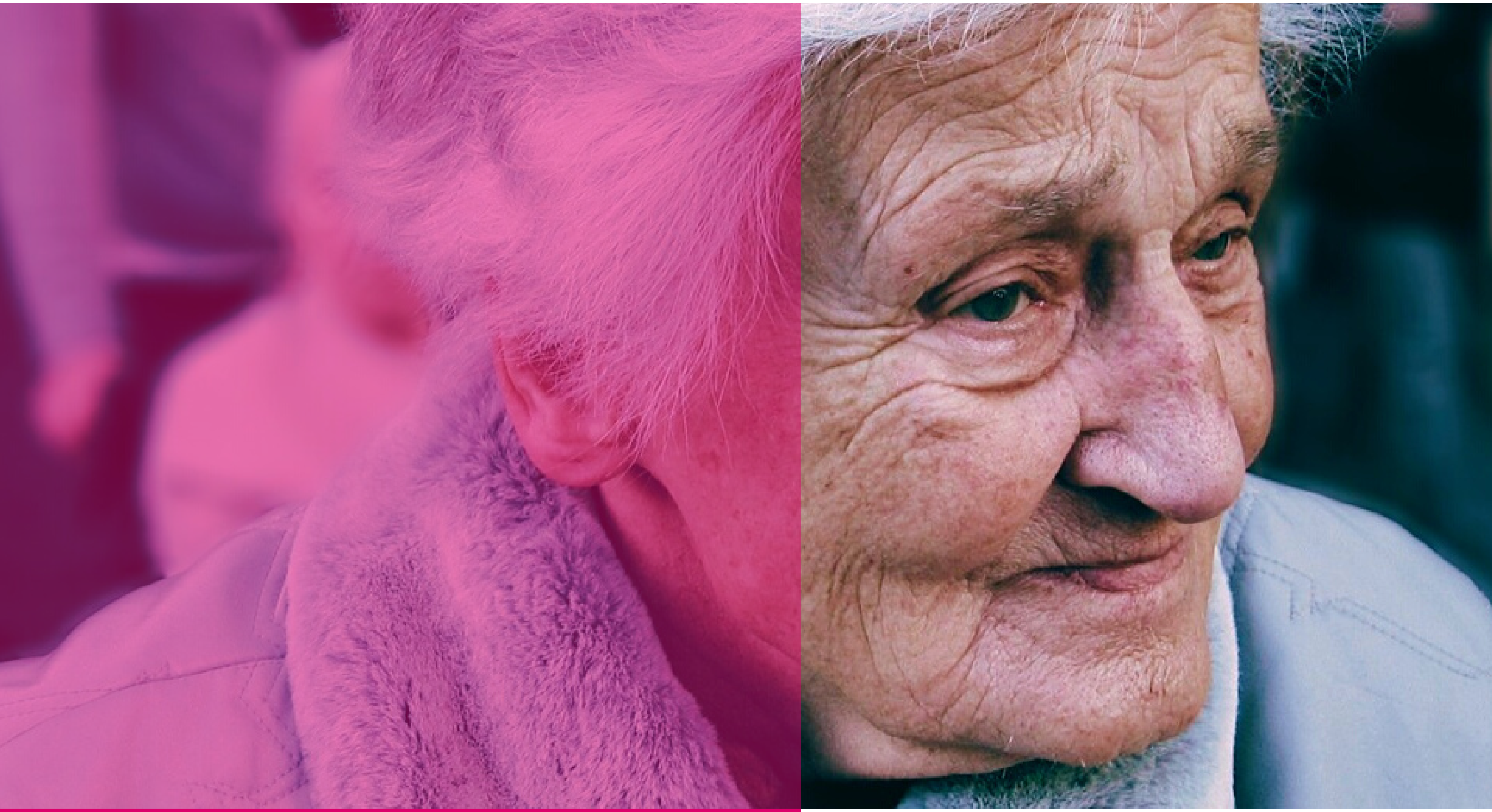
NON-PHARMACOLOGICAL MANAGEMENT OF BEHAVIOURAL DISORDERS

In people with dementia



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PRESENTATION

When we talk about dementia in general, it is very common to also talk about behavioural disturbances. These appear in 50-80% of people diagnosed with dementia at any stage of the disease.

Psychological and behavioural symptoms in dementia (SPCD) are alterations that usually generate a great sense of frustration and suffering for both the person and the family/caregiver, as they can be determinant in the progression of the disease and/or degree of dependence.

First of all, before entering this unfamiliar world for many, it is important to remember that the person next to us is ill and is not acting intentionally.

To continue, it is important to always keep in mind that in this disease it is not always possible to completely eliminate SPCD even if we follow all the recommendations and comply with the treatment, so we must try to be aware of this and sometimes adapt/comply with a decrease in the intensity or frequency of these symptoms.

PILLARS

of care for people with dementia

Before focusing on the analysis and explanation of each of the psychological and behavioural symptoms, it is important to remember that the care of these people is based on four pillars.

These pillars are: the space in which the person lives, how we help them in self-care, the way we communicate with them and how we encourage occupation as therapeutic.

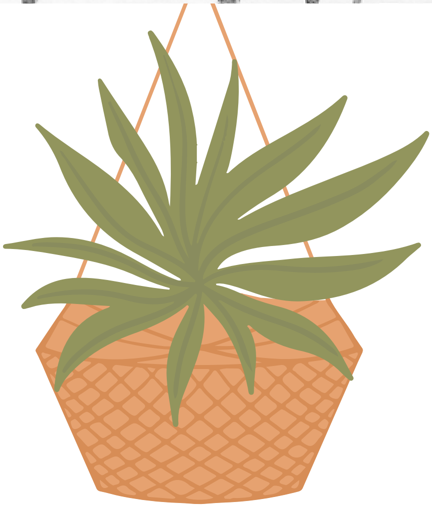
They are irreplaceable pillars for providing stability and well-being to the person with dementia, thus reducing the recurrence of these SPCD. We will now talk about each of them.

1

Space in which the person lives

It should be a space that promotes well-being and comfort, so we will emphasise some facilitating elements for a person with dementia and eliminate others that may be a barrier.

After all, everything around us can cause discomfort and as a consequence can be the trigger for SPCDs.



Order is essential

Many people living with dementia are unable to make the right choice of stimuli in the face of multiple stimuli. They need to live in an orderly environment, without obstacles in the way (carpets, furniture, etc.) or objects that they can manipulate.

All objects that are out of place can be distracting, disorienting, causing them to be more lost and irritable.

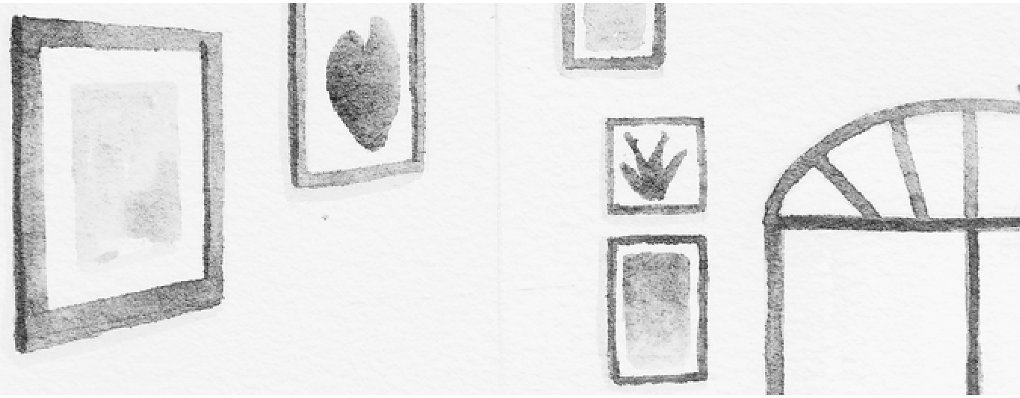
Taking care of the lighting

Bearing in mind that:

- With small plug-in devices, we provide a small ambient light at night that helps to recognise spaces and minimise the "fear" that many people feel at nightfall (disorientation, fear of loneliness, even fear of death are more intense in the dark).

- Soft light in the morning, after a nap and at bedtime helps to create a relaxing environment for both waking and lying down, activating the body and mind gradually.

- Adequate bright light for the rest of the day encourages them to stay awake, stimulates activity.



Facilitating orientation

One of the first symptoms at the onset of dementia is disorientation. They do not recognise the spaces in which they live, nor do they remember where they live in their lives.

Pictures or posters to indicate the location of each room, calendars and clocks, the latter placed in the common areas or main rooms, help in the correct spatial and temporal orientation.

Harmonious and pleasant environments

It is essential to maintain an adequate odour in the home, for this we must maintain good cleanliness of the furniture and rooms and proper ventilation.

Temperature is also an important aspect to take care of, as both too much and too little heat makes them feel less comfortable, which translates into discomfort and can be a trigger for any SPCD.

2

How to deal with care

In all cases, as the disease progresses, these people lose the ability to programme their self-care routines and sometimes refuse help from someone else. This is often the reason for the onset of SPCD, which is why attention should be paid to the following aspects:

Assessing the best time for bathing

Consider the hours and conditions that are most pleasant for the person you are caring for.

Create routines

Try to do the activity at the same time every day.
Seek to automate and better integrate daily care and routines.

Let the person know what will happen next

Tell them what you are going to do by involving them in the activity (You are going to get out of bed, now you have to get undressed...).

Sequence tasks

People with dementia are not always able to organise everyday tasks, they need someone to break them down and anticipate the steps to be taken, so that they can execute each task.

Simplify

Do only one thing at a time.

Avoid arguing with the person.

There will be days when the person is very reluctant, in which case allow some time to pass and try again later.

Allow the person to carry out those activities that he/she can still do

If necessary, help him/her with verbal cues or by asking him/her to imitate you.

Prepare everything you will need in advance

to cover personal care needs, so that nothing is lacking when it comes to the task at hand.

Encourage activity with positive messages

such as how good it smells, how good it looks... etc.

3

The communication

Communication is of great importance when it comes to caring for a person. We must always bear in mind that we are dealing with a person with feelings and that he or she is particularly uncomfortable with what is happening to him or her. We take care of the following details:

- Always use your name to get their attention.
- Speak to them using affectionate tones (use a firm and clear tone of voice, but avoid shouting too much) and look them straight in the face without being invasive. In this way you will be close and clear in your message, avoiding making them feel that our indications are an aggression or an order.

- Always address him/her in simple and very clear language. Use short, clear sentences, containing only one command or verb. After each indication or sentence, wait for a while to make sure that you are understood.

- Do not be excessively slow in speaking, as long spacing between words makes it difficult for them to keep the above-mentioned words in their memory.

- If you have to ask the person with dementia a question, always use closed questions (questions that allow the person to choose between two options).

- Avoid discussing or talking about unpleasant events in front of her, it may confuse or irritate her.

Try to use simple and clear language, with short sentences and closed questions, and in a firm and friendly tone.

- Pay special attention to non-verbal communication, especially when the person to be cared for has lost the ability to understand verbal indications or to express what is happening to them in words (watch them when they try to communicate, their facial expression or gestures can give you clues as to what they want to communicate, in the same way, move your body pointing to objects or performing actions to help them understand what we are trying to say).

- Always position yourself in a visible place, where there are no objects or people to interfere with communication. Always face the person you want to communicate with and slightly to one side to prevent them from feeling cornered. And always at their height (everyone standing or everyone seated).

4

Promoting activity

as therapeutic

Throughout our lives we all have an occupation and a role both inside and outside the home, the loss of the ability to maintain our roles and to schedule a daily routine can be clear triggers for SPCD.

It is vitally important to remember at all times who the person we are caring for has been and how they have spent their time during their life.

It is recommended to maintain as far as possible all the activities that have made you feel useful and good.

Any activity not only generates wellbeing, but also makes the person focus on something productive, leaving aside everything that generates discomfort. In turn, it will help the person to keep their residual capacities intact for a longer period of time.

SYMPTOMS

psychological and behavioural in dementia

As mentioned above, SPCD can appear at any stage of the disease, and more than one of them can be present at the same time. Among the SPCD we can find:

1. Apathy / Indifference
2. Depression / Anxiety
3. Hallucinations
4. Delusions / Suspiciousness / Confusion
5. Aggressiveness / Agitation / Irritability / Opposition
6. Disinhibition
7. Wandering / aimless motor behaviour

If any of these SPCDs appear suddenly, first of all, you must rule out the existence of any organic cause that may have caused them. These are basic needs that may not have been met, such as: thirst, hunger, sleep, the need to urinate, constipation, or the possibility that a viral process (a cold, etc.) or infection (urinary infections, etc.) may be starting.

Below, we are going to analyse each one of them and give a series of recommendations on how to act in the event that our relative/carer presents one or more of them.

SPCD

How to act?

Apathy / Indifference

Sometimes, prior to diagnosis, certain signs and symptoms such as lack of interest, motivation or enthusiasm may be present, which may attract our attention. These signs and symptoms may also appear during the course of the disease.

○ **1.-** Try to speak to him/her with affection and positivity.
○ **2.-** Always offer the option of exiting from home to walk.
○ **3.-** Identify the things that give you the most satisfaction in your daily life and offer them to them.
○ **4.-** Try to cultivate and promote the hobbies (gardening, manual work, colouring, etc.).
○ **5.-** If you like music, play the artists/songs you like the most.
○ **6.-** Try to relive memories through family photos.
○ **7.-** If possible, perform any type of physical activity.

SPCD

How to act?

Depression / Anxiety

Anxiety and depression are very common symptoms in people with dementia. Some of them may be restless, show a lack of interest in everything or deep sadness and crying for no apparent reason.

- ○ **1.-** If you identify these symptoms, ask them why they are sad or nervous. Identifying possible causes or situations can help us to avoid them.
- ○ **2.-** Always speak to them with affection.
- ○ **3.-** Carry out physical activity with the patient: Walking, stationary bike, pedals, stairs, etc.).
- ○ **4.-** Try to find an activity that helps you to improve your self-esteem, activities that you enjoy and that have an attractive result: decorating boxes or trays, painting pictures, creating baskets, cross-stitching, restoring a piece of furniture... etc.
- ○ **5.-** Try to get them to do activities with other people (day centres, retirement homes, etc.). Socialising is very important.

Hallucinations

This is a disturbance that consists of the perception of sights, sounds or smells that the person interprets as real, but which in reality are not. It should be noted that sometimes these do not cause any kind of discomfort in those who live with them, so that, if this is the case, we do not usually treat them.

How to act?

○ **1.-** In case these hallucinations cause uneasiness or any kind of discomfort, try to reassure the person with a soft voice. Do not insist on the unreality of the matter.

○ **2.-** Get them to redirect their attention to another conversation and/or activity.

○ **3.-** Ask him/her if these hallucinations affect him/her or make him/her nervous.

○ **4.-** Avoid going to new places. The inability to recognise the environment may cause distortion of reality.

○ **5.-** Avoid rooms that encourage overstimulation (with lots of decorative elements and objects that encourage restlessness).

○ **6.-** Encourage the use of glasses, prostheses and hearing aids. It is important that the person is connected to us and to reality.

○ **7.-** Being in the process of adjusting pharmacological treatment, the use or disuse of some drugs can cause hallucinations.

SPCD

Delusions / Suspiciousness / Confusion

Memory loss, hearing loss and/or confusion may cause a person with dementia to perceive things wrongly or they may misinterpret what they see and hear.

It is very common as the disease progresses that the person is unable to recognise people, places and/or presents the construction of false stories/beliefs that he/she lives as if they were real.

For example: "My house is not my house", "The caregiver wants to steal or poison me", etc.

How to act?

- **1.-** Always try to react calmly and not to make the patient nervous.
- **2.-** Try to reassure the person, but do not insist on the unreality of the issue, as this can provoke aggression and further agitation. You can try to correct the person, but do not do it constantly.
- **3.-** Avoid nagging and/or NO. Use phrases such as "I think so", "I think it is", etc.
- **4.-** If we see that this delirium is not having any emotional impact, allow your relative to express themselves and then try to change the subject.
- **5.-** If you become involved in your family member's thoughts and accusations, get someone else to intervene and redirect their attention to another conversation and/or activity.
- **6.-** Use posters or electronic media that can guide your family member at home. Always tell them what you are going to do before you do it.
- **7.-** Offer them an activity that helps them to orient themselves in reality (e.g. ask them to help with cooking or cleaning the house if that is what they are doing at the moment) or something that they enjoy and helps them to focus their attention on something productive.

SPCD

Aggressivity / Agitation / Irritability / Opposition

Some people may show aggression for no apparent reason and suddenly; others may respond in this way to situations that frustrate them.

It is very important to be able to identify the situations that may lead the person to show this aggressiveness, as we could indirectly be the cause of this problem or it could be in our power to avoid those situations that lead them to respond in this way. It is important to remember that the person with dementia may feel threatened at any time as they are not able to understand what we want to achieve when we intervene.

How to act?

- **1.-** Always remain calm. Be positive and reassuring. Speak to them slowly, in a gentle tone. If we get nervous and use force to control him we can increase his aggressiveness.
- **2.-** Avoid the confrontation. No argue. Try distract him o change conversation.
- **3.-** Avoid the over stimulation, noises strong o a environment with stimulus. Find routines, but without offer tasks that are complicated.
- **4.-** Go for walks or hikes whenever possible.
- **5.-** Try to identify which situations trigger this type of behaviour in order to try to avoid them.
- **6.-** Offer them activities that help them to channel their aggression or restlessness. We recommend those tasks that involve physical effort for the person and also entail some kind of strenuous movement, e.g. sanding, tearing paper or strenuous physical exercise (exercise bike).
- **7.-** Bear in mind that a person who has shown aggression on one occasion may show it again, protect yourself as a caregiver, do not face moments of conflict alone. But do not be invasive either over-acting can create further stress for him/her.

SPCD

Disinhibition

Sometimes people with dementia may display behaviour that is socially unacceptable. Examples of such behaviours would be: making rude gestures or comments, undressing in public, touching or making sexual advances, etc.

How to act?

○ **1.-** Always react calmly, do not scold. Remember that it is because of the illness.

○ **2.-** Tell the child gently but firmly that such behaviour is not appropriate at this time and try to distract him or her.

○ **3.-** If the behaviour is towards you, it is important to remind you of the boundaries in the relationship (e.g. "I am your caregiver and I deserve respect and I don't like what you said/did").

○ **4.-** Sometimes undressing in public may be caused by discomfort, because the clothes are uncomfortable, you feel hot or you need to go to the toilet.

○ **5.-** Bear in mind that this type of behaviour is a consequence of the illness and that on many occasions it is a problem for us, because it creates embarrassing situations, but it is not a problem for our relative, i.e. it does not cause them any harm. Therefore, despite the fact that they can give us a hard time and we may have to give more explanations than we would like, we must accept this type of behaviour and accept that they are part of the illness, trying to normalise them, which can help us to cope with them better.

SPCD

Wandering / Aimless motor behaviour

When we talk about dementia, it is not unusual to hear a relative tell us that their relative has gone astray on more than one occasion or that at home they don't sit still, they pick up objects, mess them up, open cupboards, etc.

How to act?

○ **1.-** We must remember that this behaviour may be related to low stimulation and a feeling of inactivity or boredom. At other times it may be secondary to physical discomfort, the need to go to the toilet, pain and/or other illness.

○ **2.-** Encourage physical activity.

○ **3.-** Keeping the person active can reduce anxiety and restlessness and therefore help to reduce this behaviour. Take the opportunity, if possible, to go for a walk when the person is walking continuously and is unwilling/unable to sit still.

○ **4.-** Try to involve the person in daily activities such as cooking, washing dishes, folding laundry, sweeping, etc.

○ **5.-** Create routines.

○ **6.-** Offer music, painting, drawing and/or other distracting activities.

○ **7.-** Be aware of changes in treatment in case they could be the cause of restlessness when it appears abruptly after a change.

○ **8.-** Offer to go to the toilet even if he/she does not ask for it, at least every so often, in case going to the toilet is the cause of the restlessness.

GENERAL ADVICE

✓ If you experience any of these signs or symptoms, always consult your doctor.

Share your experiences with others who are going through the same experience as you, this will help you to cope with these situations more normally.

✓ Be flexible, use the above-mentioned important pillars of care (environment, self-care, communication and occupation) in your routines.

✓ Do not take any kind of behaviour personally, remember that you are dealing with a sick person.

✓ Taking a break and relaxing is necessary and essential to be able to provide good care.

✓ Establish routines.

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