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**ALZHEIMER'S DISEASE AND OTHER COGNITIVE DISEASES:  
KNOWING, AS A MEANS TO GIVING LIFE ITS VALUE BACK UNTIL THE  
VERY END**

***Guidelines for caregivers***

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This booklet is targeted to caregivers assisting patients during all the stages of the disease, especially advanced and terminal stages, of patients with dementia (Alzheimer's disease, Lewy Body disease, frontotemporal dementia, Parkinson's disease dementia, vascular dementia, and other kinds of degenerative cognitive diseases). What all these diseases have in common is that patients suffering from them face progressive loss of their ability to interact with the outside world. Taking care of demented patients is not an easy task: the individual we're looking at now will no longer be the same person we will be looking at in six months, or in a year. There will come a moment when these changes will speed up and become more problematic and the patient's new needs will have to be recognized and dealt with.

The patient will progressively lose the ability to take care of himself, to use objects, to communicate with others, to move. This will make it at first difficult and eventually impossible for the patient to make informed decisions about himself, even medical ones.

Consequently, when new health problems or complications occur, the people who are close to him – spouse, children, loved ones – will have to “step up for him” to decide, together with the physician and, in case of hospitalization, with the medical staff, the best way to treat his condition, what the patient would have wanted for himself and what not. This is a difficult task, one that people are not usually ready to shoulder.

These guidelines first of all outline the course of the disease , offering help and advice to those who have to assist a patient they are living with; this booklet also provides some basic information to better understand the symptoms caused by these diseases and the decisions that will have to be made, up to the advanced stage of the disease where the patient is completely in the hands of his caregivers. Also in the final stage of the disease, when death is imminent or inevitable, it remains possible to do a number of things so that everyone, even patients suffering from Alzheimer's disease, can die with dignity.

We hope this information will prove of use and relief for those who are closest to the patient, above all during the final and most dramatic stage.

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The pace of life imposed by modern society sometimes makes it impossible for people to give their loved ones all the time and attention they are entitled to. We are often left with no other choice but to put our weakest loved ones (children, grandparents) in the caring hands of people outside our family. Especially in the case of assisting people suffering from cognitive diseases, taking care of them is such a demanding task that, to allow our loved one to stay home as long as possible, it is nearly always vital to look for help outside the family circle. Whoever takes care of these patients must, in order to live with them, have shared knowledge and be able to handle situations and change in a similar way.

## **Advice for the family**

### ***What is the best attitude towards caring staff?***

We finally decide to let someone enter our home, to assist a member of our family, when we realize that we need help: very often we are already very tired and frustrated because we can't make it on our own. Tensions, as well as expectations, can become very great.

At the beginning there will be examining on both parts. It is very common for caregivers assisting the elderly, and in particular patients suffering from a cognitive disease, to know nothing about the disease: they don't know that they can never leave the patient alone, that they will have to spend a great deal of time at home and not be able to go out, have visitors, and so on.

It will be necessary to acknowledge the great importance of their work, and that a relationship based on alliance and cooperation needs to be established.

It is important to negotiate pay, visits, telephone calls, meals and rest at the very beginning. The job is very demanding both physically and psychologically, and it is also in the interest of the patient's family to safeguard the caregiver's health. It is important to give clear and precise instructions on how to assist the patient (feeding, clothes, hygiene, sleeping, treatment). The telephone number of a physician to call when needed must be given. Also the caregiver must always be able to contact a member of the family.

### ***What instructions are useful for home-caregivers?***

The work carried out to assist the patient and his family is fundamental.

For those assisting these patients for the first time, this booklet will be useful to get to know better the person you are assisting and to establish the best relationship possible. If, on the contrary, you have been working in this field for quite a while, these guidelines could be helpful as a source of advice to better understand that your experience is common to that of all caregivers.

It could be very difficult at the beginning. But you must never feel discouraged, it is vital that when feeling in trouble, you ask the family and/or the family doctor for help.

As the disease progresses and takes the upper hand, it will change the patient's behaviour: what he does or doesn't do depends on the disease. If the patient

wakes up in the middle of the night and gets dressed wanting to go out, it is no use showing him that it is dark outside. The patient may not recognize those paying him visits or living with him, and may believe they are strangers who entered his home to rob him. The patient may confuse his caregiver with a member of the family (daughter, husband) and behave as he would have behaved with them. He may refuse to eat or to be washed. Or he may remain seated in his armchair all day long staring at empty space.

Every person is unique, so with each patient it will be necessary to find the best way to enter "his world" .

To establish a connection with the patient, gentleness and patience are the key. However you must be careful not to become too familiar with the patient, or you run the risk of not being able to handle the situation at best. In order to establish a good relationship with the family of the patient, it is best to define all the terms of the agreement at the beginning: try to understand if what the family want is possible, if you can receive visitors or telephone calls, if you are required to handle money to do the shopping and manage the house.

Getting to know the rooted habits of the patient (what he eats, wears etc.) will help you preserve his abilities as long as possible.

It is fundamental for the caregiver to be well aware of the time schedule for treatment and how to administer it; when necessary, the caregiver must ask the family or the physician for explanations, to clear up any possible doubt.



## FIRST PART

### Definition

*What is dementia?*

Alzheimer's disease is a disorder affecting the brain, it causes the brain to degenerate slowly and prevents the patient from carrying out his activities independently. What causes the disease is still a medical mystery. The progress of the disease leads to the progressive death of nerve cells, mainly those located in the area of the brain responsible for memory, learning and social life. The advance of the disease causes major deficits in cognitive and behaviour functions, and it compromises the ability to perform every-day activities.

Alzheimer's disease usually affects people over 60; the risk of developing the disease increases with age. Nevertheless it can also affect younger people, at the height of their working life and maybe even with little or teenage children. The first symptoms of Alzheimer's disease vary from patient to patient, in part they are caused by pre-existent individual characteristics, such as personality, general physical health, lifestyle, but it is possible to highlight some common factors: first of all an insidious start, with short-term memory disorders and attention and concentration deficit. At this stage the patient may show depression, due to the perception of the problems he is experiencing; occasional disorientation episodes, change in personality and behaviour, judgement capacity alteration, troubles finding the right words or finishing what he was saying coherently can also occur.

Alzheimer's disease is the most frequent cognitive disorder. The different diseases can show different symptoms at outbreak (for instance in Lewy Body disease memory loss is less evident and early incontinence, trouble walking and hallucinations occur) but in the most advanced stages of the disease, the scenario is basically similar.

### Diagnosis and symptoms

Alzheimer's disease can have a course of 10 years or more and it is a degenerative disease; difficulties in performing every-day tasks become more and more evident over time, until the final stage of the disease where 24/7 assistance is required.

*First symptoms are:*

- forgetting recent events easily
- reduced interests and activities
- diminished understanding of complex concepts

- delirium (meaning wrong ideas) of robbery, jealousy, etc.
- tendency to repeat oneself when speaking
- increased irritability

*When the disease is somewhat advanced , the patient:*

- will not recall recent events at all
- will repeat himself and be silent
- will be confused about time (for instance, when waking up after an afternoon nap he will think it's morning)
- will run the risk of getting lost outside known neighbourhoods
- might behave inappropriately (for example he could go outside in his pyjamas)
- will neglect his personal hygiene
- will experience eating disorders (not eating or eating too much, forgetting that he has already eaten)
- may see or hear imaginary things
- may not recognize his family or friends
- may have trouble using every-day objects
- may no longer be able to read or write

*In the advanced stage:*

- speaking will become limited to a few words at first and, eventually, to a few sounds
- urinary and faecal incontinence will appear
- walking will become more and more difficult and, eventually, impossible
- keeping his head up will be impossible
- the ability to smile will disappear

## **Pharmacological treatment**

It is of absolute importance for caregivers (people assisting the patient) to have a knowledge of the characteristics of the disease, but also to be aware of the fact that the patient is subject to ups and downs, with “positive” moments (sometimes entire days), where he cooperates, and “negative” moments, where it will be more difficult to understand and the patient will tend to refuse treatment. We don't know what causes this disease, therefore it is not yet possible to cure it. However, there exist some drugs that control, and in a good number of cases slow down the progress of the cognitive and behavioural symptoms, at least for some years. The drugs which are currently being used to slow down the progress of the disease are acetylcholinesterase inhibitors and memantine.

The drugs to treat behavioural disorders vary depending on the specific disorder: delirium, hallucinations, aggressiveness, insomnia.

These medicines must always be administered under close medical supervision. Please bear in mind that they have serious side effects, and it is therefore dangerous to administer them on your own.

Other non-pharmacological treatments (reality orientation therapy, music therapy etc.) have proven to be useful for the well-being of the patient, but only when followed in specialized centres.



## Practical advice

### *What is always best to do*

1. **Adjusting to change.** In a difficult relationship like that with a demented patient, the key to surviving is your ability to adjust to change. You must find the most useful way to perform each single every-day act, being disposed also to do things unconventionally (i.e. letting the patient eat with his hands if this is the only way he can feed himself, or sleeping with the light on if it helps him be calm)
2. **Preserving skills.** Depending on others even for the most basic needs (eating, drinking, washing etc.) reduces self-esteem and dignity. You must

preserve the patient's skills as long as possible, leaving him all the time he needs to do things, creating a quiet and relaxing atmosphere, not getting upset when the patient gets things wrong (i.e. spills food or drinks on himself when eating on his own).

3. **Explaining everything** you do, asking for permission and cooperation, especially when physical contact is needed (hygiene, bedsore treatment, etc.).
4. **Accompanying words with acts.** If you want a patient to choose what to wear, eat and do, always show him what his options are, and never make him choose between more than two possibilities at a time (if you want to know if he prefers to have pasta or rice, it is best to show him both).
5. **Creating a peaceful atmosphere.** Try to smile, don't let your problems show, keep your voice down and calm.
6. **Focus on the upside.** Emphasizing the positive achievements and the good -looking appearance gives a sense of well-being to anyone, including Alzheimer's patients.
7. **Keeping one's dignity.** Even when the patient shows childish or strange behaviour, he is still an adult who has experienced life and knows what independence, satisfaction, ability, role acknowledgement mean.
8. **Familiarizing with his habits.** Knowing what the patient likes to wear, his tastes in the kitchen, or his political and religious beliefs, can open up important channels of communication.
9. **Creating routines** in every-day life. Doing the same things at the same time of the day and in a similar way helps creating habits which are easier to remember.
10. **Recalling the date,** the day, the season. Recalling your name and that of other people who, for example, are about to come, will help keep that information longer in the patient's mind and reduce the patient's discomfort.
11. **Creating a safe and comfortable environment.** As the disease progresses, the patient will lose recollection of how to use objects; at this point everything that might potentially dangerous (knives, razor blades, razors etc...) will have to be stored in a safe place. Anything that could make the patient fall needs to be avoided (rugs, wax, blinding light or insufficient light etc.).
12. **Keep a journal of the events of the day.** Everything that is part of every-day life (mood, behaviour, food, continence) is at risk of being forgotten every day. The journal can be useful so that the caregiver can monitor how fast the disease progresses, track the benefits of a treatment. Those who are not there during the day (family, doctor) can also obtain important information from a "log" of what the patient does and to what extent he needs assistance.

### **What is best to avoid**

1. **Stopping the patient from preserving the remaining skills.** Even when suffering from Alzheimer's disease, it is possible for the patient to keep memory of every-day actions (e.g. shaving) for a long time (procedural memory), and the patient is often able to perform routine tasks (e.g. doing the washing up, hanging the laundry to dry, etc.) although with less precision than he used to. If

such actions are not dangerous, like driving a car, it is best not to stop them, helping the patient to carry them out, without ever denigrating what he is doing.

2. **Getting offended** if the patient thinks his caregiver is responsible for things he did not do (“he treated me wrong”, “he stole my pension”, “he’s cheating me”). The disease is what causes this kind of confusion and delirium. Stay calm and do not react to the accusation, do not try to explain the absurdity of what the patient is saying but try to change subject, it is the best way to resolve the incident.

3. **Getting angry** when the patient is agitated; this is not only useless but it will cause him to get even more agitated.

4. **Shouting to make yourself understood.** When the patient cannot understand what you are saying, this is generally not because he has trouble hearing you, and even so the right approach would be to speak slowly face to face: shouting is always interpreted as aggression.

5. **Scolding him if he makes trouble or has accidents.** What seems to be due to distraction or done on purpose, is actually due to confusion. It is important to always calm down and reassure the patient.

6. **Lecturing him about his mistakes or wrong behaviour.** This is useless because even if the patient were able to understand what you are saying he would forget about it immediately afterwards. It is far more helpful to show him practical examples explained gently.

7. **Denigrating the patient for episodes of incontinence.** The patient suffering from Alzheimer's disease is not a child and he doesn't learn anything from reproaching him. The loss of the ability to control biological functions usually occurs at a fairly advanced stage of the disease, but episodes of incontinence can occur even at earlier stages. It will be necessary to reassure the patient and inform the physician, as there could be a urinary infection or some other cause.

8. **Saying things such as: “how can you not remember?”.** Awareness of his defect only causes more anxiety and disappointment, and it makes it more difficult to remember things. It is far more useful to try and suggest the thing, the name, the place that you are trying to remember.

9. **Administering drugs without the prescription of the doctor.** Sometimes it is easy to get advice from other people who underwent the same experience (“my mother too used to do that, then I started giving her 10 drops of whatever and she was able to sleep again”). Together with the desired effects of a drug, there are always side-effects (for instance, neuroleptics stop delirium, but they make walking stiffer), there also exists a personal response to a drug, and only someone who knows the biological history of the patient can be aware of that; finally drugs interact with one another, increasing or reducing the desired effects.

## The peculiarities of the disease

***What to do when memory loss prevents the Alzheimer's patient from recognizing places, people, and even his own image?***

1. Some patients may not recognize themselves in the mirror, and believe that a "stranger" entered their home.

***The best thing to do would be to always keep the mirrors covered with a cloth, when this is not possible it is preferable to always go along with the patient, reassuring him that the "stranger" is a friend who by no means intends harm. If this "mis-recognition" causes anxiety or fear to the patient, pretend to kick the stranger out of the house.***

2. The patient might see or hear things that are not true (i.e. dead brothers, mother, animals climbing on the wall, people in his room, incomprehensible noises, bells ringing).

***In these cases contradicting the patient does not help, he believes his hallucination is real, agree with him and reassure him; never mock him.***

3. The patient might also no longer be able to recognize the objects correctly, or tell what the object he sees is really for (he might brush his hair with his toothbrush and his teeth with his comb or razor). He might also not remember how to do apparently simple things, which are actually the result of a sequence of actions (such as cooking pasta or making coffee).

***To preserve the patient's independence for as long as possible it is important to try and have the patient do what he can himself, guiding him gently in the gestures, completing those actions he might not be able to do, watching out for dangerous objects (razor blades, razors, knives).***

4. The patient may repeat over and over again that he wants to go home. He may be convinced that the house he is living in is not his home, and he might not understand who brought him there. Frequently the house they say they want to go back to is the one they grew up in as a child; as a matter of fact the farthest memories in time are the ones that last longest. This is why it may happen that the patient tries to go away.

***In this case it is best never to let the patient go out alone. Trying to take his mind off the idea, postponing it, helps (for example: "we'll go in a little while, before that we have to do this" or "now it's cold outside, let's wait for the sun to come out").***

5. Hygiene is often a problem. The patients forget they haven't washed themselves yet, and they do not want to be helped.

***The patient might be ashamed, in which case it is important to allow him to wash himself alone, trying to check, when unseen, that he truly goes into the shower. If on the other hand he accepts the presence of the caregiver, it is best not to do things in his place, but to suggest what to do and in what order ("now turn the shower on..., lather up..., rinse yourself"). If there is outright refusal it is important to learn how to seize the moment when he is most cooperative, or find out if among all the caregivers (carers, family) there is someone with whom this action becomes more***

**natural. Anti-slip bath mats, shower stools or bath benches can be a real help for safety.**

6. The patient may not recall having already eaten, or may think he has eaten when he has not. He might therefore want to eat continuously, or tell the members of the family he did not eat or that he wants to eat.

***It would be useful to try and distract him by all means, and try to give him food that does not interfere too much with his diet (vegetables, fruit); on the contrary, if the patient refuses to eat, just wait and try again later. Writing down what the patient ate at every meal helps. It is essential that the family be able to trust the caregiver completely.***

7. Because of the time orientation disorder the patient often mistakes day for night and vice-versa, sometimes they get up and try to go out.

***Keeping doors and windows locked and staying with the patient helps. If he ever goes out alone at night, it is likely that he would not know how to come back. It is important to reassure him, not to reproach him, at worst engage in an alternative activity (play cards, watch television..). Sometimes hot milk and biscuits help calm down the patient enough to go back to sleep. If insomnia prevents you from getting enough sleep, the caregiver must try to sleep during the day, to keep enough energy for the night. As we have said, any treatment for the night will have to be prescribed by the physician.***

## The caregiver

Dementia deeply changes the life not only of the patient but also of his family and those taking care of him, since he is such a difficult patient to take care of. The personal emotional burden is huge. Families and carers share some common feelings:

- ***anxiety***: having the feeling that we are losing something more of the person we are close to every day, not knowing how long all this will go on;
- ***guilt***: because we left someone else to take care of him, because we fear we are not up to the task, because we lost patience, for expressed and unexpressed anger;
- ***depression***: feeling useless, fear of inadequacy, frustration, discouragement;
- ***anger***: towards the patient's actions when they seem to be on purpose, towards members of the family who just don't seem to get it, towards the institutions which give no help;
- ***aggressiveness***: one can get to the point when he desires to shake or hit the patient to try to make him understand what just seems impossible that he cannot understand;
- ***embarrassment***: for the patient's behaviour in public or for untruthful declarations;
- ***loneliness***: the patient is of no company, it reduces freedom of action, no longer being adequate to social situations forces you to cut off your relationship with other people.

***How should these feelings be handled?***

- Remind yourself that you are important for yourself and for the patient
- Recognize your limits
- Satisfy your own needs and interests
- Share your problems with your family
- Don't be afraid to admit your difficulties
- Accept help from experts
- Take time off
- Look for moral relief by talking to a good listener



### The final stage of the disease

#### 1) *What happens to these patients when the disease is extremely advanced?*

In end-of-life stages of the disease, the main problems experienced by the patient are the impossibility of carrying out movements, difficulty in feeding, double incontinence (urinary and faecal) and frequent infections.

Urinary infections, linked to the incontinence and to the use of catheters, and lung infections are the most common ones.

Pneumonia appears to be the main cause of death. Although it can be caused by many different factors, bronchial infections mostly result from the ever more serious problems linked to food intake. In fact, problems in swallowing risk causing shock since saliva and food enter the airways (trachea, bronchi and lungs) instead of the digestive tract (esophagus and stomach), causing coughing fits and troubled breathing. Some patients are so weak that they are not even able to cough strongly enough: this inevitably causes them to inhale some substances, provoking "*ab ingestis pneumonia*". Even when the pneumonia reacts to the treatments and is cured, it will most certainly come back.

#### 2) *What can we do when the patient is no longer able to eat or drink?*

Doctors and nurses will first of all try to understand why the patient had trouble eating and drinking and they will do everything possible to solve the problem.

Sometimes the problem can be easily solved, for example when it is the case of a mouth infection or of undesired effects of a drug. Sometimes it is enough to find the patient's favourite food (frequently sweets) or the best way to administer it, as for example when the patient loses the ability to open his mouth (using straws). The problem is more difficult to solve when it involves the loss of the patient's "physical" ability to swallow. However, there exist technical strategies to face this problem even when prolonged in time. The most frequent solution is to prepare creamy food, such as purées (mashed or blended food), and "thickened" liquids (that is to say liquid transformed into some sort of jelly), which are easier to swallow.

To complete the patient's diet or simply to satisfy the patient's appetite, there are different kinds of food supplements. These supplements usually are to the patient's taste and they can substitute for part of the meal.

Nevertheless, as the disease progresses, these methods are less and less effective.

If the patient neither eats nor drinks, he loses weight and becomes more and more dehydrated, meaning that he becomes weaker and weaker, thus increasing the likelihood of further infection-related complications.

At this point the problem is how to continue administering food and liquids to the patient. Patients developing dysphagia after a stroke, for instance, who are lucid and with a fairly decent quality of life, preserving their ability to recover their

eating habits after rehab, can be fed with an electromechanical pump through a tube inserted directly into the stomach. The tube can be introduced through the nose (nasogastric tube) or through the abdominal wall (PEG) with a small incision and a simple surgical procedure.

Differently, when dealing with advanced dementia this feeding approach is not truly advisable, for the following reasons:

- the insertion of the tube in the stomach is a rather unpleasant procedure and it can be stressful: the nasogastric tube can be inserted at home or in nursing homes, while the PEG usually requires hospitalization, although brief;
- tube or PEG feeding, with an electromechanical pump can cause severe diarrhoea ;
- there can be obstructions in the gastric tube, which therefore needs to be replaced regularly;
- people often try to take out the tube, which can also easily come out involuntarily during hygiene procedures;
- using the gastric tube or the PEG completely eliminates any pleasure in tasting food and the patient loses that one moment of social contact, during meals, he would have had with his caregiver;
- it has not been proved yet that the use of the gastric tube or of the PEG can prolong the life of a patient with advanced dementia; furthermore *ab ingestis* pneumonia is common in people being fed by gastric tube or PEG, because of gastric reflux from the stomach into the airways.

3) *What can be done when the patient is no longer capable of independent movements?*

Movement loss is gradual, and it starts with the inability to carry out synchronised and functional acts and it ends, in the advanced stages, with no longer being able to stand or keep one's head up or trunk erect.

In this situation the body naturally assumes a position in which the patient is bent over on himself (*fetal position*). The only possible option is for the patient to be lying down or -reclining. The skin, under the pressure of the layer underneath, easily develops rashes and ulcers (bedsores) and the joints assume a flexed position and tend to become rigid. Using anti-bedsores devices (mattresses, pillows) is therefore necessary, to help keep the skin intact; it is all the more important to move the patient, trying to avoid as much as possible to force him to flex, as this complicates any feeding and hygiene operation and also favours the stagnation of bronchial secretions.

4) *What can be done for incontinent patients?*

In the final stage of the disease the patient loses urinary and fecal continence. The emission of biological fluids (feces and urine) is no longer controlled, and the caregiver has the thankless task of seeing to the patient's personal hygiene. Catheters are frequently used to avoid skin maceration, but bear in mind that catheters are also a frequent cause of urinary infections. Dry skin is a necessary

condition in order to keep the skin intact, but also for the well-being of the patient, whose dignity has already been tried too much. Laxative drugs and enema syringes are also frequently necessary because of the inability of the patient to evacuate. It is important to bear in mind that simple constipation episodes can cause aggravating symptoms which are as serious as they are preventable. Every gesture during hygiene is a moment of extreme intimacy, requiring absolute privacy and gentleness.

5) *What can the medical staff do when the patient has pneumonia?*

When a patient has trouble breathing due to food or saliva intake in the respiratory system, the structures where the air passes through need to be freed. This is not a simple procedure and it is always rather uncomfortable, it involves the use of the aspirator, a medical instrument that requires adequate preparation.

To improve the patient's comfort, it is sometimes useful to administer oxygen.

If the patient has a fever and the clinical picture suggests he has developed pneumonia, the physician might prescribe antibiotics. However, as previously pointed out, in the advanced stages of the disease the likelihood of recovering from pneumonia is very low, in fact it is highly likely that the pneumonia will come back in a little while.

However, every case must be carefully examined. The physician and the family (if a family member is the legal representative of the patient, his tutor or personal health representative, his involvement is required by law) must at this point decide whether they want to adopt an aggressive pharmacological approach or a palliative one, trying to do what is in the patient's best interest.

6) *Should a patient, in such conditions, be hospitalized?*

Admitting a bed-ridden patient, meaning in an advanced stage of the disease, is often very stressful. Agitated patients, whose agitation is aggravated or caused by finding themselves in an environment not suitable to their condition (for example, in an ER room), are usually sedated with tranquillizers and sometimes even tied to the bed to limit their freedom of movement and prevent them from falling or hurting themselves in other ways. The frequent insurgence of bedsores and muscle stiffness is due precisely to the fact that, by definition, a hospital is not able to adequately meet the needs of a bed-ridden patient, or of patients with severe movement impairment.

This is why hospitalization should be an option only when absolutely necessary, and for as short a time as possible. In some cases, however, admitting the patient to the hospital for a short period of time might be unavoidable, as when a surgical procedure is needed to stabilize a fracture which would otherwise cause great pain.

Nevertheless, as a rule, it is best not to hospitalize the patient if the problem can be solved at home or in a nursing home, with a palliative approach or with good symptom control therapies.

7) *Should doctors always perform CPR (Cardiopulmonary resuscitation manoeuvres to restore heart beat when it has stopped)?*

Most doctors agree in saying that this kind of manoeuvre, performed on these patients, is harmful rather than helpful.

The possibility of resuscitating a patient whose general condition is severely compromised is near zero. The risk of causing damage to the patient is very high, and fractures to the ribcage are practically unavoidable. Finally, the longer the patient is in cardiac arrest, the greater the likelihood that after resuscitation he might be in a coma and never get out of it again. These are some of the reasons why it is inadvisable to perform CPR on patients with advanced cerebral degenerative diseases.



1) *Who makes end-of-life medical decisions? The doctor or the person representing the patient (a family member, tutor/personal health representative)?*

At some point the moment often comes where the caregivers need to choose whether to insist in keeping the patient alive - using every technical and pharmacological means available - or whether instead to make sure that when the inevitable end does come, it is without excessive pain (palliative treatments). It is therefore absolutely necessary that doctors and family members find the time to openly discuss this issue.

The question one should ask himself is: "What is the best thing to do for this person, right now?"

The ideal circumstance is for everybody to agree on what is the best thing to do. The importance of such a difficult decision should not be left as a burden on the family alone, nor of the caregivers alone. The best thing is when a long, good and consolidated relationship has been established between the medical staff and the family members, long before the patient reaches the final stage of the disease. Usually, the more you are informed on your loved one's conditions and on the severity of the disease, the more your point of view has been taken into account previously, the more you can be confident that the decisions made will be the best possible ones.

2) *What is the role of the patient's family member or legal representative (tutor/personal health representative) in the decision-making process?*

The Italian law establishes that medical decisions concerning the health of a citizen can only be made by the person himself.

When he is not capable of taking his own decisions, these are the responsibility of his legal representative (tutor named by a judge, or personal health representative), who, in practical terms, has to accept or reject medical advice, based on what he thinks is best for the patient himself. When accepting medical decisions, he must give informed, voluntary consent and it must not result from forced actions: the person representing the patient must be informed of all the different treatment options and he must not be under the impression that a choice was imposed on him.

When there is no legal representative, these choices are de facto the responsibility of the doctor.

The family member has no legal power to accept or reject a medical decision, unless, as previously stated, he was appointed tutor or personal health representative. Nevertheless, family members play a very important role, since they can guide, criticize or confirm the doctor's proposals, precisely because they usually know the patient better and have known him for longer than his caregivers.

Never hesitate to share your doubts and problems with the doctor.

When uncertainties are not talked about and questions are not asked, family members undergo useless and avoidable stress.

3) *What to do in case of conflict or when in doubt?*

Family members sometimes refuse what the doctors advise, or do not agree with each other on what should be done.

The doctor cannot force his decision on the family and, on the other hand, the caregivers can oppose the decision of the family or of the legal representative when they think that decision is not in the patient's best interest.

What can be done, then, under these circumstances? A compromise is sometimes necessary.

For example, you may agree to try a certain treatment for a given period of time and then decide whether to continue it or suspend it, based on the effects.

You can also ask for a second medical opinion, or go to the ethical board, which is a panel of experts made up not only of medical doctors, but also of experts in ethics, jurists and citizens' representatives.

4) *If you have decided not to undertake certain treatments, will the patient, as a result, be abandoned?*

In the past, in the final stage of the disease, doctors used to tell the family: "there's nothing we can do". This felt like true abandonment, as if the patient were condemned from that moment until the end of his life, to experience pain and trouble. Palliative medicine, indeed, opened up a new way of assisting the patient throughout the end of his days. "There's nothing we can do" is no longer a sentence used by caregivers. Making the most of the experience of palliative medicine staff dealing with cancer patients, also people assisting severely demented patients can play a key role in keeping the patient as comfortable as possible near the end. Moreover, every member of the caring staff can play a very important role, in terms of psychological support, for the family members

5) *Under these circumstances do the religious authorities agree on the decision not to suspend or not to initiate treatments to prolong the life of the patient?*

Religious authorities, who were asked these questions, in most cases agree that it is morally acceptable not to administer treatments to a terminal patient to prolong his life, when the chances to improve the quality of his life are practically non-existent. However, if there is any doubt family members should discuss this in advanced with a minister of their own faith. In hospitals and nursing homes there are priests, reverends, and ministers of other religions who are well acquainted with a patient's problems and with what people assisting patients are worried about, and who are willing to talk about it with the family.

6) *Is euthanasia an acceptable option?*

In most countries, including Italy, it is commonly thought that passing a law stating that euthanasia is legal will do more harm than good; this is why euthanasia is illegal also in the final stage of a terminal disease.

However, we should not confuse two different concepts. The Italian law too, does acknowledge the right to suspend or not to start a useless or ineffective treatment (that is to say, a treatment which will not reach the stated goal), when it is a manifest form of relentless treatment.

Therefore, even in the advanced stages of dementia, it is best for doctors and family members to make shared decisions concerning the intensity of the treatment currently being administered or that is going to be administered to the patient, balancing the pros and cons and the best interests of the patient, case by case.



The most frequent symptoms in end-of-life are dyspnea (troubled breathing) and pain. Other frequently-present symptoms are agitation and anxiety.

1) *How can respiratory problems be resolved?*

Respiratory problems can be caused by many factors: the most frequent are pulmonary infections and heart problems. Treatment depends on the cause: bronchial spasms, a disorder which is similar to an episode of asthma, can be reduced pharmacologically, with drugs that can be inhaled through an inhaler or a mask; if the problem is inefficiency of the heart, creating an excess of fluids in the lungs (cardiorespiratory insufficiency) the drugs of choice are diuretics, drugs increasing urine production. In the final stage, in order to alleviate the difficulty experienced by the patient when breathing, morphine can be used.

2) *Should antibiotics always be administered to patients with an infection?*

Some infections are also a direct cause of pain or indisposition (for example, bladder infections). In this case antibiotics are the best treatment to give the patient immediate relief. When dealing with pneumonia, if there is a high fever and purulent secretions, prescribing antibiotics could be useful. Doctors can decide to start the patient on a treatment and suspend it later if it turned out to be ineffective. As a general rule, when dealing with terminal patients, the real problem is not fighting an acute parallel disease, but rather eliminating or reducing the disorders and pain it is causing.

Caregivers should discover, talking to the family, what the patient's will would be, his profound ethical and religious beliefs, to be in a better position to decide what is the best treatment strategy.

3) *How can secretions be kept under control when they make breathing troublesome and noisy?*

When there is a big quantity of secretions in the airways, the patient must be put in a semi-reclining position in bed. If bronchial secretions are substantial, an aspirator might have to be used in order to eliminate them; this procedure, besides being slightly unpleasant, also tends to increase the creation of other secretions, therefore it is only used when absolutely necessary. The patient must be administered drugs reducing the production of secretions. Usually the drugs work at the beginning, but over time secretions become too abundant and dense, and it is common for patients to have a noisy breathing (rale). This rale is distressing for those next to the patient, and it gives the impression that the patient is in pain or fatigued. Indeed, if the patient is in a coma or if he is being administered tranquilizers or painkillers, it is very likely that he is not even aware that he is breathing.

#### 4) *Is administering oxygen useful?*

If the patient has trouble breathing, oxygen can alleviate some muscular pain and respiratory problems. On the other hand, oxygen dries out the mucous membranes of the airways, increasing the sensation of burning thirst. When death is near or the patient is in a coma, oxygen is unlikely to be useful when not damaging, and it risks prolonging a painful agony.

#### 5) *How can someone who cannot express himself show signs of pain?*

Pain expression in Alzheimer's patients is not usual. It is possible that lack of "recollection" makes a patient with a broken thigh-bone, for example, keep on walking, seemingly unaware of the pain that it is causing him. It is therefore very difficult, although not impossible, in an advanced stage, to understand if a patient is capable of expressing pain, and to what extent. In this case, the "body language" needs to be observed, facial expressions, vocalizations (meaning the sounds emitted by the mouth), how the body moves.

It is always necessary and important to tell the doctor and/or medical staff assisting the patient if we think he is in pain, or if we think that the painkillers the patient is already being administered are insufficient.

#### 6) *How can the pain be reduced?*

Pain can be caused by many factors, and it is accordingly important to identify the right one.

In some cases pain can be due to discomfort: the first thing to do is therefore to make sure that the patient is in a correct and comfortable position, in a suitable and comfortable bed. There are many drugs treating different kinds of pain, and sometimes they must be administered in a cocktail in order to be really effective. There is a *pain grade* suggesting, based on the intensity of the pain, the use of one drug or the other. Opioids (morphine, buprenorphine, fentanyl etc.) are certainly to be used to reduce pain which is from moderate to extreme. At this stage of the disease painkillers, in order to be helpful, must be administered regularly. When using opioids, doctors can prescribe extra units of the drug in the chart, to be used between pre-established units when necessary, so that if the pain comes back the patient is not left in agony for hours before the treatment is changed. Since, however, over time the organism gets accustomed to a certain dosage of opioids, this needs to be increased from time to time (under medical surveillance) in order to remain effective. Constipation is a possible undesired effect of opioids: this must be taken into account, thus administering together with opioids also drugs favouring evacuation, to prevent the patient from experiencing pain linked to constipation and possible intestinal obstructions.

## 7) *Can morphine kill the patient?*

It is wrongly thought that the last unit of morphine is what causes the patient to stop breathing, especially if this is higher than the previous dosage. Indeed, patients can take in a very high dosage, provided that the increase is gradual. In theory, it is also possible that very high dosage may accelerate death. Bioethics experts maintain that, where recovery is impossible, the target of a medical intervention is to relieve the patient: it is therefore always morally acceptable to administer the needed dosage to this end.



## 8) *How can anxiety and agitation be kept under control?*

A patient with advanced dementia can be anxious, restless, agitated for a number of reasons, including pain, in which case administering painkillers is the best way to calm down the patient. In other cases what causes the patient to be anxious is something other than pain, which we cannot identify; here the use of psychotropic drugs (anxiolytic, neuroleptics) may be indicated. These drugs must also be administered at regular hours, as with painkillers, and not as needed. A good use of painkillers and psychotropic drugs, which are sometimes combined, can reduce the patient's anxiety, thus soothing his pain.

9) *Is administering other drugs, or measuring blood pressure, temperature glycemia etc. necessary?*

Near the end of life, when swallowing becomes difficult, it is often necessary to suspend pharmacological treatments administered orally. The drugs that are deemed vital will have to be administered otherwise (intravenous, intramuscular, subcutaneous). It is important to choose the administration method that causes the least pain to the patient: for instance instead of many painful attempts to find a good vein, it is preferable to shift as soon as possible to subcutaneous treatments (the small needle under the skin can stay there for several days).

Taking the temperature, measuring blood pressure or glycemia levels etc., becomes less and less important when nearing the end. The patient should not, at this stage, be woken up to take the blood. Nursing care aimed at personal hygiene and skincare (fundamental to avoid bedsores) should continue until the very end, since they contribute to the comfort and dignity of the dying individual.

10) *How does the patient feel when he no longer eats nor drinks?*

Alzheimer's patients cannot tell if they are hungry or thirsty, in the same way that they cannot tell if they are in pain. On the contrary those patients who are lucid to the end (cancer patients or with other diseases), tell us that they are not hungry: indeed, most patients refuse everything, even small quantities of food. What bothers them the most is not even thirst but rather dryness of the mouth. To solve this problem there are some products which can treat dryness of the mouth, lips and throat effectively. Treating this symptom is an absolute priority in the nursing care plan.

On the other hand, a reduction in the overall quantity of fluids in the body (dehydration) is not painful per se. The blood becomes thicker and the kidneys' functioning is progressively reduced until they completely stop working: all these changes do not, usually, increase the patient's pain, they are even helpful sometimes (for instance the reduction of fluids in the body also reduces secretions, thus making breathing easier).

11) *Should an intravenous therapy be started?*

Some family members think that the patient is better off with an IV.

Based on our experience, the opposite is true. In the final stages of the disease fluids administered through IV increase evacuation of feces and urine; consequently it is easier for the patient to get wet or dirty; moreover bronchial secretions increase, creating further breathing problems, and delaying the final dozing off, thus prolonging suffering.

12) *What to do when the patient already has a tube for artificial feeding?*

Ethics experts think that deciding to stop feeding a patient through a feeding tube is morally equivalent to not inserting the tube at all. The leading scientific societies think of artificial feeding (naso-gastric feeding tube, PEG or

intravenous feeding) as a treatment which, at a final stage would be the same as relentless treatment. As of today, the Italian law has not yet taken a final position in this sense. Therefore if the disease is near its final stage and/or if the complications caused by feeding (vomit, regurgitation inhaling, bedsores, patient's intolerance to the feeding tube) increase in frequency, after talking about it with a family member or with the legal representative (tutor or personal health representative) when there is one, it is possible to suspend artificial feeding since this choice is made in the best interest of the patient.

*13) How long will a person live without eating and drinking?*

When a patient stops eating and most of all drinking, he usually lives on a few days. However those patients who are in better physical conditions, or who take some fluids in (for instance during mouth cleaning) could live on for a few weeks.

Each case is different, and it can be difficult for the caregivers to tell precisely how much time is left before death; there are, however, some symptoms (diuresis reduction, change in the frequency and intensity of heart beat and breathing) which tell us that the end is near.



## The very last moments

### 1) *How should one behave when the patient is unconscious?*

Things that turn out to be helpful to end-of-life patients are very simple. For demented patients at the end of life it is often impossible to know what they understand of themselves and of the surrounding world. Once again studies on cancer patients, who are almost lucid at the end of life, teach us what terminal patients desire when they are dying.

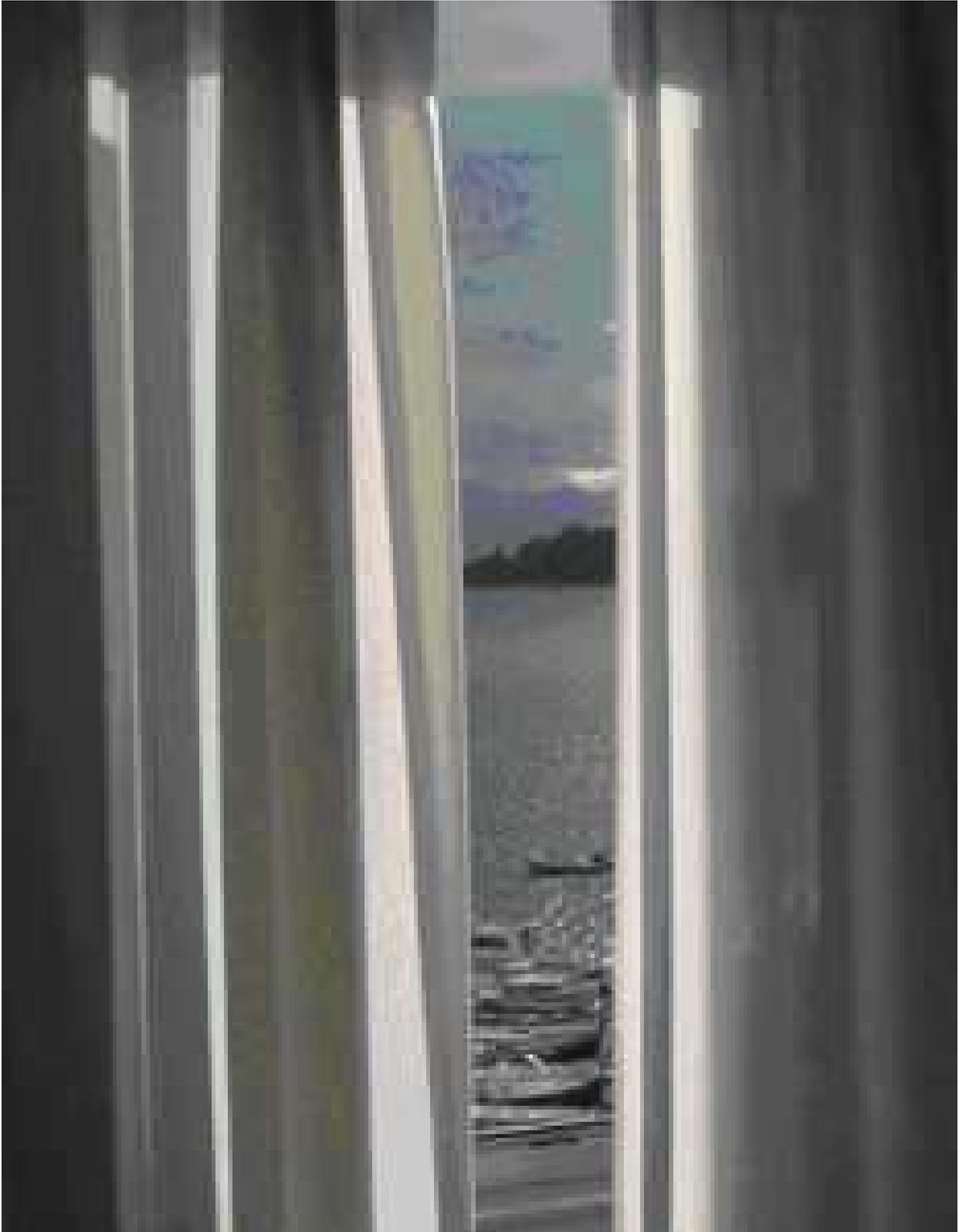
Touching and hugging them, talking to them gently or playing their favourite music: these are only a few things which can help make the patient feel comfortable and safe. Bed rails, creating a distance between people, are no

longer necessary and it is often better to turn off the screens monitoring vital parameters which, at this point, are completely useless. When possible, family members should organize themselves to be there 24/7. Nursing homes and hospitals too tend to be well-disposed towards the family of a dying patient, making it possible for them to spend even the whole night next to their relative. If the family member is old, or ill, or if there are just a few relatives available, one could ask someone else (friends, volunteers) to be there and call the staff if the patient shows signs of suffering. Demented patients don't seem to acknowledge our being there, but no one can tell for sure that is true.

## 2) *What is the end like?*

If the dying person is receiving proper treatment, breathing becomes weak and irregular, pauses between breaths become longer and longer. At the end, the patient is completely unconscious, he will take some deep breaths and then he will leave us for good. If this is happening in a hospital or nursing home ward, the presence of staff members can be comforting, but this should not keep away the love of the family from the dying relative.

Many relatives and friends who have been there in these difficult moments report that the very end is not as difficult and as sad as they would have thought; the person who left us always leaves behind a life experience, previous to the disease, which stays with us as a deep bond.



## Care beyond the end

### *What happens after death?*

If you are in a hospital ward a doctor will call the time of death and the nurses will prepare the body, following the indications of the family before bringing him to the morgue. If you are at home, you will always have to call your doctor to notify the death.

On very rare occasions, the doctor might ask your authorization for an autopsy; this could be helpful if the deceased was suffering from a disease of which the cause had not yet been identified. Moreover, the results of the autopsy might be of great importance in case of hereditary diseases or in families with a history of developing the same disease more frequently. Thus the disease could be diagnosed early in blood relatives.

All the feelings and circumstances linked to the loss of a loved one constitute the "Mourning Syndrome". Some of the feelings caused by grieving are very common: denial, anger, guilt, depression, loneliness, fear. Some people may be surprised to find that they are relieved rather than depressed. This is a normal reaction when the loved one died of a long disease, and even more so in case of some form of dementia: in these cases the loved one has already been "gone" for many years, because of his inability to communicate and relate with others.

However, you will always have to live, for a shorter or longer period of time, with the sense of loss. To help yourself overcome this difficult moment, after the death of a loved one you will have to take care of your "emotional needs", express your feelings, ask for and accept help, be forgiving with yourself, take care of your own health by getting as much sleep as needed. You will have to set short-term and long-term goals, and never give up your projects.

People who are close to someone who is mourning (friends, acquaintances, remote relatives) must be aware that it is important for someone who lost a loved one to share memories and talk about the pain caused by that death. The love for the lost one outlasts the mourning period, and in any true relationship there is an unspoken compromise to go on with one's life fully, even when one of the members of the couple will no longer be there. If you need expert advice or support, please contact the social services of your town, or call the toll-free number of AIMA (Italian Alzheimer's Disease Association), 800.679.679.



This guide is an attempt to answer some of the most frequently asked questions when we are near to someone who is suffering from a cognitive degenerative disease, and above all, at the end. We think it is important for caregivers (carers, family members) to have a very clear idea of what the caring staff can and should do, at each stage of the disease, but even more so in the final stage. It is also essential that the doctor and the medical staff are willing to give you all the necessary information, and that they make time to find an agreement on what therapies should be adopted in the patient's interests and in full respect of his wishes.

However, since it is rare for a patient to have previously clearly expressed such wishes aloud, or in writing, our advice is when in doubt, especially at the end of a long and painful caring process, take a palliative approach, aimed at the maximum possible physical and psychological wellbeing.

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