This document represents the written script of the STUDICODE online dementia course (Intellectual Output „Online Dementia Course“.

The interactive materials can be downloaded on the project website under the section „results“ (https://www.studicode.med.tum.de/en/results).

The next two pages display an example on how the course materials can look like when implemented on Moodle.

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The European Commission support for the production of this publication does not constitute an endorsement of the contents which reflects the views only of the authors, and the Commission cannot be held responsible for any use which may be made of the information contained therein.

Treatment

You already know that...

...most dementias are due to irreversible and usually progressive diseases of the brain.
Only very few causes of dementia can be amended or removed. Therefore, the overall goal of treatment is to maintain an optimal quality of life for persons with dementia and their carers. During the course of dementia the needs of people change, as well as their capacities.

At the early stage, maintenance of function and continuation of the individual lifestyle are paramount. At the moderate stage, management of behavioural symptoms and adaptation of the living environment become increasingly important.
At the more advanced stage, preservation of psychological and physical wellbeing is the key objective. Counselling and support of family carers is essential throughout the course of dementia.

Components of dementia treatment

To take advantage and coordinate all available treatment options according to individual needs, preferences and resources, including pharmacological and non-pharmacological interventions, modification of the environment, as well as appropriate services and facilities, an individual care plan should be set up which serves as a guide for professionals and carers.

Immediately after the diagnosis has been disclosed to the person the management of dementia should start. Ideally, an individual care plan is set up which considers the person's specific needs, preferences and resources and involves a multidisciplinary team of professionals as well as the family. The care plan can be based on international guidelines as for example on those of the European Federation of Neurological Sciences (opens new tab) . A regular monitoring of the course of dementia and the effects of treatment interventions should be performed.

Pharmacological interventions

The major groups of medications for persons with dementia include antidementia drugs, antidepressants and antipsychotics. The currently available antidementia drugs address chemical changes in the brain that are due to the disease underlying dementia (the cholinesterase inhibitors donepezil, galantamine and rivastigmine; and the glutamate blocker memantine). The slow down the progression of symptoms but do not cure dementia. Novel antidementia drugs are currently being developed which remove abnormal protein accumulations in the brain. Their clinical benefits have yet to be demonstrated. Antidepressants and antipsychotics are used to treat severe behavioural problems. Since these drugs have significant side effects they must be used with caution.

Non-pharmacological interventions

Non-pharmacological interventions should be employed as complement to medications with the aim of improving the quality of life of persons with dementia and their carers. Importantly, they are recommended as the first-line treatment for behavioural problems. The most important forms of non-pharmacological treatments are cognitive stimulation, occupational therapy and physical exercise. These treatments have no side effects and can be delivered by professionals or trained allied workforce.

Let's explore some of the most common non-pharmacological interventions. Please click on the "+" buttons to get information about specific interventions.

Environmental modification and assistive technology

Appropriate modifications of the living environment can enable persons with dementia to live in their own home for a longer time and to reduce hazards. Such modifications include grab bars, handrails, lighting, signs, raised toilet, removal of clutter and loose carpets. The most frequently used forms of assistive technology are memory aids and reminders (e.g. computer apps, Amazon Alexa), sensors and alarms (e.g. fire, gas, water, falls) and GPS-based person locators.

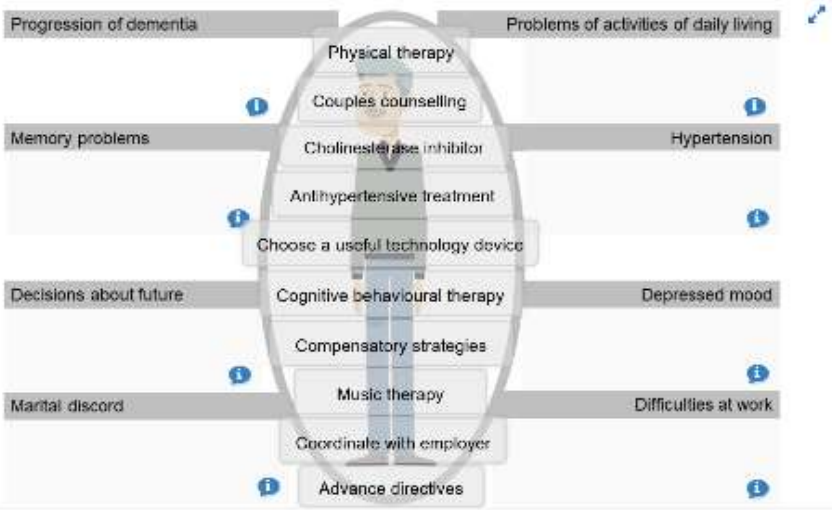
Can you bring together a set of appropriate interventions for Toni?

You now have gained insights into the different forms of pharmacological and non-pharmacological interventions available to persons living with dementia.

Try your skills and drag the correct interventions to Toni's issues. But first, please review his case file:

Case file Mr Toni Kovač, 63 years old

- Social status: Lives in private home with his wife Marija, two sons; working in leading position at industrial company
- Previous health problems: Arterial hypertension, well managed
- Major complaints: Memory issues; executive and visuospatial problems; word finding difficulty; impaired complex activities of daily living
- Diagnosis: Dementia due to Alzheimer's disease with early onset and comorbid depression



Check

Key points

- Key components of treatment – medication alone does not do the trick
- Contribution of non-pharmacological interventions – there are many opportunities to help; interventions should be chosen according to persons' needs, abilities and resources
- Importance of collaboration – working together in an interprofessional team makes the management of dementia easier, more effective and rewarding
- Carer support – cares are not alone

List of course chapters

Welcome to this 90-minute online course on dementia

Format: Self-paced, complementing the lecture on dementia
Duration: 90 minutes
Objective: To enhance your skills in dementia diagnosis and treatment
Certificate: Downloadable certificate of participation will be provided at the end of the course after passing a 14-questions quiz (success criterion is 75% correct answers; *the percentages to pass may differ from country to country*)
If you have any issues accessing the material, please don't hesitate to reach out for support *(insert here your email address/ Live Q&A session during the semester)*

This course was developed by the EU project "STUDICODE – Stepping up digital competence in dementia education" and has received co-funding by the European Union.

How to start with this course?

Before starting with the first chapter of this online course, please review the following tips for making the most out of online learning. If you are new to using Moodle, you can find some instructions for navigating this course below.

Four tried and tested tips to make the most out of this online course

1. Identify your learning style

In order to make studying a pleasant experience, identifying your learning style can direct you to tools which help you to retain new information easily. Overall, four basic learning styles have been observed: auditory, kinaesthetic, read & write, visual.

- Auditory learners benefit from learning by hearing. Their tools may include:
  Verbal repetition, mnemonic techniques, reciting verbally, discussions (e.g. at this course's live Q&A session)

- Kinaesthetic learners benefit from learning during physical activities. Their tools may include:
  Repetition techniques during movement, tactile representations of the learning content

- Read & write learners benefit from learning by reading and writing. Their tools may include:
  Note taking, making their own flashcards, re-writing notes for repetition

- Visual learners benefit from learning by sight. Their tools may include:
  Mind-maps, sketch notes

2. Create your learning schedule

Once you understand how you learn most efficiently, it is time to setup a schedule to ensure that you allocate enough time for completing the course. This course takes about 90 minutes and is structured into 7 chapters. Thus, you may break-down the course into chunks of 15 minutes. Techniques to manage your time when studying online include:

- Prioritising tasks
- Taking breaks
- Setting reminders and alarms
- Time blocking

3. Create your workspace

Your learning environment can contribute to a great online learning experience. Tools to set-up your workspace include:

- Turning off social media
- Using headphones
- Creating a folder for storing your notes and this course's pdf summaries

4. Set goals and eliminate distractions

Remembering the benefits of taking this course and the resulting advantages for your future work can contribute to motivating yourself to finish the online course. Techniques for holding yourself accountable may include:

- Checking-in with your learning schedule
- Joining actively (e.g. in the Q&A session of this course)
- Rewarding yourself (e.g. this course will provide a downloadable certificate of participation if you complete the quiz at the end successfully)

In order to further improve this course and make the learning contents easy to study, we kindly ask you to please participate in the course evaluation at the end of this course.

Navigating this online course

This course is structured into 7 chapters. Each chapter is displayed on one course page. You can move to the next chapter at the end of a page. In order to obtain a downloadable certificate of participation, you must successfully complete the multiple-choice quiz at the end (75% correct)

In this course, you will find different kinds of media formats:

– Videos: In order to start a video, please click on the "play" button at the lower part of the video. You can pause the video by clicking on the button "pause".

– Hotspots: In certain illustrations, you can find further information about a specific topic by clicking on the button "+" inside the illustration.

– Flashcards: You can turn a flashcard by clicking on the button "turn" and move to the next card by clicking on the small arrow on the right side.

– Drag-and-drop games: In drag-and-drop games, your objective is to drag the items to the correct places on the screen. Click on "check" to see your result.

– Scenarios: In scenarios, you can move to the next part of the scene by clicking on the button at the top right. Sometimes, you can find additional information by clicking on the small arrow button on the lower right.

Please note that your scores in the drag-and-drop games as well as in the scenarios are only for entertainment purposes. Your certificate of participation will only be based on your result in the multiple choice questions at the end.

The Cast

Hello, I am Ana. I have received the diagnosis of dementia a few days ago. It was a shock. All my plans and hopes are suddenly gone. I am so afraid of the future.

Good day, my name is Toni Kovać. It was at work that I first noticed something is wrong with me. The doctor has suggested that things might get worse. However, I will fight it as long as I can.

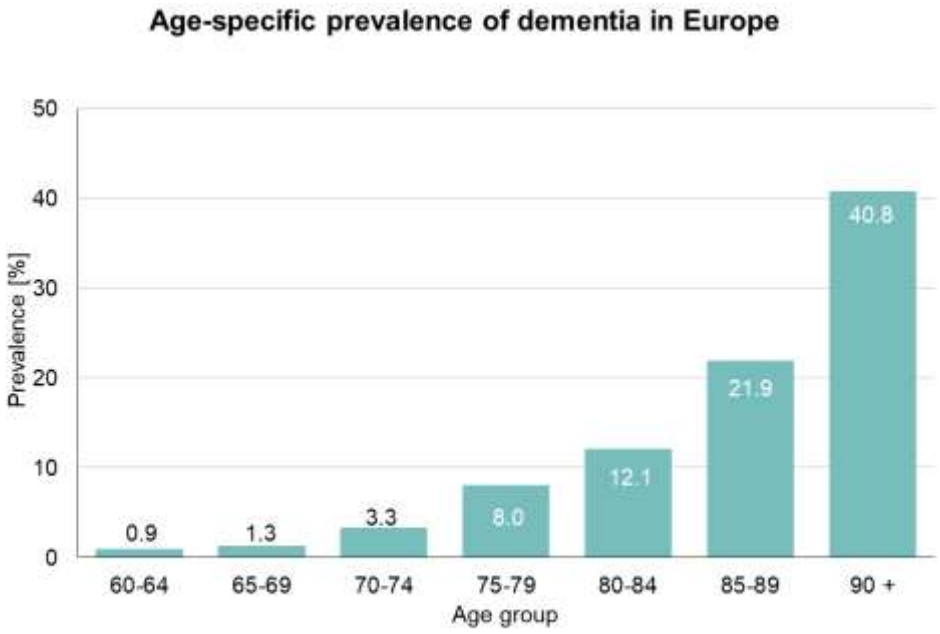
Hi, I am Marija, Toni's wife. I came with him when the doctor disclosed the diagnosis. My husband's problems are changing his life as well as mine.

Hi, I am Doctor Lucy. Thank you for supporting me in the office for a few days. I trust you will manage the cases that come in. However, if you run into difficulty I will always be there to help you out.

Societal impact of dementia

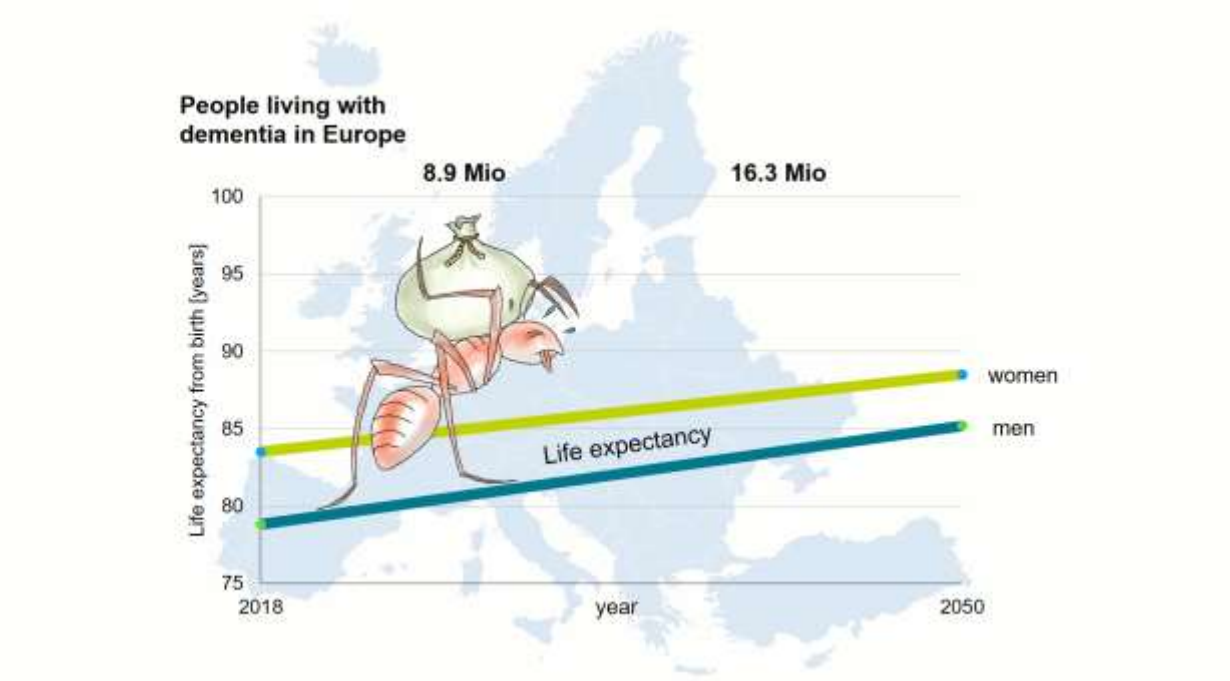
You know that…

…dementia is not a disease but a syndrome that is usually caused by chronic and progressive diseases of the brain. The specific pattern of symptoms depends on the nature and localisation of the underlying disease. However, it universally involves cognitive decline, impairment of activities of daily living and alterations of behaviour. These changes significantly lower the person's quality of life and puts a huge burden on their carers. Although age is not a cause, dementia becomes significantly more frequent with advancing age (see infochart below). The illustration below shows that the prevalence of dementia almost doubles every five years.

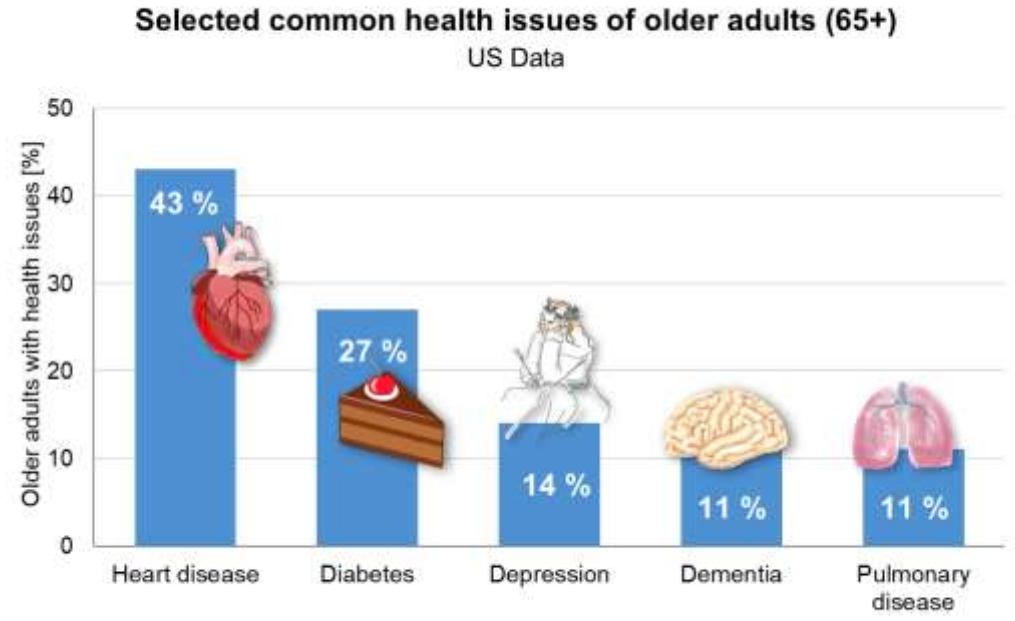


Alzheimer Europe: Dementia in Europe Yearbook 2019

As life expectancy is continuously rising, which means that more and more people reach a higher age, dementia has become a top health and social issue in many countries worldwide. For example, in Europe, about 9 million persons are currently living with dementia. This number is predicted to increase to 16 million by 2050.



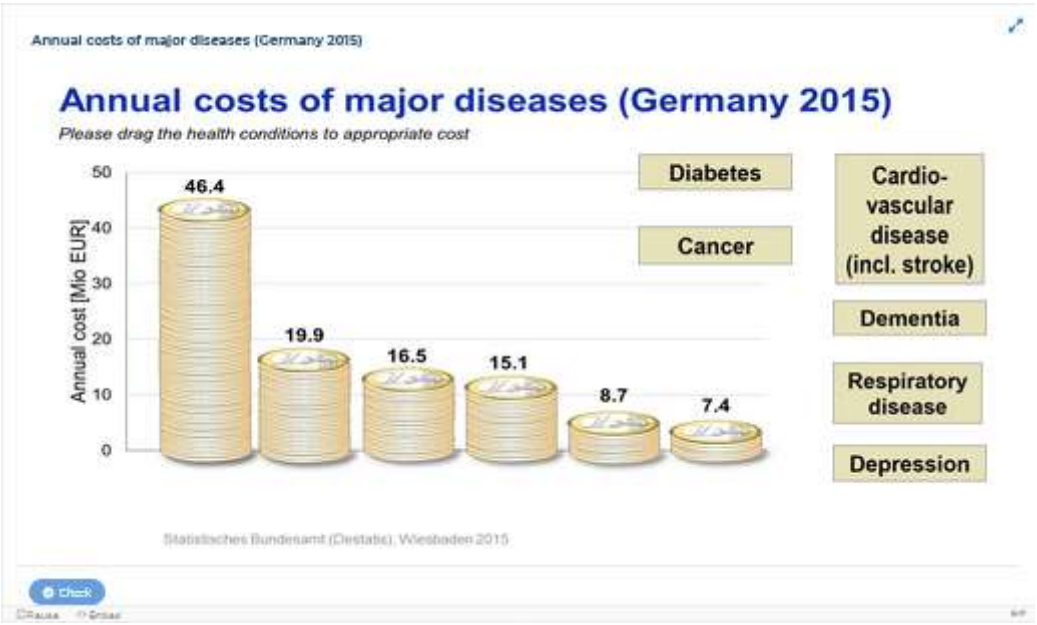
This is why dementia ranks among the most frequent health issues and one of the major causes of disability and dependence of older adults. The illustration below shows the percentage of people aged 65 years or older who have a specific health problem.



Figures taken from National Council on Aging, Arlington, VA, 2021

Dementia is also a very costly health problem, even if one only looks at the *direct* costs, i.e. the expenditures for medical treatment which are estimated to account for only two thirds of total cost. Do you wish to know more about the financial impact of dementia? Then please

draw the health issues to the appropriate level of cost (a hint: dementia is one of the middle columns).



However, about 80 % of people living with dementia are cared for by unpaid family members, usually by spouses or children. Considering the estimated costs for their efforts as well as the loss of income the total societal costs of dementia are much higher.

Although dementia is so prevalent and has enormous health, social and economic implications it still is a stigmatised disorder. Persons with dementia are often viewed as abnormal, deviant, unpredictable or even dangerous. These negative labels overshadow the person's personality, history, abilities, and possible quality of life. Moreover, they are frequently associated with the denial of basic rights and freedoms available to others. On an individual level, stigma is a major concern of persons living with dementia and their carers, a barrier to seeking help, timely diagnosis, treatment, activity and participation. On a societal level, stigma impedes initiatives to support persons with dementia and carers and lowers the priority of dementia in research funding.

Key points

- Dementia is a huge societal challenge in terms of prevalence, individual and family burden, as well as cost
- The number of persons living with dementia in Europe will increase from 9 million in 2018 to 16 million in 2050
- Dementia is among the most frequent health issues in older adults
- Without prevention or cure in view this will strain health and social systems to their limits
- Including indirect costs through caregiver efforts and loss of caregiver income dementia is one of the costliest health conditions
- Dementia is associated with stigma which intervenes with help seeking, timely diagnosis and treatment, development of services and appropriate priority in funding research

Impact of Dementia

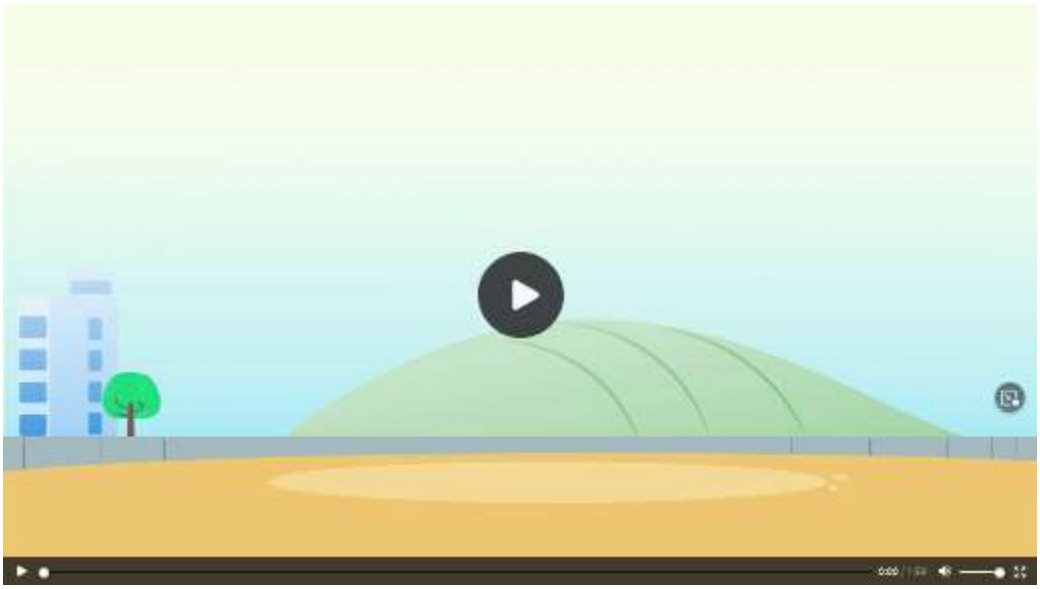
You know that…

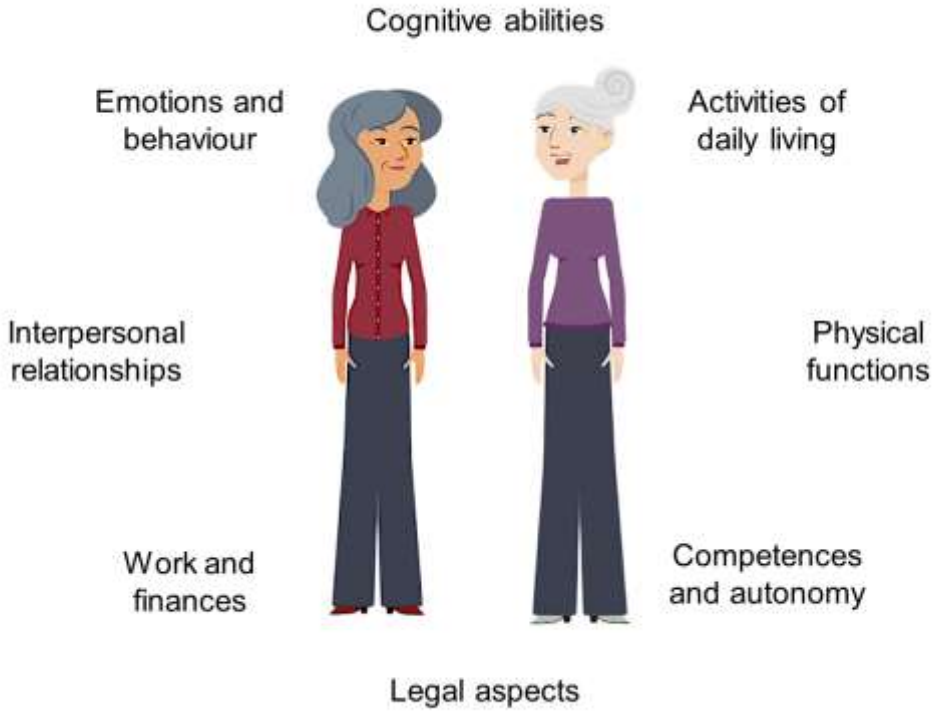
diseases can cause dementia if they damage widespread regions of the brain or areas of key strategic importance. Therefore, not only single functions of the brain are compromised (e.g. memory or language) but multiple. Moreover, most of the diseases underlying dementia are irreversible and progressive. As a consequence, dementia has a huge impact on all aspects of life, including cognitive abilities, activities of daily living, emotions and behaviour, interpersonal relationships and physical functions. Since dementia makes the person gradually dependent on others, but at the same time disrupts communication and challenges social ties, it also imposes a heavy burden on family members.

Impact on the person with dementia

When dementia breaks into life it has a profound impact on the individual and their social network. Professionals can provide a more comprehensive and person-centred care if they understand what people with dementia and their families go through.

Watch the video below to explore how dementia impacts on the lives of Ana and Marija:





Cognitive abilities

Impairment of cognitive abilities is a key feature of dementia. It refers to episodic memory (remembering recent events), attention and concentration, language (verbal expression and comprehension; reading and writing), executive functions (organising, planning, solving problems), social cognition (appreciating others' emotions, reading facial expressions and gestures), as well as object identification and use.

Activities of daily living

Decline of activities of daily living initially involves complex („instrumental") tasks such as performing at work, organising the household, planning a holiday, or dealing with financial issues. Later, simpler („basic") tasks become compromised, including travelling alone, preparing meals, taking medications, choosing proper clothing, maintaining personal hygiene. Finally, people with dementia need assistance with bathing, feeding, grooming, and finding their way even in familiar surroundings.

Emotions and behaviour

Dementia, particularly in the early stage, is associated with very unpleasant emotions such as embarrassment, insecurity, depression, and reduced self-esteem. Often, it elicits psychological defence mechanisms such as denial, minimisation of problems or excuses. The most frequent behavioural changes („behavioural and psychological symptoms of dementia – BPSD") include apathy, agitation, irritability, depression and anxiety. Delusions (unrealistic beliefs) and hallucination (seeing or hearing things that are not there) are rare.
Self-esteem and personalidentity: There are at least three major sources of self-esteem and identity: the recall for personal experiences including past roles and achievements, the

interaction of the person with other individuals, and the person's current habitual preferences and activities. Throughout the course of dementia, these sources of personhood become weakened.

Interpersonal relationships

The roles of a person within partnership, family and the wider social network are likely to change. Dementia may lead to marital tension and discord, reversal of roles among family members, friction and conflict as well as withdrawal of friends, colleagues and neighbours. Children living in the family may need to take on caring tasks.

Physical functions

Dementia does not only cause problems in cognition, behaviour, and mood, it also affects the body. Physical symptoms may include gait disorder, slowness of movements, falls, difficulty swallowing, sleep disorder, weight loss and incontinence.

Competences and autonomy

As a result of cognitive decline many – but not all – competences of a person will deteriorate. Examples are the ability to make decisions, provide consent to treatment, drive are car, make a will, manage finances or organise the household. Such capacities are fundamental for personal identity and self-esteem.

Work and finances

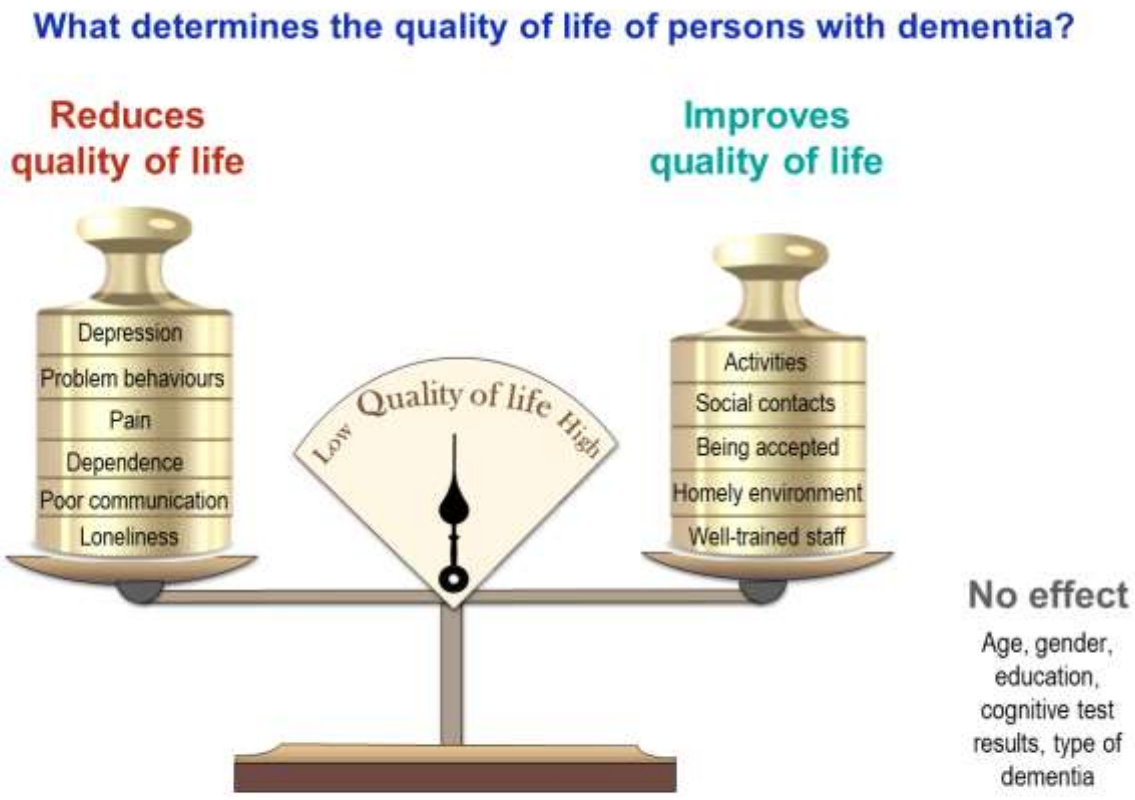
Dementia makes it difficult if not impossible to deal with the tasks of working life. However, with appropriate support a person with dementia may be able to continue working e.g. by offering reducing hours or by assigning less difficult tasks. More often than not, dementia leads to loss of employment and income.

Legal aspects

The capacity to make decisions about finances, medical interventions, or living situation will deteriorate as dementia progresses. People with mild and moderate dementia are generally able to make decisions, and absence of decision-making capacity should only be assumed at the severe stage of dementia. Supported decision-making is preferable to surrogate decision-making.
Older persons with dementia are particularly vulnerable to the risk of abuse and neglect. Abuse can take psychological, physical and financial forms. Healthcare professionals have a significant role to play in detecting abuse and neglect.

Quality of life

It is evident from the above that dementia has an enormous impact on all aspects of a person. However, this does not mean that people with dementia no longer have a quality of life. For the quality of life of persons with dementia, not the type or severity of symptoms is primarily important but their consequences for activity, participation, personal goals and social relationships – in other words the disability that follows from them. The infographic below illustrates the aspects of quality of life:



Data taken from: Poulos et al. Alzheimer's & Dementia: Translational Research & Clinical Interventions 3: 450-458, 2017
Martyr et al. Psychol Med 48: 2130-2139, 2018; Holopainen et al. Dementia 18: 1507-1537, 2019

Unlike most symptoms, many factors of disability are amenable to modification, e.g. the type and level of activity, the quality of relationships, the style of living environment, the degree of dignity and respect received and appropriate communication. Therefore, many professions can contribute to improving the quality of life of people with dementia and their carers across the course of the usually progressive disorder.

But how can this look like in real life? Watch the video below to learn how Tomaž Gržinič who has been recently diagnosed with dementia continues to live an active life:

Impact on carers

When a family member develops dementia, the people around them will also experience profound changes in their lives. They need to deal with unpleasant emotions including embarrassment, anger and feelings of loss, abandonment and being trapped. The tasks and responsibilities of caring are usually associated with huge burden and psychological distress. Dementia carers are at increased risk for psychosomatic (such as fatigue, insomnia, muscle pain, high blood pressure, indigestion, headache or migraine) and physical health problems.

The shift of roles, expectations and responsibilities, as well as new and unfamiliar tasks may lead to friction within the family and conflict with previous or concurrent duties. If still employed, caregivers may need to reduce working hours or quit work entirely, which commonly leads to economic constraints. Their social network is likely to shrink. On the other hand, the caregiving role can lead to personal and spiritual growth, improvement of the relationship and a sense of accomplishment.

The strongest contributors to carer burden are the behavioural changes in the person with dementia. However, carer burden is not determined by disease-related factors alone. Sufficient knowledge about dementia, appropriate caring skills and coping styles and the amount of support received are also important.

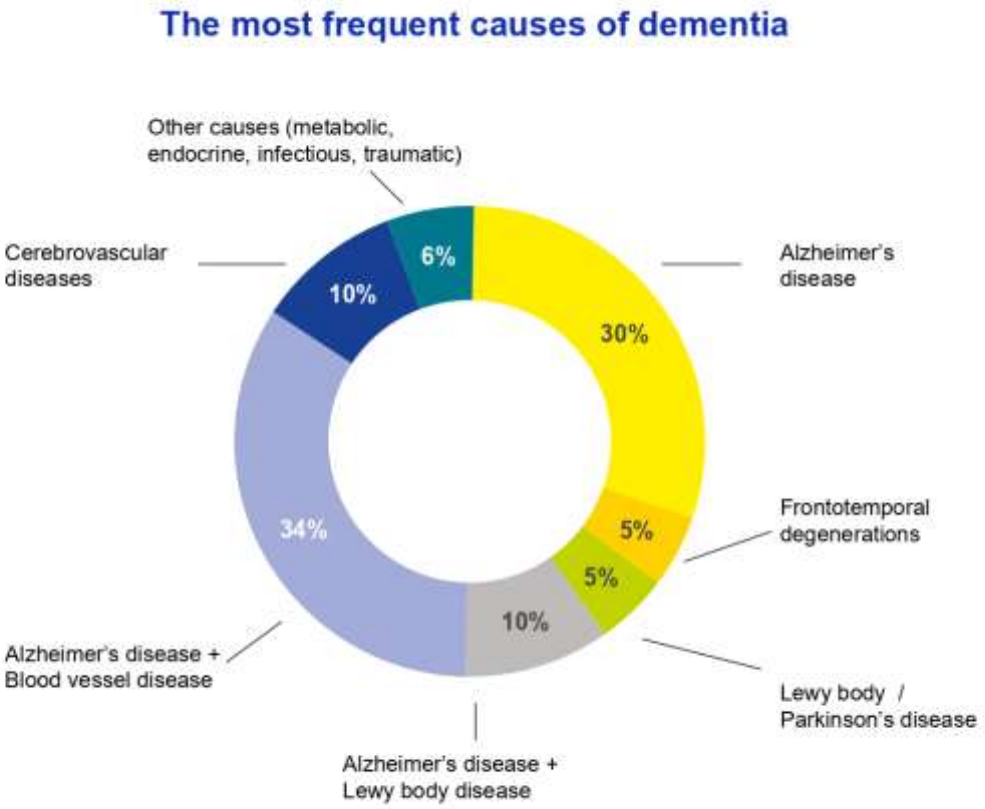
Key points

- Dementia affects the entire person and therefore, dementia cannot be managed by a medical treatment alone
- Many factors determine quality of life and much can be done to improve quality of life
- Several factors affect carer burden, and this burden is not solely determined by symptoms of the person with dementia

Causes

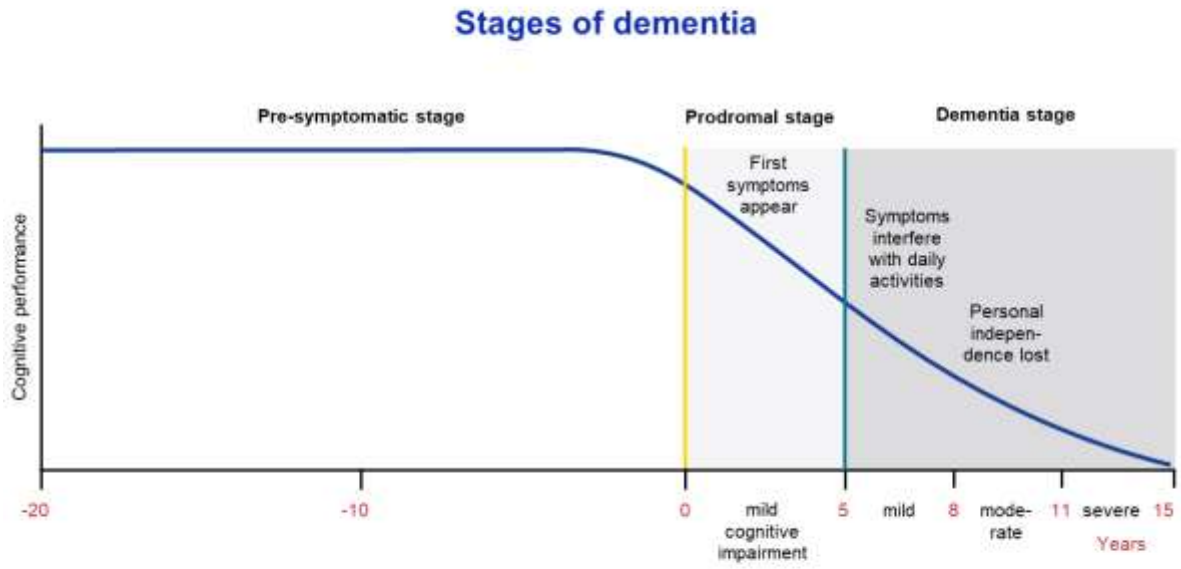
You know that…

dementia is usually due to diseases which damage widespread regions of the brain or areas of *key strategic importance. The former include neurodegenerations as well as metabolic, endocrine and infectious disorders. The latter comprise cerebrovascular diseases and head trauma (see chart below).*



Since the major brain functions are organised in neuronal networks which involve specific parts of the brain, the symptoms of dementia do not depend on the nature of the underlying disease but rather on its localisation. Therefore, dementia due to diseases in the temporal lobe (e.g. Alzheimer's disease) looks quite different from dementia due to diseases in the frontal lobe (e.g. frontotemporal degeneration) or dementia due to diseases in the occipital lobe (e.g. Lewy body disease).

With few exceptions, the underlying brain disease begins years or even decades before symptoms become apparent (see infographic below). The reason for this is the considerable resilience of the brain against slowly progressive disorders. Therefore, a clinically silent (asymptomatic) stage can usually be distinguished from a prodromal stage (mild cognitive impairment) where symptoms gradually develop, and from the stage of dementia (where cognitive impairment is severe enough to interfere with activities of daily living). The degree of personal autonomy is the yardstick for subdividing the severity of dementia into mild (independent living is still possible), moderate (independent living gets lost) and severe dementia (complete dependence on others, continuous supervision required).

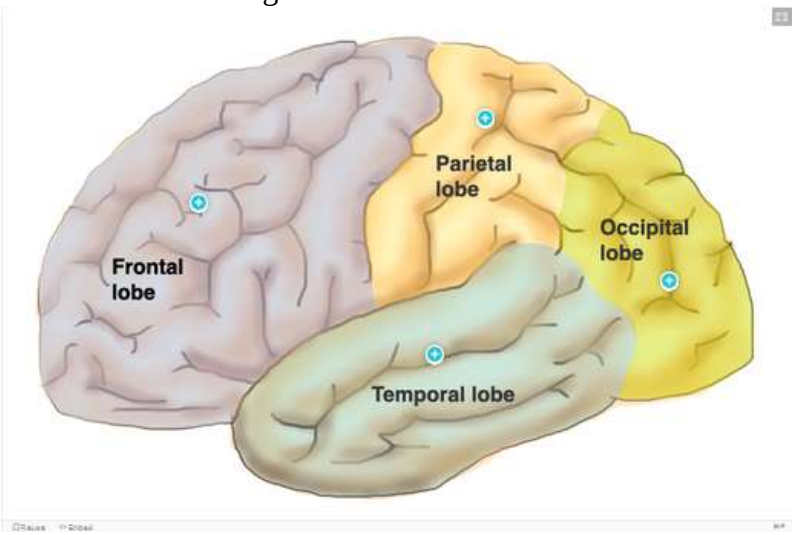


Categories of causes

Major causes of dementia include functional impairment or loss of nerve cells in widespread areas of the brain (due to neurodegenerative diseases) or in strategically particularly important regions (due to cerebrovascular diseases) and damage to nerve cell connections (due to metabolic diseases or, again, cerebrovascular diseases). Depending on the regions of the brain that are primarily affected, dementia can look different. Very few causes of dementia such as vitamin or hormone deficiency, trauma, tumours, drugs, or cerebrospinal fluid circulation disorder are potentially reversible.

Localisation determines symptoms

Major functions of the brain are associated with specific parts of the brain. Explore the functions of brain regions in the illustration below:



Therefore, the symptoms of dementia depend on the localization of the underlying brain disease.

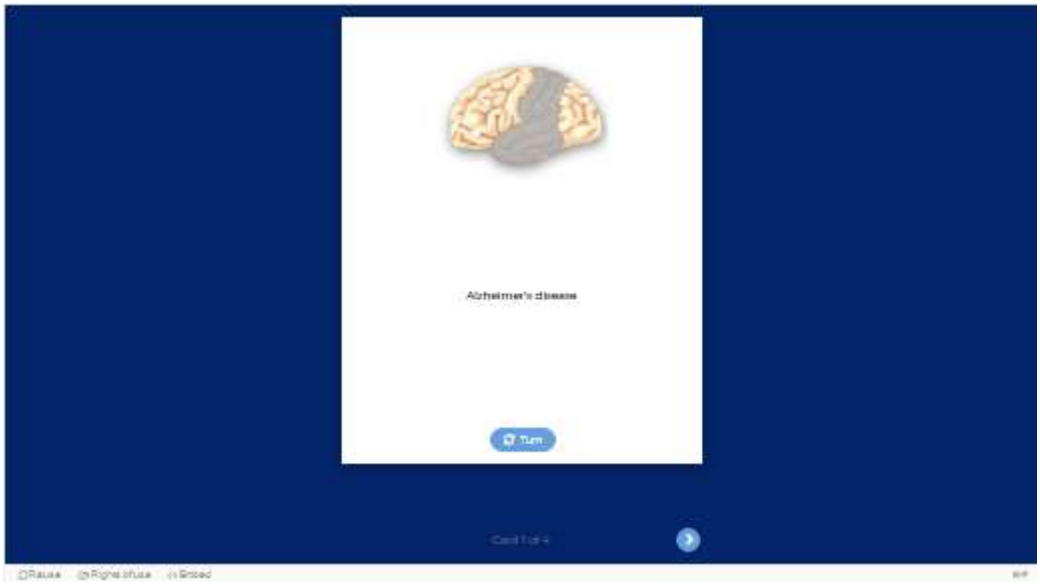
Neurodegenerative diseases

The most frequent causes of dementia are neurodegenerative diseases where nerve cells become dysfunctional and are gradually lost. Among the neurodegenerative diseases, Alzheimer's disease is the most common, followed by frontotemporal degenerations, and Lewy body diseases (which include Parkinson's disease). In the neurodegenerative diseases, errors in the processing of nerve cell proteins lead to the accumulation and deposition of the modified proteins within and outside of nerve cells, which has a negative impact on nerve cell functioning and viability.

Cerebrovascular diseases

The second most frequent cause of dementia are diseases affecting the blood vessels in the brain (cerebrovascular diseases), which supply nerve cells with blood, oxygen and nutrients. Small vessels deep in the brain are particularly affected. Deposition of materials in blood vessel walls or blood clots (thrombi) obstructing the lumen reduce or abolish the energy supply of nerve cells and nerve cell connections. Alzheimer's disease and small vessel changes often coexist, particularly in older people.

Explore the brain changes and key symptoms of major forms of dementia below:



Potentially reversible causes

Only few causes of dementia are potentially reversible. These include drug effects, vitamin or hormone deficiencies, brain tumours, and circulation disorders of the cerebrospinal fluid (normal pressure hydrocephalus). Earlier treatment is usually associated with better outcomes. However, full remission of symptoms may not be achieved. Although rare, the potentially reversible causes of dementia need to be identified and treated.

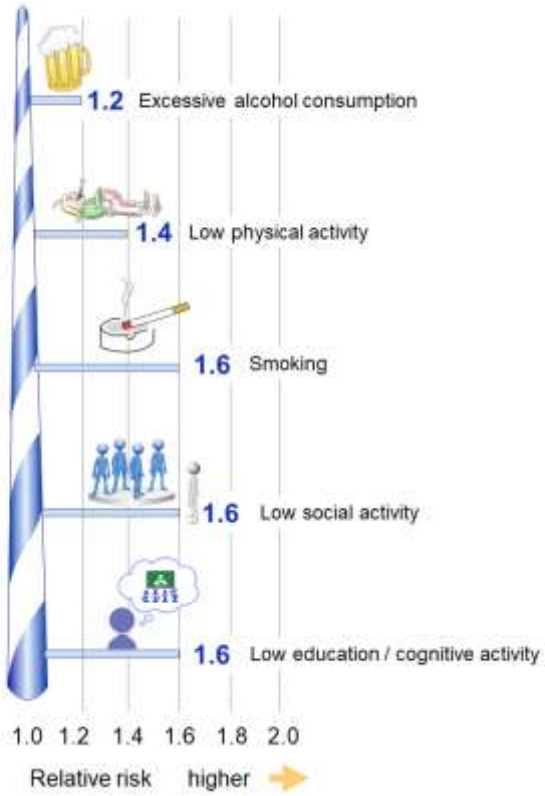
Risk reduction

Some risk factors for dementia are not modifiable. These include age and genetic predisposition. Several other risk factors are modifiable. These can be divided into medical and lifestyle-related factors. In the order of associated relative risk (the risk of people who carry the factor in relation to those who don't), the most important medical risk factors are depression, hearing loss, head trauma, arterial hypertension, obesity, diabetes and air pollution:

Medical risk factors

The lifestyle factors with the largest effects are low education and low cognitive activity, low social and physical activity, smoking and excessive alcohol consumption:

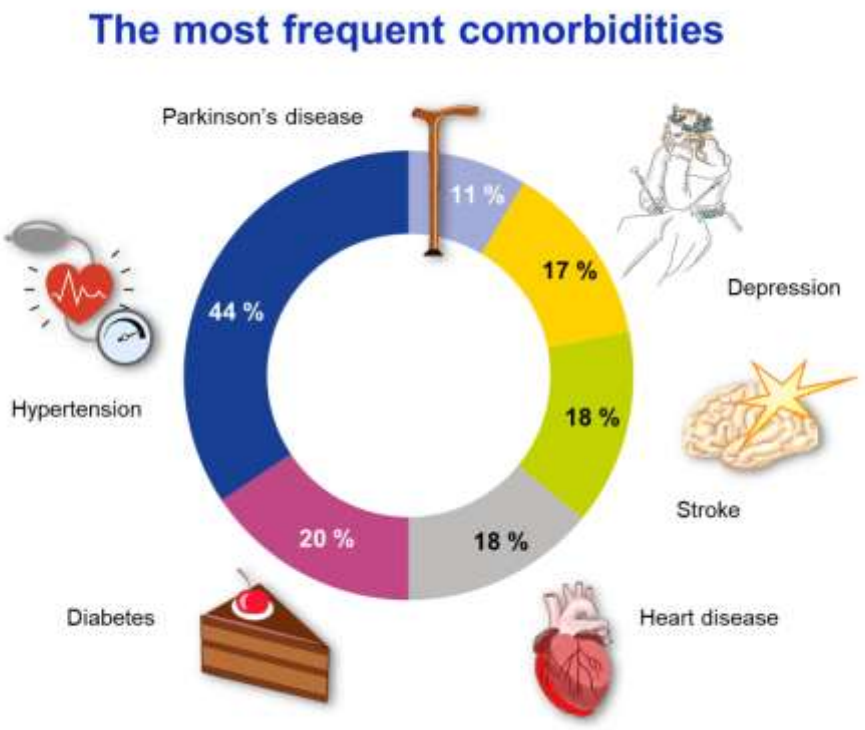
Lifestyle factors



Theoretically, modification or removal of risk factors could eliminate part of dementia. However, the evidence for preventive effects is currently limited. Nevertheless, treatment of medical risk factors and adoption of a healthy lifestyle are advisable as shown in the video below:

Comorbidities

Since most people with dementia are older, they often have other health conditions in addition to dementia. The presence of comorbidities may reduce cognitive abilities, decrease activities of daily living, worsen behavioural changes and accelerate the progression of symptoms. Therefore, they need to be adequately addressed to maintain an optimal quality of life. On the other hand, the management of comorbid conditions can be complicated by dementia and should be carried out with special diligence. The most frequent comorbidities in persons with dementia are hypertension, diabetes, heart disease, stroke, depression and Parkinson's disease – please keep in mind that persons living with dementia are more likely to have multiple health conditions:



Episodes of severe depression may be associated with temporary impairment of cognitive abilities which rarely reaches the threshold of dementia. In the past, this condition has been termed "pseudodementia" because it was reversible unlike "true" dementia.

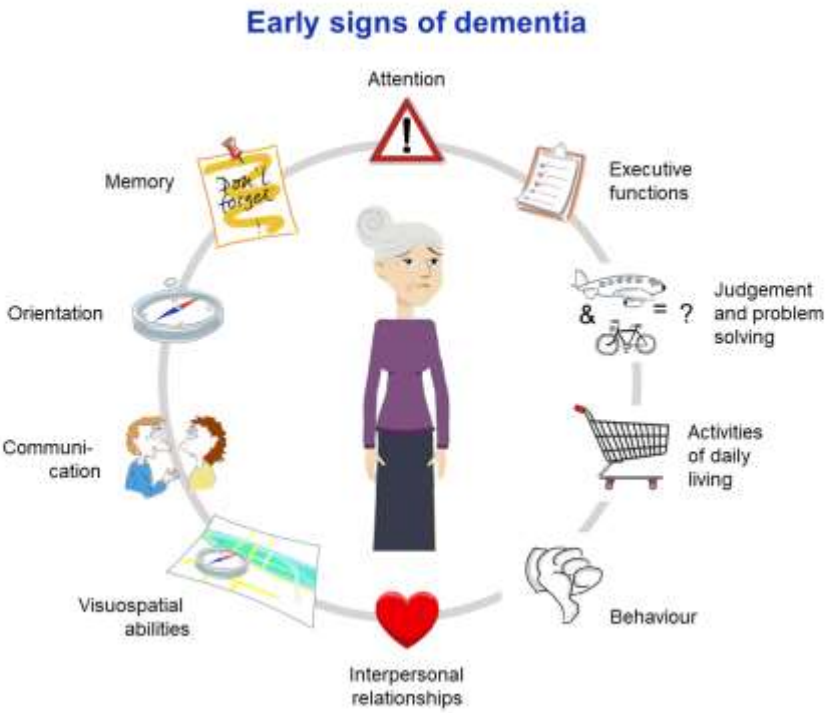
Key points

- The many causes of dementia show a clear clustering
- Diseases affect specific parts of the brain which is important for the problems they cause – but also for detecting and distinguishing them
- Pathology proceeds symptoms and therefore, we only see the tip of the iceberg – when it comes to risk reduction we need to start early
- For risk reduction, treat medical risk factors and recommend a healthy lifestyle

Diagnosis

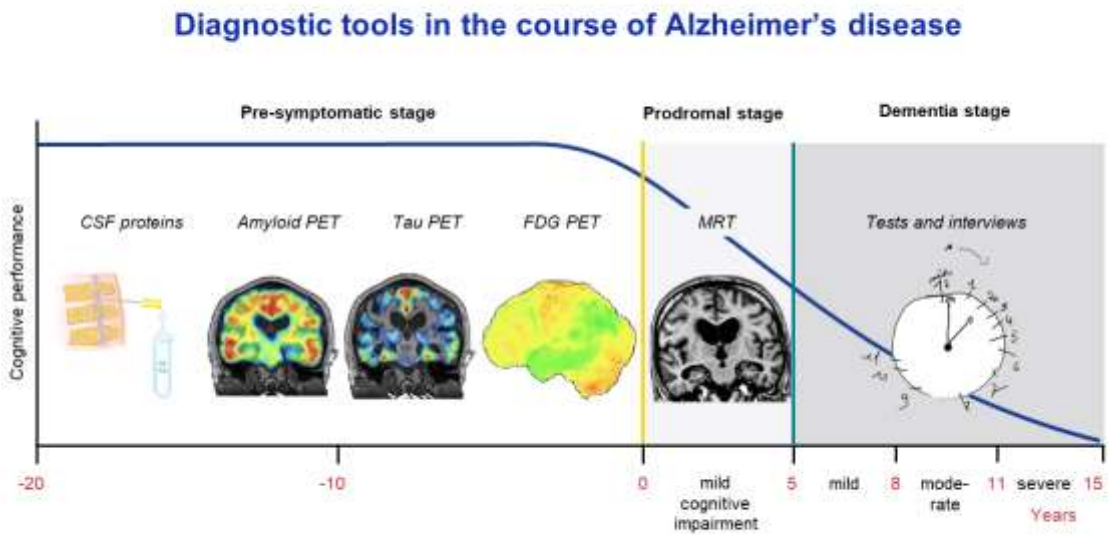
You know that…

the diagnosis of dementia is a stepwise process. Usually, this process does not start in the doctor's office or in the hospital, but in everyday life when someone notices a change in a person's performance or behaviour. This can be the person itself, a family member, a friend, or a colleague at work. You may use the infographic below as a brief reminder of the early signs of dementia.



The suspected changes then need to be verified by a physician or a psychologist using tests and interviews. If the changes are confirmed, the cause(s) and contributing factors (comorbid conditions) must be identified. The tools used at this step include physical examination, laboratory work-up, brain imaging (for brain structure magnetic resonance imaging, MRI; for brain metabolism positron emission tomography, PET), in selected cases biomarkers (protein concentrations in the cerebrospinal fluid), and rarely genetic testing. Due to the progress that has been made in brain imaging and biomarkers the underlying disease (particularly Alzheimer's disease) can be identified before the typical symptoms have

developed. This scientific advance raises ethical concerns. An overview of the diagnostic tools in the course of Alzheimer's disease is provided below as a brief reminder:



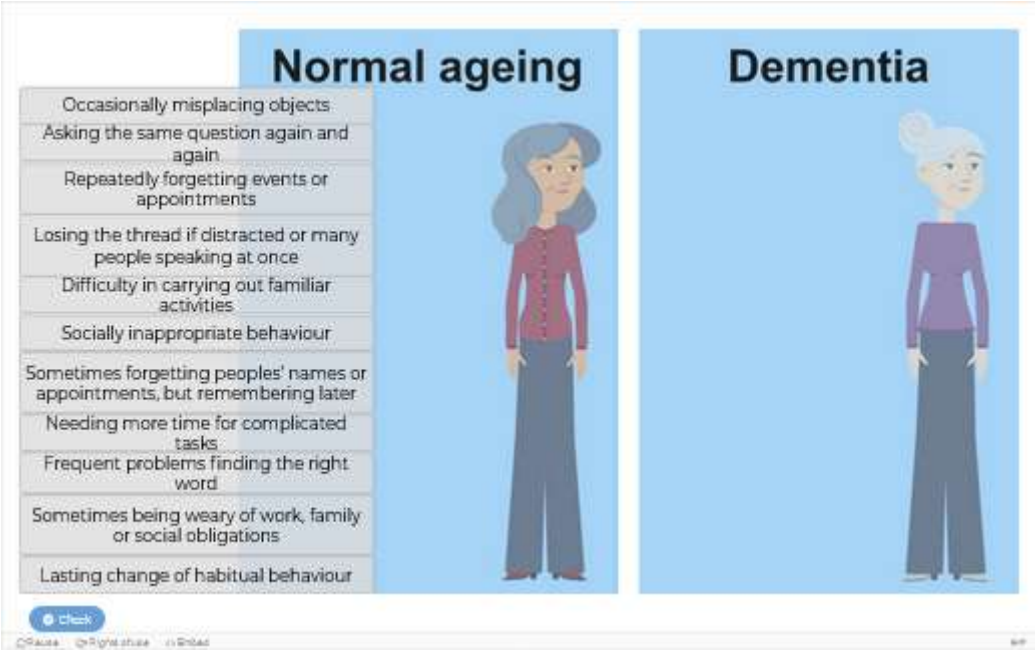
The illustration above shows at which stage of the disease diagnostic instruments become positive.

The final step of the diagnosis is to find out points of intervention as the basis of a care plan (e.g. individual needs, comorbid conditions, special risks, unfavourable environmental features or interpersonal issues).

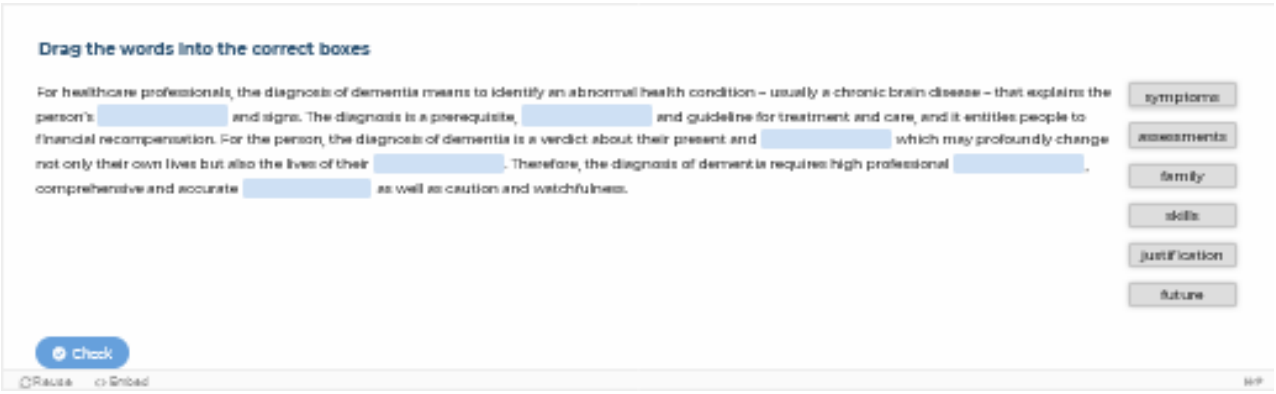
Normal ageing versus dementia

Very often, dementia is not diagnosed at an early stage. A major reason for this that the public and even professionals consider the early signs and symptoms as part of normal ageing. To change this, a clear concept of the differences between normal ageing and dementia is required.

Test your knowledge about the differences here:



What does the diagnosis of dementia mean?



Why is the diagnosis important?

An early and correct diagnosis of dementia is important for several reasons. The diagnosis provides an explanation for signs and observations that may have been worrying or distressing a person or their family. It is often coming as a relief to learn that changes in cognition, daily activities, behaviour or personality are symptoms of a disease.
Some causes of dementia are partly or completely reversible if identified early and treated adequately (e.g. vitamin or hormone deficits, normal pressure hydrocephalus, bleedings within the head). A number of other medical conditions that worsen dementia or accelerate its course (e.g. depression, elevated blood pressure, diabetes, abnormalities of lipid metabolism, heart diseases) can be effectively treated.

Most importantly, the diagnosis is a prerequisite and guidance for all treatment and care interventions, and for establishing an individual care plan. Therefore, the diagnosis needs to be comprehensive and must go beyond the assessment of symptoms by including individual needs, preferences, risks, resources and available support. Timely diagnosis provides time for people with dementia and their families to prepare for the future and plan ahead.

Another role of the diagnosis is to enable access to social and financial benefits (e. g. from health or social insurance, disabled person's pass) and to counselling and support. Even if support is not currently needed, it is important to know what kind of help is available.

Who makes the diagnosis?

Usually, general physicians (GPs) are the first point of contact for people with suspected dementia. Using brief tests and questionnaires they can perform an initial assessment of cognitive abilities, activities of daily living and behaviour. GPs are also in a good position to identify or rule out physical causes or contributing factors of dementia. Specialists (neurologists, psychiatrists, psychologists, geriatricians) apply more sophisticated diagnostic instruments and technologies (neuropsychiatric tests, CSF analyses, brain imaging) to detect prodromal and early stages of dementia and distinguish between causes of dementia. Specialists are also important to review the diagnosis upon follow up.

Since dementia impacts on all aspects of life, other professional groups can contribute to the diagnosis by providing valuable information, e. g. nurses, social workers, occupational therapists and physical therapists.

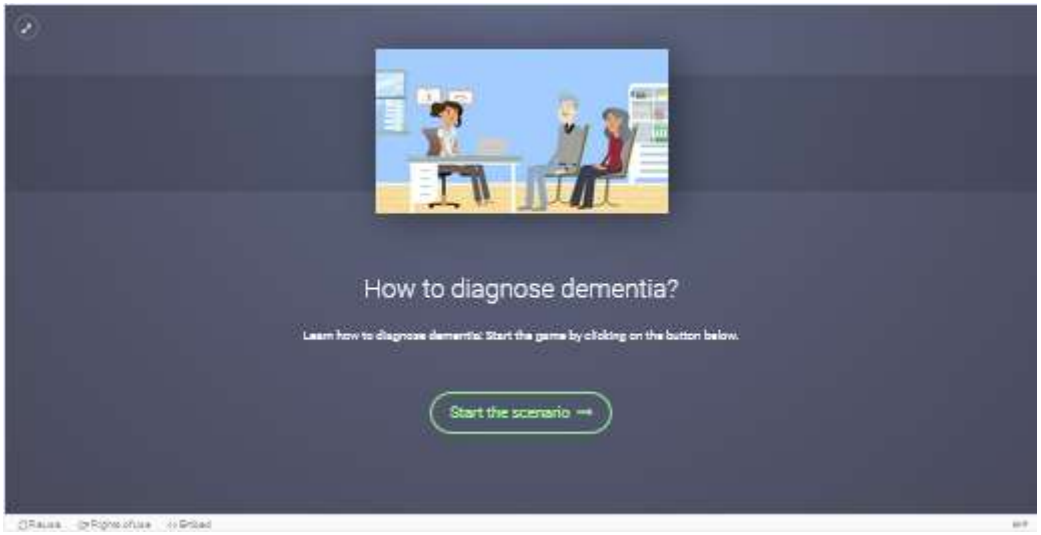
Detection of dementia in the physician's office

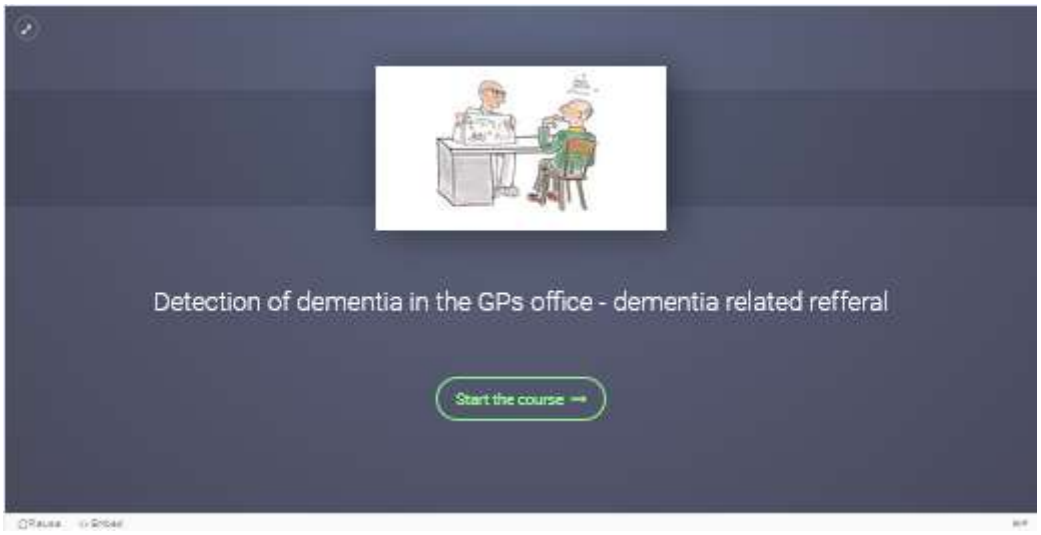
GPs and their staff are in a unique position for detecting dementia, as they often have known the people who come to their office for a long time, and are likely to notice subtle changes in cognition, functional abilities or behaviour. At the GP level, brief tools for the detection of cognitive decline may be used, complemented by interviews with carers. Assessments need to take into account the individual's age, family history, educational level, socio-economic status, comorbidities, medication list and the range of habitual daily activities.

Detection of dementia in the general hospital

About 20 % of older adults who are admitted to a general hospital have dementia. Only half of them had been diagnosed with dementia prior to admission. Usually, people are not admitted because of dementia, but because of another (physical) health issue. Systematic screening for dementia is rarely performed in general hospitals. The suspicion of dementia only arises when people exhibit behaviours that do not fit the structures and processes of a hospital. For example, people may not find their way in the unfamiliar environment, misinterpret situations, have difficulty expressing their needs, refuse treatment, exhibit night-time restlessness, or develop delirium. Delirium (acute confusional state) must be distinguished from dementia because it is usually caused by an acute physical condition which requires immediate treatment. Delirium shows some similarity with dementia (impairment of attention, memory, and orientation; changes of sleep pattern and behaviour) but is differentiated by rapid onset, fluctuating course and clouding of consciousness.

And now it is your turn! Please try diagnosing in the games below:


How to diagnose dementia?
Learn how to diagnose dementia! Start the game by clicking on the button below.
Start the scenario


Detection of dementia in the GPs office - dementia related refferal
Start the course


Detection of dementia in the GPs office - non-dementia referral
Start the course

Key points

• Dementia is a life-changing event – the diagnosis changes the present and future of an individual and their family; it changes the way of life, shifts roles, annihilates hopes and alters timelines
• Importance of early and correct diagnosis – diagnosis can be a relief, it has important positive aspects because it makes individuals able to act and get support
• Differences between normal ageing and dementia – to distinguish the two you don't need to know many details but simple criteria
• Be aware of the signs of incipient dementia in daily life
• Detection of dementia in the GP's office – minor abnormalities to watch out for
• Detection of dementia in the hospital – there is a mismatch between a persons' abilities and demands on the environment

Communication

You know that…

communication connects a person to other people and to the world around them. Communication channels are not limited to language, but also include signs, symbols, gestures, sounds and facial expressions. Therefore, appropriate communication is a key aspect to living well with dementia both for persons with dementia and for carers. A particular communication challenge for physicians is the disclosure of the diagnosis.

Impairment of communication in dementia

Dementia restrains communication by affecting verbal comprehension and expression, making reading and writing difficult, and interfering with interpreting visual cues.

The interpersonal role of communication

At the same time, persons with dementia become increasingly dependent on signals that provide meaning, orientation, guidance, support, affirmation and affection. Therefore, communication has an important relationship role. Here are some basic facts about the interpersonal aspect of communication:

1) It is not possible to not communicate: For example, by not talking to a patient or a carer, you send out a signal of disinterest or rejection.

2) The relationship aspect of communication frames the content: How you say something is often more important than what you say.

3) Body language and pitch of voice are important: The message you give out with your facial expression, posture and gestures accounts for 55 % of communication. The tone and pitch your voice accounts for another 38 %.

The interpersonal role of communication is particularly important for persons living with dementia, because their role in the family and the wider network is changing, their personal identity is weakened and their self-esteem is challenged.

Communication rules

At the beginning of this chapter, you have learned that appropriate communication is particularly important for persons living with dementia. Explore some simple communication rules below:

1. Make sure the person sees and hears you well:
-> no noise, bright lighting, glasses and hearing aids if appropriate

2. Pay respect to the person:
-> use their academic title if appropriate, allow questions

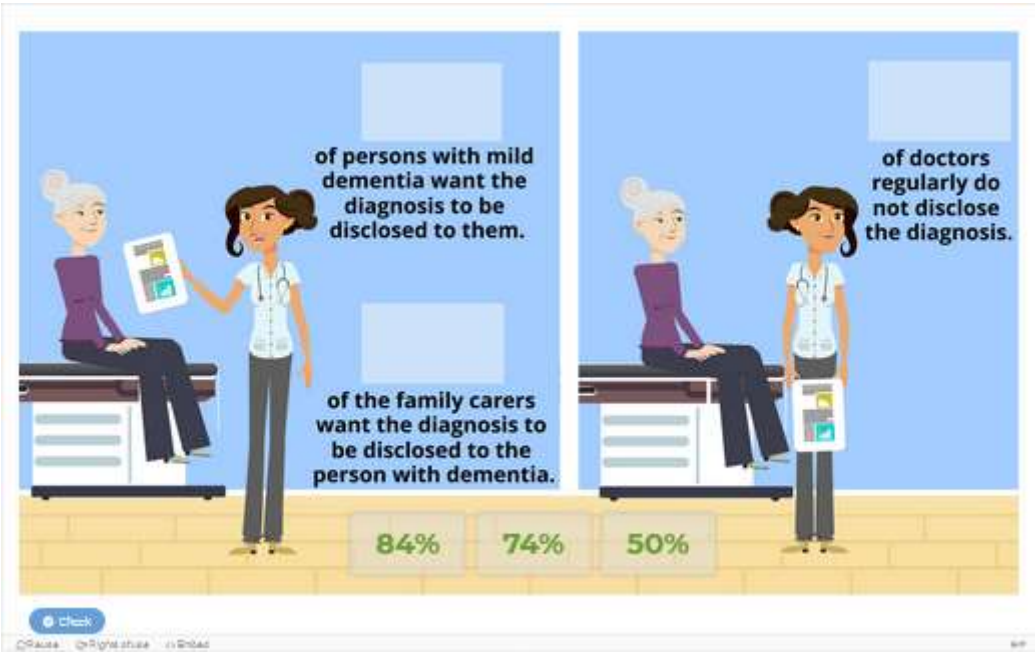
3. Speak slowly and clearly:
-> provide one piece of information at a time, pause between sentences, use short sentences, repeat important parts of your message, summarise what you have said

4. Support your words by facial expressions and gestures:
-> be friendly and approachable, do not exaggerate

5. Express compassion and understanding:
-> be aware that you always convey emotions, showing no emotions may be a negative message

Disclosure

How do persons with dementia, their families and doctors think about disclosure? Can you drag the percentages below to the correct statement?



Disclosing the diagnosis of dementia is not only an informational act, but also a delicate psychological intervention that requires an appropriate setting. Four components of disclosure may be distinguished:

1) Providing information
Tell the person the diagnosis as precisely as possible; provide information that is needed and can be absorbed at a time; use a language style that the person understands and take into account the persons' previous knowledge, misperceptions or fears.

2) Dealing with emotions
The diagnosis of dementia is a life-changing event that is likely to elicit emotional turmoil;

meet feelings of grief and despair with compassion and empathy; deal with disbelief and doubt.

3) Giving hope
Explain all options of treatment and support; outline their contribution to maintaining an optimal quality of life; describe the therapeutic team if appropriate; provide a realistic outlook on the course highlighting the huge variability.

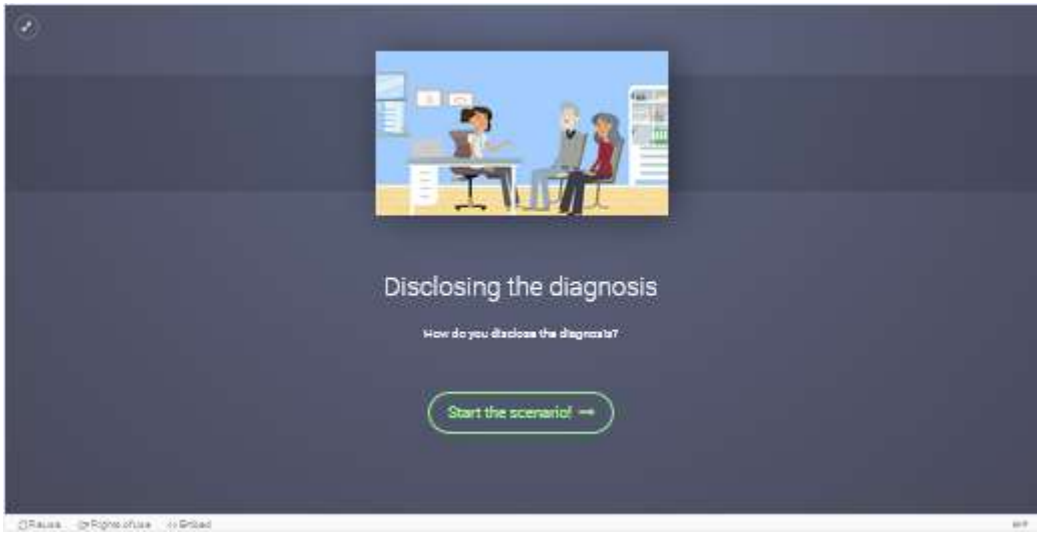
4) Establishing a therapeutic relationship
Express your commitment, approachability and role in the therapeutic team.

To provide these components of disclose, the conversation requires careful preparation, sufficient time and proactive planning:

- decide on your key messages
- consider your words for closing the meeting
- take notes of the persons' questions and remarks as well as open issues
- have your calendar ready for scheduling a follow-up meeting
- make sure you have appropriate information material ready (e.g. flyers of the local Alzheimer's [link to German/Romanian/Slovenian/Slovakian Alzheimer's Association]

Would you like to try disclosing the diagnosis in a game? Start the scenario here:

[Or use this one if your institution is not using the SPIKES-D protocol]



Key points

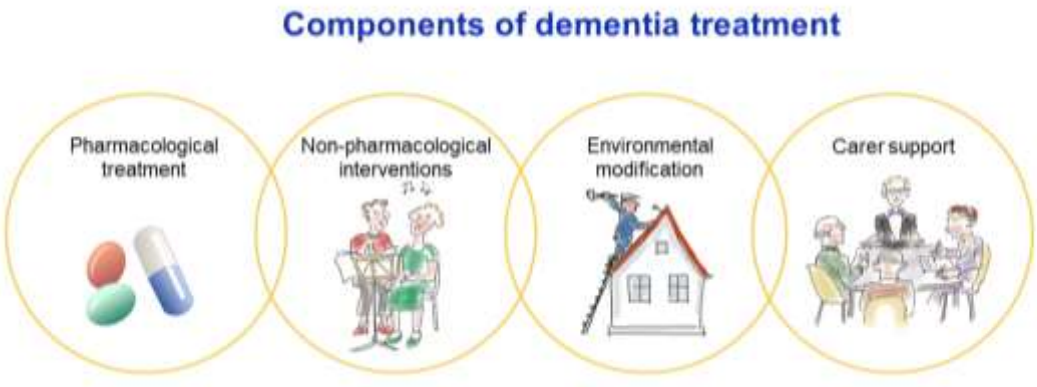
- Impairment of communication in dementia – it not only affects verbal communication and linguistic ability, but also the understanding of gestures, body movements and facial expressions as well as the ability to understand signs and symbols
- Interpersonal role of communication – communication is an essential part of social support
- General communication rules – observing simple rules makes life easier for those who interact with persons with dementia
- Disclosure of diagnosis – disclosure is not only an act of providing information but also a psychological manoeuvre

Treatment

You know that…

most dementias are due to irreversible and usually progressive diseases of the brain. Only very few causes of dementia can be amended or removed. Therefore, the overall goal of treatment is to maintain an optimal quality of life for persons with dementia and their carers. During the course of dementia the needs of people change, as well as their capacities. At the early stage, maintenance of function and continuation of the individual lifestyle are paramount. At the moderate stage, management of behavioural symptoms and adaptation of the living environment become increasingly important. At the more advanced stage, preservation of psychological and physical wellbeing is the key objective. Counselling and support of family carers is essential throughout the course of dementia.

To take advantage and coordinate all available treatment options according to individual needs, preferences and resources, including pharmacological and non-pharmacological interventions, modification of the environment, as well as appropriate services and facilities, an individual care plan should be set up which serves as a guide for professionals and carers.



Immediately after the diagnosis has been disclosed to the person the management of dementia should start. Ideally, an individual care plan is set up which considers the person's specific needs, preferences and resources and involves a multidisciplinary team of professionals as well as the family. The care plan can be based on international guidelines as for example on those of the European Federation of Neurological Sciences. A regular monitoring of the course of dementia and the effects of treatment interventions should be performed.

Pharmacological interventions

The major groups of medications for persons with dementia include antidementia drugs, antidepressants and antipsychotics. The currently available antidementia drugs address

chemical changes in the brain that are due to the disease underlying dementia (the cholinesterase inhibitors donepezil, galantamine and rivastigmine; and the glutamate blocker memantine). The slow down the progression of symptoms but do not cure dementia. Novel antidementia drugs are currently being developed which remove abnormal protein accumulations in the brain. Their clinical benefits have yet to be demonstrated. Antidepressants and antipsychotics are used to treat severe behavioural problems. Since these drugs have significant side effects they must be used with caution.

Non-pharmacological interventions

Non-pharmacological interventions should be employed as complement to medications with the aim of improving the quality of life of persons with dementia and their carers. Importantly, they are recommended as the first-line treatment for behavioural problems. The most important forms of non-pharmacological treatments are cognitive stimulation, occupational therapy and physical exercise. These treatments have no side effects and can be delivered by professionals or trained allied workforce.

Let`s explore some of the most common non-pharmacological interventions. Please click on the "+" signs to get information about specific interventions.

Environmental modification and assistive technology

Appropriate modifications of the living environment can enable persons with dementia to live in their own home for a longer time and to reduce hazards. Such modifications include grab bars, handrails, lighting, signs, raised toilet, removal of clutter and loose carpets. The most frequently used forms of assistive technology are memory aids and reminders (e.g. computer apps, Amazon Alexa), sensors and alarms (e.g. fire, gas, water, falls) and GPS-based person locators.

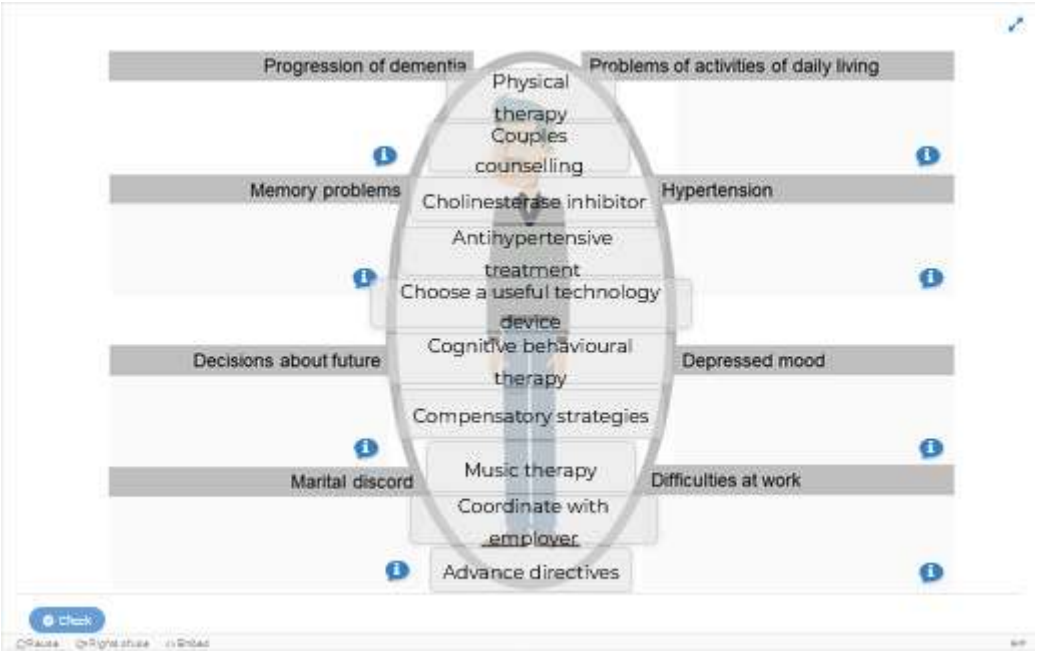
Can you bring together a set of appropriate interventions for Toni?

You now have gained insights into the different forms of pharmacological and non-pharmacological interventions available to persons living with dementia.

Try your skills and drag the correct interventions to Toni's issues. But first, please review his case file:

Case file Mr Toni Kovać, 63 years old

- Social status: Lives in private home with his wife Marija, two sons; working in leading position at industrial company
- Previous health problems: Arterial hypertension, well managed
- Major complaints: Memory issues; executive and visuospatial problems; word finding difficulty; impaired complex activities of daily living
- Diagnosis: Dementia due to Alzheimer's disease with early onset and comorbid depression



Carefully selecting the interventions based on the individuals' needs and wishes is important for developing a person-centred care plan. A care plan is a written plan that explains the treatment and care the person is receiving, contain contingency plans for the future and include arrangements for review. The plan usually also contains goals, identified support needs and an approach for monitoring the progress.

Key points

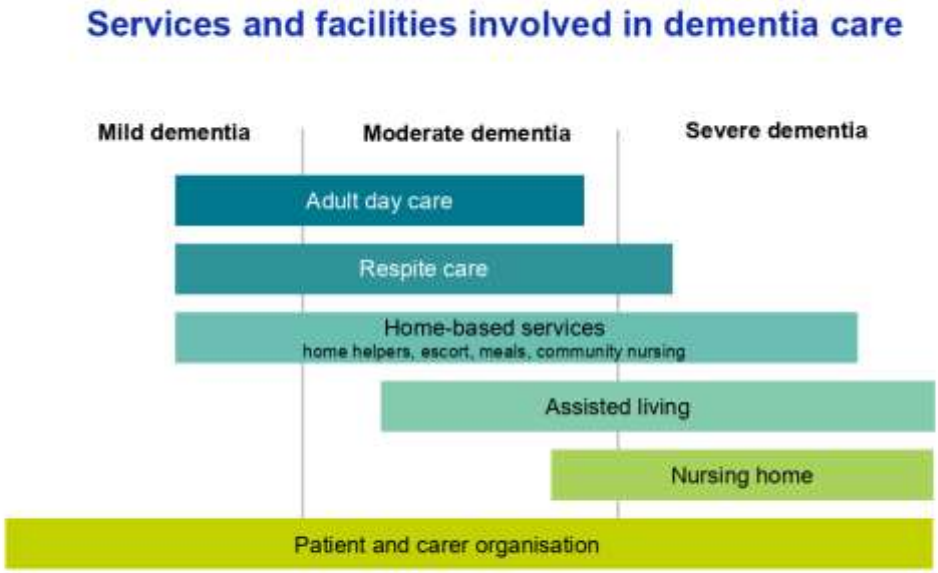
- Key components of treatment – medication alone does not do the trick
- Contribution of non-pharmacological interventions – there are many opportunities to help; interventions should be chosen according to persons' needs, abilities and resources

- Importance of collaboration – working together in an interprofessional team makes the management of dementia easier, more effective and rewarding
- Carer support – cares are not alone

Services and facilities

You know that…

as part of an individual care plan, services and facilities should be suggested in order to support persons with dementia and their carers. Services can be distinguished that provide support in the home, in the community, or in an institution. The choice of the appropriate service depends on the stage of dementia (see infographic below), on individual needs and preferences, and also on the available financial resources.



What are the needs that should be met by services and facilities?

The needs of people with dementia and their informal carers change as the condition progresses. In the early stage, persons with dementia and their carers need services that support them in maintaining their usual routines and continuing their lives at home with as

little changes as possible. At the moderate stage, services that are provided in the community may be required to complement support in the home and maintain an optimal quality of life. At the advanced stage, the growing need for assistance but also safety issues may necessitate to replace home-based and community-based support by institutional care.

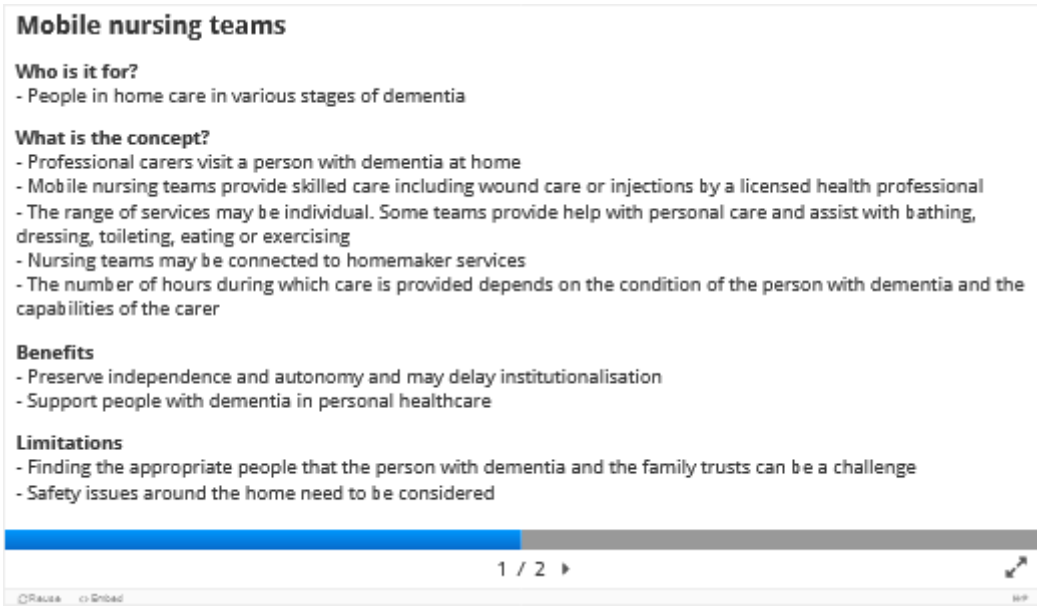
Services providing support in the home

The main advantage of in-home support is that the person's environment does not change – so no adjustment problems occur, previous interests and hobbies as well as social relations can be maintained, and costs are relatively low. However, services provided in the home may not be sufficient in case of an acute illness of the person with dementia or the carer, for people who wander frequently or show other severe behavioural disorders, have significant physical symptoms, or of there are home hazards that cannot be amended (e.g. gas, fire, water).

Services providing support in the home include:

- **Home emergency call** – 24/7 helpline activated by a device that can be worn on the wrist, provides monitoring, convenient and rapid access to emergency services.
- **Mobile nursing teams** – professional services that take care of medications, injections, personal hygiene, incontinence care and provide advice on dealing with challenging behaviours.
- **Home helpers** – specially trained staff who help with cleaning, shopping, and supervising people in the home.
- **Meals services** – many organisations offer meals that are brought to people's homes at any time during the day.

Let's discover some of the most common services that support persons living with dementia at home:

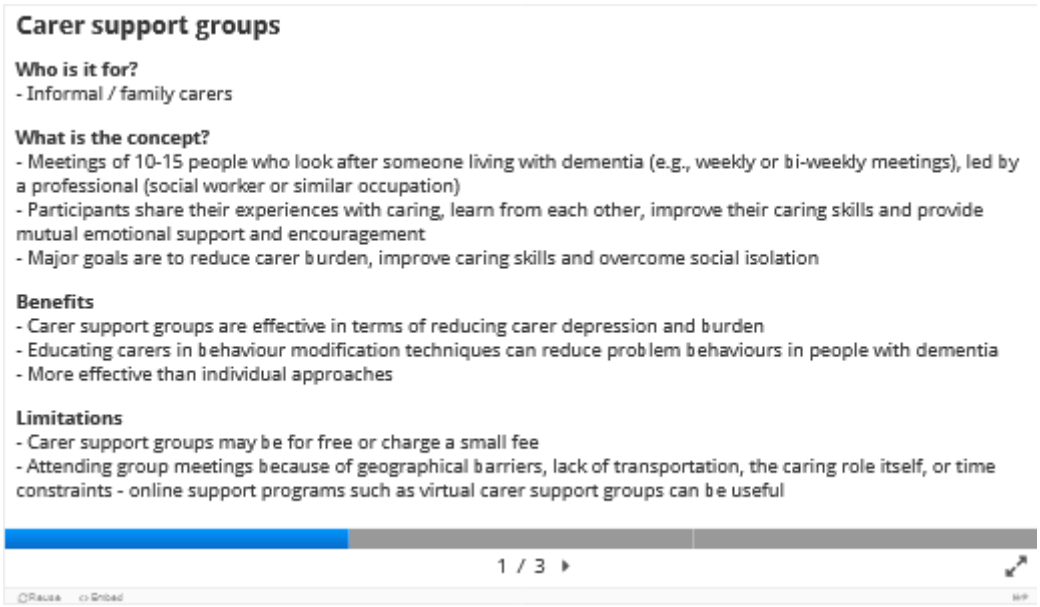


Services providing support in the community

This setting provides care outside the home at specific times during the day and days of the week. It allows caregivers to take a break, look after themselves or pursue other tasks. Services providing support in the community include:

- **Peer groups** – regular meetings of people with early-stage dementia where they can exchange experiences, participate in activities, and receive emotional support.
- **Carer support groups** – regular meetings of family and other informal carers where they receive information about the diseases and acquire skills regarding the management of behavioural problems, communication, meaningful activities as well as information on available services and resources.
- **Respite care** – some institutions temporarily admit people with dementia.
- **Adult day care centres** – Admit 10 – 20 guests for one or more days per week and provide meals, supervision as well as activity and training programs.

Let's explore some of the most common services for persons with dementia and their families provided in the community:



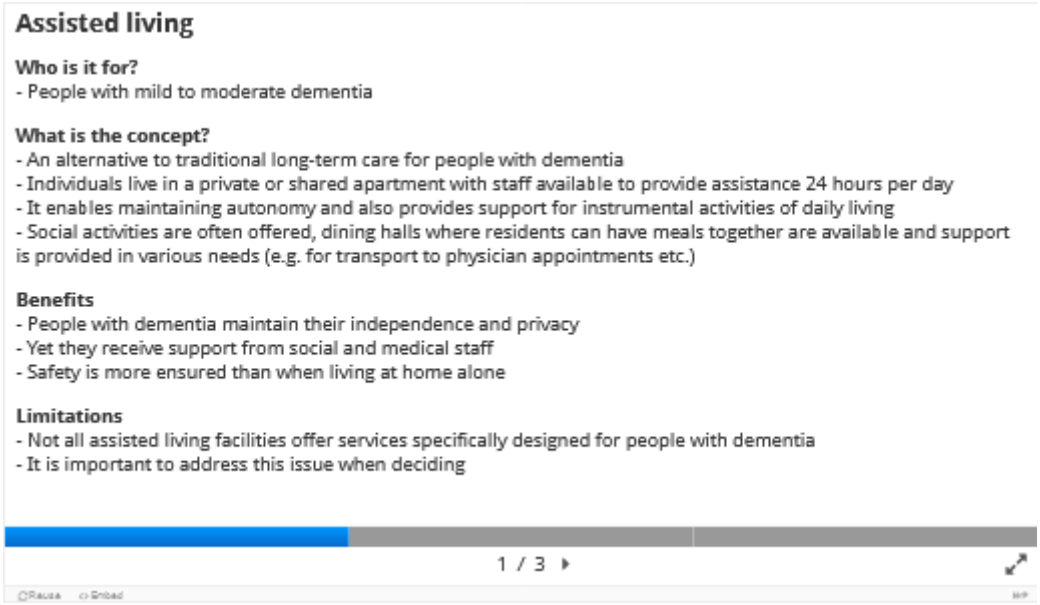
Institutional services

Institutional services are necessary when the person with dementia requires a greater amount of care or more supervision than can be provided at home or when no informal carer is available. Institutional services include:

- **Assisted living** – appropriate for people with dementia who do not have many medical problems but need support with more complex activities of daily living. Residents usually live in a private apartment and staff is available for assistance 24/7. „Assisted living" is often referred to as "residential care", but this is not quite the same. The main difference is the size of the setting and the amount of services provided. Usually, the number of residents is lower in residential care than in institutions of assistive living. Therefore, a more individualised style of care can be offered.
- **Special care units in nursing homes** – small-scale and homelike with 8 -12 individuals. Ideally, the units are especially designed for people with dementia, providing resident safety through door locking systems and signposting. Supervision is provided 24/7 by staff who are trained to manage behavioral and psychological symptoms of dementia.
- **Palliative care** – can be provided within other types of institutional services (e.g., in special care units) by professionals educated in providing end-of-life care. There is also possibility in

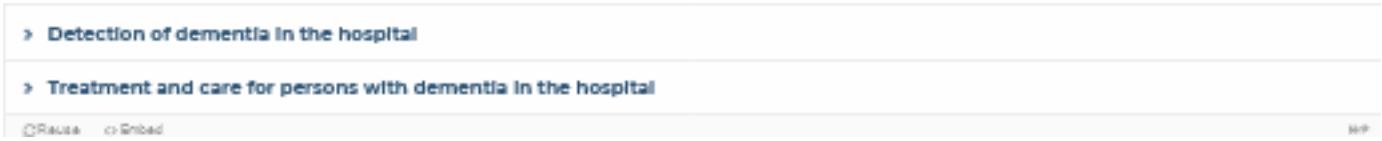
the final stages of life to move to a palliative nursing home for more specialized palliative care.

Let's explore some of the most common institutional services for persons with dementia:

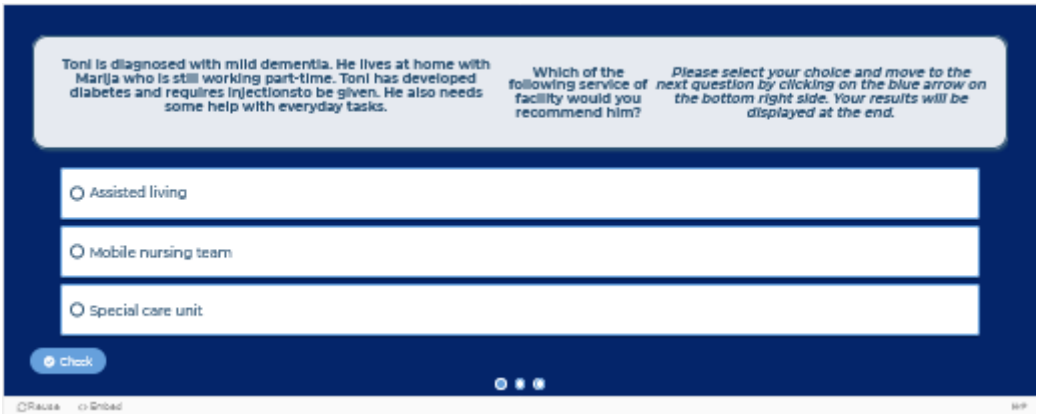


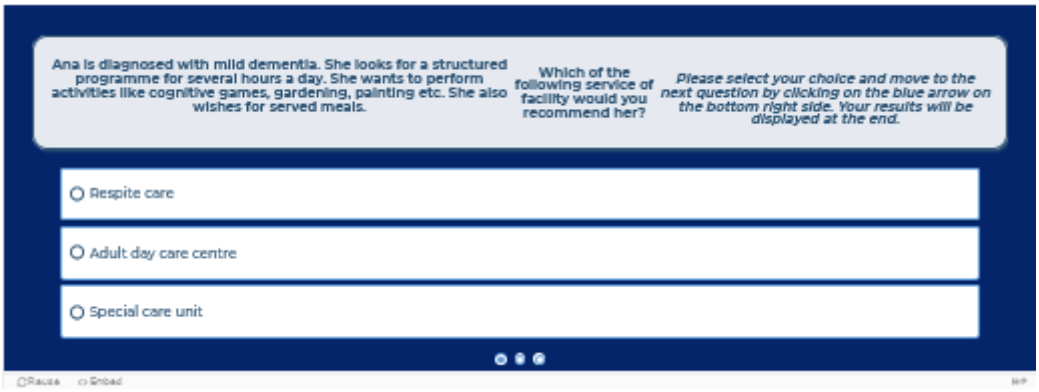
Dementia in the hospital

About 20 per cent of older adults who are admitted to a general hospital have dementia. The reason of hospitalisation is usually not dementia, but a physical health problem such as urinary tract infection, dehydration, trauma, or pneumonia. Hospital admission is associated with a number of adverse outcomes in persons with dementia, including accelerated cognitive decline, deterioration of activities of daily living, increase in behavioural symptoms, longer length of stay, more medical complications, development of delirium (acute confusional state) and increased likelihood of discharge to residential care.



Now that you have an overview of the broad spectrum of services and facilities for persons with dementia, let's see which services may be helpful for Ana and Toni:





Key points

• Major types of services along the course of dementia – services must be useful at particular stages of dementia
• Services and facilities for persons with dementia must be carefully selected based on the individuals' needs and provide many benefits for the person and their family

Knowledge check

[Solutions in **bold**.]

1) The major reason for the increasing number of persons with dementia is …
a. digital overload.
b. a yet unidentified virus.
c. the increase in life expectancy.
d. the spread of unhealthy lifestyles.

2) The stigma surrounding dementia …
a. cannot be changed by awareness campaigns.
b. is a barrier to seeking help and getting timely diagnosis and treatment.
c. only affects the person living with dementia.
d. is a characteristic of low-income countries.

3) Which of the following statements is true?
a. A person with dementia cannot make independent decisions anymore.
b. In persons with dementia, the ability to make decisions declines during the progression of dementia.
c. The diagnosis of dementia implies the that the person cannot make independent decisions.
d. When someone else needs to make decisions on behalf of the person with dementia, the person's previously expressed wishes are irrelevant.

4) Which of the following statement is true:
a. The quality of life of a person with dementia is largely determined by their age.
b. The quality of life of a person with dementia is largely determined by their gender.
c. **The level of activities and the quality of relationships are key determinants of quality of life in persons with dementia.**
d. The quality of life of a person with dementia is largely determined by the underlying disease.

5) Which neurodegenerative disease is characterised by changes of behaviour, personality, and language expression?
a. Alzheimer's disease
b. Frontotemporal degeneration
c. Lewy body disease
d. Parkinson's disease

6) Which of the following is not a potentially reversible cause?
a. Excessive alcohol consumption
b. Dysfunction of the thyroid
c. **Parkinson's disease**
d. Normal pressure hydrocephalus

7) Choose the wrong statement:
a. Occasionally forgetting events, conversations, appointments or peoples' names is part of normal ageing.
b. Frequently confusing the day and getting lost is not part of normal ageing.
c. Needing more time to perform complex activities is part of normal ageing.

d. Word finding difficulty, making grammatical and phonematic errors as well as difficulty reading and writing are part of normal aging.

8) Choose the wrong statement:
a. **Timely diagnosis of dementia is important because dementia can only be cured at an early stage.**
b. Timely diagnosis of dementia is important as a prerequisite and guidance for treatment and person-centred care interventions.
c. Timely diagnosis of dementia is important because it provides time for persons with dementia and their families to plan for the future.
d. Timely diagnosis of dementia can be a relief for the person with dementia because it explains changes in cognition, daily activities, behaviour or personality.

9) Choose the wrong statement:
a. We must always find out if persons with dementia want to know their diagnosis.
b. Most people with dementia and the majority of carers wish to be informed about the diagnosis.
c. If a person with dementia does not want to know the diagnosis, it is mandatory to inform the close family about it.
d. The disclosure can cause frustration and anxiety.

10) Which question can be asked to persons with dementia?
a. Which medications are you currently taking and at which dose?
b. Under which telephone number can I reach your wife?
c. Two weeks ago, we started treatment with donepezil. Do you tolerate it well?
d. When was your last hearing check-up?

11) Choose the wrong statement:
a. Treatment interventions for dementia can be categorised into pharmacological and non-pharmacological interventions as well as environmental modifications and assistive technologies and caregiver interventions.
b. Current pharmacological treatments contribute little to the quality of life of persons with dementia.
c. Expectations, risks and benefits of antidementia drugs should be discussed with the person with dementia and their family.
d. The choice of treatment does not need take into consideration age, medical history and the severity of the disease.

12) Choose the wrong statement:
a. Physical therapy is one form of non-pharmacological interventions.
b. Music therapy is an example for emotion-focused interventions.
c. Occupational therapy is an example for emotion-focused interventions.
d. Cognitive behavioural therapy is an example for behaviour-focused interventions.

13) Choose the wrong statement:
a. Respite care organisations temporarily take care of the person with dementia outside the home.
b. Palliative care can only be provided in a specialised institution.
c. Day care programmes are for persons with mild to moderate dementia.
d. Respite care provides informal carers with time to temporarily unwind or engage in activities without the person with dementia.

14) At which level of severity may a person with dementia require a special care unit?
a. Mild
b. Mild to moderate
c. Moderate to severe
d. Persons with dementia never require a special care unit