The International Association of Lions Clubs
MD 108 Italy

ALZHEIMER
Not to feel alone

Ed. PDG Franco Marchesani

Introduction

Today we can consider specific forms of cognitive degeneration in some way connected with better conditions of human life. As a matter of fact, in those areas where a longer life represents an important goal, at the same time a prolonged ageing
involves a series of health, social, economical and ethical problems that demand a reaction, now and much more in the future.

Alzheimer's disease is among these forms; once it was called early dementia, since it appeared in people below 60, now it affects older people, with an increasing number of cases due to a longer life span.
In particular, as we will underline hereinafter, the disease troubles two kinds of subjects: the patient and who lives with him/her and we can't think about the former ignoring the latter.
This booklet - which is published by the Lions Clubs of the 5th Region, District 108 L - Italia - may represents an important support, easy to consult, in order to help the Alzheimer patient daily. As a matter of fact, it has been thought not for the "experts" but for those people who are involved with these kind of patients and don't know "what to do".

For me, the task I received, by the Board of the "Mediterranean Observatory of Solidarity", of writing a version available to the supporting Countries, has been a great honor and an incitement to go into this argument more deeply and concretely.

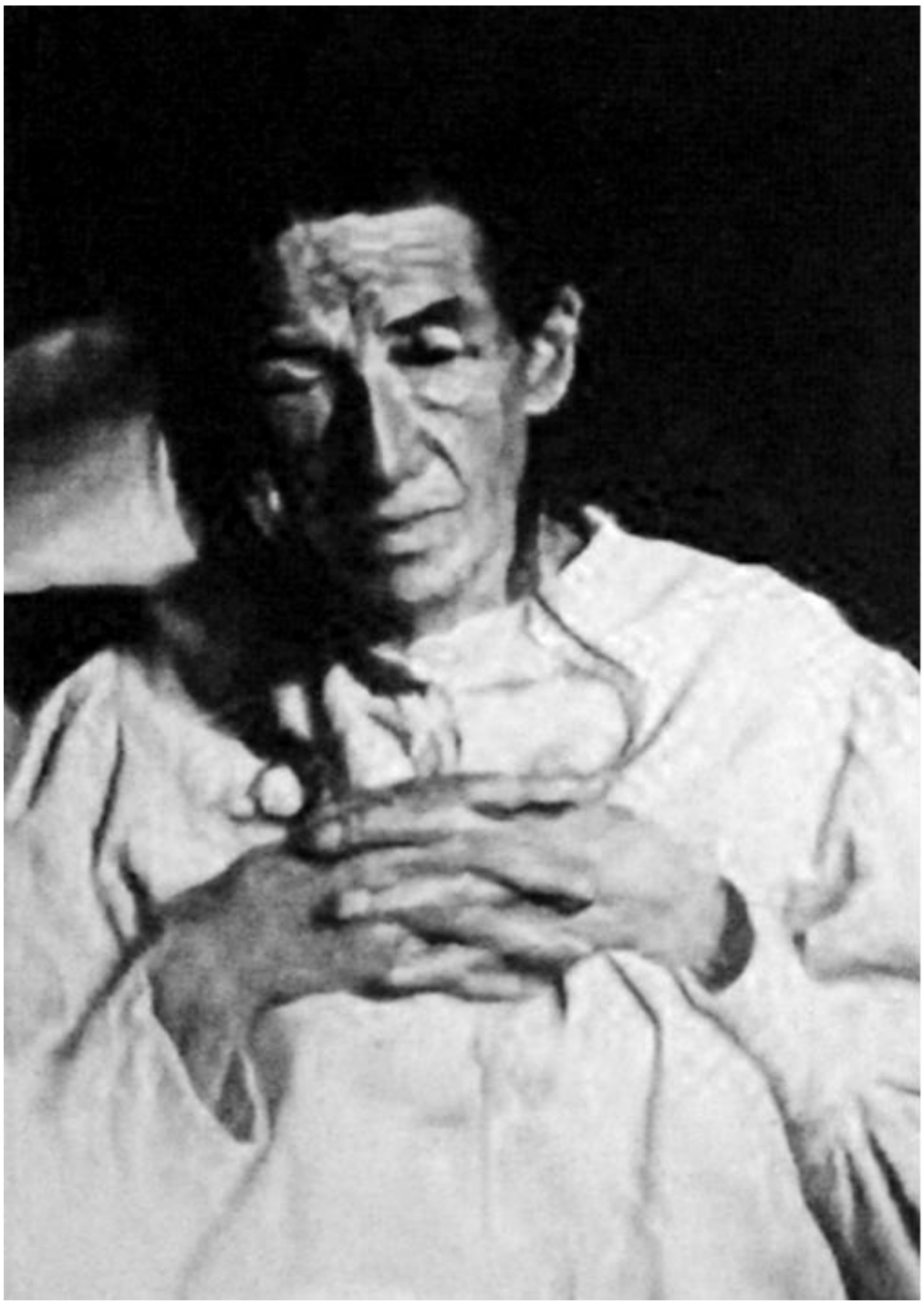
I wish to point out that I had to modify the original structure of this work a little bit; I removed those sections regarding organizational, regulatory and social security topics that are strictly connected to the Italian context, which the booklet was born for, while the section we can call technical has been totally unchanged.

Also, as an appendix, I have added some brief annotations, concerning the attentions to be addressed to the relatives and those people assisting the Alzheimer patient.

In the end, I wish to pay a special thanks to the Lions Laura Fedigatti and Katherine Morgan of the L.C. Mortara Silvabella D 108 Ib 3 - Italy, for the impeccable translation.

PDG Franco Marchesani

M.D.108 – Italia



The first case diagnosed by dr. Alzheimer,
the female patient “Frau Auguste D.”

Generally speaking, and not referring to the etiology, dementia is among the first reasons of disease in the older population, before heart attack and angina pectoris, alarming the national health service and welfare interventions.
In dementia, there are two different kinds of sick people: the patient, who is sick, and the family, who is slowly but gradually torn apart and sometimes destroyed by a 24 hour a day assistance.

Is family role essential?

Relatives are the most important support in coping with dementia patient: for most of his/her sickness, the patient is assisted by his/her family, who must be adequately sustained, because the risk of diseases in the caregivers are extremely important and frequent.

THE DISEASE

For dementia we mean a decrease of the intellectual functions, that is acquired or genetic, characterized by the prejudice of memory, thinking, language and bearing. Such damage interferes with social and working activities of the affected person.
The symptoms seriousness leads to a progressive loss of personal autonomy and a progressive increase in assistance.

In addition to cognitive symptoms, do other disorders appear?

There are other disorders affecting behavior, caring, ideation, vegetative functions. Among these symptoms we remember anxiety, depression, hallucinations, aggressiveness, apathy and insomnia, about which we will talk later.

The most frequent clinical form, responsible of more than 50% of the dementia cases, is the Alzheimer disease, described for the first time in 1907 by the German Alzheimer and the Italian Perusini. Nowadays, the definition “Alzheimer Dementia” is used for all the different forms of dementia.

What is the disease evolution?

Generally, we can recognize three stages: early, moderate, advanced. The early stage has an average span of 2-4 years; the moderate stage of 2-10 years; the advanced stage of 1-3 years.

What are the characteristics of the early stage?

The beginning presents mild symptoms, that can often go unobserved.
The patient can’t remember the latest events; he/she can forget to switch the gas off, to close the house door.

In this stage, he/she is inclined to blame the others for his/her mistakes. He/she adapts with difficulty to changes, has difficulty to decide and to plan, shows a great loss in his/her interests and moderate depressive symptoms can also turn up.
Slowly, the patient starts confusing people and names of objects, getting lost in known streets, not remembering dates.
In this stage, the relatives ascribe the symptoms to particular situations of life, that contribute to underline an existing pathological condition.

What happen during the moderate stage?

The patient starts being unable to perform his/her common activities.
In addition to lose the short term memory, he/she forgets events which happened a long time before; he/she confuses the hours of the day and alters the sleep/wakefulness rhythms; he/she sleeps during the day and wanders restlessly during the night. The behavior becomes strange, feeding is ignored; he/she is unable to get dressed correctly, gets lost in familiar and smaller settings, sees or thinks of seeing and hearing unreal things and can become aggressive and lose control.
In this stage, the patient is unable to perform common activities of day living and needs more assistance and supervision.

What are the characteristics of the advanced stage?

The patient is totally dependent, needs assistance to get dressed, to be fed, to be washed, suffers incontinence.
Memory is completely lost, he/she can't walk, move, swallow, communicate.
In this stage, physical complications are frequent, such as pressure ulcers, pulmonary and urinary infections, dehydration, bad nutrition.

How long does the disease last?

It lasts about 10-12 years.

Is it important an early diagnosis?

In the Alzheimer disease the early diagnosis is very important as well, to obtain the best therapeutic benefits. For this reason, it is important to inform the physician about the first symptoms as soon as possible and not ascribe them to aging.

Does a pharmacological therapy exist?

Treatments that can prevent and cure dementia doesn't exist yet. Available medications can only contrast with the development and deterioration of the disease.

Which are the most common behavioral changes?

The most serious and frequent changes in the patient's behavior are restlessness, anxiety, aggressiveness, inappropriate social behavior, wondering. Moreover, there can be delirium and hallucinatory state.

We must remember that anxiety is most likely the most common symptom: it can be revealed by simple restlessness and impossibility to stay still, or serious form of aggressiveness can appear; anxiety is due to the patient who can't adapt to the disease, but more often is due to concurrent reasons.

It must always be checked the presence of a triggering event with the help of the family doctor.

What must be done with anxiety?

Aggressive stimulations must be avoided, check that the patient does not present physical pain or symptoms due to other diseases. A relaxed and quiet location should be set up, with background music and diffused light.

The patient should be stimulated to do moderate physical activity.

How does aggressiveness appear?

Common and harmless situations make the patient react unreasonably. He/she shouts, reproaches in a loud voice and can beat, kick or pack a punch up to assault who is near him/her with objects.

In a few minutes, the aggressiveness disappears.

In what ways is this behavior triggered?

Generally, the patient reacts to a situation he/she fears and to a feeling of danger. He/she can be frightened by a despotic attitude of the caregiver.

The reason can lie in the impossibility to accomplish some daily activities: fasten a button; open the closets; tie ones own shoes. Loud noises and excessive light or dark locations can provoke alarming stimulations.

We must always remember that aggressiveness can be an alarm bell for existing physical problems such as constipation, fecalomas, pain, infections of the urinary system with retention.

For these reasons, it is most important to inform the physician when aggressiveness appears all of a sudden.

What is the behavior with an aggressive patient?

The patient's aggressiveness must not be considered as a personal offense.

The actions are not against the caregiver because the patient cannot control his/her own emotions. It is important to be calm, create a diversion, talk in a low voice, do not attack him/her.

When the anxiety is over, it is important to understand the trigger reasons; check if the patient has fever, pains, problems to urinate or defecate; control the room and think about a behavior that can be misunderstood by the patient.
If we lost tolerance in front of this aggressiveness, we must not worry, but maybe it is time to consider a help to assist the patient.

Do sleeping problems exist?

Usually, older people sleep less than younger ones, but with dementia these problems worsen.

What are the main sleeping problems?

An inversion of sleep/wakefulness rhythms very often appears.
This problem can become difficult to manage due to night wonderings that must be monitored. As a matter of fact, the patient tries to get out, makes a noise, wants to have breakfast or lunch while the others are asleep.
This agitation usually begins in the late afternoon and it is called sundown syndrome.

What are the reasons for these sleeping problems?

The patient often sleeps too much during the day and he/she is not tired at night. The dark is scaring because he/she cannot perceive the environment, silence causes an anxious syndrome. We must also remember that urinary incontinence can disturb the sleep, as pain, constipation and infections can do.

What are the steps to undertake in order to prevent these problems?

The patient should spend active days with short strolls and tiring activities even in the late afternoon so as to get tired.
The diet must be regulated, avoiding stimulating food and drink in the afternoon or at dinner. Before going to bed, do not administer drinks that can stimulate diuresis, and consequent incontinence, during the night.
If it is possible, night lights should be placed in the house in order to help the orientation and the patient does not feel alone.
Mirrors should be avoided because they could scare the patient; TV should be limited too, because it could create confusion between imagination and reality.

Do delirium, hallucinatory states, false identifications belong to the symptoms of the disease?

False and unreal convictions are important elements of the disease and they can make the patient's management difficult.
The patient can blame the relatives for stolen valuable objects; he/she can have visual and auditive sensations, without real objects, and he/she can be seriously disturbed.
At the end, the patient cannot identify his/her own relatives and even the caregiver.

How is it possible to deal with these problems?

The relatives must always be calm, smiling, reassuring the patient with nonverbal communication, looking at him/her in the eyes, with a physical contact.
With most serious cases, the situation must be communicated to the family doctor for pharmacological prescriptions.

What are the most frequent complications in the advanced stage?

Respiratory and urinary infections, decubitus ulcers.

How can respiratory infections be prevented?

Respiratory infections are the most frequent cause of death and it is important to prevent them.
The patient must be seated as long as possible, trying to mobilized him/her. It must be checked that the patient can swallow and he/she must be fed with solid food.

How can urinary infections be prevented?

External urine containers must be used, emptied frequently; local cleanliness must be meticulous and permanent catheter should be used as later as possible.

How can decubitus ulcers be prevented?

The risk areas must be massaged many times during the day, paying attention to the local hygiene, not leaving the patient wet or dirty, changing his/her position, using antidecubitus devices such as mattresses, woolen pile, special beds.

Advices for a good management of the patient

Daily life activities request the biggest attentions by the relatives, because they are the most damaged, with serious psychological and behavioral consequences for the patient.
Let's try and explain as simpler as possible how to deal with the patient without offending him/her, even involuntarily, and to make him/her cooperate with the caregiver.

DIET

Early stage:

Even if the person can lose interest in his/her own nutrition, in this stage specific dietary problems seldom appear.
Diet must be balanced, meals must be regular, at the same hour with the right order.

Moderate stage:

In this stage, dietary problems worsen.
The patient can forget about meals, since he/she is not interest in food any more; sometimes, he/she can hide the food and eat it later when it's gone bad. On the contrary, he/she can asked to eat at strange hours, for example during the night.
Therefore, in this stage it is necessary to control the diet with great attention; the caregiver must prepare food and control that the patient eats the meals by him/herself as longer as possible.
It must be controlled that the patient doesn't forget to drink.
Food must be served one at a time in the right quantity.
If the use of cutlery becomes difficult, let the patient use the spoon only, and, before feeding him/her, let him/her use his/her own hands.

Advanced stage:

In this stage, feeding problems are among the most serious ones. The patient cannot cooperate because he/she does not remember how to chew or swallow. Sometimes, he/she can tighten the jaw so strongly so that it's impossible to feed him/her.
Forced feeding is not recommended, because this procedure increases the risk of an aspiration pneumonia.
In this stage, if the patient categorically refuses to eat, a feeding tube must be used.
When the patient refuses to eat all of a sudden, the family doctor must be informed immediately: as a matter of fact, the reason of this refusal can be a simultaneous disease (kidney failure, constipation, fecaloma, electrolytic imbalance).
In this situation, however, it is important to stimulate the suction reflex by bringing a little wet sponge near the patient's lips.

CLOTHING

Clothing is a way to get identification and self-confidence.

Early stage:

The person generally can get dressed by him/herself and choose clothes.
In the late early stage, the patient starts having problems: he/she cannot chose the garments to wear, get dressed with the wrong sequence, with difficulty to recognize the right season and, consequently, he/she chooses the wrong garments; he/she can show difficulties in lacing the shoes, fastening the belt or using buttons and hooks.
It's necessary make the choices as easier as possible, controlling the patient's choices calmly and in no hurry.

It should be considered the possibility of using velcro instead of buttons and shoe laces. Slippers must be avoided, use shoes to prevent falls.
The relatives should intervene only if necessary.
The caregiver is often tired because of too much help.

Moderate stage:

In this stage, the person is no longer able to choose the garments and wear them correctly, he/she doesn't want to get changed if someone else does not do it for him/her.
The early stage advices are even more important now. Since in this stage a desire for manipulation is present, it is recommended to wear garments with big pockets, for objects to handle.
In this stage, the patient should use an apron during the meals.

PERSONAL HYGIENE

Early stage:

Generally, there are not hygiene problems.

Moderate stage:

The patient cannot provide for his/her own persona hygiene so someone else must do it for him/her.
A serious loss of personal privacy follows this problem, so when the patient takes a bath or a shower, this moment becomes a difficult one and can trigger an aggressive reaction. Bath time must be flexible and, for privacy, it would be better that a person outside the family could help the patient.
The bathroom must be a safe room, without physical obstacles, with banister and non-slip carpets, warm and comfortable.
If the use of underwear is reassuring for the patient, this is allowed without problems.
In this stage, a shower is more advisable; a bathtub full of water can be perceived as a great danger by the patient.
It's important to control the sphincters: for this reason, the caregiver must often encourage the patient to empty the bladder, in order to avoid incontinence. It is easy to detect the urgency to evacuate looking at the face of the patient and his/her uneasiness.
Oral hygiene and prosthesis must be accomplished carefully.
A clear sign of identification should be placed on the bath door.

Advanced stage:

In this stage, the patient cannot take care of his/her own hygiene and can't cooperate. The patient is in bed and suffers of incontinence; a continuous assistance is necessary and one relative is not able to give it.

Finally, it is time to ask for help from the local health service.

SAVETY

Safety is very important during the early and moderate stages of the disease, both because the patient can get hurt in the house and he/she can get lost outside.

Domestic safety

In the house, it is necessary to place security systems used for children: for gas cookers; for windows and doors, even using ringing alarms.

Chemicals, medications and knives must be kept in safe places, inaccessible for the patient.

Handrails and security devices should be placed in the house and in the bathroom; bed height should be appropriate in order to avoid falls.

The use of French windows and mirrors in the house should be limited because they can frighten the patient.

Dangerous electric devices must be kept in safe places, free electric wires must be removed, wall sockets must be secured.

Increase outside safety

Dissuade the person from driving, even if this can restrict his/her own independence.

Sew labels with name and address on the patient's clothes when he/she goes out alone.

ATTACHMENT

Who takes care of the caregivers? Summary

Sanitary education for families and caregivers is a crucial point in the assistance of the dementia patients.

- The assistance of the patient with dementia is demanding and often stressing.
- Families are often not aware of the disease evolution, of the right method and solution of the daily problems (such as, persuade the patient to wash, get dressed, eat, etc.).

- The crucial point in the “management” of a patient with dementia is the sanitary education of the people who live with him/her.

… therefore, what to do? Just few aims:

1. Assistance to families and external people for sanitary education, debate and discussion
2. Setting up of security devices (locks, cookers, smoke detectors…) in the house and of automation domestic systems
3. Access to new technologies such as GPS and sensors
4. Improvement of existing residential estates.

It is necessary to supply

- Meetings with specialists to inform families about medical knowledges and about practical and organizational aspects (It’s difficult but it’s crucial in housing patient care)
- Meetings and sharing with other families and caregivers help to avoid a common problem, that is emotional breakdown.

This booklet has been presented in its Italian edition during the Mediterranean Solidarity Observatory meeting, occurred in the occasion of the Lions Conference of the Mediterranean in Athens in 2012.
Later, the Observatory approved the initiative as a Mediterranean service during the Ljubljana meeting in 2013, giving PDG Franco Marchesani the responsibility of editing the text to adapt it for the real necessities of the different countries. The final text has been presented and approved, undertaking the task to translate it into English and French, in the Tangier meeting in 2014.
The text will be at every Lion's disposal in the Mediterranean area, downloading it from the official website of the Mediterranean Solidarity Observatory, www.MSOLions.org.

Initiative organized by V Region - District 108LA

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