AD-ART

GUIDELINES FOR THERAPISTS

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What is dementia:

Dementia is a clinical syndrome (set of symptoms) due to a disease affecting the brain, chronic and progressive that involves the degeneration of: mental faculties such as memory, reasoning ability, language and the ability to recognize objects and people; affectivity and emotionality such as depression, anxiety and anguish; behavior and personality such as agitation, aggression, paranoid reactions and apathy.

These symptoms affect the normal social and working activities of the patient, with a deterioration in the quality of life and loss of autonomy.

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What is dementia:

There are several forms of dementia, the most frequent being Alzheimer's disease, which affects 50% of cases. It is a progressive disease that takes its name from Alois Alzheimer, the German neuropsychiatrist who first described the disease in 1906.

The second in order of frequency is vascular dementia, due to cerebral arteriosclerosis and in particular to multiple brain lesions caused by the interruption of blood flow (ischemic lesions).

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The diagnosis :

It is of fundamental importance to consult a doctor when the first signs of a cognitive deterioration appear; to spot the first signs of the disease, the American Alzheimer Association in 2005 published 10 warning signs for Alzheimer's disease:

- the person often gets confused and has memory lapses;
- he is no longer able to do everyday things;
- struggles to find the right words;
- gives the impression of having lost the sense of direction;
- she wears one dress over the other as if she doesn't know how to dress;

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The diagnosis (Cont.) :

The first signs of a cognitive deterioration:

- puts objects in the strangest places;
- has sudden and unmotivated mood swings;
- it no longer has the character of the past;
- it has less and less interests and spirit of initiative

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Description of some common symptoms in Dementia:

It is very common to find in the patient a series of behavioral manifestations that create a lot of worry and fatigue in those around him.

The most frequent behavioral disturbances concern personal autonomy, the management of daily life and relationships.

It is important to remember that the behavior adopted by the sick person is the only one at this moment that allows him to cope with the demands that the world around him makes.

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Description of some common symptoms in Dementia:

Listed below are some of the indicators that a person with dementia can perform:

- **Restrictive activity**: The person with dementia can forget what they said or did after a few moments by taking actions and asking questions repetitively. In many cases it is appropriate to reassure him by inviting him to do simple actions trying to maintain a calm and affectionate attitude.

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Description of some common symptoms in Dementia (Cont.):

- **Attachment**: Alzheimer's patients can be extremely dependent on the person who cares for them and therefore do not want them to leave them, even for a short time. Such behavior may derive from the patient's fear that the person in question might abandon him and therefore be caused by a more general feeling of insecurity.

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Description of some common symptoms in Dementia (Cont.):

- **Loss of items and allegations of thef**t: Alzheimer's patients often forget where they store items and consequently may accuse other individuals of having stolen them. In such circumstances it is advisable to respond to the person's accusations kindly, trying to avoid conflicts, and to help him find the lost object, bearing in mind that his behavior depends on the disease and not on his will.

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Description of some common symptoms in Dementia (Cont.):

- **Loss of orientation**: disorientation can be one of the most difficult problems to manage. The PwD can wander and get lost even near their home. Ensuring his safety is of primary importance. Guaranteeing the patient frequent walks in company can however reduce the anxiety linked to the desire to leave the house independently.

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Description of some common symptoms in Dementia (Cont.):

- **Delusions and hallucinations**: Delirium or hallucinations take forms of a true thought and can be considered, by the PwD, as absolutely real, creating a state of fear that can result in self-defensive behavior. To lower his state of anxiety, one must indulge him and not try to bring him back to reality abruptly, giving him the opportunity to make him talk about what he believes is happening.

- **Uninhibited behaviors**: although it happens rarely, the patient's behavior in public can be particularly inappropriate and uninhibited; constantly speaks aloud, greets everyone, from expressions of affection even to unfamiliar people, etc ...

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Description of some common symptoms in Dementia (Cont.):

- **Violence and aggression**: in particular circumstances the PwD an become short-tempered, aggressive and even violent; this can happen for various reasons such as the loss of self-control in public, the degeneration of critical skills, the inability to confidently express unpleasant emotions and feelings and the difficulty in relating to other individuals.

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Description of some common symptoms in Dementia (Cont.):

- **Depression and anxiety**: the sick person may feel depressed and sad, tend to be isolated, speak, act and think with particular slowness and difficulty. This can result in a further alteration of the daily rhythm of life and habits such as a decrease in appetite. We must try to induce the PwD to feel loved, never asking him more than he can give, gratifying him, making him feel the affection of the family and avoiding harshly reproaching him in the face of failure.

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Therapies for PwD:

To date, Alzheimer's disease is incurable but it remains treatable, as it is possible to take care of the PwD by accompanying him on his path in order to safeguard the quality of life as much as possible. This can be done through both pharmacological and non-pharmacological interventions.

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Therapies for PwD:

By non-pharmacological treatment we mean those precautions relating to the relationship with the sick person and the organization of the surrounding environment; this allows us to better accommodate the new needs and requirements of the patient. Behavioral disturbances (agitation, restlessness, growing nervousness especially in the evening hours, anguish, crying, tendency to run away from home and resistance to change) are difficult to manage, create many difficulties for the patient and his general well-being and, consequently, also to the person who assists and takes care of him.

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Therapies for PwD:

Some attitudes are affected by anxiety, fatigue or difficulties manifested by those who care, creating a circuit in which the more the patient "is difficult", the more the carer "loses patience". The relationship with an Alzheimer's patient, accompanying him in the various stages of the disease requires above all "patience" and knowing how to stay in times of need. The abilities most compromised by the disease such as language, memory, personal autonomy and daily life require a particular attitude of those who treat the patient. We need to place the various expressions of the disease within a more complex picture: the person affected by dementia loses his abilities but does not lose his identity, he remains the person he was before he fell ill, with his life story.

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Therapies with PwD:

The present involves new elements: symptoms, difficulties not addressed before, all in a life project to be re-created in the family that must constantly keep together the new situation of the sick relative. Some relational techniques (for example conversationalism and possible conversation) help to find new communication channels respectful of the person and the disease, offering the person who treats new ways Extremely important are the creation and maintenance of environments (the home, room, furniture) that can favor the spatial orientation of the sick person and that help protect themselves from possible risks. It is essential to make safe environments that can be dangerous for the patient (eg kitchen ...).

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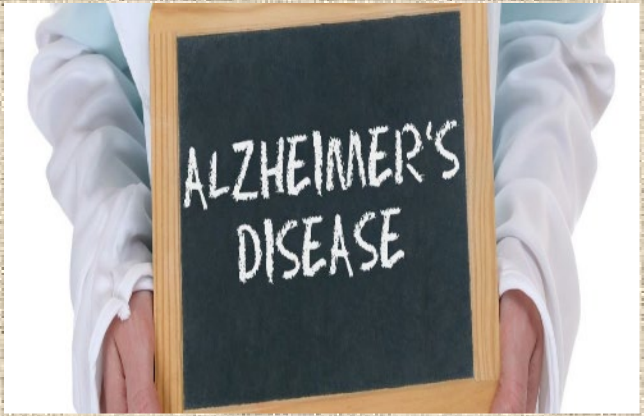
The ten principles of good care for PwD:

Now let's see what are the 10 principles to keep in mind for good care of the person with dementia:

1) **Recognize the functions of the brain**: everything we experience in life, every decision or action we take can be traced back to our brain.
2) **Alzheimer's is a brain disorder**: although more and more people are aware of it, many still believe that this is a mental illness, a psychological weakness or simply a condition of aging.



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The ten principles of good care for PwD (Cont.):

3) Alzheimer's affects everything the brain controls: the variety of symptoms that can be traced back to a process of cognitive deterioration should not be underestimated.

4) Unpredictability is around the corner: Alzheimer's affects different parts of the brain at different times and rhythms. Ever had a light bulb that all of a sudden only works occasionally? This is what happens in the brains of people affected by dementia which will go through certain pre-established stages even if they are not clearly defined and often overlap.

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The ten principles of good care for PwD (Cont.):

5) Each goal should be divided into smaller, simpler goals: tasks that seem simple to us may appear difficult to the people we take care of. For example, brushing your teeth may seem like a single action, but in reality it can be broken down into several stages: take the toothpaste tube, remove the cap, place the contents on the bristles of the toothbrush, turn on the tap etc ... If Dementia hit the brain in such a way that it does not remember all these steps or the order in which they must be performed, it will be impossible to complete the sequence unless the task is divided into many small actions.

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The ten principles of good care for PwD (Cont.):

6) Remember the cause of problem behaviors: Behavioral disorders are caused by damage to the brain and are not something that can be controlled or prevented, if anything. manage by minimizing costs in terms of stress.

7) You don't have to look sick to suffer from a physical illness: even Alzheimer's being an organic disease often does not change a person's outward appearance, at least up to the most severe stages. This can be confusing despite a "facade" appearance. The patient has clear signs that something is wrong. You may be suffering from Dementia without sounding sick in the true sense of the word.

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The ten principles of good care for PwD (Cont.):

8) **Discussion is useless**: It is extremely difficult, if not impossible, for any Alzheimer's patient to learn, understand, reason or remember. It is more productive to provide comfort or to try to engage in pleasant activities, such as a walk, watch a movie or remember the old days with some object or photograph from the past.

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The ten principles of good care for PwD (Cont.):

9) **Understanding signs of stress**: people with dementia have a progressively lower stress threshold and this is associated with a reduced linguistic ability to explain the reasons for discomfort.

10) **Accepting the brain-behavior relationship**: a key to providing good care is not only understanding the brain-behavior relationship but also accepting it. This allows the patient to be cared for with compassion and without judgment as to the appropriateness of any behavior.

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The use for CAT for PwAD:

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The use for CAT for PwAD:

Mental faculties benefiting from the use of CATs:

- memory,
- reasoning skills,
- language and ability to recognize objects and people;
- increase affectivity and emotionality,
- decrease depression, anxiety and distress;
- decrease behaviors such as agitation, aggression, paranoid reactions and apathy.

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Competences of Professionals:

There is increasing research showing how the arts can improve clinical skills, personal skills and communication among health-care professionals.

In relation to communication skills, arts engagement and reading can foster empathetic imagination, thereby supporting effective communication and collaboration between medical staff, as well as attune individuals more with their own emotions.

Art appreciation classes have been found to improve verbal and nonverbal communication skills in clinical teams.

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Competences of Professionals:

The use of theatre formats, including interactive theatre and role play, can also improve communication skills.

Arts classes have been found to improve emotional recognition, cultivation of empathy and awareness of multiple perspectives in clinicians, and music and dramatic arts can enhance relatedness to people from different backgrounds.

The arts can support mental health and well-being in health-care staff. The development of empathy through music and movement has been linked with lower stress and burn-out and higher resilience.

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Competences of Professionals

Creative arts classes can enhance confidence, well-being, identity and self-care in both professionals and students.

Music has been found to improve mood and reduce stress while working, as well as improving levels of concentration, efficiency, enthusiasm and ordered working. Participatory arts classes have been found to enhance feelings of support for staff within health-care settings, and visual arts have been found to improve the working environment for staff.

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How to make PwD cooperate in Group Dynamics:

"Group dynamics" is a system of behaviors and psychological processes occurring within a social group (intragroup dynamics) or between social groups (intergroup dynamics).

Group dynamics applications are studied in psychology, sociology, anthropology, political science, epidemiology, education, social work, business, and communication studies.

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How to make PwD cooperate in Group Dynamics:

The study of group dynamics can be useful in understanding:

- decision-making behavior;
- tracking the spread of diseases in society;
- **creating effective therapy techniques;**
- following the emergence and popularity of new ideas and technologies.

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How to make PwD cooperate in a Group Dynamics:

Self-management programs can be effective in assisting people with chronic conditions to learn new skills, organize their lives, and create a sense of order as they deal with the transitions and responses to illness, but **the stigma** that accompanies a diagnosis of dementia causes reluctance to apply ideas of self-management.

Moreover, the diagnosis of dementia can supersede all other aspects of one's identity and people with dementia often feel that they are treated with less respect and labeled with a loss of self and capabilities and a tendency to feel **'less than'** and they are often presumed to lack capacity to oversee their own lives.

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How to make PwD cooperate in a Group Dynamics:

Person-centered care has been described as a way to address **stigma** because it promotes a lens that sees the person behind the dementia as a person, as an active social agent.

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How to make PwD cooperate in a Group Dynamics:

This social agent framework posits a **rights-based lens** – as opposed to **needs-based lens** – that draws attention to six basic components of living well as a social citizen:

1. opportunities for growth, change and development;
2. a power analysis that recognizes how one's social locations help shape one's experiences of the world;
3. respect for personal meaning-making and finding purpose;
4. **promoting active participation (as opposed to simply being included)**;
5. the importance of building community and solidarity as both a social and political goal;
6. creating a context that challenges stigma and discrimination

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How to make PwD cooperate in a Group Dynamics:

Additionally, changes can occur within family relationships as family members take on increasing responsibility for overseeing the needs of the person with dementia - particularly marital or intimate partnerships - and researches suggest an important shift in the relationship, as partners begin to see themselves as ‘**carers**’ rather than within their relational role of **husband/wife**.

The dominant understanding of the relationship between the person with dementia and his or her care-partner positions the person with dementia as ’dependent’ and potentially a ‘burden’.

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How to make PwD cooperate in a Group Dynamics:

Participating in groups with other PwD can be liberating, empowering, and build confidence providing opportunities for growth, change, and development.

Important considerations need to be made when designing groups for PwD.

The purpose of the group is significantly important, and should determine whether or not care partners become involved in the group.

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How to make PwD cooperate in a Group Dynamics:

Consulting PwD before the group is structured can provide important insights into the needs of PwD and ensure that groups are empowering for them. However this needs to be done with caution, so that it would not be seen as demonstrating lack of gratitude to family members.

The facilitation of the group needs to be taken into account, the facilitator needs to understand that PwD may feel inadvertently threatened and/or silenced and/or they may go marginalized or over-shadowed with caregivers around. So, a skilled facilitator will have to pay attention to group dynamics to ensure that people with dementia can maintain voice.

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How to make PwD cooperate in a Group Dynamics:

At any point in time, people with dementia should be consulted about their wishes and desires in relation to the structure of the group on a regular basis in a sensitive way to potential power imbalances and **outside the presence of family care partners.**

One size does not fit all, so group facilitators should avoid making assumptions about either the need for care partners to be involved in groups for PwD or the importance of care partners not participating.

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How to make PwD cooperate in Group Dynamics:

The three main factors affecting a team's cohesion (working together well) are:

- Environmental;
- Personal;
- Leadership.

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<u>How to make PwD cooperate in a Group Dynamics:</u>

Group composition:
Concepts of **voice**, **empowerment**, **advocacy**, **caring**, and **support** emerge as dominant issues. Discussion around group composition coalesced around four inter-related themes:

1. <u>Creating Safe Spaces:</u> These safe spaces ensure that participants, especially PwD feel comfortable and confident expressing their ideas and feelings. Creating safe spaces reflects the respect that people have for others' experiences and personal meaning-making in living with dementia;

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How to make PwD cooperate in a Group Dynamics:

Group composition(cont’d):

2. Maintaining Voice and Being Heard: At the heart of feeling safe is creating the space to maintain voice and be heard. This theme refers to two things: first, being heard means that not only do people feel they are safe to share thoughts and feelings within their groups, but that they are listened to by others; and second, maintaining voice means that people have something specific to contribute within the group, whether it be through giving advice or collective problem solving.

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How to make PwD cooperate in a Group Dynamics:

Group composition (cont'd):

3. A Balancing Act : A tension emerges between the desire to speak on one's own behalf and the recognition of the importance of the care partner in one's life. While those with dementia can feel inadvertently silenced by their care partner, a number of people with dementia may also talk about self-silencing in groups with care partners. Specifically, PwD clearly recognize the importance of care partners in supporting them, and do not always wish to express their feelings for fear of inadvertently alienating or hurting.

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How to make PwD cooperate in a Group Dynamics:

Group composition (cont’d):

4. Solidarity: “You’re Not Alone”: Solidarity is a sense of being a unique and similarly aligned community that surfaces where people feel connected because they share common experiences.
5. One size doesn’t fit all: The need for flexibility of structure is very strong. Like with most things in life, nothing stays the same. What worked this time doesn’t necessarily mean it will again. Flexibility is the key word accompanied by the need to adapt.

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How to make PwD cooperate in Group Dynamics:

Common features for groups to work well:

- Making sure that people with dementia are involved at every level as equals, preferably leading and making decisions;
- Agreeing terms of reference or a constitution and ground rules, to make people be clear about the purpose of the group and their roles in it;
- Having interesting things to work on. May begin by focusing on health and social care issues, but often branch out into other areas e.g. accessible transport, dementia friendly communities and product development;

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How to make PwD cooperate in Group Dynamics:

Common features for groups to work well:

- Being clear about how other people and organisations will engage with the group; asking for accessibly written documents, straightforward engagement processes and feedback after people have been involved;
- Providing strong support in the form of paid group co-ordinators and/or volunteer support. Their role should be to take care of the practicalities of involvement (e.g. diary co-ordination, booking venues and transport) as well as maintaining positive group dynamics;

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How to make PwD cooperate in Group Dynamics:

Common features for groups to work well (cont’d):

- Using approaches that enable all group members to contribute to the work and discussions of the group; maybe include turn taking, using props such as a red card to indicate when a person wants to speak, or a person with dementia acting as chair;
- Using different ways for people who are not comfortable speaking out in larger groups to contribute their views, e.g. small group discussions, sticky notes to write down ideas, individual support from a volunteer;
- Reviewing processes to ensure that all members of the group are being appropriately supported and still feel that the group is relevant to them;

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How to make PwD cooperate in Group Dynamics:

Common features for groups to work well (cont'd):

- Developing relationships with key local commissioners and decisionmakers – in terms of achieving change it really helps to have direct access to local professionals who can help to take forward the goals of the group;

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How to make PwD cooperate in a Group Dynamics:

Some practical hints for groups to support PwD to be involved:

- Give a lot of attention to the practicalities e.g. transport (booking taxis etc), choosing venues, time of day, refreshments, support, reminders;
- Use a range of methods to help people with dementia to understand the issue or the engagement activity, such as visual prompts to reinforce the discussion (e.g. discussing menus in a dining room or kitchen), using photos and pictures, using flipcharts and posters to record ideas and summarising discussions at regular intervals so that people can re-connect to the ideas;
- Check and double check people’s viewpoint. It may be that your own expectations or feelings colour what you think you are hearing people say or communicate;
- Give enough time to any specific involvement activity;

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How to make PwD cooperate in a Group Dynamics:

Some practical hints for groups to support PwD to be involved (cont'd):

- Give people the space to communicate their ideas, and ensure people who need it receive support so they can contribute;
- Be aware that involvement can be challenging – inviting people to think about tricky issues may raise emotions and cause people to be cross or anxious. Do not avoid these tricky issues but ensure you have thought through how you might respond;
- Make any involvement experience and any written materials are as accessible as possible, but without being patronizing;
- Use straightforward language without any acronyms;
- Make sure that events and meetings are structured well, with restricted agendas and good approaches to allow a range of people with dementia to participate fully;

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How to make PwD cooperate in a Group Dynamics:

Some practical hints for groups to support PwD to be involved (cont'd):

- Acknowledge that involving PwD can feel challenging. It needs time, creativity, flexibility, strong listening skills, and often a real drive to keep it a priority within stretched organizational settings;
- Ensure that PwD are consenting to be involved and engaged; involvement isn't something that should be done to people. Follow an appropriate consent procedure that is accessible for people with dementia;
- Avoid assuming that people lack capacity to be involved which often results automatically in excluding people with more advanced dementia;
- Remember, it is not just about work. Build in some fun and social time – often the best ideas come out in these moments;

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How to communicate with PwD:

Dementia is a clinical syndrome involving a continual and gradual loss of intellectual function, leading to cognitive impairment and memory loss. Patients have **difficulty in communication** and self-care in their daily lives. If carers do not have clear understanding of the illness, they may feel very frustrated about the communication blockage.

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How to communicate with PwD:

Factors leading to communication problems:

1. **Patient's factors:** memory loss and difficulties in retaining information, difficulties in carrying out complex tasks due to cognitive impairment, low concentration span, mood swings and increased level of irritability;
2. **Carer's factors:** speaking too fast or in a high-pitched voice, causing stress to the patient, too much information or unnecessary gestures which may be misleading and distract the patient's attention, too tired, feeling frustrated and impatient, improper tone of voice, e.g. shouting may cause patient to feel threatened and offended;
3. **Environmental factors:** noisy environment, poor lighting.

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How to communicate with PwD:

Ten keypoints for good communication:

1. Maintain a **quiet environment**. Turn off radios or televisions if necessary;
2. Sit **face-to-face** with the patient, and try to maintain eye contact at all times;
3. Speak **slowly and clearly**. Encourage the use of hearing aids in patients with hearing problems. Do not shout at the patient. Try not to raise the voice.
4. Keep the sentences **as simple as possible**. Convey one message at a time. Avoid the use of certain terms such as he/she/it, and use names instead. Avoid words with abstract ideas, e.g. replace the terms 'hungry' and 'thirsty' with terms like 'eat' and 'drink';
5. Ask one question at a time and keep questions simple. Ask close-ended questions with **limited choices** such as 'Would you like an apple or an orange?' instead of asking 'What types of fruit would you like?';
6. Pay attention to **facial expressions and body languages** to interpret the patient's feelings, e.g. is the patient smiling or wincing in pain? Respond to patients' feelings accordingly, e.g. nodding and smiling can be signs of encouragement to the patient;
7. **Repeat** yourself or prompt the patient if necessary;
8. Use real **objects to aid communication**. For example, show the patient a towel and soap to indicate it is time for a bath;
9. Conversations should be kept **concise** as patients have difficulties in concentrating for long periods;
10. If the patient is tired, pat him on the shoulder or hand over a drink for refreshment. **Take a break** before starting again.

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How to communicate with PwD:

We aren't born knowing how to communicate with a person with dementia—but we can learn. Improving one's communication skills will help make caregiving less stressful and will likely improve the quality of relationship with one's loved one. Good communication skills will also enhance the ability to handle the difficult behavior encountered while caring for a person with a dementing illness.

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How to communicate with PwD:

For effective communication:

- **Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts more strongly than your words do.
- **Get the person's attention.** Limit distractions and noise, address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.
- **State your message clearly.** Use simple words and sentences. Speak slowly, distinctly, and in a reassuring tone. Refrain from raising your voice higher or louder; use the same wording to repeat your message or question. Use the names of people and places instead of pronouns (he, she, they) or abbreviations.
- **Ask simple, answerable questions.** Ask one question at a time; those with yes or no answers work best.
- **Listen with your ears, eyes, and heart.** Be patient in waiting for your loved one's reply. If she is struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and *listen for the meaning and feelings that underlie the words.*

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How to communicate with PwD:

For effective communication:

- **Break down activities into a series of steps.** encourage your loved one to do what he can, gently remind him of steps he tends to forget, and assist with steps he’s no longer able to accomplish on his own.
- **When the going gets tough, distract and redirect.** If your loved one becomes upset or agitated, try changing the subject or the environment.
- **Respond with affection and reassurance.** People with dementia often feel confused, anxious, and unsure of themselves .confused *Avoid trying to convince them they are wrong.* Stay focused on the feelings they are demonstrating (holding hands, touching, hugging, and praise will get the person to respond when all else fails.
- **Remember the good old days.** Remembering the past is often a soothing and affirming activity, *avoid asking questions that rely on short-term memory,* such as asking the person what they had for lunch. Instead, try asking general questions about the person’s distant past—this information is more likely to be retained.
- **Maintain your sense of humor.** *Use humor whenever possible, though not at the person's expense.* People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

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How to communicate with PwD:

Communication in the early stage of Dementia:

In the early stage of the disease, an individual is still able to participate in meaningful conversation and engage in social activities. However, he or she may repeat stories, feel overwhelmed by excessive stimulation or have difficulty finding the right word.

Tips for successful communication:

- Don’t make assumptions about a person’s ability to communicate because of a dementia diagnosis. The disease affects each person differently;
- Don’t exclude the person with the disease from conversations;
- Speak directly to the person rather than to his or her caregiver or companion;
- Take time to listen to the person express his or her thoughts, feelings and needs;
- Give the person time to respond. Don’t interrupt unless help is requested.

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How to communicate with PwD:

Communication in the early stage of Dementia:

Tips for successful communication:

- Give the person time to respond. Don’t interrupt unless help is requested.
- Ask what the person is still comfortable doing and what he or she may need help with;
- Discuss which method of communication is most comfortable. This could include face-to-face conversation, email or phone calls;
- **It’s OK to laugh. Sometimes humor lightens the mood and makes communication easier.**
- Don’t pull away, your honesty, friendship and support are important to the person.

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How to communicate with PwD:

Communication in the middle stage of Dementia:

The middle stage of dementia is typically the longest and can last for many years.
As the disease progresses, the person will have greater difficulty communicating and will require more direct care.

Tips for successful communication:

- Engage the person in one-on-one conversation in a quiet space that has minimal distractions;
- Speak slowly and clearly;
- Maintain eye contact. It shows you care about what he or she is saying;
- Give the person plenty of time to respond so he or she can think about what to say;
- Be patient and offer reassurance. It may encourage the person to explain his or her thoughts;
- Ask one question at a time and ask yes or no questions. For example, “Would you like some coffee?” rather than “What would you like to drink?”;
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what the person says. Repeat what was said to clarify;
- Avoid arguing. If the person says something you don’t agree with, let it be;
- Offer clear, step-by-step instructions for tasks. Lengthy requests may be overwhelming;
- Give visual cues. Demonstrate a task to encourage participation. Written notes can be helpful when spoken words seem confusing.

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How to communicate with PwD:

Communication in the late stage of Dementia:

The late stage of the disease, may last from several weeks to several years. As the disease advances, the person may rely on nonverbal communication, such as facial expressions or vocal sounds. Around-the-clock care is usually required in this stage.

Tips for successful communication:

- Approach the person from the front and identify yourself;
- Encourage nonverbal communication. If you don’t understand what the person is trying to say, ask him or her to point or gesture;
- Use touch, sights, sounds, smells and tastes as a form of communication with the person;
- Consider the feelings behind words or sounds. Sometimes the emotions being expressed are more important than what’s being said;
- Treat the person with dignity and respect. Avoid talking down to the person or as if he or she isn’t there;
- It’s OK if you don’t know what to say, your presence and friendship are most important.

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How to prepare a document for PwAD: General guidelines

- It is important for people with dementia to have the opportunity to communicate in their own language. A person's mother tongue is usually retained longer while languages acquired later in life are the first to be affected.
- The language used needs to reflects each person's culture, traditions and religion. Try to avoid making assumptions about what people from one ethnic group do and do not have in common with people from another ethnic group. If in doubt, check.
- Use short statements with common words that are easy to remember and understand.
- Break up complex information into smaller chunks.

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How to prepare a document for PwAD:

Practical Tips about formatting:

- No single format will meet everyone's needs. Where possible personalise formats to people's known needs.
- Keep written information short, simple and free from jargon and abbreviations
- Larger print helps.
- Use contrasting colors for rows of information. Present information in manageable chunks.
- Diagrams and pictures alongside text are helpful. However, too many images can be confusing. They should be relevant and not used just for decoration.
- Photographs are often preferable to illustrations which might be difficult to interpret.
- Use boxes for information you want to stand out.

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How to prepare a document for PwAD:

Practical Tips about content:

- Organise information logically, one piece at a time.
- Keep language simple without being patronizing. Remember that you are writing to an adult audience.
- Paragraphs should make sense on their own. People should not have to remember what was in the first paragraph in order to understand the current one.
- Avoid using words that frame people as a group and assuming they are different.

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To understand the concept of planning:

How to plan a workshop with a person with dementia:

- The activities in the workshop should be suitable for an adult and tailored to an individual.
- The instructions should be simplified and adjusted to the appropriate level of each individual participants needs who may have different cognitive decline. It is important to be aware of individuals' capabilities and level of understanding.

Source: https://www.jskd.si/gledalisce-in-lutke/delavnice_gledalisce/2019_20/kamisibaj_20.htm

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To understand the concept of planning:

- Determine the number of participants in the workshop and prepare the materials accordingly.
- All the materials needed for the workshop should be prepared and ready by hand. There should be enough for all the participants.
- Written materials should be adapted and understandable for people with dementia.
- It is good to provide extra space and facilities for people with dementia who would not want to participate in the prepared activity so that they can withdraw at any time.

Source: https://www.mklj.si/prireditve/item/10447-kamisibaj-delavnica

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To understand the concept of planning:

- We design the invitations in written and pictorial form, with large enough letters, and should be short and simply understandable.
- We present the purpose and goals of the workshop to potential participants, and we also encourage relatives to help with additional explanation and adaptation of instructions to specific needs of the participant.
- Send reminders about the workshop beforehand.

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General guidelines for professionals/relatives:

- Give people enough time and space to express themselves.
- Show understanding and empathy when someone has difficulty trying say or do something. It can be frustrating and embarrassing for them.
- Pay attention to various forms of non-verbal communication (gestures, facial expressions, physical touch, noises) that might indicate stress or happiness.
- Try to be aware of your own non-verbal communication and use it in a positive way. Make positive facial expressions and try to have some physical contact.
- Remain calm, talk slowly and clearly, without exaggerating (to avoid people feeling like they are being treated like a child).
- Try to think about adjustments that could be made to demonstrate acceptance of culturally appropriate approaches.
- Adjust duration and content according to the person’s physical and mental abilities.

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General guidelines for trainers: how to prepare the environment:

The space should be

1. quiet, without distractions (noise, too many people, loud conversations),
2. properly lit, heated/ventilated
3. large enough for all participants to have enough space for themselves, not too many things in a room.
4. Remove any dangerous items.
5. At the beginning trainer tells participants that anything we talk about in workshops stays between us.
6. Trainer encourage participants that it is not an art contest, so they don't need to worry about messing up.

Source: https://www.twwspacehire.com/goodiesblog/2020/4/6/free-zoom-backgrounds

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General guidelines for trainers: how to prepare the environment:

We should make environment where participants will feel safe.

It is important that participants feels that they can say anything they want.

It is good to provide extra room and facilities for people with dementia who would not want to participate in the prepared activity so that they can withdraw at any time.

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Comments and questions

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