

InfoCARE | Supporting Informal Caregivers of People with Dementia

Module 1

Recognising the symptoms of dementia



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Module's Index

LET'S GET STARTED

Module's Overview

Learning Goals

LET'S DEEP-DIVE INTO CONTENTS

- What is dementia?
- How dementia affects brains
- Types of dementia
- How dementia is diagnosed?
- Why it's important to diagnose dementia
- Connection between dementia and alzheimer's disease
- Symptoms of dementia
- How to recognize symptoms of dementia
- Differences between normal aging and dementia
- Differences between dementia and cognitive impairment
- What to do next?

CHECK WHAT YOU LEARNED

- Lessons Learned
- Quizz time!

EXTEND YOUR KNOWLEDGE

- Glossary
- Where to find more information
- > Bibliography



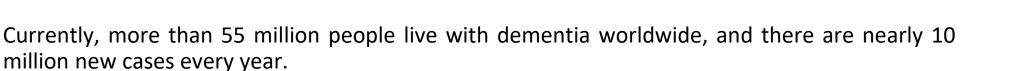
Let's get started...



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Module's Overview



People with dementia are able to lead active, fulfilling lives with support from informal caregivers – wives, husbands, partners, children or other family members, as well as friends. The key is understanding dementia symptoms and being able to timely recognize them.



Let's get started



Module's Overview

The early diagnosis of dementia contributes to improving the quality of life of the patient and their family, as it makes it possible to plan for the future and progressively adapt to the new situation and role of caring a loved-one, as well as look for suitable support, treatment and professional assistance.

This module will provide learners, specifically informal caregivers of people with dementia, with practical information, awareness and advice to understand and recognise the symptoms of dementia.

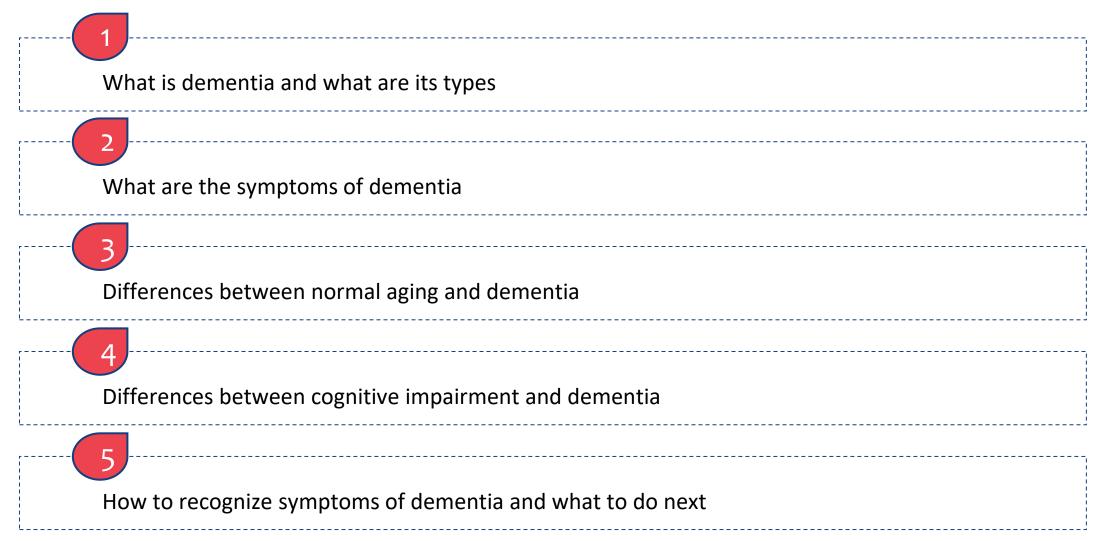






Learning Goals

By the end of this module, you will know:



Let's deep-dive into contents...



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Let's deep-dive into contents 8

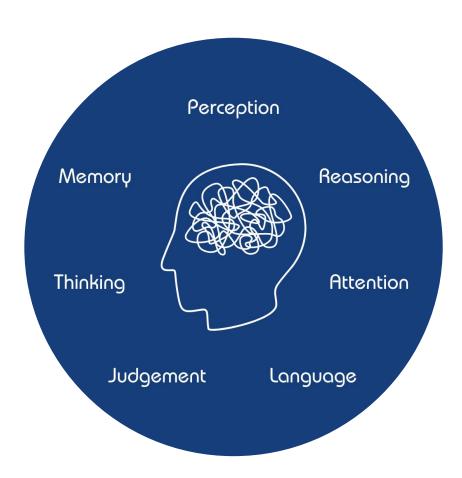
What is dementia?

Dementia is not a single disease. It's an overall term like heart disease — that covers **disorders affecting the** brain and having an impact on memory, thinking, behavior and emotion.

Dementia is another step in **aging**. Assuming that with the passage of time, increasing age and individual circumstances, people will present different alterations in their ability to function, and with this, we might have either normal aging, cognitive deterioration and even **dementia**. Dementia is a the most serious impairment of ability.

The aging progression would be as follows:

Normal Aging \rightarrow Cognitive Impairment \rightarrow Dementia







The effects of dementia are severe enough to negatively interfere with daily life and person's ability to function, who experiments a growing impairment of speech, learning and/or memory.

Dementia's evolution is usually **chronic**, **progressive** and **leads to a complete dependance** of the person affected, both physically and mentally. Its evolution can be divided into three common stages:

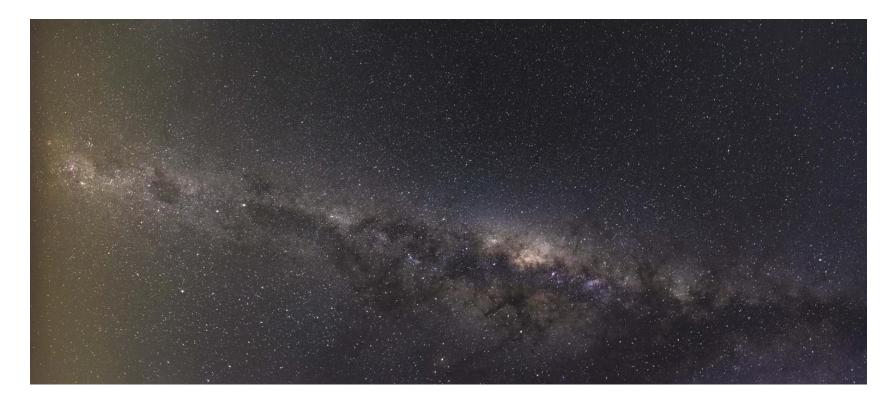
- **Early Stage:** it is often overlooked because it progresses very slowly.
- > > Middle Stage: symptoms become more pronounced and more restrictive as dementia progresses.
- > > Advanced Stage: memory disorders are serious and physical symptoms become more pronounced, the person progressively loses their mobility.





How dementia affects brains

A human brain contains over 86 billion nerve cells, which is almost as many as the stars in the Milky Way.



Dementia damages nerve cells so they are no longer able to communicate effectively and this impacts on our body functions.



The types of dementia can be classified based on several criteria: age of onset of the disorder, brain structures affected, etiology (origin), whether they are reversible or irreversible, etc.

The most used classification is according to its **etiology** (causes behind the dementia) and this is the one that we will present in this module.

According to its etiology, we distinguish between:

 \rightarrow **Primary Dementia** \rightarrow without known cause. Dementia is the main disorder and therefore it is not the result of any other disease or disorder.

 \rightarrow Secondary Dementia \rightarrow dementia appears as a consequence of a main disorder, physical disease or injury.







PRIMARY DEMENTIA

The most common types are:

>> Alzheimer's disease: it causes the brain to shrink and neurons to die. It is the most common type of dementia (around 60% of cases) and involves a progressive deterioration in memory, thinking, behavior and social skills.

>> Dementia with Lewy bodies (DLB): it causes alterations in thinking, movement, behavior and mood. Visual hallucinations are a common symptom and tend to happen from the beginning.

>> Frontotemporal dementia (FTD): It causes damage to the frontal and temporal lobes, areas of the brain that are associated with personality, behavior and language. Some people with frontotemporal dementia have dramatic changes in their personality and become socially inappropriate, impulsive, or emotionally detached, while others lose the ability to use language appropriately.

>> Mixed dementia: It happens when the disorder produced in the brain is associated with more than one types of dementia.



SECONDARY DEMENTIA

The most common is **vascular dementia**, also called multi-infarct dementia. In reality, it comprises a whole group of alterations as a result of diverse causes (hemorrhages, thrombus, infarcts, etc.) in the brain. It is necessary to highlight that some experts, depending on the country, consider vascular dementia a primary dementia.

There are also other types of secondary dementia, caused by various factors::

- >> medications
- >> toxics
- >> cranial trauma
- > > vascular and collagen alterations
- >> infectious origin
- > > associated to carcinomas
- >>> metabolic endocrine origin, etc.





How dementia is diagnosed?

The first step in diagnosing dementia is to perform a **thorough medical history review and physical examination** to identify any symptoms, as well as any vision, hearing, cardiovascular, thyroid, or other disorders.

Before dementia can be diagnosed, deficiencies in function and skills must be identified. Additionally, other treatable conditions characterized by similar symptoms must be ruled out.





How dementia is diagnosed?

Two key aspects about the diagnosis of dementia are:

> > A person has cognitive and behavioral symptoms that interfere with their ability to function in their activities, represent a decline from previous levels of functioning, and cannot be explained by delirium or a psychiatric disorder.

>> The condition is diagnosed by interviewing the patient and someone who knows them (family member or close friend). This type of interview is very important because someone close to the patient knows the individual's previous level of functioning and helps the physician determine whether cognitive impairment is present.





How dementia is diagnosed?

The following tests are recommended during the evaluation of a patient with suspected dementia:

>> Complete blood cell count

>>> Blood electrolyte levels (potassium, sodium and chloride)

Blood glucose (sugar), urea nitrogen and creatinine levels

- >> Vitamin B12 levels in the blood
- >> Liver function tests and thyroid function tests
- >> Depression screening







There is currently no cure for most types of dementia, but an early diagnosis brings many benefits:

> There are medicines and other treatments that can help with dementia symptoms, specially on early stages, as they usually are more effective. Additionally, the progression of some types of dementia can be slowed, or reversed, with treatment and changes in lifestyle.

>> If the person diagnosed still conserves their cognitive functions, they can make decisions on aspects related to their future care and medical assistance, finances, properties, ... which can be reflected in a living will.

> It allows more time to adapt to the new situation and deal with physical and emotional impact for both the patient and the informal caregiver, as well as to look for support.



Why it's important to diagnose dementia



Let´s deep-dive into contents 18

"An early diagnosis of dementia is so, so important. Once diagnosed, I knew what I was up against. As they say: know your enemy.

If I hadn't been diagnosed early and I hadn't been seen by consultants on a regular basis, I wouldn't be as well as I am today. I don't know what my future holds, but at least I'm prepared for it."

Norman McNamara, diagnosed with dementia at the age of 50

("Why Early Diagnosis Is Important - Dementia - SCIE")





Connection between dementia and Alzheimer's disease

As already specified, **Dementia** is an umbrella term for a range of disorders characterized by cognitive impairment.

Alzheimer's accounts for one of the most common types of dementia under this umbrella. There are many complex and interrelated factors in the development of Alzheimer's disease.

The causes of the disease and some of the risk and protective factors are still controversial. **Certain risk factors include age, genetic characteristics, and the presence of a type of protein, apolipoprotein, in the blood.** The incidence of the disease doubles every five years after the age of 65.





Connection between dementia and Alzheimer's disease

Individuals with first-degree relatives with Alzheimer's have an average of four times more probability to develop the disease. Also, women have a higher risk of Alzheimer's than men. Head trauma, depression and low education level are also considered risk factors. However, what exactly triggers the disease is still unknown.

In some cases, while the pathological findings and genes of the disease are present in the brain, the symptoms of the disease are not observed.





Connection between dementia and Alzheimer's disease

Traditionally, the certain diagnosis of dementia was made only after-death by examining brain tissue, nowadays the diagnosis can be made at a high rate (85-90%) with patient history, examination, neuropsychiatric tests, imaging methods and laboratory tests.

Currently, **no treatment can completely cure Alzheimer's disease** and totally regress its development. However, there are medical drugs that can slow the progression of the disease, alleviate the symptoms of the patient and improve their activities in daily life.





Symptoms of dementia

The early stage of dementia is often overlooked because the onset is gradual and symptoms cover many aspects of cognitive functions.

Generally speaking, its onset can be noticed by changes in emotional behaviors and personality, as well as in perception, memory, language, judgement and reasoning.

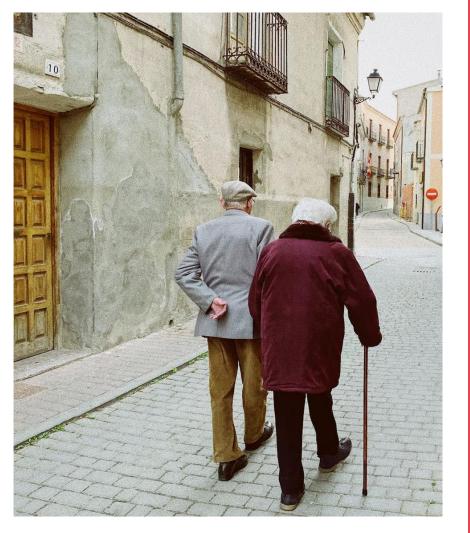
Common symptoms of early dementia are:

>> Forgetfulness: the difficulty to remember recent conversations, memories and the decrease on mental agility is noticeable.

>> Difficulty to do several tasks at the same time, make decisions or solve problems.

> > Losing track of the time.

> > Loss of orientation: becoming lost in familiar places.

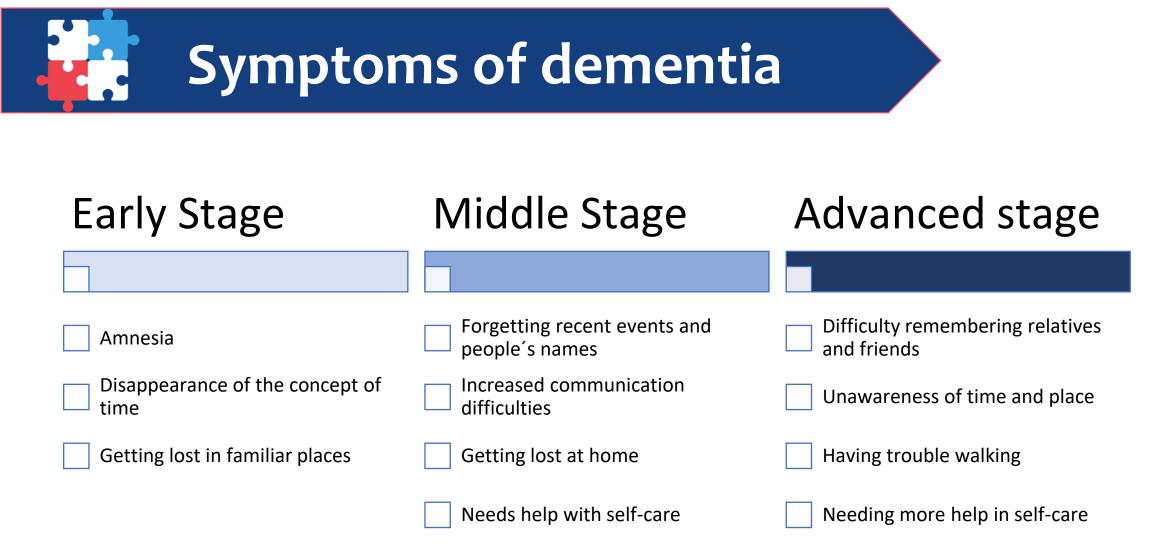




Symptoms of dementia

As **dementia progresses**, new symptoms will come up:

- >> More difficulty to do activities that require thinking and memorize.
- >> Loss of social skills and changes in personality, which might result on inappropriate behavior in public.
- Loss of judgement, so the patient is not able to consider the risk of their actions.
 - More difficulty with coordination and motor functions.
- Communication problems, linked to the inability to find the right words and remember names, objects, data, etc, as well as to the loss of orientation.
- >>> Changes in sleep patterns, which might lead to delirium and hallucinations.
- >>> Worsening of psychological wellbeing: anxiety, depression, agitation, confussion, etc.



Experiencing behavioral changes

Agressive behavior changes



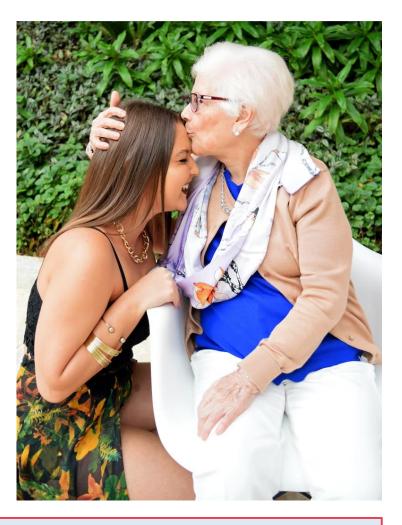
How to recognize symptoms of dementia

If your loved one seems more forgetful, try taking one of the at-home dementia tests.

SAGE test stands for Self-Administered Gerocognitive Examination, and while it is not exactly self-administered, it does not require a doctor.

> > A modified CDR Test only takes about 3 minutes and requires no personal information. A family member can answer 6 questions about the person's mental acuity and receive an immediate result.

Clock Drawing Test – the person being tested is usually asked to draw the numbers and hands so the clock shows a specific time (11:10). If the person finds this difficult or draws the clock wrong, it could be a sign of dementia.





Go to "Where to find more information" to find links to SAGE and other test samples





Normal aging includes a series of physical and mental changes in people, the main ones are:

>> Physical changes: decrease in collagen, the appearance of wrinkles and loss of skin firmness; loss and weakness of hair and nails; gradual decrease in elasticity and muscle power, etc.

- >> Deterioration of senses: sight, hearing and taste.
- >> Loss of immune capacity, increasing the probability to contract diseases.
- >> Increase in cholesterol levels and excess of glucose in the blood.

> > Aging of the cardiovascular system: Veins and arteries lose elasticity, making it difficult for blood to pass through and leading to the development of high blood pressure.

>> Degeneration of bone structures, inflammation and joint pain.

>> Loss or decrease in sexual desire.

Some other typical changes of normal aging are:

> > Memory loss: Aging causes lost in the volume of our brain neurons, so the flow of information tends to slow down, we lose attention and concentration. The assimilation of new information is also slower. It is important to note that normal aging does not influence in the loss of distant memories or regularly practiced skills.

Sleep disturbance: Sleep becomes more fragile, it is interrupted more frequently at night and we wake up earlier.

> > Mood disorders: Another symptom of normal aging nowadays is vital sadness, depressed mood or depression. These alterations in mood translate into a loss of interest in things.

A priori, it might seem that these changes would be associated with dementia, but this is not the case, since they are part of what we consider normal aging.

Let's see on the next slide how to differentiate certain typical symptoms of normal aging and dementia.



Though dementia mostly affects older adults, it is not a part of normal aging. It can be difficult to determine whether symptoms are due to normal aging or early-stage dementia. Here's how to differentiate:

NORMAL AGING	DEMENTIA
Occasional trouble recalling people or places	Not remembering the names of close friends or relatives
Forgetting appointments or events occasionally	Frequently forgetting appointments and events
Taking longer to process information	Trouble verbalizing thoughts, frequent pauses in conversations and substituting common words
Sometimes losing track of a conversation	Regularly repeating statements or questions
Occasionally forgetting where an item is	Constantly misplacing items
Occasional trouble recalling people or places	Not remembering the names of close friends or relatives





Mild Cognitive Impairment (MCI) is sometimes diagnosed in people who have minor problems with memory, speech, or decision-making. In simple words, it is worse than normal aging, but not as worse as dementia, since MCI is not severe enough to significantly impact daily living and, in some cases, it might be reversible.

Although MCI is not a form of dementia, patients with MCI have a higher risk of eventually suffering from it. Check some common differences between them:

MILD COGNITIVE IMPAIRMENT	DEMENTIA
Mild forgetfulness. Example: difficulty in recalling particular data (medical appointments, phone numbers, etc)	Loss of memory that worsens with the time. Example: difficulty in remembering recent events and people
No major changes in personality or behavior	Changes in personality and behavior occur: repetitive behavior, hiding, losing inhibitions, accusing, social withdrawal, etc.
Minor problems with speech. Example: some trouble finding the right words to say	Significant problems with speech. Example: serious difficulty to find the right words to say
Ability to care for themselves, even if they feel mildly anxious	Need reminding and some assistance with personal care, sometimes appearing no interested



The first step in following up on symptoms is **making an appointment with a doctor to get a professional diagnosis and a suitable treatment plan**. Additionally, much can be offered to support and improve the lives of people with dementia, for instance:

- >> optimizing physical health, cognition, activity and well-being
- >> identifying and treating accompanying physical illnesses
- >> understanding and managing behavior changes
- >> providing information and long-term support to carers.



Keep learning on how to support and provide assistance to dementia:

>> Module 2. Prevention for tips on how to prevent dementia, delaying its onset or slow its progression.

Module 3. Mind-stimulating Activities for Early-Stage for tips and activities to support and stimulate your relative with mild dementia.

Module 4. Mind-stimulating Activities for Advance-Stage for tips and activities to support and stimulate your relative with advanced dementia.

Check what you learned...



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Lessons Learned



In this module, we've learned that not all elderly people end up with dementia and not all dementia is the same. Also, we've figured out how to recognize the symptoms of dementia.



A good rule of thumb is don't delay your appointment with the doctor if you think or suspect something is wrong. Because it is for your safety and for your beloved ones.



Stalling means missing the chance to get the right support on time and keep dementia from progressing.





What is the connection between dementia and Alzheimer's disease?

- A. Alzheimer's disease is a form of dementia.
- B. Dementia is a form of Alzheimer's disease.
- C. Dementia is the same as Alzheimer's disease.

What are the symptoms of dementia?

- A. Occasional difficulty remembering people or places, occasional forgetting of appointments or events, occasional loss of thread of conversation.
- B. Unable to remember names of close friends or relatives, frequent forgetting of appointments or events, regularly repeating statements or questions.
- C. Persistent low mood or sadness, feeling hopeless and helpless, difficulty making decisions.

Mild cognitive impairment (MCI) is a form of dementia.

True

False



Answers at the end of the module!

Extend your knowledge...



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Dementia > > overall term that covers disorders affecting the brain.

Mild Cognitive Impairment (MCI) > > diagnosed in people who have minor problems with memory, speech, or decision-making. MCI is not a form of dementia.

Alzheimer's disease > > disorder that stops nerve cells from working properly and communicating with each other.

Vascular dementia > > result of problems with the blood supply to the brain.

Dementia with Lewy bodies > > similar to Alzheimer's. It reduces the levels of chemicals that carry messages around the brain.

Frontotemporal dementia > > caused by damage to areas of the brain known as the frontal and temporal lobes.

Apolipoprotein > > protein that transports lipids in blood. Apolipoprotein E is implicated in the Alzheimer's.

Living will > > legal document that includes a person's wishes regarding care and medical decisions to be made in case they become seriously ill and/or uncapable of making decisions by themselves. It can also include the selection of a chosen agent or decision-maker.



Where to find more information

Alzheimer's Disease International (ADI)

is the international federation of Alzheimer associations around the world and maintains official relations with the World Health Organization. Each member is the Alzheimer association in their country who support people with dementia and their families.

Link: www.alz.co.uk

Alzheimer Europe

is the European association dedicated to providing information on all forms of dementia and raising awareness of dementia. Link: <u>http://www.alzheimer-europe.org/</u>

>>> Helpguide

provides expert, ad-free, user-friendly educational materials and resources to help people improve their emotional well-being and make more informed health decisions. Link: https://www.helpguide.org/home-pages/alzheimers-disease-dementia.htm

>> WebMD

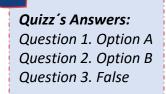
provides health information, tools for managing health, and support to those who seek information. Link: <u>http://www.webmd.com/alzheimers/default.htm</u>

Dementia Tests

You can find SAGE and other test samples in different languages from the links below: <u>https://wexnermedical.osu.edu/brain-spine-neuro/memory-disorders/sage/download-the-sage-test</u> <u>https://www.dementiacarecentral.com/alzheimers-online-test/</u> <u>https://www.aeldresagen.dk/viden-og-raadgivning/helbred/demens/demenstest</u>







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InfoCARE | Supporting Informal **Caregivers of People with Dementia**



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InfoCARE Consortium









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