



Module 1: Dementia

Illness

Dementia is a set of brain disorders that affect memory, thinking and the ability to interact socially. It is caused by damaged nerve cells that can occur in various areas of the brain. As a result, people experience dementia differently, depending on the area of the brain affected.

Aging is the most robust risk factor for dementia. Its incidence and prevalence increase exponentially with age, where more than 90% of dementias appear after age 65.

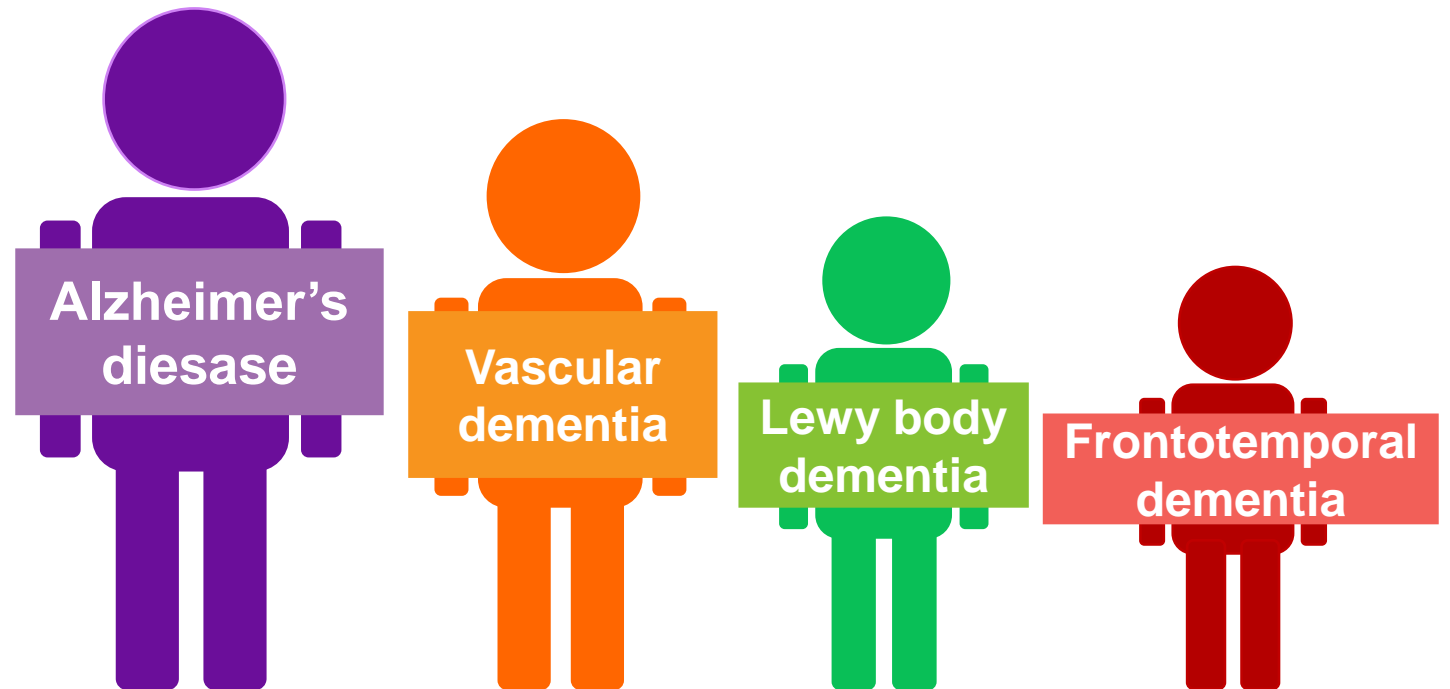


Illness (continuation)

Types of dementia are classified in several ways, usually according to what they have in common or if they get worse over time (progressive dementias). Types of dementias that are not reversible and worsen over time include:

DEMENTIA

Term used to describe a range of symptoms associated with cognitive impairment



Alzheimer's disease

Is a **progressive degenerative brain disease** and the most common form of dementia. At the moment, we don't know what causes Alzheimer's disease. We know that people with this disease have abnormal protein that accumulates in the brain. These 'tangled' proteins (made up of the tau protein) and 'plaques' (made up of amyloid beta protein) interrupt communication between brain cells and lead to eventual cell death and brain shrinkage.



Vascular Dementia

The second most common type of dementia, occurs as a result of brain damage due to reduced or blocked blood flow in blood vessels leading to your brain. Blood vessel problems may be caused by stroke, infection of a heart valve (endocarditis) or other blood vessel (vascular) conditions.





Lewy body dementia

Shares clinical and pathological features of other dementias that may occur during the course of Parkinson's disease and other neurological conditions. Pathologically, it is characterized by abnormal aggregation of, so called α -synuclein synaptic protein as 'Lewy bodies' in neurons associated with cerebral atrophy.

Frontotemporal dementia

Frontotemporal dementia: is a heterogeneous **neurodegenerative** group of dementias with a variable clinical and pathological profile. It is characterized by a marked dysfunction of the frontal and temporal lobes, usually associated with the atrophy of these structures.



Symptoms and behaviour of Alzheimer's disease



Memory loss that
disrupts daily life



Challenges in planning
or solving problems



Difficulty completing
familiar tasks



Confusion with time or place



Trouble understanding
visual images and spatial
relationships



New problems with words
in speaking or writing



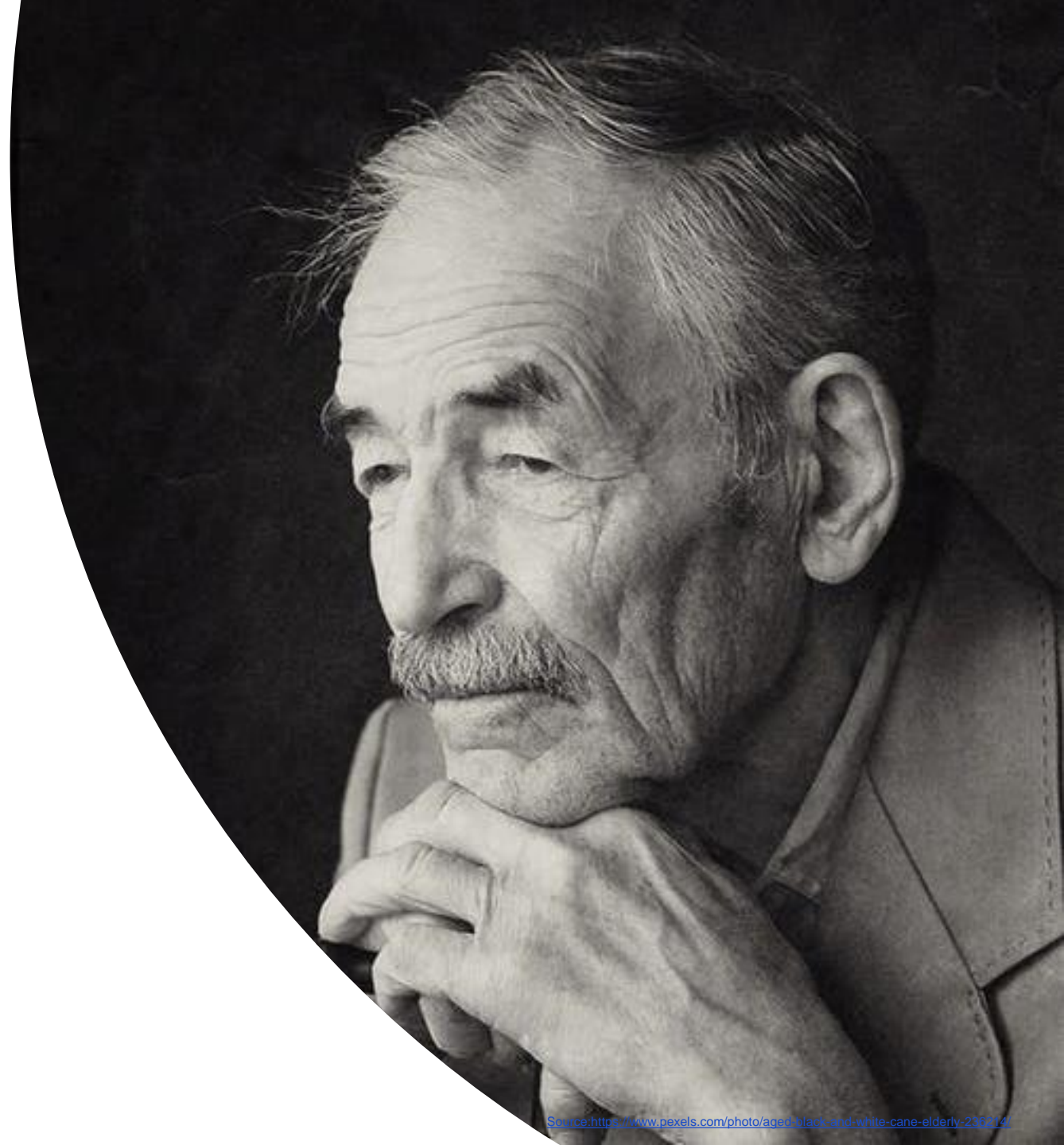
Withdrawal from work
or social activities



Changes in mood
and personality

Symptoms and behaviour of Vascular dementia

- Confusion
- Trouble paying attention and concentrating
- Reduced ability to organize thoughts or actions
- Difficulty deciding what to do next
- Problems with memory
- Restlessness and agitation
- Unsteady gait
- Sudden or frequent urge to urinate
- Depression or apathy





Symptoms and behaviour of Lewy Body Dementia

- Changes in thinking and reasoning
- Confusion and alertness that varies significantly from one time of day to another or from one day to the next
- Slowness and gait imbalance
- Well-formed visual hallucinations
- Delusions
- Trouble interpreting visual information
- Sleep disturbances
- Malfunctions of the "automatic" (autonomic) nervous system
- Memory loss that may be significant

Symptoms and behaviour of Frontotemporal dementia

- Increasingly inadequate social behavior
- Loss of empathy and inhibition
- Repetitive compulsive behavior, such as clapping or tapping the lips
- A decline in personal hygiene
- Difficulties in naming objects
- Not knowing the meaning of words anymore
- Make mistakes in sentence construction
- Muscle tremor, stiffness and spasms
- Muscle weakness
- Poor coordination
- Difficulty swallowing





Concerns about Dementia - Role of the family

Family caregivers play an important role in the early recognition of signs of dementia, as they come into contact with patients daily and know them well. However, the family often finds it difficult to make the decision to see a doctor; feel guilty for suggesting that something is not right or betray trust. In any case, after being able to take the patient from the family to the doctor, he is subjected to a series of tests that allow a timely and safe diagnosis.



Source: <https://www.pexels.com/photo/adult-affection-baby-child-302083/>

Concerns about Dementia - Implications of Dementia in Family Dynamics

The illness or physical limitation in a person causes changes in the lives of other family members, who have to make changes in the functions or role of each one within the family, such as: the daughter who takes care of the mother; the wife who besides all the tasks now takes care of the bedridden husband; the husband who has to assume the housework and care for the children, because the wife is disabled. All these changes can generate insecurity and disagreements, so it is important that the family, the caregiver and the health team talk and plan home care actions.



Source: <https://www.freepress.com/free-photo/13/senior-mother-daughter-supporting-each-other-4166761.html?page=1&query=parent%20and%20a%20old%20daughter&position=13&position=13&page=1&query=parent%20and%20a%20old%20daughter>

Concerns about Dementia - Implications of Dementia in Family Dynamics (continuation)

The best place for an elderly person with dementia will be one where effective and quality care is guaranteed. It will be within family that each person will receive the necessary care to feel good physically and emotionally. The advantage of staying at home is the person keep his references that has been acquired throughout his life, especially a person with dementia (his room, his bed, his paintings, his belongings, his history), which conveys security and greater tranquility.

When person with dementia moves to in with his child or another family member, this change can cause some adaptation problems due to the lack of references, which can worsen his mental and functional state. If this is the only possible solution, it is necessary to implement strategies to mitigate the impact of the change, trying to make the "new" environment more familiar.

What can be done for individuals with Dementia

In the **initial phase** of the disease, when there are symptoms such as, gradual memory loss, the elderly person is autonomous but has frequent forgetfulness, there is some disorientation and language is affected and there are changes in character (fears, mistrust), family caregivers may have in mind account the following topics.



Be understanding

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Helping you stay autonomous

Source: <https://www.pexels.com/pt-br/foto/comida-alimento-refeicao-pessoa-3171128/>



Motivate to perform memory exercises

Source: <https://www.pexels.com/pt-br/foto/homem-pessoa-relaxamento-descanso-3393375/>



Organize the house so that it is safe

Source: <https://www.pexels.com/pt-br/foto/abajur-acolhedor-aconchegante-aconchego-584399/>



Don't argue or contradict it; what you do is not meant to irritate you

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What can be done for individuals with Dementia (continuation)

In the **middle phase** of the disease, when symptoms such as loss of autonomy, difficulties in speech, inability to perform self-care, not to recognize family members and have strange and incorrect behaviors, family caregivers can take into account the following topics.



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Keep daily routines and avoid changes of any kind.



Source: <https://www.pexels.com/pt-br/foto/alimento-almoco-aperitivo-bacia-1211887/>

Increase security, monitor health and care for food



Source: <https://www.pexels.com/pt-br/foto/adultos-ao-ar-livre-arvores-aventura-1307391/>

Keep the daily walks and keep it integrated, as much as possible, in your family and social circle.



Source: <https://www.pexels.com/pt-br/foto/adulto-alegria-antigo-atraente-2050999/>

Try to learn to deal with problems in her/his behavior. Remember that these behaviors are due to the disease and not because he/she wants to.

What can be done for individuals with Dementia (continuation)

In the **final phase** of the disease, when the person with dementia is totally dependent, not recognize family members and have a loss of speech, family caregivers can take into account the following topics.



You must know how to feed it, clean it, move it in bed, etc.

Source: <https://www.pexels.com/pt-br/foto/acao-adulto-afecto-amor-339620/>



Caress him, smile at him and show your affection for him.

Source: <https://www.pexels.com/pt-br/foto/adultos-afecto-amor-alegria-1642883/>



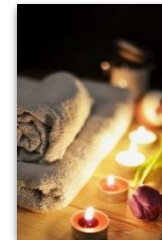
Accept the changes that occur.

Source: <https://www.pexels.com/pt-br/foto/pessoa-amor-mulher-face-3408198/>



Remember that what you are doing is very valuable to the patient family, do not feel guilty when something fails.

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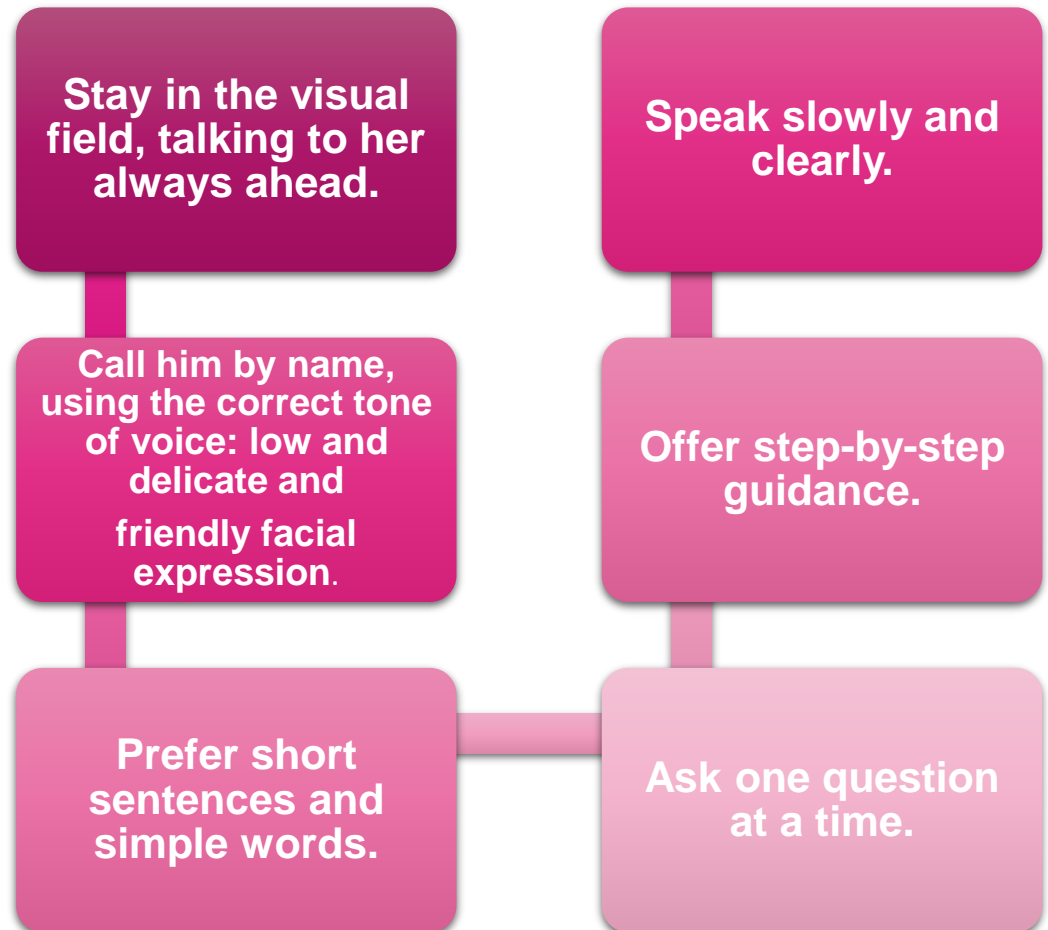
To take care of your relative, you must take care of yourself:
seek help; take a rest; have free time to do the activities you enjoy; keep your circle of friends

Source: <https://www.pexels.com/pt-br/foto/banheiro-bem-estar-descanso-facial-3188/>

What can be done with families

Losing communication skills can be one of the most frustrating and difficult problems for people with dementia, their families and caregivers. As the disease progresses, a person with dementia experience of gradually losing their ability to communicate becomes increasingly difficult to show clearly and understand what others are saying.

Tips for communicating with the person with dementia:



What can be done with families (continuation)

Tips for communicating with the person with dementia:

Repeat information and questions, offering simple information.

**Turn questions into answers.
For example: "the bathroom is on the right" instead of "do you want to go to the bathroom? ".**

**Never talk about the sick relative with someone, as if he were not present.
When verbal communication seems confusing and understanding is not good, try using written explanations to remind him. If you still don't succeed, it is best to postpone the conversation.**

If the dementia person is looking for something, instead of saying "is here", use "here is your newspaper" (or what he/she was looking for).

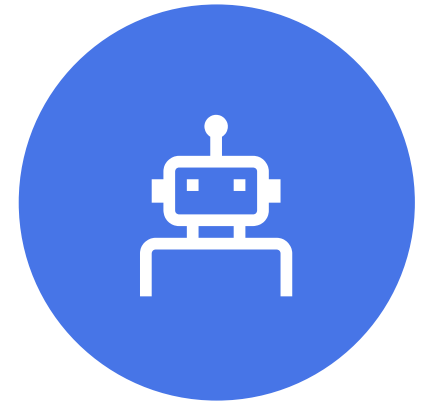
What can be done with families (continuation)



Although repetitive behaviors can be uncomfortable for the caregiving family, the behavior of walking without stopping by itself does not harm or put the person with dementia or her family at risk.



If the behavior is constant, family caregivers should organize walks outdoors, preferably in the afternoon, in places with little traffic.



Regarding repetitive questions, there is no reason to be angry or try to argue; just answer and understand that this is the maximum elaboration that elderly people with dementia can achieve.

What can be done with families (continuation)



Saying, for example, “I’ve answered more than twenty times” or yelling at elderly people with dementia will only increase his/her insecurity.



The family should let the elderly person with dementia ask and should try to answer the question clearly, accurately, slowly and articulate, and ask the elderly person to repeat what has been said.



If the repetitive question refers to the time (“what time is it?”), The family who cares should try to relate the answer to some activity (“it’s lunch time”, “dinner time”, “showering” etc). The activity can still serve as a mention of time, while the hourly value has probably lost its concrete meaning.

Do you want to learn more?

Our interactive Resource Pack will give you information about

- concerns that you as caregiver might have
- what can be done
- useful tips how to handle the burden of care
- how to avoid stress and burnout
- how to deal with your emotions
- acceptance of the disorder
- and more!

You will also find exercises and activities for YOU and for the care receiver!



**More information is available in
the Resource Pack:**

https://developfc.csicy.com/?page_id=11708