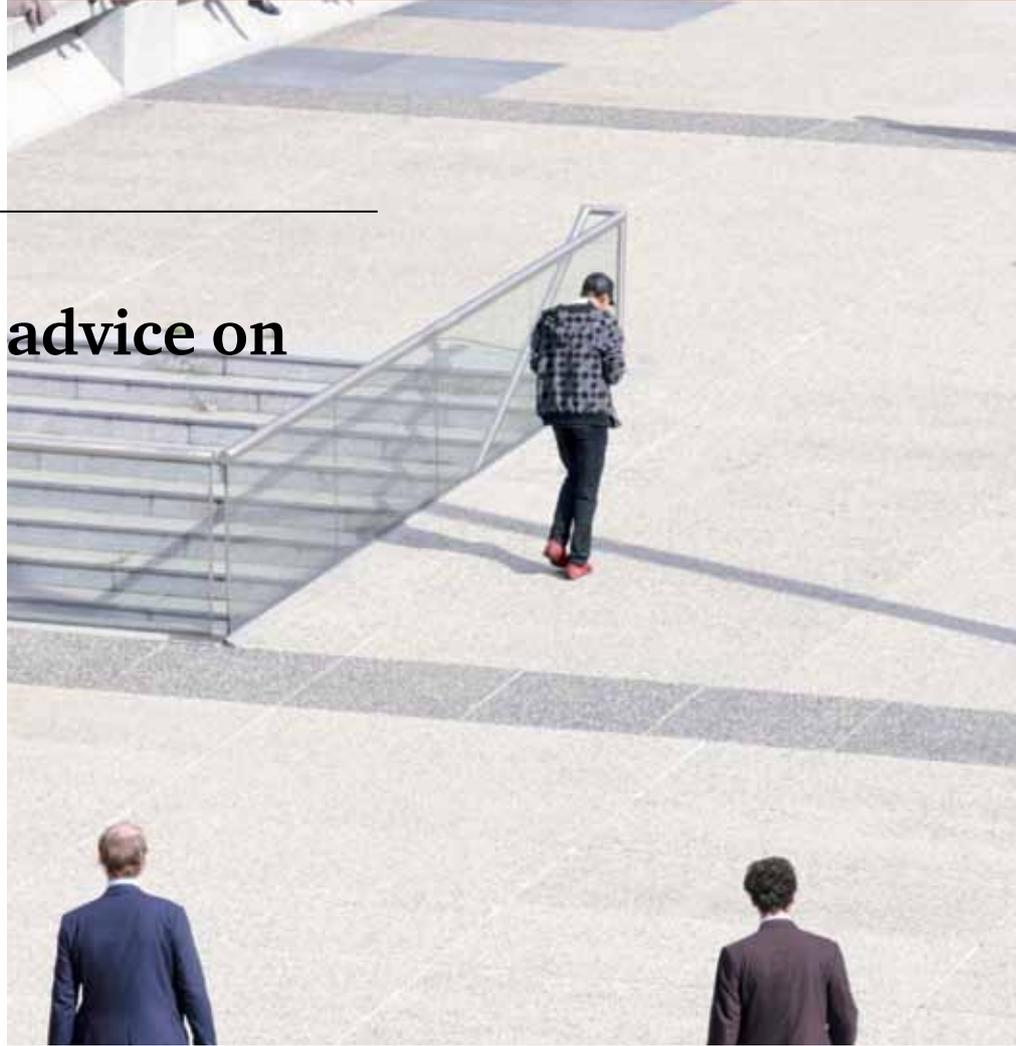
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8.1. Basic activities of daily living

8.2. Instrumental activities of daily living

Chapter 8 Limitations and advice on daily activities

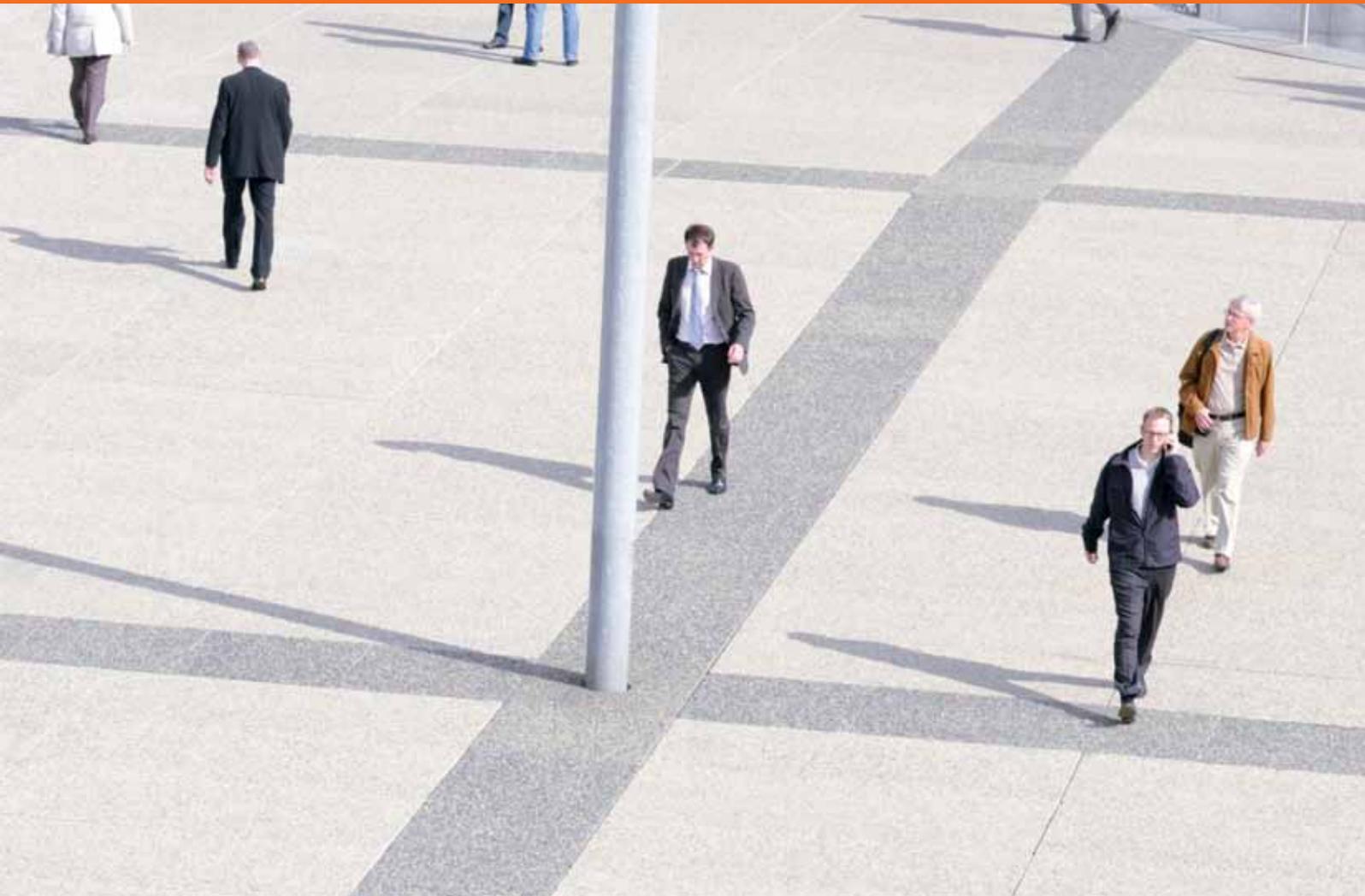
Cynthia Pérez Muñano.
Occupational Therapist



We have seen how Alzheimer patients will lose their abilities as the disease progresses. Although we have seen that the changes will in principle be cognitive, starting with the loss of memory, orientation or language, problems will later appear in carrying out movements together with physical deterioration. Therefore Alzheimer sufferers will be increasingly less able to carry out their daily activities alone and will need external help to complete them. In short, our loved one will become increasingly dependent, a term which we will have to use without taboo and which we have to consider in

order to offer solutions to the problems that we may face.

Cognitive and physical stimulation will help the dementia patient go on with their activities of daily living, particularly, instrumental activities, such as using the telephone, handling money or housekeeping, where they need such abilities. In order to carry out what we call the basic activities of daily living (dressing, eating, washing etc), it is necessary to maintain cognitive functions and physical ability in peak condition. However, procedural memory, which we talked



about at the beginning, is also very important. The repeated performance of certain actions will ensure that the person learns such movements better, carrying them out without the need to think about what they are doing, or, in the case of Alzheimer's disease, the routine repetition of such activities will help the patient to retain the ability to perform them and therefore remain as autonomous as possible for longer.

It is important for our loved one to carry out activities alone, providing them with the least help possible. Help should be provided slowly since

otherwise we run the risk of making the person feel useless and more dependent earlier. There are different types of assistance that we can provide to help patients carry out their activities of daily living and thus avoid having to carry them out for them.

The techniques and facilitation aids available are presented in order, according to the difficulty faced by each person:

Activities of Daily Living

Supervision	This consists of regulating actions without having to interfere. If a mistake is noted, the patient will be advised for them to correct it. Such supervision can also increase the patient's privacy since their family or caregiver may watch over them at a distance and outside the room.
Verbal instructions	Tell and / or remind them of what they have to do. Provide guidelines.
Imitation	We will carry out the gesture so that the patient knows what they have to do. For example, we will pretend to wash our face for the patient to remember the action and carry it out afterwards.
Physical incitement	Touch the person for them to know what they have to do (touch their hand for them to pick up their cutlery and eat).
Initiation of movement	Take the person and guide their movement (eg, take their hand with a spoon to their mouth) for them to continue the action alone.
Aid	
Adapting the home and use of technical aids	Changing the home to facilitate activities and using special and tailored utensils

Before starting to offer such help and carrying out activities of daily living, we should take into account a series of aspects concerning the patient. We have to assess what the difficulties are or why the activities cannot be carried out

It will be important to consider:

- **The person's physical state.** See if they have difficulty moving, sores or wounds that makes the activity difficult
- **Medical problems.** For example, a urinary tract infection may make a person less likely to collaborate in carrying out activities.
- **Medication.** Sometimes the medication that they are taking may make the person sleepier or less alert.
- **Environment.** The excess of objects at their disposal or layout of the furniture may make it difficult to carry out these activities
- **Cognitive state.** Depending on the functions that they retain, Alzheimer sufferers may be able to carry out some or other type of activities and the need for help will differ.

- **State of mind and self-esteem.** This is essential when carrying out daily activities and taking care of oneself. If the person is not motivated and does not trust themselves, the activity will be harder to carry out. This is something we will need to work on.

Set out below are activities of daily living (basic and instrumental), together with an explanation of the difficulties that may be encountered in carrying them out and possible solutions to improve or allow the patient to continue doing them.

It should once again be stressed that everyone has a different personality and different daily activities and therefore

even if we suggest alternatives, it is the family and caregivers who will identify the strategies to improve the patient's care. Helped by their familiarity with the Alzheimer patient and their habits, they will recognise the best way of working with them.

One patient may benefit from a shower at night while another may not. Someone with behavioural disorders may eat better if they are listening to relaxing background music while someone else may become more distressed.

In the end, the treatment has to be as personalised as possible, enquiring about, knowing and respecting the patient's tastes and habits.

8.1. Basic activities of daily living

Basic activities of daily living include: feeding, dressing, washing and bathing, going to and using the toilet, continence (urination and bowel movements) and wandering and transfer.

We should always bear in mind the assistance that we have talked about earlier for the patient to carry out the actions alone (supervision, verbal instructions, physical incitement and initiation of movement), although we will look at the different activities one by one together with the limitations that may arise and other advice to be followed.

8.1.1. Feeding

The patient should make adequate use of cutlery and other eating utensils in order to eat properly.

What problems may arise?

- They may want to eat all day or not eat at all.
- They may not know how to use cutlery correctly.
- They may eat greedily.
- They may choke.
- They may not stop moving.
- They may not drink sufficient liquid and become dehydrated.

What can we do?

- We should check the condition of their mouth and teeth for any wounds that may make them not want to eat.
- Motivate them with meals they like or allow them to choose within a varied diet. It will also be important to take care of the way the food is presented.
- Offer more, albeit smaller, meals during the day.
- Present the cutlery and plates one by one.

- If they eat greedily, remove their plate between bites.
- Provide assistance gradually. If the patient is unable to eat, we will cut their food up for them. If they are still unable to eat, we will adapt the cutlery or give them a spoon for them to pick up their food (even if the food is not normally eaten with a spoon) and lastly, we will let the person eat with their hands if possible, before we actually feed them.
- Adapting the cutlery and other utensils.
- Crushing food to avoid choking.
- Use of thickeners in liquids.
- Offering liquids continually. Liquid refreshment can be offered in the form of water, juices or jelly in order to attempt to encourage the patient.

8.1.2. Dress

What problems may arise?

- They do not change their clothes.
- They do not find appropriate clothing.
- They do not dress properly.
- They are unable to do the buttons or laces up or dress alone.
- They are constantly undressing.

What can we do to encourage independence?

- Have sufficient time. Not to be in a hurry.
- Remove dirty clothes from the room as soon as they take them off.
- Only leave appropriate clothing in the wardrobe.
- Mark the wardrobe to show where each item of clothing is (underwear, socks and tights, trousers, shirts etc) using labels with names or drawings.
- Allow the person to choose what they want to wear.

- Leave clothes for the following day in the order in which they should be worn.
- Use comfortable and easy to wear clothing. Replace zips and buttons with velcro adhesive and elastics. Correctly fitting shoes with elastic or velcro instead of laces.
- Use of technical aid.
- Offer help gradually. The person may not know how to button up but they will remember how to put their shirt on or they may be able to put on the top part but not the bottom part of their clothes. We should always let them do as much as possible.
- If they undress constantly, we should choose clothes which are increasingly difficult to take off: tights instead of socks, one-piece pyjamas etc.

8.1.3. Personal hygiene and bathing

This includes showering and all activities related to personal hygiene and own care such as washing one's face, combing one's hair, shaving etc.

What problems may arise?

- They do not want to bath / wash.
- They cannot get in or out of the bath tub.
- They may slip and fall.
- They are unable to bathe and wash alone.
- They are afraid of the water.
- They confuse the instruments to be used.
- They are unable to stand.

What can we do to encourage independence?

- Respect their habits as far as possible. Many old people are not used to having a shower every day. We can reduce how often they have a complete bath a week and other days just wash different parts.
- Ensure privacy, be patient and let the patient have time to enjoy.
- Ask them to touch the water before getting into the bath for them to get used to it and overcome their fear.
- Adapt the bath and use technical aids.
- Withdraw all objects that are not necessary for activities. If they are going to brush their teeth, they should only have their toothbrush and toothpaste in front of them and not their comb, shaver etc.
- Offer assistance gradually. Although we have to help them shower, for example, washing their hair, the person may be able to wash their body. Or when washing, we can put the toothpaste on the toothbrush and let them then brush their teeth.
- Encourage the person to look tidy, put make-up on or use cologne.

8.1.4. Access and using the toilet

What problems may arise?

- They are unable to find the bathroom.
- They get there late.
- They are unable to sit on or get up from the toilet.
- They do not remove their clothes or put them back on properly.

What can we do to encourage independence?

- Place a sign on the bathroom door.
- Leave the bathroom light on (particularly at night) to help them find it.
- Adapt the toilet and install hand rails.
- Use loose, easy to take off and put on clothing.

8.1.5. Continence (urination and bowel movement)

What problems may arise?

- Loss of initiative to go to the toilet.
- Not doing anything.
- Not sitting for sufficient time.
- Incontinence.
- Sores, irritation and scabs appear.

What can we do to encourage independence?

- Lay down visits to the bathroom every 4 hours, 3 hours etc. The time will decrease as incontinence increases. We will put off the use of incontinence pads as far as possible.
- Observe timetables and usual guidelines.
- Give them time and ensure privacy.
- Remind them of what they have to do.
- Use incontinence pads: change frequently to ensure that they are not left wet for long and keep the skin dry and moist to avoid ulcers or small wounds.

8.1.6. Wandering and transfer

What problems may arise?

- They tire when they walk.
- They slowly lose the ability to walk, first on long strolls and then on short journeys.
- They need to use a wheelchair.
- They do not move from the chair to the bed, from the wheelchair to the settee, from the wheelchair to the toilet etc.

What can we do to encourage independence?

- Keep up physical mobility through the stimulation activities described above.
- Take daily walks.
- Encourage them to walk by taking them to places they are interested in.
- Keep the person walking on short transfers although they may use a wheelchair when they go out.

- Having them help themselves as far as possible when they are moved. We help them move but they make the effort to get up.
- Use of technical aids.

8.2. Instrumental activities of daily living

Instrumental activities of daily living are more complicated and enable the person to be more autonomous and independent in their work both in and out of their home. They are those activities related to the handling of money, the shopping, use of transport, preparation of meals and domestic tasks (making the beds, cleaning, laying the table), taking medication or using the telephone.

In order to carry out these activities, Alzheimer patients need to retain their cognitive functions such as memory, orientation, physical ability, ability to understand the succession and duration of events etc. Unlike the basic activities of daily living which, through routine repetition, the patient can go on performing, in this other type of activities, the functions must be retained because once they are lost, recovery or re-training will be complicated unless it is carried out within a short period of time.

The work we have to do is that discussed in previous chapters related to cognitive and physical stimulation. We have to allow our loved one to carry out these activities as far as possible and gradually include supervision, verbal instructions, etc or adapt the task and simplify it (let them peel the garlic, cut the runner beans or wash the vegetables instead of actually cooking them). They will thus be able to carry out these activities for longer.

Certain adaptations such as the use of a telephone with large clear numbers or writing numbers down in the same way in an agenda, accompanied by photographs, may help them use the telephone.

These guidelines can help our loved ones to remain independent in their daily activities for as long as possible, with a gradual and not sudden decline in their ability. As we have mentioned, we are often the ones who make them dependent. We have to think about what is best for them even if they do not want to do it or complain. We should leave feelings of pity or protection, which often turn into overprotection, aside.

In addition, there are other considerations that will help our loved one go on carrying out these activities.

- Creating routines for the person to remember what they have to do through repetition.
- Respecting the small everyday things and those habits and tastes that the patient may have had in the past.
- Being patient, leaving time for them to carry out activities. They have a different rhythm from us.
- Encouraging them to do things themselves.
- Positive reinforcement when they do things right, encouraging them to go on doing so. In this way, we will work on their motivation.
- Avoiding having distracting stimuli around which may hold their attention, helping them to focus on what they are doing.
- Explaining what we are doing from time to time.
- Feeling empathy and putting ourselves in their shoes, particularly at times such as when they have to take a shower, wash or use the toilet and our presence may make them feel uncomfortable
- Reinforcing the patient's self-esteem and avoiding that they feel useless.

It is important to work on the patient's self-esteem since they will gradually lose interest in things and the motivation to go on with their activities. Moreover, because of their deterioration, they will gradually be able to do fewer things around the house or it will be increasingly complicated for them to go out to do what they used to do. They may then begin to feel frustrated or useless, making them think that they are worthless or unable to do anything.

We should be aware and offer them that extra motivation, allowing them to help out at home and making them feel useful, taking decisions on their daily and future activities (from what clothes to wear to what decisions they would like to take in the future provided that they still have the necessary ability) or giving them something to do through stimulation. In short, letting them be as independent as possible.

Content

9.1. Adapting our home

9.2. Recommended technical aid

Chapter 9 Recommendation on adaptations and technical aid

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Occupational therapist



When we live with an Alzheimer patient, we have to pay special attention to their surroundings. The layout of the furniture, the materials used or the lighting may be essential to allow the patient to function and move around easily.

Depending on the symptoms that we know may gradually appear during the disease, we will be able to take decisions and advance solutions as to how we wish to change our environment, what specific needs our loved one has and what we can buy. It

will also be important to have the opinion of a professional who provides advice on the assistance that we can apply for to do what we want to do. Although some adaptations or utensils may be expensive, it is necessary to weigh up the benefits for the patient and the improvement in the quality of life of their family and caregivers if we allow them to be more independent.

We have two opportunities to make life easier and help our loved one with their activities of daily living:



first of all, adapting the home and secondly, the use of technical aids. Adapting the home refers to any type of change made to the patient's environment which allows them to carry out their daily activities in a simple, safe and independent manner.

Technical aids are those instruments that help the patient to carry out their activities of daily living. They are used to help movement or are compensatory when they are essential to perform the activity. In

this latter case, without technical aid, the action would be impossible.

The need for these adaptations and instruments lies in the difficulty and at times the danger that Alzheimer patients face at home every day. Unprotected sockets that everyone can see, toxic products at hand, slippery carpets or floors or items of furniture that get in their way are some examples of the difficulties that we may find.

We will therefore implement this type of resources in order to:

- Facilitate activities of daily living.
- Improve the patient's quality of life, giving them more independence and privacy, making them feel useful.
- Take maximum advantage of all the abilities that the patient still has.
- Avoid dangerous situations.
- Lighten both the physical and emotional burden for the family and / or caregiver.

9.1. Adapting the home

We will try to ensure that the changes we make to our home are carried out gradually and not suddenly in order to allow the patient to adapt and not feel disoriented or distressed by them.

9.1.1. General adaptations

- Wide spaces without obstacles for the person to move around freely.
- Avoiding too many decorative objectives in rooms.
- Furniture with rounded edges or with protectors to avoid slipping or problems with knocks.
- Chairs with back and arm rests to help them with their good posture.
- Anti-sore cushions.
- Floors have to be non-slip, smooth, the same colour and the same level.
- Indicate level changes.
- Place non-slip floor tape on the stairs.
- Take care if we polish the floor or common areas of the building as they can become slippery and increase the risk of falls.
- Avoid carpets or fix them to the floor with non-slip materials.
- Place socket protectors.
- Good lighting in the home. Avoid bright lights (they dazzle) or poorly lit or dark areas since they can make it look as if there is a hole or hollow and make it difficult to see steps where they can trip.
- Conversely, we can place a carpet, doormat or black tile at the front door to avoid escapist behaviour generally. When they see that dark area, they will not approach because they are afraid and we will stop them leaving the house alone.
- Light switches at the start and end of the corridor, at the door of their room and headboard.
- Lights with movement sensors so that there will be no need for them to turn the light on.

- Place handrails along the corridor for them to hold and walk longer distances alone and up and down the stairs.
- Improve door knobs and door handles to help them open doors.

9.1.2. Adapting the kitchen

- Using cupboard locking systems to stop the patient from eating constantly.
- Locking cupboards containing toxic products, medicines and sharp or cutting objects.
- Putting non-slip protectors on chair legs.
- Placing gas and smoke detectors.

9.1.3. Adapting the bedroom

- Putting the bed at medium height to help the patient sit up.
- Having articulated beds to make position changes and the caregivers' work easier, helping the patient sit up, for example, to eat. Also very useful for people with respiratory problems as the head can be elevated slightly.
- A firm mattress that does not sink and is anti-sore if the patient spends a long time in bed.
- A faint light and curtain at night to ensure that the patient is not disoriented when they wake up.
- A light switch which they can get to from bed.
- Cupboards classified by clothing and labelled (underwear, t-shirts, trousers etc).

9.1.4. Adapting the bathroom

- Non-slip floor throughout the bathroom (this same kind of floor can be used in the shower).
- Shower preferable to a bath to help the patient get in and out.
- Place a chair in the shower.
- Place hand rails in the shower/ bath.

- Use non-slip materials or a bath/shower mat.
- Place rails on the side of the toilet.
- Mount blocks under the toilet to lift it and help the patient sit and stand. There are toilet blocks which include a washbasin if they are no longer able to use the bidet.
- Washbasins for wheelchairs. Take care with pipes to avoid burns.
- Differentiating taps using colours for hot and cold water, better than chrome taps as more modern fixtures will be harder to use.
- Assess the need to remove mirrors in the more advanced stages of the disease since they can favour behavioural problems.
- Eliminate locks or use button type locks that can be opened from the outside.
- Leave the bathroom light on at night.

9.2. Recommended technical aid

These devices will be used to try to increase the Alzheimer patient's independence in their activities of daily living. For each activity, we can find materials. Besides, we can also assess each person's needs as these aids are individual and adapted to each kind of impairment.

9.2.1. Feeding aids

- Non-slip tablecloths or mats.
- Kitchen utensils, resistant plastic cups and plates.
- Use cups with two handles.
- Anatomical cutlery (adapted to the form of the hand), with larger handles.
- Flexible or angled cutlery for people with limited ability to move their arms.
- Non-slip plates with an inclined surface that makes it easier to pick up food.
- Wristbands with weights.
- Using adapted peelers and openers.

9.2.2. Technical bathing / bathroom aids

- Longer sponges and combs.
- Toothbrushes with specially designed handles.
- Use of electric shavers instead of razors.

- A board or lift to get into the bath.

9.2.3. Technical dressing aids

- Dressing rod with a hook at one end to reach jackets or trousers to get dressed.
- Buttoner.
- Different kinds of shoehorns: tights, shoes, socks, etc. with longer handles.
- Velcro or elastic shoes instead of lace-ups.

9.2.4. Technical wandering aids

- Walking sticks.
- Walking frames.
- Wheelchairs.

It will be important to have the help of a professional when recommending technical assistance since each device will differ depending on the person, their difficulties and needs.

Moreover, these aids should be provided slowly and with specific instructions.

Therefore when someone starts to have trouble walking, it may be advisable to give them a walking frame and continue stimulating their

physical capacity to a maximum instead of using a wheelchair.

Wheelchairs may in turn differ for each patient, depending on their physical and cognitive impairment.

Technical aid may help patients to carry out activities when abilities start to be lost. But if we give them too early we can stop or impair the person's ability before time.

Nonetheless, such aids and advice on adapting the patient's surroundings will favour their autonomy, increase the meaning of their day to day existence, favouring their state of mind and motivation, and as we have already mentioned on several occasions, improve the quality of their life.

Content

10.1. The caregiver

10.2. Stages of the disease from a family perspective

10.3. Training and information

10.4. Family conflicts

Chapter 10 Living with Alzheimer's; The family

Vanesa Sánchez-Valladares Jaramillo.
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There are approximately 24 Alzheimer sufferers in the world today, 6 million in Europe and more than 500,000 in Spain. Alzheimer's affects 10% of the over 65s and almost 50% of people over 85. The increase in life expectancy has turned this disease into an epidemic since the only risk factor that we know for sure is age.

But this disease not only affects the patient but also their families and caregivers who often suffer physical, psychological, economic problems etc,

as a result of caring for the patient. The next two chapters are therefore devoted to them, the caregivers.

We should bear in mind that we are living in one of countries of the European Union where the number of hours devoted to caring for people in situations of dependency is highest. It may therefore be said that Spain is the country where the burden for family caregivers and their environment is greatest.



10.1. *El cuidador*

We can talk about two groups of caregivers: the non-professionals, for example, the family, and professionals, public institutions or non-profit or for-profit entities. This is only a classification based on caregivers, but there are more. We will focus on the non-professional caregiver, i.e., the family.

Undoubtedly the family is the main source of care for anyone in a situation of dependency. If we focus on the elderly, it should be borne in mind that 70% of the care they receive derives solely from their family environment while only 30% derives from formal professional services. For dementia sufferers, it is estimated that

approximately 80% live with their families. However, in most cases, though not in all, care of the patient is not shared by all members of the family but it is usually just one of the members who takes on the task and will suffer the negative consequences.

Initially the family caregiver volunteers spontaneously. It is normally the person who is physically and emotionally closest to the patient and they take on the entire burden of care.

The main caregiver is normally a woman who is related to the patient and is generally his wife (77.6%) in the case of men. If the patient is a woman, the main caregiver is generally their daughter (65.9%). This is the case despite the social changes that have taken place such as women entering the workforce. Moreover, it is calculated that 8 out of every 10 caregivers are women who are 45 to 65 years old although there is a group of caregivers who are over 65 (around 25% of the total), generally the patient's spouse. In some cases, we are looking at elderly couples (over 70 years old) who live alone with no kind of help and often without any diagnosis of dementia (despite suffering from it).

We should mention that there are increasingly more men caring for or involved in caring for the patient, in particular, when it is their wife who is ill and who become the main caregiver and provide care in a highly satisfactory manner.

When you take on caring for an Alzheimer patient, the caregiver does not normally think that the situation will last long and that the patient will require increasingly more care

The task of caring often causes a wide range of physical, mental and social-family problems as it involves

multiple activities, conditioning the caregiver's life. Moreover, caregivers can be regarded as first class healthcare workers as they provide different kinds of care and attention (nutrition, hygiene etc). In addition, it is the caregivers who first detect new symptoms or the deterioration in patients' health and therefore help healthcare professionals with a new treatment.

It is also the caregivers who are directly responsible for offering a safe environment and helping the patient retain their functional level.

As we have said before, looking after an Alzheimer patient entails both physical and emotional work which in most cases will wear the caregiver down. In the next chapter we discuss these changes. But we will provide a brief overview below of the physical and psychological changes:

Physical problems:

- General discomfort.
- Sleep disorders.
- Severe headaches.
- Stomach ulcer.
- Anaemia.
- Diabetes.
- Osteomuscular disorders (pain, contraction, hernias, slipped disks).
- Alterations of the immune system.

Psychological problems:

- Sadness.
- Irritability.
- Anxiety.
- Depression.
- Feelings of guilt.
- Negative thoughts.

In order to avoid these problems, it is very important that the caregiver understands that they have to look after themselves and that they have to find and accept help. As the disease progresses, the caregiver will have to adapt to the constant changes that this entails and they will even have to learn

certain techniques to ensure that the patient's care is satisfactory and avoid injury.

The caregiver will not only have physical and psychological problems but also social and economic troubles.

Social problems:

As the disease progresses, the caregiver will have to devote increasingly more time to the patient who will eventually need round –the-clock care. This will entail organisational and time problems as the caregiver will not have time to do anything else, not even for themselves. This situation also means that the caregiver will become isolated and feel lonely since they will lose all their friends and have to stop all kinds of leisure activities.

We have said that the patient will need increasingly more care. Sometimes the caregiver may even have to give up their job as it becomes impossible for them to combine their caring and work obligations. The caregiver is often unable to devote time to

themselves because they do not receive any help from other people and if they do, it is very difficult for them to delegate because of their strong feelings of guilt. In those cases, they should look for psychological help.

Financial difficulties

As we have said, caring for the patient affects work. If we take into account that the patient will need more materials and drugs as the disease advances, it is logical to assume that caregivers will be faced with growing financial difficulties.

10.2. Stages of the disease from the family's perspective

Mild stage

During this early stage, the family is at a loss and cannot believe what is happening. At the start, the family believes they can cope with it all but with time, they realise, they can't and they feel frightened. Their negative feelings will grow as the patient's personality changes, but they do not know how to face it.

The family may refuse to believe the diagnosis and may look for other professional opinions (GPs, neurologists, psychologists etc.).

The caregiver has to be aware of how important it is for the patient to start treatment as soon as possible in this stage and not wait for the symptoms to become more evident. When we talk of treatment, we also refer to non-pharmacological treatment (as explained in previous chapters).

Moderate stage

The family accepts the disease and starts up the actions to live with it. The patient has become more impaired and is increasingly vulnerable. The family has to plan how to meet each of their needs, from domestic tasks to the economic or legal aspects.

This is possibly the most difficult and longest stage because of the patient's growing deterioration and the onset of the feared behavioural disorders which undermine the caregiver physically and mentally. Caregiver have to look after themselves and look to the public and private healthcare systems for help.

Severe stage

This is the last stage of the disease and the caregiver is by now burnt out. During this stage, it is very difficult to carry out therapies with the patient and the treatment will basically consist of maintaining an adequate quality of life and carrying out basic activities of daily living (hygiene, food etc). Similarly, in this stage, many families move the patient to specialist centres since they are seriously ill and need specialist care which they are unable to provide.

10.3. Training and information

It is very important that the families of Alzheimer patients are well informed from the onset of the disease. Information on the stages of the disease, its development, symptoms and the patient's needs must be clear and precise. The first person to inform the family is the doctor who diagnoses the disease (usually the neurologist or psychiatrist). Alzheimer associations and specialist centres can then provide significant help in informing and training caregivers.

At the start of the disease the absence of information wears the family down physically and emotionally, as they find themselves in situations where they do not know how to react. It is important for them to receive legal information in the early stages concerning existing resources and the difficulties they may encounter. As the disease progresses and the patient suffers cognitive and physical impairment, they will need to receive information and training on behavioural disorders and postural

hygiene to avoid injury when moving the patient in the advanced stage.

Reliable information on the Web

Internet is another source of information that allows us to make a quick search for resources. Nonetheless, there are web pages which offer unverified and confused information. We therefore offer a list of reliable pages where to find information and training related to Alzheimer's:

- Centro Alzheimer Fundación Reina Sofía: www.centroalzheimer.es
- Portal de la Confederación Española de Familiares de Enfermos de Alzheimer y otras demencias (CEAFA): www.ceafa.es
- Centro de Referencia Estatal de Atención a personas con Enfermedad de Alzheimer y otras demencias de Salamanca: www.crealzheimer.es
- Fundación Alzheimer España: www.fundacionalzheimeresp.org
- Federación Madrileña de Alzheimer: www.fafal.org

10.4. Family conflicts

With the diagnosis of Alzheimer's disease and because of the demands and work that it will entail, family conflicts are bound to arise. It is true that in many families where there is good communication, as well as organisation and planning, conflicts will be minimal or non-existent.

Family conflicts derive from living together as the different interests and desires and values of family members come to the fore. It is therefore normal for disagreements to arise.

This disease will affect the entire family, as they live through the different stages of its progression. Conflicts can arise in each of these stages. We are wrong if we think that the best way of solving them is to avoid them by not talking about them, which is what happens in many families. The best thing is to find the most appropriate way to settle them.

The best way of settling conflicts is through good communication. But we need to be careful because when emotions are running high, our ability to listen and understand will be affected. Before we start talking, it is important to calm down.

Clearly communication is our most important tool in order to relate to others and settle conflicts. To make communication easier, we need to choose the right time to report information and express our feelings, taking other people's into account so as not to hurt them.

When the other person is talking, we should listen actively, without interrupting or judging them. If something is not clear, we should ask.

We should not look to lay the blame on anyone and should accept our part of the blame for the conflict.

Some of the most common techniques used to settle conflicts are:

10.4.1. Negotiation

One of the techniques most commonly used to settle conflicts is negotiation. The parties meet and look to settle the issues triggering the conflict by talking to each other in order to reach an agreement.

We can say that negotiation is a way of settling conflicts when the parties wish to maintain a sharing relationship, on a different basis or under new accepted conditions. For negotiation to be successful, the parties involved must want to reach an agreement. We need to combine competing positions in order to reach objectives and cooperate, to help and make concessions.

There are different ways of negotiating. The two most basic are as follows:

Competitive negotiation or negotiation from different positions:

Each party looks to secure the maximum benefit possible for themselves and agrees to compromise only where it is essential. When this strategy is adopted, the parties are not really interested in reaching an agreement satisfactory to all and nor are they interested in the future of the relationship, which therefore normally just fades away.

Cooperative or principled negotiation:

The parties focus on locating common interests, allowing them to move forward towards agreement. If each

party knows what the other expects, communications between the parties may be good and allow understanding and agreements to be adopted.

Sometimes several meetings are needed to reach an agreement. In this case, the process comes to an end when one or several solutions to the conflict have been found. Agreement may be verbal or in writing.

10.4.2. Arbitration

This technique, as its name indicates, calls for the involvement of a third party who listens to what each party has to say and on the basis of this, takes a binding decision. The arbitrator does not decide who is to blame but instead confines himself to expressing his opinion.

10.4.3. Mediation

There is the collaboration of an unbiased third party who does not decide the solutions. The aim is the reconciliation of the parties and to find possible joint solutions.

The mediator's function consists of identifying the issues in order to help the parties reach a consensus and enter into long lasting commitments.

As mentioned earlier, the family caregiver must be aware of the legal resources available and know all the difficulties that they may encounter in the course of the disease, as in most cases families are unaware of these resources.

Content

11.1. Problems deriving from care

11.2. What is self-help?

11.3. How should caregivers look after themselves?

11.4. What assistance is available to the family?

11.5. Advice for the caregiver

Chapter 11 Emotional self-help

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The main caregiver, in their eagerness to cater for all the patient's needs, neglects their own. Some caregivers devote almost all their time (and even give up work) to looking after the patient, generally alone, for a very long time.

Living in a constantly stressful situation, carrying out monotonous and routine tasks day in, day out, with a feeling of

not having any control over the final outcome of their work, can exhaust the caregiver's psycho-physical reserves (Goode y cols, 1998).

They may also develop a negative attitude and feelings towards the patients they are caring for, with de-motivation, depression- anxiety, psychosomatic disorders, fatigue and exhaustion not linked to their effort and



irritability sitting in (Rodríguez del Álamo, 2002).

Some people in this situation develop the burnt-out caregiver syndrome: the profound emotional and physical exhaustion experienced by some people living with a chronically ill incurable patient. Some signs which may help to signal that there is an overload are the following: sleep problems, loss of social

contact, drinking more alcohol and taking more tranquilisers, change in eating habits, difficulty concentrating, loss of interest in activities that were previously enjoyable, routine and repetitive actions such as constantly cleaning the house, getting angry easily or treating the rest of the family and friends with a lack of consideration (Méndez y cols.).

11.1. Problems deriving from caring

11.1.1. Alteraciones físicas

The main family caregivers of Alzheimer patients are usually in poorer health than non-carer family members and run the risk of suffering more organic and physiological problems. A survey of Alzheimer patient caregivers in Spain (Badia et al, 2004) revealed that most (84%) develop physical problems: 52.2% have headaches, 60.4% backaches, 73% have episodes of breathlessness, 68.7% suffer insomnia or do not sleep properly, 77.6% experience fatigue and 14.2% have bone fractures or sprains.

However, despite their many physiological problems, they normally do not see a doctor. They also tend to take less care of themselves, not sleeping enough, not eating well, doing less physical exercise, smoking and drinking too much, not having the necessary vaccinations or not doing what the doctor tells them (Webber et al, 1994).

They also normally have too much coffee, smoke too much, drink too much alcohol and / or take too many tranquilisers and sleeping pills.

11.1.2. Psychological problems

Badia et al (2004) also recorded the psychological problems to which the main caregivers of Alzheimer patients recounted. Practically all of them, 94.4%, referred to psychological symptoms: 68.7% mentioned stress, 64.4% anxiety, 56.3% depression or symptoms of depression, 67.2% guilt feelings, 60.1% irritability and 36.9% feeling more aggressive.

Caregivers frequently perceive that they have changed. They say that they feel overwhelmed by the problem (spending the entire day focused on the patient), they recognise that they pay too much attention to every day trivia and are more irritable than usual. They also stop taking care of themselves (hairdresser, eating, clothes etc.).

11.1.3. Personal relationship problems

54% of caregivers recognise that from the time that they started looking after the patient, they stopped caring for or neglected other family members. They also express losing interest in activities that were important to them before such as spending time with friends or spouse.

11.2. What is self-care?

Self-care is defined as: “The decisions taken by an individual to present, diagnose and deal with their personal situation; all individual actions aimed at keeping healthy and the decisions concerning the use of both information support systems and formal healthcare services”.

This definition of self-help refers to abilities such as: carrying out simple diagnoses (taking temperature, blood pressure and pulse), caring in simple acute conditions (constipated, burns), observing medical guidelines on chronic diseases etc.

But self-care, in addition to healthy habits (exercise, food, stopping smoking and drinking alcohol, etc.) and looking after our physical needs, means looking after our emotional selves.

It is essential to first of all pay attention to what we feel and allow that emotion to rise up without going into value judgments. It is not easy for the caregiver to recognise some of their feelings as they are usually negative: anger, sadness and fear. Once these emotions are recognised, there is no need to act on them although it is sometimes important to channel them in order to avoid venting them in areas of our lives where our reactions would not be understood.

We sometimes think that by denying our feelings or suppressing them, we make them go away. But that's not the

case. We just add more tension and we often feel overwhelmed when we least expect it. Therefore once we recognise what we feel, it is important to channel it in a positive manner. It is a learning process that entails relaxing the body and conscious breathing. Learning breathing and relaxation techniques takes time and requires an effort.

Once we learn to relax, it is good to question those emotions, accept that they arise spontaneously, feel them and redirect them.

11.3. How should caregivers look after themselves

Physically

The burden of looking after the patient takes its toll on the caregiver's health. It is essential to try to maintain routines that include healthy habits such as eating well and at the right time and having a balanced diet, doing daily exercise (walking, dancing, cycling), if possible, and sleeping and taking a break several times a day.

Psychologically

Caring for a patient can trigger different feelings. It is important to learn to recognise these feelings and vent them, to ask and look for professionals to talk to and who will help clarify doubts and teach breathing (diaphragmatic or alternate breathing) and relaxation techniques (Jacobson, visualisation, etc.).

Psychotherapy (individual or group) may help you better understand how you feel and face new situations of care. Sharing experiences with people in similar situations is very useful in order to face life with the patient every day.

Personal relationships

Caring for the patient can take up all the main caregiver's time. Socially, this has major repercussions on the caregiver's personal relationships.

Having an adequate social network helps prevent stress and reduces the caregiver's burden. They have to try and keep up personal relationships with the people around them (other family members, friends, neighbours etc) and adapt them to their new personal circumstances. Perhaps they cannot arrange to meet up with friends to spend the day or a weekend away but they can often chat over the phone and not relinquish that support.

Communication with Alzheimer patients is another source of frustration for the

caregiver. Communication will deteriorate as the disease progresses. Spontaneous language declines and conversation becomes shorter as both the production and comprehension of verbal language is affected. The day will come when they do not understand what we say to them and we will have to resort to non-verbal communication (gestures, imitation, caresses, and smiles).

We set out below a series of recommendations to be taken into account when talking to the patient:

- Get their attention before starting the conversation and always look them in the eye when they talk and listen.
- Always call them by name in order to maintain their personal orientation.
- Use simple language with short clear phrases. Talk slowly and clearly.
- Try to talk in the positive. It is better to say what they have to do rather than what they should not do ("sit in the chair" rather than "don't get up").
- If you have given them a choice, do not offer more than two alternatives to avoid confusing them.
- As they are slow to understand and will take longer to reply, give them the time they need.
- Try to divide up tasks (eg, getting dressed) into other more simple tasks and avoid going on until the previous steps have been completed.
- When the patient repeats the same question time and time again, try to keep calm and answer them briefly.
- Treat them with respect and do not talk with someone else as if they were not there.
- Spare no effort and make friendly gestures: smiles, hugs etc. This will give them confidence and make communication easier.

Planning time

It is essential to take time out and do something pleasant without necessarily having the patient around. They will have to plan who will take care of the patient during this time (some member of the family, respite, day centre etc) and then decide what they want to do and how to do it. Perhaps initially they will find it difficult to be away from the patient, they may even find that they are unable to enjoy the activities as they used to. But slowly they will enjoy their free or leisure time. Everything requires learning.

While looking after the patient they should do things they can share and which make both their lives more agreeable: they can listen to music together, read a book out loud (better if it is known), look at photos or watch old films or meet family members whom they recognise.

11.4. What help is available?

11.4.1. Formal support

Formal support is provided by community respite services for the caregiver. We can approach the Social Services in each municipality and complete the formalities to see a social worker.

Home teleassistance service

Teleassistance is a device which is installed at home and connected to the telephone network. It involves a hands free emergency telephone communication service which does not require the actual use of a telephone. It works 24 hours a day, every day of the year. It offers immediate and permanent attention to people who need support to continue living at home. This service is recommended for people who live alone or with either another elderly person or the main caregiver.

Home help service

Home help services are all those that the patient receives at home to allow them to live independently for as long as possible. The services are adapted to the patient's needs to ensure their maximum autonomy. The services that may be offered are: personal hygiene, managing and washing of bed-ridden patients, household tasks (cleaning the house, washing and ironing clothes, food etc.), company and adaptation of the home or other technical aids. This work is carried out by nursing assistants or geriatric care professionals.

Day centres

Day centres provide social – preventative healthcare and rehabilitation services to people with some type of cognitive impairment (Alzheimer's or other dementias) or with some physical limitation.

Some of the services that may be provided in this kind of centres are: adapted transport, personal hygiene, meals, healthcare, occupational therapy, physiotherapy, recreational activities, family and caregiver support.

The centre's main aim is to encourage patients to remain independent and in their own homes. The time they spend at the centre offers the families of Alzheimer patients a significant respite.

Day centres often offer caregivers information, advice and support.

Elderly care homes

Care homes are centres that offer permanent accommodation and specialist care for Alzheimer patients. In some cases, the progression of the disease or family, economic or social situation make it impossible for patients to be properly looked after at home.

Care homes try to keep up, as far as possible, the patient's physical abilities (individual physical exercises) and mental abilities (cognitive psycho-stimulation) and ensure the proper monitoring of medical, mental and social problems.

Like day centres, they usually have a family support programme.

11.4.2. Informal support

Training / information programmes

The main objective of training programmes is to offer information and tools to help the caregiver cope with the new situations that may arise in caring for the patient.

Physicoeducational programmes aim to make the characteristics of the disease known (symptoms, development and critical situations) and provide information on its consequences and the handling of the problems that may arise when caring for the patient (moving the patient, adapting the home etc). Possible solutions or strategies are addressed that help the caregiver to face the uncertainty and cope as well as possible.

Courses are normally offered by other caregivers with similar characteristics and therefore provide an opportunity to relate to and share experiences with other people. The professionals who give courses also treat the patients according to their discipline (occupational therapy, physiotherapy, psychology, medicine etc).

Caregiver training programmes permit the information on the disease to be improved, helping caregivers to have a feeling of control over the situation and become self-efficient in providing care. The downside is that information does not reduce emotional distress and some people feel some anxiety when they hear about the normal progression of the disease before the patient enters that stage.

Self-help groups

These groups are based on the principle “We share the same problem and when I help others, I am helping myself”.

The groups are made up of families and caregivers of Alzheimer patients who regularly attend (every week, two weeks or month) 90 minute sessions with the commitment to spend time together as a way of receiving support, advice, protection or company during the learning process in which they are involved (Hornillos y Crespo, 2008). The purpose of these Groups is that caregivers can meet other people with similar problems, giving them the opportunity to receive psychological, emotional and social support. They are normally managed by non-professional volunteers.

Psychotherapy (individual and group).

In this case, it is a mental health professional (psychologist or psychiatrist) who tries to help the caregiver to adapt as best they can to the difficult situation of caring. They aim to improve symptoms and reduce the caregiver’s personal suffering by offering them strategies to cope with their situation.

There are lots of kinds of therapy (psychodynamic, cognitive – behavioural, systematic, etc.) and psychotherapy may be individual or in a group. Normally the group format is used by Alzheimer Associations and has proved to be the most effective.

11.5. Advice for the caregiver

Self-conception

- Accepting that reactions of exhaustion are frequent and even predictable in the caregiver. They are normal reactions before an extreme situation where support is needed.
- Not to always put oneself in second place. Total self-sacrifice makes no sense.
- Asking for personal help when these signs are detected, not disguising them for fear of feeling we have reached our limit or blaming or feeling guilty for not being a super caregiver.
- Valuing the efforts made, focusing on the successes of daily life and not so much on the weaknesses and faults.

Consulting professionals

- Getting information on the characteristics of the disease: symptoms, development, treatment, possible complications etc.
- Getting practical training to face related problems such as nutrition, hygiene, home adaptation, moving the patient etc. This all helps to increase the feeling of control and personal efficiency.
- Resorting to professionals (psychiatrists or psychologists) usually located at Alzheimer Patient Family Associations for them to help you understand the disease and the effect on your lives.
- Going to self-help groups or group psychotherapy. You can learn a lot about how other people solve problems similar to yours.
- Learning breathing and relaxation (Jacobson, Schultz) visualisation techniques.

- Professionals can help make you more assertive. You need to learn how to place limits on patients' demands: to learn to say no without feeling guilty.
- Giving vent to feelings, openly expressing frustrations, fears or resentments. An emotional release is always beneficial.

Organising

- Devoting time to plan objectives. They should be realistic, appropriate in the circumstances and involve doable tasks. There is no point in denying reality or crossing our bridges before we come to them.
- Establishing priority tasks, differentiating what's urgent from what's important. Being realistic and accepting that there are things that we will be unable to do. Not having enough time is one of the main reasons why we panic.
- Delegating tasks and letting other family members or caregivers (healthcare professionals or home workers) look after the patient. Not thinking that we are indispensable.
- Alternating moments of activity and rest.
- Planning pleasant activities without the patient every day, every week and once a month.
- Encouraging the patient's independence. Letting patients do things for themselves even if they do it slowly or wrong.
- Using available resources to care for the patient: day centre, temporary respite centres or homecare workers.

Taking care of oneself

- Trying to do aerobic exercises (walking, swimming, cycling, dancing etc) every day.
- Having an appropriate diet.
- Get enough sleep.
- Mixing, keeping up contact with friends and other family members. Warm affectionate ties help reduce stress and avoid our feeling isolated.

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