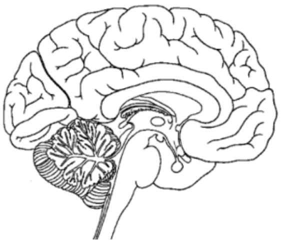
It's Not Alzheimer's .... It’s Lewy.



A guide for families of Lewy Body disease patients.

Authors: J. Antonio Monge Argilés MD,Ph.D.

María Serralba

With the social support of the Spanish Neurological Society and *La Fundación del Cerebro*.

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"It's Not Alzheimer's .... It's Lewy."

GUIDE FOR FAMILIES OF PATIENTS WITH LEWY BODY DISEASE

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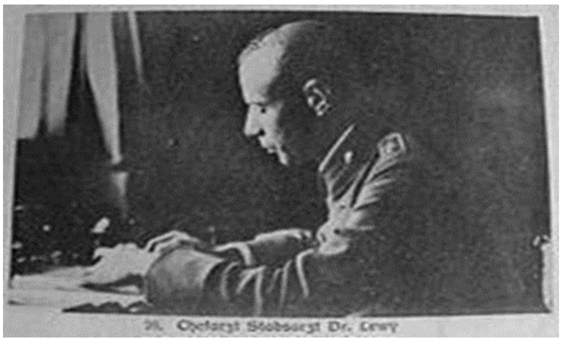

Dr. F.H. Lewy

DEDICATED TO OUR FAMILIES.

Dr.Kenji Kosaka

Lewy body in a cortical neuron.

WITH THE APPROVAL OF THE SPANISH SOCIETY OF NEUROLOGY AND THE FOUNDATION OF BRAIN.

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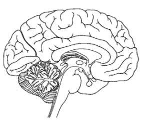

Prologue

Dementia in general, and Lewy Body disease in particular, is an extraordinarily prevalent and peculiar pathology, requiring on the part of all social groups, an “à la carte” care plan, and which has implications for each and every one of its protagonists, particularly the patients, their relatives and carers.

This guide for relatives of patients with Lewy Body disease entitled **It's Not Alzheimer's .... It’s Lewy**, is derived from our formative, essential and daily practice.

Its diagnosis can be extraordinarily complex, especially in the early stages. The difficulty involved in correctly identifying the first symptoms by the patients themselves and their relatives is the fundamental driver of this guide. Its eminently practical format, centered on three points of view, patient experience, family testimony and professional commentary is very accurate in my opinion. Since this guide has been developed from a personal perspective, meanwhile maintaining scientific rigor, which is difficult to do simultaneously.

In addition, it is essential to refute the idea that every patient who trembles or is clumsy must be diagnosed with idiopathic Parkinson's disease; as well as the idea that anyone who loses his memory has Alzheimer's disease. The general population does not know much about this entity and it is our job to report its existence as well as its diagnosis and approach.

Without doubt, when a family member or carer has been informed about the disease entity from which patients suffer, there is more than a 50% success in therapeutic management and improvement in prognosis. Without being sufficiently knowledgeable about these chronic medical conditions, it is difficult to confront them.

Finally, I would like to thank all those involved for their participation in this project, both Dr. J. Antonio Monge Argilés and Mrs. María Serralba. Only through the initiatives of our colleagues, professionals of Neurology, the Neurology Study Group on Neurology and Conduct of Dementia of the Spanish Society of Neurology, can the rewards of their work be seen.

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Introduction

Lewy Body disease (LBD) is due to round and smooth protein structures, called Lewy bodies, which are seen in the neurons of the affected brain (see photograph on page 4). They are distributed throughout the outer layer of the brain (the cerebral cortex) and deep in the midbrain or brainstem. These "abnormal protein structures" were first described by Dr. Frederich Heinrich Lewy in 1912 (see photograph on page 3), a contemporary of Alois Alzheimer, who defined the other most common form of dementia which is known by his name.

Since Lewy bodies are also commonly found in the brain of patients with Alzheimer's, Parkinson's (PD), Down syndrome and other diseases, in 1995 the researchers agreed to use the term "Lewy bodies disease" to describe at the same time a specific disease (sometimes called "pure LBD") and a whole range of disorders with similar or related pathology.

LBD, as a defined pathological process, is considered to account for up to 20% of the seven million cases of dementia in the United States, and up to one third of these diseases presented by the elderly in that country. This means that LBD is the second most common form of dementia, after Alzheimer's disease (AD).

Doctors and other clinical experts sometimes use other names to refer to LBD or other Lewy body syndromes, including "Lewy Body diffuse disease," "Lewy Body cortical disease," " Lewy dementia "or the" variant with Lewy bodies of Alzheimer's disease ". Although the debate over the nature of Lewy body-related diseases remains controversial, most consultants today agree with the terminology and diagnostic criteria of the LBD developed in 1996 by an international conference. However, the first author who published a detailed study using the current terminology was the Japanese doctor K. Kosaka in 1996 (see photo on page 3).

The causes of LBD are unknown and no specific risk factors have been identified. Families with multiple cases of this disease have been seen, but there does not seem to be a marked tendency to hereditary transmission. In the future, genetic research may reveal more information about the causes and risk factors.

Our task with this guide is to try to impart, as clearly as possible, the symptoms that may appear during the illness, as well as the guidelines to be taken into account by the family members in their daily treatment.

To do this, we have structured each chapter into three parts: the experience of the patient, that of the family and the comments and clarifications provided by the neurologist. In our opinion, this structure will make it easier to read. Of course, not all patients have all the symptoms of the disease described below, much less at the same time, but we think that knowing how to recognize them will help us all (family and professionals) improve treatments.

Many times we have around us people who suffer some of the symptoms of this disease in an incipient way; however, these are easily confused with the individual's way of being, character, etc. We hope that this guide will serve to distinguish them and thus get a diagnosis as early as possible since it is the most appropriate way to help patients and families.

Epidemiological information

Lewy Bodies disease (LBD) is a common but little known condition. It is proven that it affects 1% of the population who are over 65 years. For an average population of 270,000 inhabitants, as in our health district of Alicante-General Hospital, it is estimated that 43,000 people are over 65, which accounts for 430 patients alone a year in our closest environment. For every million people it would affect about 1600-1700 patients per year. Therefore, in Spain there may be about 70,000 patients per year who currently suffer from this disease.

There is no extensive epidemiological data available, nor are there population studies of the condition, but in the recent publications, LBD could constitute between 10% and 36% of all dementias, only surpassed by Alzheimer's disease (AD) with which it may be associated. The age of onset of LBD is usually between 70 and 80 years, as with other degenerative dementias.

Some longitudinal studies record a faster course of development and a worse prognosis than that of AD, with a shorter duration for LBD, whereas other studies find no significant differences in this aspect. In most of the groups of patients studied, male gender predominates.

Although in the most part developing LBD is sporadic, there are a few families in which this condition and Parkinson's disease (PD) are genetically determined by abnormalities in the α-synuclein gene, the protein whose aggregation forms the Lewy bodies. The gene may have a mutation or have repeat sequences (duplication or triplication).

The presentation in such families can be of both PD and/or LBD, providing strong evidence that these two disorders share a common basis. Families with a duplication of the gene have only PD, suggesting that there is a "dose-dependent" effect, meaning that a greater overproduction of α-synuclein is required to develop an extensive cortical histopathology that produces dementia.

OBJECTIVES OF THIS GUIDE:

- To improve knowledge of the disease in society, because although common, it is not well known.

- To convey what life is like for patients and how they feel when they suffer, so they can be better understood and treated.

- To guide and inform families about the different primary symptoms of this disease and how to deal with them both at a medical level and in the family environment.

- To provide some strategies for caregivers that may be helpful to both patients and themselves.

WHAT IS HAPPENING TO ME, DOCTOR?

PRIMARY SYMPTOMS OF THE DISEASE.

1. REM sleep disorders: "Violent nocturnal dreams".

2. Anxiety, internal nervousness and late onset depression.

3. Self-limiting episodes of confusion: "sporadic somnolence and disorientation".

4. Parkinsonian signs: tremor, changes in gait, slow movements, rigidity.

5. Visual hallucinations: "daydreaming" or olfactory hallucinations "everything smells bad".

6. Dysautonomic symptoms: "dizziness, weakness, falls".

7. Disorientation, alterations of memory and in the execution of tasks.

8. Visual agnosia: cerebral inability to recognize or understand visual stimuli: "I do not recognize what I see or it is confusing me."

9. Delusional ideas of prejudice: "they are attacking me, they are robbing me...”.

10. Sensitivity to neuroleptic medications.

1.- REM SLEEP DISORDERS

Patient experience

“According to my wife, for many years I have been moving a lot when I am sleeping. It must be true because on some occasions I have found myself on the floor or about to fall out of bed. She says that I scream, move, and even start to fight during a dream. This has resulted in me hitting her several times. For that reason, we decided to sleep in separate beds a few weeks ago. In fact, I do not usually remember my dreams, unless I wake up as a result of injuring myself. A few days ago, I woke up on the floor with a bruise on my shoulder due to a fall, and then I remembered that I had been dreaming that I was defending myself from an attack on the street.

In addition to sleeping in separate beds, I will have to put cot sides on my bed to prevent falls.”

Testimony of relatives.

“I have found small bruises on my father’s forehead and knuckles. I knew that he had not suffered any blows or falls during the day; so why were they there? I watched him while he was sleeping and I could see that he was moving violently. His injuries were the result of a frustrated attempt to leave from the side of the bed where the wall is. He told me when he woke up someone was chasing him, and the dream was so real that it made him act that way. These dreams continue to repeat themselves, albeit differently, and he reacts in the same violent way”.

Professional Comments

During sleep, we go through different stages that can be summarized in REM and non-REM phases. In the REM phase of sleep, what we generally call "dreams" are produced. These are periods of great brain activity. However, a fundamental characteristic of this phase is that, at the same time, externally we remain completely relaxed muscularly. For this reason, when a person presents movements during that phase, a REM sleep disorder (RSD) is considered.

The symptoms outlined above are RSD, which occur when dreams are very intense and sometimes turn into violent actions and attitudes. RSD may appear several years before cognitive symptoms. We frequently hear that partners have received physical injuries when this disorder has not been treated appropriately. RSD can respond suitably to treatment with some drugs.

2.- ANXIETY, INTERNAL NERVOUSNESS AND LATE ONSET DEPRESSION

Patient experience

“I have been nervous for no apparent reason for some months. It is true that there is always something to worry about, but I do not consider that these things are important enough to provoke this state of anxiety. I can barely stand still and I cannot concentrate on doing the things I like to do. That's why when I get in a bad mood everybody around me has to pay for it. Sometimes I scream or get angry at things that are not important and then I realize that I am not well. I have also become more sensitive than before. In fact, several days ago I was told that an old acquaintance, who I had not seen for some time, had died and this filled me with a sadness that I still feel.

In the afternoons, I usually feel better, but it is difficult to get started in the mornings and it seems that the bed attracts me like a magnet. I do not have the strength to get out of it, despite sometimes being awake for several hours.

I do not understand as I was never like that. I now seem to see only the sad part of life without being able to avoid it, and this in itself increases my worry and bad moods.”

Testimony of relatives.

“For some months I have noticed that my mother reacts strangely when there is some discussion at home. Instead of taking part, she goes into her room or walks into the kitchen and stays there for hours or until she hears that everything has returned to normal. Now she even does it for no particular reason, even though there are no arguments; she has even left the house and come back after a few minutes. Hearing loud voices or noises really upsets her, she says. We cannot contradict her at all. She starts to cry or she gets angry, but she does not seem to have a happy medium.”

Professional Comments

These neuropsychiatric symptoms, which appear at advanced ages, are common in people at the beginning of the process of the development of dementia. They are considered as a part of the disease, and even some authors have used the concept of "depressive dementia" to refer to them.

These symptoms require proper treatment, which usually improves them but does not always cure them, as is often the case when there is an underlying dementia. So close follow-up is necessary and consultation with a specialist will be done if there is no improvement after a reasonable period of some months. These treatments are not always well tolerated at first, but may be effective after a few weeks. In many cases, the same drug can be used to improve all symptoms, which usually improve tolerability and compliance with the treatment.

3.- SELF-LIMITING EPISODES OF CONFUSION

Patient experience

“For a few months, I have occasionally fallen into a deep sleep unexpectedly. Even during the day, although I may have slept well the previous night. The problem is that sometimes it lasts almost the whole day and I am not even able to eat or dress myself. My wife says that it is very difficult to communicate with me, that even if I do wake up a little, it is to say things that do not make sense; for example, not knowing where I am, or not remembering my age or the number and names of my own children. I am not able to remember what I have just been told, much less to do easy mathematical calculations. When this happens, my memory is very vague and I feel that I have been absent for quite some time. This situation is very annoying for my family. Sometimes they worry and urgently call the doctor, who asks them if I have been drinking alcohol or taking any sleeping tablets. When they say no to both questions, the doctor sends me to the hospital urgently; I have already been hospitalized three times in the last 6 months for this reason.”

Testimony of relatives.

“My father used to sleep everywhere, and when I say "everywhere" it is literally true. Sometimes when he has fallen asleep on the bus, somebody has had to waken him at the end of the journey; or while he has been eating in a restaurant, we have watched as his head has fallen on the plate. We thought it might be a symptom of anxiety or the result of having to get up frequently at night to go to the bathroom because of his prostate problem. Now that we know it can be a consequence of LBD, we wonder how long he has been sick without us noticing.”

Professional Comments

Patients with LBD often have episodes of confusion of variable duration with no apparent cause. It is possible that the patient is disoriented with regard to time or place; having speech problems in finding words or having a conversation; suffering difficulties of spatial perception in finding the correct way or solving certain puzzles. In addition, they may also display problems of thinking such as lack of attention, mental inflexibility, difficulty in making decisions, loss of good judgment and understanding of things.

There are fluctuations in the appearance of these cognitive symptoms from minute to minute, from hour to hour, from day to day, or from week to week. In fact, the patient may converse normally at a given time and be unable to talk few moments later or even the following day. While this characteristic is often considered to be an important component of LBD, it can also occur in other dementias, and it is sometimes very difficult to determine whether fluctuations actually occur in a specific patient. There is not a specific treatment for this symptom.

4.- PARKINSONIAN SIGNS

Patient experience

“For a few months, my right hand has been shaking a little when I'm reading, watching TV or just talking. Sometimes, I do not notice it, but I am aware that people around me do. I have become accustomed to it, to the point that it hardly bothers me. I can eat, drink, and do many activities without problems. It is true that my handwriting has changed lately and I write smaller. Sometimes I have some problems buttoning my shirt or trousers. I have no problem having a shower, although I notice my movements are somewhat slower, which makes me more careful when getting into and out of the bath.

When I go for a walk I also feel that I am slower than before. This makes me shorten my route. For a walk that I would have done in an hour, I now need 15 minutes more. When I walk, I realize that my right arm is stuck to my body and this unbalances me a bit, but it does not prevent me from walking.

I have read that these symptoms may be triggered by Parkinson's, but I am waiting to consult with the neurologist to find out if that is the cause.”

Testimony of relatives.

“My father was recently diagnosed with LBD. We have watched him walk, and he does so with much slowness and difficulty. He says that although he wants to walk, it is as if his brain does not receive the order and that is why the parts of his body do not help him to begin the process. However, at other times when his brain sends the order, it is as if he is wound up, and begins to walk and walk endlessly at great speed, and no one is able to stop him. Whenever this happens, we are surprised. As an example, a few weeks ago he was hospitalized for a urine infection. During the days of his hospital stay, he got out of bed and walked down the corridor in a practically normal way, did his personal hygiene and even was able to write better than at home. It was explained to us that this improvement may be due to the stimulation of hospitalization.”

Professional Comments

These Parkinsonian motor symptoms may start abruptly or slowly. Among them are the flexed posture, the shuffling of the feet, a reduction in the swinging of the arms, rigidity of the extremities, propensity to fall down, slow movements and tremors. These symptoms may appear in a prominent way one day and much less noticeable on others. It is not uncommon for some families to be astonished to see a patient who one day can barely walk, and another day gets out of bed alone and has almost normal mobility without any justifiable cause. Sometimes, these fluctuations make the family think that the patient is pretending, when in fact it is a symptom of the disease´s oscillations. When Parkinsonian symptoms are very pronounced, the neurologist may prescribe a specific medication, usually in low doses to avoid side effects.

5.- VISUAL HALLUCINATIONS "DAYDREAMING"

Patient experience

“I've been having strange experiences for a few months. It seems like I am having daydreams. It all started one night when I woke up and felt the presence of someone I could not see. This feeling made me a bit nervous, but after getting up and checking that there was no one I went back to bed and soon resumed the dream. Also at night a few weeks later, I began to see strangers coming in and out of my room. In the first few days I did not pay much attention, but when those people began to insult me and try to attack me, I was on my guard and I had to defend myself. As a consequence, I have fallen a few times and I have injured in my hands and my legs. These *dreams* usually disappear in the mornings but it is not uncommon that at the end of the afternoon strangers appear at home again. When this happens, I try not to pay attention and focus on another activity. The problem is that sometimes even the television broadcaster addresses me accusing me of doing my job wrong and that makes me very nervous. Since I have been taking the medication prescribed by the neurologist, I have noticed that fewer strangers come home and, at least, they do not annoy me nor accuse me of anything.”

Testimony of relatives.

“When I first heard my father speaking when he was alone, he did it, according to him, with a very kind gentleman who was sitting next to him in the room and my father was showing him his books. There was no one. The same "invisible friend" often visits him.”

Professional Comments

Patients often have vivid and well-defined visual hallucinations. In the early stages of the disease, it is possible for the patient to admit and describe the hallucinations as something external, what we call "hallucinosis". However, when the hallucinations are patent, the patient lives them as an indisputable fact since the images they see are clear. There are other types of less frequent hallucinations, but they also occur occasionally. They can be auditory (*hearing sounds*), olfactory (*smelling something*) or tactile (touching something that objectively does not exist). These symptoms greatly alter patients because in some cases the visions can be violent, threatening or even frightening. Telling them that the images are false does not improve the situation. Maybe things can be made better by changing the room or the lighting in the event that the hallucinations are provoked by external situations. It **is also very important on the part of the family to remain calm; otherwise, the situation may worsen.**

Treatment of these symptoms almost always requires major tranquilizers which must be prescribed by a physician. The most appropriate dose will be used, taking into account the already discussed fluctuations of the disease.

Given these symptoms, caregivers and the family can follow some guidelines that can be very useful:

1. Stay as calm as possible.
2. For the patient these hallucinations and delusions are an incontestable reality, it is important that the carer does not deny their occurrence in a direct or radical way.
3. Try to check the degree of credibility that the patient gives to delirium or hallucination: "I know you see something, but do you think it's real?" "Are you completely sure of what you think?"
4. If the patient is conscious that what is happening is unrealistic or over-exaggerated, try to explain that this is a symptom of the illness.
5. If the patient believes what he or she sees or thinks, however exaggerated it seems, as far as possible, just pretend to believe it and try to shift his/her attention to other ideas or topics that he or she takes pleasure in.
6. In case of uncontrollable nervousness as a consequence of these symptoms, contact the health service so that the patient can be evaluated by a doctor.
7. Communicate these symptoms to the patient’s general practitioner and neurologist.

6.- DYSAUTONOMIC SYMPTOMS

Patient experience

“For a while now, when I get up quickly, I feel dizzy so much so that sometimes I have to sit back down again. It happens mostly in the mornings but if I go out shopping or I am standing for a few minutes, I get very tired and I have to sit down as soon as I can. A few days ago, it was very hot and when I left home I was dizzy. I took a bottle of water with me because I noticed I had a dry mouth. However, I had to go home before doing my errand because I thought I could not complete it.

Lately, I've also been suffering constipation for which I use medication, after having been using home remedies. It is true that some fruits help more than others, as well than some food is better than others. However, from time to time I cannot do without taking some treatment which has been recommended by my doctor.

I have always had a good appetite and I have enjoyed food, but for several months I have noticed that the food has become flavourless. I have told my family, but they say the food is the same as always. But for me, it does not taste the same. I will have to discuss this with my doctor.”

Testimony of relatives.

“For some months my father has not been able to distinguish what kind of food he is eating. At first, we thought that it was an excuse not to eat, or that he did not like what he was being served. We tried with his favourite dishes, but it made no difference: he cannot even differentiate between meat, fish or vegetables. It is as if he had lost his sense of taste or his mind no longer receives that information.”

Professional Comments

Sometimes there are significant changes in the autonomic nervous system, including regulation of temperature, blood pressure, and digestion. Dizziness, fainting, sensitivity to heat and cold, sexual dysfunction, early urinary incontinence, or constipation are common symptoms of LBD. Each of these symptoms should be treated in a specific way since not all of them usually occur at the same time and do not have the same treatment.

Loss of taste is a symptom that can appear in neurological pathologies other than LBD, such as Parkinson's disease, even months or years before the disease has been diagnosed.

7.- DISORIENTATION, ALTERATIONS OF MEMORY AND IN THE EXECUTION OF TASKS

Patient experience

“A few days ago I went out to buy some things for the house. The shop which supplied the original materials is quite far away, but I told myself that it would be good to walk a little. I deliberated whether to take the bus, but I finally decided against it. I have known my city for more than 30 years and it was a perfect day to walk. So I walked toward the supplier's area and arrived without a problem. I bought the spare part but on leaving I got confused. I went through a different exit and was soon lost. I did not know where to turn, my mind went blank and I had to ask a passer-by. In spite of this, I struggled to find my way. The same thing happened to me a few months ago, so I have decided to always bring my mobile phone when I leave the house to be able to call my family in case it happens again.

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When I tell my friends that sometimes my memory fails me, they all tell me that it happens to them too. In truth, the other day, a friend, who suffers from frequent absent-mindedness, says that he forgot to go to a meal he had planned with his family. That has never happened to me. However, I feel that ideas do escape me and I need to write things down that I have to do if not I will forget them. It is not uncommon for me to think about doing something and when I arrive there I do not remember what I was going to do, or going to the supermarket and forgetting about the things I was going to buy. Although when I really concentrate on remembering something important, I get it. I will have to exercise my memory further.

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I really like DIY. For years it has been a form of relaxation for me. I have a lot of tools that I have been using to make furniture, decorative objects and gifts. For some months now, I have noticed that if I have to organize myself to complete a task that has to have several phases, otherwise I slow down and I have a difficult time finishing it. It is a strange feeling that although there are different tasks to complete, the steps which need to be taken to finish them are always the same. I need to plan things better, even writing the steps to take before starting a task, to make everything easier.”

Testimony of relatives.

“My father has always had both feet on the ground, but for some time now his mind has begun to fail. When he is spoken to, he takes some time to reply, despite knowing the answer, or, as he says, having it on the tip of his tongue. He asks us to wait a few minutes as meanwhile he is sending a message to the "library" of his brain in order to allow it respond to him. We have verified that the technique works, although this delay in the response often causes people to stop paying attention.

Since my relative has had LBD diagnosis, we have noticed that he can no longer coordinate when dressing or doing his personal care, it is as if it were difficult for him to follow a sequence; more often than not he asks us: "And now, what do I have to do?" We have to remind him, which has led us to help him in almost every activity. We do not know if that is good or bad because possibly we are reducing part of his independence, as there may still be somethings which he knows how to do himself."

Professional Comments

Alterations of memory in patients with LBD are not usually as severe as in the case of Alzheimer's disease (AD). It is not uncommon for patients to talk about the changes to memory, but when they are asked to make an effort to remember something, they do it well. Spatial disorientation is also frequent but not specific since it is not uncommon in patients with AD. Finally, the difficulty in planning the tasks is also a symptom found in other dementias which can make essential activities for daily living, such as using the telephone, the washing machine, the remote control of the TV or catching the bus very difficult to complete. Especially at the beginning of treatment, these symptoms usually improve with drugs called acetylcholinesterase inhibitors. Although currently the technical file for this group of drugs does not include this indication, there are important medical publications which support their use.

Faced with these changes, the role of the family should be as a guide and support while trying to maintain the autonomy of the patient to the maximum. This task is difficult considering the fluctuations in the level of awareness, and even cognition, which we have given in this guide.

Cognitive stimulation performed in a relaxed, but an active environment, and occupational therapy can clearly help to better maintain these brain functions.

8.- VISUAL AGNOSIA: CEREBRAL INABILITY TO RECOGNIZE OR UNDERSTAND VISUAL STIMULI: "I DO NOT RECOGNIZE WHAT I SEE OR IT IS CONFUSING ME"

Patient experience

“For some time now, something strange has been happening to me. On several occasions, I have met people I have always known and I do not recognize them until they speak to me. It is as if they were strangers to me, and therefore I do not greet them. A few days ago, the neighbour on the fifth floor asked me if I have bad eyesight and I said no. This neighbour was someone I did not recognize in the elevator, although we are frequent companions in dominoes games which are organized in the social club. A few weeks before I had been to the ophthalmologist and he told me that my eyesight was good.

Something similar happened to me the other day when visiting my daughter's house. I had the feeling that it was the first time I had been there. Even though I have sometimes stayed overnight to take care of my grandchildren when their parents have gone out. I told my daughter and she advised me to tell the doctor. I did not think it is as bad as that, but I will tell the doctor next time I go for a consultation.”

Testimony of relatives.

“For some weeks I have tried everything to get my father to shave with the electric razor. He says that he does not use it because he does not like to use others people things and that he has always shaved with a manual razor. In fact, he has had the device for years but he does not recognize it as his own.

Sometimes something similar happens to him with clothes. When I help him to get dressed he always asks me whose those clothes are. I explain that he has owned them all his life and he argues over and over again, even denying that he has ever had them in his wardrobe. The following day, it is the same; nonetheless, there are other objects that he remembers perfectly.”

Professional Comments

Visual agnosia is the cerebral inability to recognize or understand visual stimuli. This symptom usually goes unnoticed until the advanced stages of the disease, except when it is explored in a directed way because of the suspicion of the diagnosis of the disease. However, it is considered one of the most characteristic symptoms and its early appearance is very indicative of LBD and is valuable in differentiating it from AD. As with most of these symptoms, we can perform cognitive stimulation that will alleviate the situation, but we do not have drugs which can deal specifically with it.

9.- DELUSIONAL IDEAS OF PREJUDICE

Patient experience

“Last night I had a strange experience. For a while, I had the impression that my family was taking advantage of me. In particular, they were spending my money, without telling me and without asking for my permission. I vaguely remember that I reproached them about this. At the time, all my children and their partners were present, something that does not often happen, especially since one of them lives far away. Despite telling them what I thought, they barely defended themselves and hardly spoke or said anything that convinced me I was wrong. My wife was crying but she did not say anything either, which made me think that I was right.

They called a young doctor who came to see me, and after asking me some very uninteresting questions, she prescribed some medication for me. After taking it, I felt more relaxed and I had doubts about my suspicions and the behaviour of the family. I began to remember that I had given my children permission to make a purchase with my money but I had forgotten about it. When I saw my current account was greatly diminished that was when I thought they were robbing me. Now I understand that it did not happen, but it has been a very unpleasant experience. I have asked forgiveness from my family and I must try to avoid such forgetfulness.”

Testimony of relatives.

“Regarding my father’s behaviour, I thought at first that it was his character. All our conversations ended in an argument. He used to verbally attack me and his opinion often was contrary to the opinions of other people, particularly mine, almost in everything. I ended up not giving him any reason to argue with me. Something told me that this was not normal behaviour. Most of the time, his reaction to the issues we talked about was excessive and he was easily irritated, even touching on fury. He saw me as his enemy, the person who tortured him by not letting him do what he wanted.”

Professional Comments

This is one of the most serious symptoms of the disease. The patient is convinced that he is being harmed by people or situations around him. It is not recommended to argue against his conviction, even if he is contradicted, it is very difficult to reach an agreement or understanding with the patient. In general, where possible, families are encouraged to try to avoid these situations by changing the subject or looking for some topic of conversation that is in the best interest of the patient.

When it is not possible to control the symptoms, major tranquilizer medication usually becomes necessary, as always, in the lowest necessary dose, so that the caregivers and the patient himself can continue in reasonable harmony.

10.- SENSITIVITY TO NEUROLEPTIC MEDICATIONS

Patient experience

“In the last week, I have had some medical experiences that worried me. My problem started with gastroenteritis which made me vomit a lot. I went to my GP and he prescribed some medicine to be taken every 8 hours. After two days, I noticed that I was very rigid and I had trembling in my hand. I was sleepy and ate very little. My family decided take me to the hospital, where they gave me an IV after which I improved a lot, and I did not need to take the medicine anymore. The emergency doctor told me that I should not take that medicine again because it caused me to have symptoms similar to Parkinson's. Indeed, the stiffness and tremor disappeared in a few days. I do not understand why this medication let me to develop these symptoms now when previously I had taken it and had no side effects. I will need to talk to my GP at the next appointment.”

Testimony of relatives.

“My father was being medicated for the symptoms of anxiety and depression with tranquilizers and other drug from the antipsychotic family. Then he began to have Parkinsonian tremors in the arms and difficulty in walking. When he stopped taking this medication, almost everything disappeared, but he was diagnosed with LBD”

Professional Comments

Acute sensitivity to neuroleptics drugs is common in LBD. Neuroleptics, also known as antipsychotics, are medications used to treat hallucinations or other serious mental disorders, but also these drugs may be included in treatments for other illnesses such as gastroenteritis. Although antipsychotic medications are sometimes prescribed to treat behavioural changes in patients with AD, these medications can affect a person's brain with LBD differently, and usually cause serious side effects. For this reason, traditional antipsychotic medications should be avoided. Some newer antipsychotic drugs called "atypical" may also be problematic in some people with LBD, but in general, less than the traditional ones. Some experts advise the use of the atypical drugs because they have a less likelihood of provoking those symptoms. If this drug is not tolerated or does not produce the expected results, the possibility of switching to another should be considered. Therefore, it is recommended that hallucinations and in general psychotic symptoms should be treated in a very conservative manner. The lowest possible dose should be used with careful medical observation in order to prevent possible side effects.

CARE FOR THE CAREGIVER

Caregivers are a fundamental mainstay of the patient with LBD. Keeping their well-being at the forefront is a very important goal so that the patient can find in them the deliberate and compassionate guidance they need. Without doubt, and especially in this neurodegenerative disease, the availability of a well-trained caregiver becomes increasingly necessary, given the enormous variability of symptoms. In the most symptomatic stages of the disease, it is not uncommon to need several caregivers in the care of these patients.

Knowledge of the peculiarities of this disease, especially of the fluctuations both psychic and physical, will help them to understand, accept and better adapt to the situation.

Currently, we use the motto "care for the caregiver" for several purposes. On the one hand, for the best treatment of patients; on the other hand, to avoid caregivers becoming ill as a consequence of their responsibilities. We recommend being alert to the appearance of new "symptoms of over load" in caregivers such as:

- Sleeping problems.
- Loss of energy.
- Physical problems: palpitations, digestive discomfort, etc.
- Problems with memory and concentration.
- Decreased interest in previous activities.
- Change in appetite.
- Getting angry easily.
- Frequent mood swings.
- Becoming accident prono.
- Difficulty overcoming feelings of depression or anxiety.

The carer should be mindful of the need to take care of him or herself. Therefore, we advise a series of measures as follows:

- Try to control stress through techniques which are familiar to the caregiver.
- Eat regularly with a balanced diet.
- Get enough sleep and rest.
- Avoid social isolation.
- Use time management techniques.
- Exercise regularly.
- Incorporate relaxation exercises.
- Value the positive aspects of "caring".

Finally, it is important not to forget that we are facing a disease of which is nobody’s faults, but the support of many can make it as bearable as possible.

Epilogue

It was by chance that this guide was being written in the year in which the 4th centenary of the death of the most illustrious writer of Spanish literature is commemorated.

When Don Miguel de Cervantes Saavedra wrote his **Don Quixote de la Mancha**, he probably had *in mente* a whole series of reasons why he carried out his work. Many of them have been very well detailed by different literary critics throughout history. However, it is very unlikely that these analysts would have noticed that Quixote could also be revealed as the first description of Lewy Body disease.

When the neurologist reads this great work and is drawn by professional conditioning, he may progress to attempting to diagnose Don Quixote's disease. Let’s remember that he is a man of advanced age, who without a known history of psychosis during youth, develops obsessive ideas. These were manifested in compulsory reading of chivalry books, visual illusions such as windmills as aggressive giants, and visual hallucinations where *Dulcinea del Toboso* appears as the most beautiful of the maidens in the world. Besides, he suffered from some fluctuations of his mental state such as moments of clairvoyance which intermingle with almost no semblance of continuity with periods of aggressiveness. With this data, the diagnosis of the disease for the purpose of this guide could be considered. If we accept this theory, we might consider Don Quixote as one of the pioneering works in describing Lewy Body disease. After almost four hundred years have passed, this current medical description could add a new dimension to the already previously recognized multiple analysis of this novel. Naturally, this observation is open to debate and we gratefully accept all opinions!

Using the anniversary to which we made reference at the beginning of this section, we hope that these words may serve, therefore, as a small tribute to a writer whom we consider little valued in his own country, despite the quantity and quality of what is said and what has been published about him.

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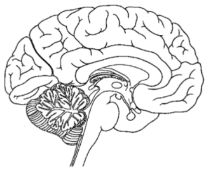

BACK COVER

How many times we have told ourselves that having a sick person at home can change our lives, especially if we fail to understand what is happening to them. In order to overcome this uncertainty, we have created this guideline for family members of patients with Lewy Body disease (LBD), a variant of dementia that is not as well-known as Alzheimer's or Parkinson's, but which, however, is increasingly present in our society.

Dr. José Antonio Monge Argilés, as coordinator of the dementia consultation of the Department of Neurology of the General University Hospital of Alicante and the writer María Serralba, a direct relative of a patient with this pathology, clarify for us both at the scientific level and personal experience, some of the mysteries displayed by people suffering from this condition, while offering us advice and alternatives in coping with the situation in the most possible favourable way.

We sincerely hope that this guide can help you. However, we always recommend consulting with a specialist, as he or she may be the best adviser in your particular case.

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