E-Learning

YOUNG-D

Non-pharmacological interventions for anxiety, stress and sleep problems in Young Onset Dementia (YOUNG-D)

Odisee
UNIVERSITY OF APPLIED SCIENCES

With the support of the Erasmus+ Programme of the European Union

YOUNG-D

Co-funded by the
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E-learning YOUNG-D-English

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Foreword

YOUNG-D

This e-learning is a product of the overarching **project YOUNG-D**. The YOUNG-D project is a continued initiative following a Belgian JONG-D research project on anxiety, stress and sleep in young onset dementia, lead by Odisee University of Applied Sciences (Belgium) and co-funded by the Erasmus+ Programme of the European Union.

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The YOUNG-D consortium is composed out of researchers (Dr. Julie Vanderlinden, Drs. Liza Musch and Sophie Dohogne) from **Odisee University of Applied Sciences** (Belgium) (consortium lead and principal investigator, further referred to as P.I.), and collaborating partners from Belgium ("**Familiezorg Oost-Vlaanderen"**), The Netherlands ("**Hanze University of Applied Sciences"** and "**Interzorg"**), Germany ("**Ostfalia University of Applied Sciences"**) and Denmark ("**SOSU Østjylland"** and "**Aarhus community"**).

Familiezorg o-vl
uw zorg in goede handen

Hanze University of Applied Sciences Groningen

interzorg

Ostfalia University of Applied Sciences

SOSU Østjylland

SUNDHED OG OMSORG
Aarhus Kommune

This publication is a product of this YOUNG-D program and is developed for professional caregivers involved in the care for people with young onset dementia. However, nothing from this publication may be duplicated, as a whole or in part, by whatever means, without properly citing it's original source.

This e-course can be accessed via: https://ecourses.odisee.be/icto/cursus/e-learning-young-d/

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More information on the YOUNG-D project can be found on

https://www.odisee.be/en/researchprojects/young-d

Contact principal investigator (Odisee University of Applied Sciences, Belgium)

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Part 1: Introduction

1. Background

The aim of this **YOUNG-D e-learning** is to enhance the competences of (future) health care professionals in the care for people with Young Onset Dementia in order to get an insight in a non-pharmacological approach in stress, anxiety and sleep problems in Young Onset Dementia.

This e-learning course is developed by partners of the YOUNG-D project (co-funded by means of Erasmus+ program) and provides a summary of the non-pharmaceutical interventions part for anxiety, stress and sleep problems for people with Young Onset Dementia (YOUNG-D program).

This e-learning will help students and professional caregivers to:

- Understand anxiety, sleep and stress problems in people with Young Onset Dementia;
- Explain non-pharmacological interventions that can be used to reduce anxiety, stress and sleep problems;
- Explain why non-pharmacological interventions can help people with Young Onset Dementia with anxiety, stress and sleep problems.

This YOUNG-D e-learning is a part of the overarching YOUNG-D project. The overall aim of this **YOUNG-D project** is to increase awareness and coping skills on anxiety, stress and sleep problems in YOD for people with YOD and (future) health care providers in Young Onset Dementia. Within the YOUNG-D project, a YOUNG-D program is developed for people with Young Onset Dementia to help them cope with anxiety, stress and sleeping problems.

More information on this YOUNG-D project and the YOUNG-D program can be consulted via the YOUNG-D website: https://www.odisee.be/en/researchprojects/young-d

The YOUNG-D consortium is composed out of researchers from **Odisee University of Applied Sciences** (Belgium) (consortium lead and principal investigator, further referred to as P.I.) and collaborating partners from Belgium ("**Familiezorg Oost-Vlaanderen"**), The Netherlands ("**Hanze University of Applied Sciences"** and "**Interzorg"**), Germany ("**Ostfalia University of Applied Sciences"**) and Denmark ("**SOSU Østjylland"** and "**Aarhus community"**).

If you want to know more about the YOUNG-D program and YOUNG-D project, you are advised to contact the partners in the YOUNG-D program who are mentioned on the YOUNG-D website: https://www.odisee.be/en/researchprojects/young-d

- Principal investigator: dr. Julie Vanderlinden (PhD), Odisee University of Applied Sciences, Julie.vanderlinden@odisee.be
- Do you wish to contact the other project partners? You can find their references on the YOUNG-D website: https://www.odisee.be/en/researchprojects/young-d

2. Target group of this e-learning

Main target groups

- **Students** in health and social care, European Qualifications framework (EQF) levels 3, 4, 5, 6 (Bachelor) and 7 (Master)
- **Health and social care professionals working with people with Young Onset Dementia**

  (e.g. nurses, occupational therapists, social workers, community professionals, dementia case managers, health consultants)

Additional target groups

Although this e-learning is not specifically designed for informal caregivers and people with Young Onset Dementia, this e-learning can be informative for:

- Informal caregivers of people with Young Onset Dementia
- People with Young Onset Dementia
- Trainers of the YOUNG-D program

This e-learning can also be used as a preparation for an internship or an employment in a setting with people with Young Onset Dementia and their informal caregivers.

This e-learning does not offer a course to become a YOUNG-D trainer. In order to become a trainer, you'll need to:

(1) be/get acquainted with the care for people with Young Onset Dementia;
(2) read the train-the-trainer and;
(3) gain practical experience in coaching skills regarding psycho-emotional coping as well as the sessions in the YOUNG-D program.

3. How to use this e-learning?

Outline of this e-learning

- The **first part** contains general information on this e-learning
- The **second part** contains more background information on Young Onset Dementia and the anxiety, stress and sleep problems in this target group
- The **third part** is composed out of 4 subsidiary chapters with theory and interventions on **1) Emotions and feelings; 2) Breathing, 3) Mindfulness and 4) Sleep**

How to use this e-learning?

- When you use the e-learning for the first time we advise you to follow the modules in the presented order. But you are free to pick and choose any topic you would like to read/visit by scrolling down the menu on the right
- Each module contains basic theory, exercises and illustrations with examples from practice. If you want to acquire knowledge on a more advanced level, you can consult the suggestions for further reading
- Every module ends with an assessment including a quiz to test your own knowledge and some questions to reflect on how theory can be used in practice

Who are you?

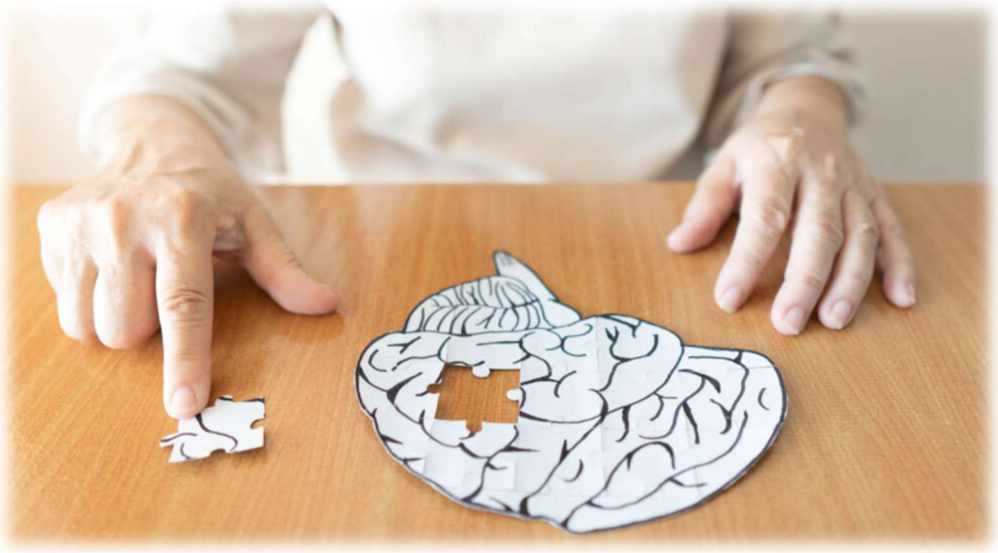
- If you are a **Healthcare professional** who wants to know more about how to implement this program, please consult the information on the YOUNG-D website where you can find the trainers' manual: https://www.odisee.be/en/researchprojects/young-d
- If you are a **student**, you are able to navigate through all modules of this e-learning. The assessment at the end of each chapter will help you to gain a deeper understanding of the content of this e-learning. If you need more background information on Young Onset Dementia, you are

advised to go through the background information in the trainers' manual, to be found on the YOUNG-D website

- If you are a **teacher/lecturer** and you wish to implement this course in your class, you are able to navigate through all modules of this e-learning together with your students. Students can also be instructed to follow the e-learning at ow pace. The assessment at the end of each chapter will help students to gain a deeper understanding of the content of this e-learning. There will be no certification issued upon completion of this course. Teachers who request students to have a certificate of completion, are advised to issue these certifications in their own institution.

Part 2: Young Onset Dementia

1. Diagnosis and impact



Diagnosis

Dementia is characterized by a decline in cognitive functions and occurrence of behavioral abnormalities which interfere with an individual's activities of daily living. Disfunctions such as memory loss or disfunctions in executive function, language, praxis, and gnosis are often present when living with dementia.

- Dementia usually affect older adults: late onset dementia (LOD)
- Dementia may also occur in individuals younger than 65 years: **Young Onset Dementia (YOD)**

Young Onset Dementia is often misdiagnosed or its diagnosis is delayed due to the fact that it has a more varied differential diagnosis than is the case in late onset dementia. Therefore, clinicians face major diagnostic challenges in Young Onset Dementia. A rapid diagnosis is however crucial for patient counselling and management.

There are different forms in Young Onset Dementia:

- **Alzheimer's disease:** is the most common cause of Young Onset Dementia and usually affects people in their 40s, 50s and early 60s
- **Vascular dementia:** is the second most common cause of young onset dementia and occurs when blood vessels in the brain are damaged. This affects how brain cells work and causes them to become damaged too, leading to dementia symptoms
- **Frontotemporal dementia (FTD):** Is a form of dementia when there is damage to cells in areas of the brain called the frontal and the temporal lobes. These areas of the brain control personality, emotions and behaviour, as well as speech and understanding of words
- **Lewy body disease (DLB):** is a form of dementia that occurs when clumps of protein (alpha-synuclein) build up in the brain (called called Lewy bodies). This build up is accompanied by damage to the nerve cells affecting the way the brain cells communicate which leads to the symptoms of dementia
- **Other forms of dementia:** alcohol-related dementia, Parkinson's disease with dementia, Huntington's disease and multiple sclerosis related dementia

Impact of Young Onset Dementia

The psychosocial and economical consequences of Young Onset Dementia are often severe. Young Onset Dementia can affect individuals at the level of career and productivity which often translates in financial consequences for the patient's family as well as for the society.

Furthermore, given the more aggressive course of Young Onset Dementia when compared with late onset dementia, and given the age of the patient when the diagnosis is received, the age-related psychosocial needs often differ in Young Onset Dementia when compared with late onset dementia. Although the management of Young Onset Dementia is similar to that of late onset dementia, special attention should be focused more age-appropriate psychosocial support and education.

2. Prevalence and incidence

Alzheimer Europe described there is a lack of research and available data on younger people with dementia (i.e. those aged under 65), which made it impossible to publish prevalence estimates for this specific group.

Estimated prevalence* (Alzheimer Europe, 2019) of Young Onset Dementia for people (60-65 years) was:

- 0,6% in general
- 0,9% for females
- 0,2% for males

**this prevalence estimate is probably an underestimation and should therefore be interpreted with caution.*

Prevalence of Young Onset Dementia

"*An overall global age-standardized prevalence of 119.0 per 100 000 population in the age range of 30 to 64 years, corresponding to 3.9 million people aged 30 to 64 years living with YOD in the world*"

(Hendrickx et al., 2021)

Estimates* of YOD prevalence per country:

- Belgium: 1.800-4.464 people
- The Netherlands: 15.000 people
- Germany: 20.000-73.000 people
- Denmark: 3.000 people

*Although the prevalences of Young Onset Dementia have been published on national websites, all included sources indicated that interpretation of these data needs to be done in a prudent manner. Considering the difficulty and validity of diagnosis and the lack of (national) registration of the condition, these prevalences are often outdated and an underestimation of the real prevalence.

Incidence rates of Young Onset Dementia

- Worldwide: "*The global age standardized incidence rate of people aged 30 to 64 was 11 per 100,000 person-years worldwide, corresponding to ≈370,000 new cases each year.*"
- Europe: *"The age standardized incidence rate was 14 per 100,000 person-years, whereas in the United States the incidence rate was 11 per 100,000 person years."*
  (Hendricks, 2022)

3. Anxiety, stress and sleep problems in Young Onset Dementia

People with early-onset dementia often experience **anxiety, stress, and sleep problems** due to the profound changes in cognitive function and daily life.

The decline in memory, reasoning, and other cognitive abilities can lead to **confusion and frustration**, making everyday tasks increasingly difficult and creating a sense of loss and helplessness. This cognitive decline disrupts normal routines and social interactions, leading to social isolation and **increased stress**.

Additionally, changes in brain chemistry associated with dementia can directly affect **mood and sleep patterns**, resulting in **anxiety and sleep disturbances**.

Behavioral and psychological symptoms of dementia can be:

Emotions and feelings

- Depression
- Anxiety
- Apathy
- Irritability
- Agitation
- Agression

Changes in sleep patterns

- Sundowning: People with dementia often experience sleep challenges when the sun is setting and it becomes dark outside. As a result of that, they can become increasingly restless, confused, agitated, or distressed
- Disrupted sleep: A loss of brain function as a result of dementia might impact the regulation of sleep-wake cycles and therefore disrupt sleep periods
- Daytime sleepiness: The disturbances in sleep patterns often increase daytime sleepiness
- An increased experienced number of nightmares has been reported in people with dementia

As these sleep challenges often coincide with experienced **feelings of anxiety, distress, irritability, apathy and depression**, the quality of life of both the person with Young Onset Dementia and the informal caregiver is often impacted.

(DementiaUK.org, Sleepfoundation.org)

4. Non-pharmacological interventions to cope with emotions and sleep problems in Young Onset Dementia

Considering that Young Onset Dementia often goes along with increased **anxiety, stress and sleep problems** along come specific needs in the treatment of Young Onset Dementia.

However, the current care for people with Young Onset Dementia often exists out of pharmacological treatment options to reduce feelings of anxiety, stress or sleep problems.

Non-pharmacological treatment options have less side effects, are more durable and provide more long term improvement when it comes to the reduction of anxiety, stress and sleep problems. Therefore, it is important to focus on **non-pharmacological interventions** for people with Young Onset Dementia that help them cope with these issues.

This **e-learning** will provide insight in several **non-pharmacological techniques and methods** that can help reduce **anxiety, stress and sleep problems** in people with Young Onset Dementia. The next part is composed out of 4 subthemes:

1. **Emotions and feelings**
2. **Breathing**
3. **Mindfulness**
4. **Sleep**

5. Quiz Young Onset Dementia

1. What is Young Onset Dementia? (choose the most fitting answer)
   - Young Onset Dementia or early onset dementia is a form of dementia in youngsters
   - **Young Onset Dementia is a form of dementia when diagnosed prior to the age of 65 years**
   - Young Onset Dementia is a form of dementia that can only be diagnosed prior to the age of 65 years

2. What is the most common cause/form of Young Onset Dementia?
   - Vascular dementia
   - Lewy body disease
   - **Alzheimer's disease**
   - Frontotemporal dementia

3. Why is it important to differentiate the care for people with young onset when compared with people with late onset dementia?
   - Because people with Young Onset Dementia suffer from a different condition than is the case in late onset dementia
   - **Because people with Young Onset Dementia often have different lives or are still actively involved in several live domains/activities than is the case in late onset dementia**
   - Because people with Young Onset Dementia are too young to live in nursing homes

4. What psychosocial symptoms do people with Young Onset Dementia often suffer from?
   - Agitation, irritability and aggression
   - Anxiety, depression and apathy
   - Sleep changes and sleep disorders
   - **All of the above**

5. How does late onset dementia differ from Young Onset Dementia?
    - A)The age of diagnosis
    - B)The progression of the condition
    - C)The different types of dementia
    - D)The time to diagnosis
    - A and B
    - A, B and C
    - **All of the above**

Part 3: Interventions

1. Emotions and feelings

Emotions and feelings: rationale and learning goals

Keeping **emotions** bottled up can lead to **stress and troubled sleeping**. It's important to be aware of how you feel, as this awareness can help you **manage your emotions better**.

Recognizing and acknowledging one's emotions is crucial, as this awareness enables more effective emotional management.

For **people with Young Onset Dementia**, this awareness is especially important as they may **experience a range of emotions differently**. Providing support, adapted to their unique emotional needs, can greatly **enhance their quality of life**.

Techniques such as **mindfulness, breathing, and music therapy** can help individuals with **Young Onset Dementia** to connect with and express their emotions more effectively.

Additionally, creating a supportive environment where **they feel understood and validated** can play a significant role in **promoting emotional well-being in people with Young Onset Dementia**.

Learning goals: After completing this part, participants can…

Basic

- Explain why unexpressed emotions are related to anxiety, stress and sleeping problems
- Understand why recognizing emotions is important
- Understand how emotions are related to behaviour

Advanced

- Know challenges and techniques how to talk about emotions

Emotions and feelings: theory

Emotions are complex psychological and physiological responses that arise in reaction to internal or external stimuli.

Basic emotions are:

- happiness
- sadness
- anger
- fear

Besides these basic emotions, there is a wide range of other feelings

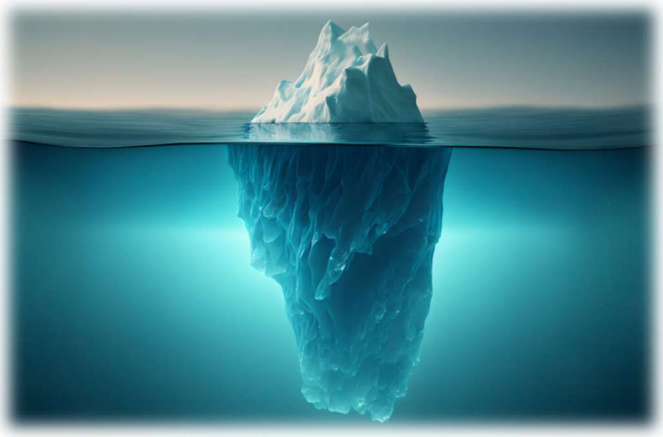
People experience emotions as a result of a **combination of biological, cognitive, and environmental factors**. Strong emotions may also be caused by unmet needs.

Emotions:

- have served adaptive functions
- help individuals navigate in their environment
- facilitate decisions that enhance survival and well-being
- serve as social signals and help conveying information to others
- influence social interactions

- play a crucial role in shaping human behaviour, cognition, and interpersonal relationships, influencing everything from decision-making to memory formation
- are a fundamental aspect of human experience, contributing to our understanding of ourselves and the world around us

The iceberg as a metaphor



The iceberg serves as a powerful **metaphor for emotions**. Above the waterline, only the tip of the iceberg is visible, while the vast majority remains hidden beneath the surface. When encountering behaviour that you don't understand, it becomes crucial to find out what the individual is truly trying to say or what the individual requires. This involves examining, contemplating, and probing beneath the surface to uncover the **underlying needs, feelings, and emotions**.

Reading example: Displeased

"Hey, hello! this is where you need to be", Mrs Moordrecht happily calls out from her apartment.

miMakker Sophie points at herself and –nonverbally- asks: "Do you mean me?". "Yes, I mean you" she says with a grin. (miMakker is a specially trained professional to make contact with people with dementia.)

The moment Sophie enters the room Mrs. Moordrecht continues doing what she was doing, rummaging through her cupboards, diligently looking for something. What she is looking for she can't explain. "I am looking for something", she grumbles.

It quickly becomes clear to Sophie that the woman no longer remembers why she started her search. She is displeased, sad and angry, only she doesn't remember why.

It throws Sophie off for a moment. The woman called out happily. At the same time, she doesn't ask more from Sophie than just being present.

The photos Mrs Moordrecht comes across in a drawer brings them onto an old path together. "Here, my old neighbour", she shows Sophie quickly. "Boozer she is", it sounds bitter.

Like dirt the photo was thrown back. Everybody in her life has abused her kindness Sophie understands from the loose words she can make out.

"I never did anything right in my mother's eyes, she always favoured my brother and that's not fair", she says angrily.

From this point there are different ways to respond. One is to make Mrs Moordrecht change her mind by saying: 'It must not have been that bad, there are lots of people who are very happy with you.' This is probably recognisable and sounds effective but how does this one feel? Can I say it? It feels terrible! 'Why?' you wonder? With this response you are completely dismissing Mrs. Moordrecht's feelings. She has been told this her entire life. This is of no use to her. With this reaction she is not seen or heard. You do not validate her feelings. It makes people angrier, or you silence them.

What I think with such a reaction is: 'You're useless to me' and move on.

As a sender you think this was an effective response because the anger has gone, hasn't it? People who don't feel heard often choose a different strategy and if you're not careful it will add another problem.

Sophie chooses a different response, one that lots of people find tricky if someone is already angry, she moans along with Mrs. Moordrecht. "No, your mother is not fair, she should not let you pay for this any longer" she says feisty. "Exactly", Mrs Moordrecht confirms.

After moaning together for a while Mrs. Moorsdrecht spontaneously says: "Hey, I am back and that is because of you!"

The displeased feeling has visibly left her body. So, this was why she happily or maybe more with relieve invited Sophie with "Hey! Hello, this is where you need to be".

Expressing anger let's adrenaline leave the body. Moaning or even cursing together creates a bond or connection. Connection to look ahead. Without a connection you only create more distance. That does not help anybody.

Emotions and feelings: interventions and exercises

Exercise 1: Reading emotions

- **Description**: the participants look at different pictures of people/emojis and talk about what emotions/feelings they represent according to them. This way we get to know what kind of feeling they think of when they see certain pictures. That way we learn more about how they interpret the feelings of other people before they talk about how they feel themselves
- **Goal**: getting to know how the participants recognize different emotions. Getting comfortable with talking about emotions
- **Method**: present pieces of paper with emojis or pictures with real faces on the table. The participant chooses a picture and tells what kind of feeling they see. Let them do it without correcting them but only be open and curious about how they interpret them. There is no true or false answer
- **Tools:** pictures of people/emoji, do this game in small groups with a maximum of four people. During the session it is not necessary to know if something is true or not – just focus on the feelings
- **Experiences from practice**: this exercise made participants talk about feelings in another way, and somehow made them add more words when they afterwards talked about how they felt themselves

Exercise 2: Listening to music

- **Description**: use music as a tool to connect with the emotions of the participant
- **Goal**: to connect with their own emotions and feelings and facilitate talking about emotions
- **Method**: ask participants for a song that touches/moves them. Something that makes them happy, something they listen to when they are sad. Also give people time to think about this (e.g. give the instructions to reflect on this after a session)
- **Tools**: music box and audio (e.g. Youtube)
- **Experience from practice**: Talking about emotions remains difficult for people with Young Onset Dementia, but while listening to the music, we noticed emotions in people with young onset we did not see before

Exercise 3: Talking jar

- **Description:** using prepared questions in an introspective way to learn to talk about emotions. By using a jar of questions on a piece of paper you make it less personally and more randomly
- **Goal:** talking together about emotions that people experience
- **Method**: make cards with different questions about emotions. Put the cards in a jar or place them upside down on the table. All participants are invited to take a card and read it out loud. The question is not specific to the person reading it, but to the whole group. Come up with examples yourself if you notice that people are having trouble with the question. If the participant is not comfortable with the question, he/she can take another one. Sample questions:
    - *How are you feeling today?*
    - *Can you describe what happiness means to you?*
    - *Can you describe what grief means to you?*
    - *Can you describe what being angry means to you?*
    - *Can you describe what being anxious means to you?*
    - *How would you like to feel?*
    - *Is there someone you can talk to when you're feeling happy, sad, angry, or anxious?*
    - *Which emotions do you know well? And do you share them as well?*
    - *Do you talk about your emotions and feelings?*
    - *What emotions are you hiding or don't you like to feel?*
    - *What emotions did you talk about in the past?*
    - *What are you bummed about, but you don't say?*
    - *What do you feel and don't express?*

- **Tools**: the trainer starts a conversation by using prepared questions from the toolbox. Feel free to add follow-up questions to stimulate the conversation. People are free to make their own questions
- **Experience from practice**: ask the people with Young Onset Dementia if they want to read the questions themselves in order to stimulate autonomy and commitment

Emotions and feelings: assignments

Basic: Quiz

1. What emotional challenges can people with Young Onset Dementia commonly experience? (Indicate with true or false)

- Increased emotional stability and control. True/**false**
- Difficulty recognizing emotions in others. **True**/false
- Limited range of emotions, such as happiness, sadness, and contentment. **True**/false
- Enhanced ability to express emotions verbally. True/**false**

2. Why is mindfulness helpful for regulating emotions in persons with Young Onset Dementia?

- It distracts people from their emotions
- It encourages avoidance of emotional experiences
- **It enhances emotional regulation and awareness**
- It leads to a decrease in emotional sensitivity.

Read the story **"Displeased" with miMakker Sophie and Mrs Moorakker** and answer the following questions:

3. How does miMakker Sophie responds to Mrs Moorakker's anger?
   - She's ignoring the anger feeling
   - **She's also getting angry**
   - She's talking about her own problems

4. Why does she do that?
   - **To make a connection.**
   - She's feeling angry that day
   - To show her what her anger looks like

Advanced: Case study

Wendy has been diagnosed with Young Onset Dementia some years ago. She has written different books and blogtexts about the feelings she experienced.

Emotions revisited

Read the following blog text about "Emotions revisited" (https://whichmeamitoday.wordpress.com/2019/11/27/changing-emotions-revisited/) and reflect on the following questions (if possible, discuss with your colleagues or peers):

Question 1: What difference does Wendy describe between normal aging and what does she experience?

Question 2: What is an insight from this blogpost that is important for professionals working with people with Young Onset Dementia?

Feelings of guilt

Read Wendy her blog post about "Feelings of guilt (https://whichmeamitoday.wordpress.com/2024/01/19/friday-extract/) and reflect on the following question (if possible, discuss with your colleagues or peers):

Question 3: Where do you think the guilt comes from?

Standardised answers

Answer to question 1: Wendy describes losing her emotions. This is different from people getting softer as they age.

Answer to question 2: One insight is to keep in mind that emotions can change in people with dementia. Wendy indicates that she has only three emotions left.

Answer to question 3: Here the perspectives of different people with dementia are mentioned. This seems to be a good question to reflect on with your colleagues, fellow students, in a group discussion (in-depth question).

Emotions and feelings: advanced further reading and references

English

Scientific articles

- People with dementia have difficulties reading other people's emotions: Shiota, M. N., Simpson, M. L., Kirsch, H. E., & Levenson, R. W. (2019). Emotion recognition in objects in patients with neurological disease. *Neuropsychology, 33*(8), 1163.

Podcast

- https://www.homecare.co.uk/news/article.cfm/id/1616488/podcast-wendy-mitchell-dementia-biggest-fear-daughters

Other

- https://alzheimer.ca/en/help-support/im-living-dementia/managing-changes-your-abilities/managing-emotions-stress-living
- https://www.tandfonline.com/doi/full/10.1080/09638237.2020.1739241
- What I Wish People Knew About Dementia, by Wendy Mitchell

Dutch

- https://www.gezondleven.be/themas/mentaal-welbevinden/geluksdriehoek/balans/emotie-en-stressregulatie
- https://leer.tips/tip/zelfregulatie/
- https://www.jongdementie.info/2014-05-08-14-37-59/nieuws/187-emotie-wordt-slecht-herkend-bij-ftd
- https://www.zegjabijdementie.nl/

Danish

- https://videnscenterfordemens.dk/da/personcentreret-omsorg
- https://www.alzheimer.dk/temaer-om-demens/vores-liv-med-demens/mit-liv-med-alzheimers/

German

- https://link.springer.com/article/10.1007/s41906-020-0796-6
- https://www.demenz-brandenburg.de/wp-content/uploads/2017/09/2_Vortrag-Frau-Dr.-B%C3%A4r.pdf
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- https://www.researchgate.net/publication/263303293_Emotionen_als_Wirkfaktoren_psychosozialer_Interventionen_bei_Alzheimer_Demenz

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- https://www.alzheimers.org.uk/sites/default/files/2020-01/688LP%20-%20Understanding%20your%20diagnosis%20young%20onset%20dementia.pdf
- https://whichmeamitoday.wordpress.com/

2. Breathing

Breathing: rationale and learning goals

Breathing exercises aim to increase awareness and control over the rate of breathing. The breathing exercises stimulate the vagus nerve, which is part of the parasympathetic nervous system, leading to reduced anxiety and stress.

Breathing exercises have been a cornerstone of various wellbeing practices and therapeutic interventions. The effectiveness of these exercises lies in their significant impact on both physical and mental wellbeing.

Breathing exercises can be beneficial for individuals with dementia, including **people with Young Onset Dementia**, as these exercises can help **promote relaxation, reduce stress, and improve overall well-being**.

Learning goals: After completing this part, participants can…

Basic

- Remember the effects of slow/awareness breathing on the body and mind
- Understand the importance of breathing techniques for relaxation and stress management (for people with Young Onset Dementia)
- Apply slow/awareness breathing techniques in practical situations to manage stress

Advanced

- Connect their knowledge about people with Young Onset Dementia with the knowledge on breathing techniques and link them to the positive effects on anxiety and stress

Breathing: theory

Stress can impact **breathing patterns** and **breathing** can influence experienced stress levels.

Why do we breathe?

We breathe so our bodies can get the oxygen they need for energy. When we breathe in, air goes into our lungs. Oxygen from the air gets into our blood through tiny blood vessels called capillaries around little air sacs in the lungs called alveoli. The blood carries oxygen to all our cells.

Integrating regular breathing exercises into one's routine can contribute to:

- stress reduction
- improved respiratory function
- enhanced cognitive performance, and an overall sense of balance and vitality

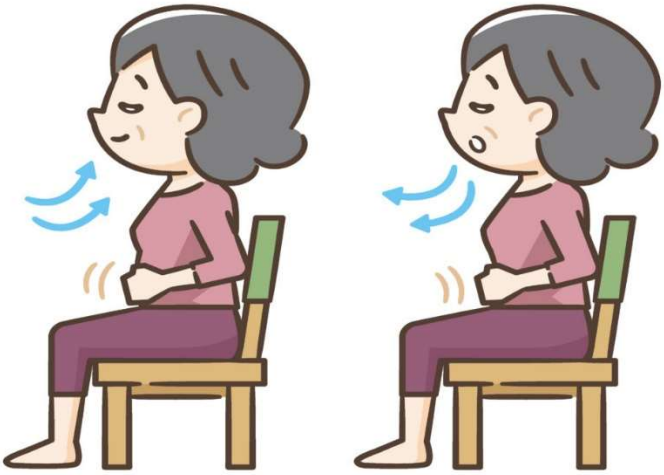
It is important to address poor breathing considering untreated respiratory issues can have significant impacts on overall health and quality of life.

Strategies that may help improve breathing:

- **Deep Breathing Exercises**: Practicing deep breathing exercises, such as diaphragmatic breathing (also known as belly breathing), can help improve lung capacity and oxygen exchange. These exercises can train the diaphragm to work more efficiently, allowing for more efficient breathing
- **Increase physical activity**: Engaging in regular physical activity can strengthen respiratory muscles and improve overall lung function. Aerobic exercises like walking, swimming or cycling can be particularly beneficial
- **Posture Correction**: Poor posture can restrict breathing by compressing the lungs and diaphragm. Improving posture through exercises and ergonomic adjustments can help optimize breathing mechanics
- **Stress Reduction Techniques**: Stress and anxiety can lead to shallow breathing patterns. Techniques such as mindfulness, progressive muscle relaxation, or yoga can help reduce stress and promote deeper, more relaxed breathing
- **Quit Smoking**: Smoking can damage the lungs and impair respiratory function. Quitting smoking can significantly improve lung health and breathing capacity over time
- **Stay well hydrated:** Staying well-hydrated helps keep the airways moist and facilitates efficient oxygen exchange in the lungs. Aim to drink plenty of water throughout the day
- **Dietary considerations**: Consuming a balanced diet rich in fruits, vegetables, lean proteins, and whole grains can support overall health, including respiratory function. Certain foods, such as spicy foods or those high in antioxidants, may also have respiratory benefits.
- **Medical treatment**: If poor breathing is due to an underlying medical condition, such as asthma, chronic obstructive pulmonary disease (COPD), or sleep apnea, it's essential to consult a healthcare professional for proper diagnosis and treatment. Treatment may include medications, inhalers, oxygen therapy, or other interventions tailored to the specific condition

Breathing: interventions and exercises

Exercise 1: Abdominal breathing exercise

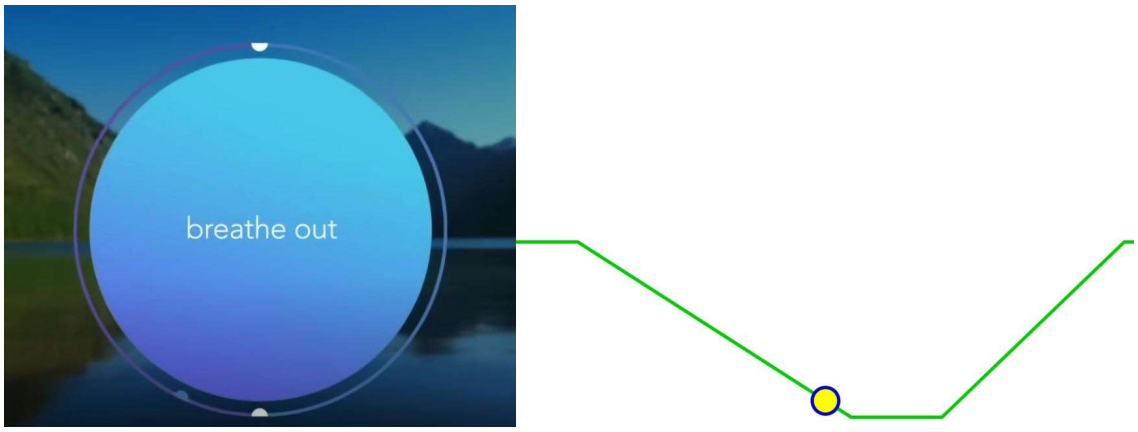


- **Description**: abdominal breathing: sitting on a chair placing hands on the chest and abdomen
- **Goals:** participants are offered different breathing techniques and exercises
- **Method:** individual exercise (in group) for 3-5 minutes. Sit or lie down comfortably in a quiet environment. Place one hand on your abdomen and the other hand on your chest. Tell them to breathe in and out. Let them focus on their breathing.

  "Inhale slowly and deeply through your nose, allowing your abdomen to rise as you fill your lungs with air. Exhale slowly through your mouth, emptying your lungs completely and allowing your abdomen to fall. Repeat for several breaths, focusing on the sensation of your breath filling your body".

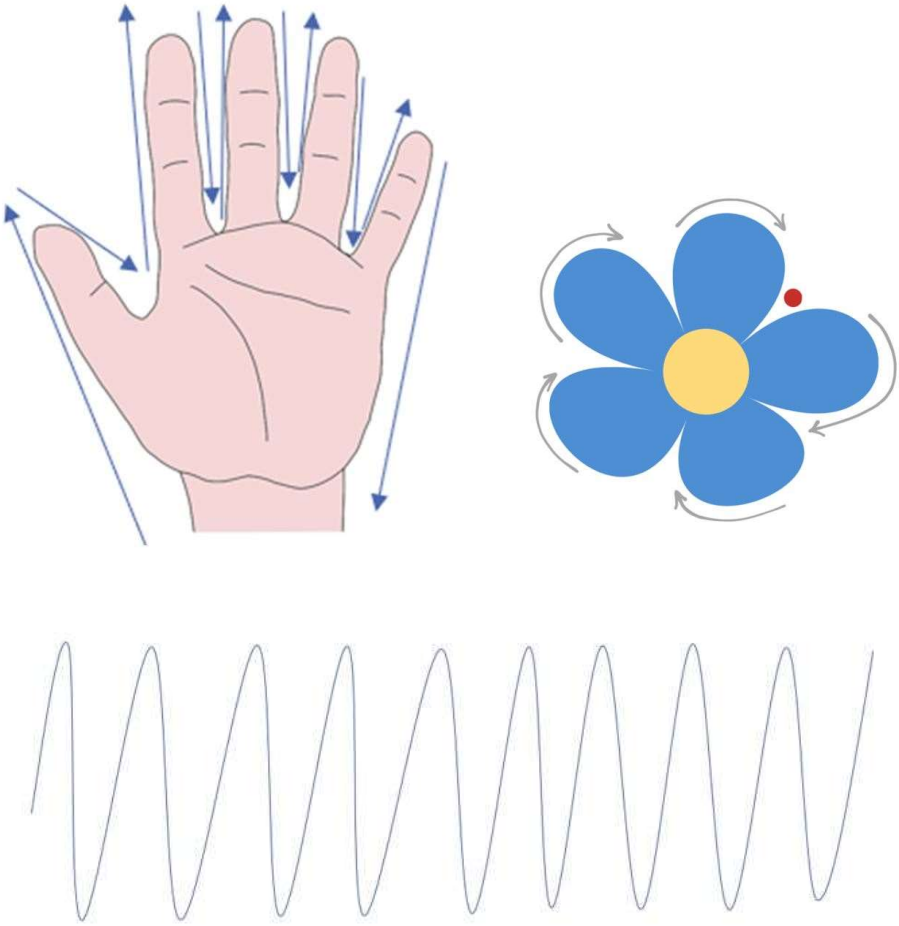
  Give all participants the chance to practice and reflect on/share their experiences
- **Tools:** quiet environment, yoga mat or chair
- **Experience:** When the participants used this breathing exercise it made them feel more calm. It helped them to perform the exercise at home as well

Exercise 2: Breathing by means of a digital visual breathing tool



- **Description:** introduction of a visual breathing tool on internet or an app on an own device
- **Goals:** participants are informed on breathing and the effects of awareness breathing.
- **Method:** individual exercise (in group) for 3-5 minutes. Play the exercise on a large screen. Give all participants the chance to practice and reflect on/share their experiences
- **Tools:**
  https://www.grc.com/breathe.htm (Follow the ball on the line. Adjust the levels correctly.) https://www.youtube.com/watch?v=5DqTuWve9t8
- **Experience:** the combination between looking at the screen and breathing can be challenging for some. This exercise brought calmness when the participants were feeling restless.

Exercise 3: Breathing by means of an analogue visual breathing tool



- **Description:** introduction of a visual breathing exercise
- **Goals:** participants are informed on breathing and the effects of awareness breathing. Participants are offered different breathing exercises (Breathing with hand, figure or curves)
- **Method:** individual exercise (in group) for 3-5 minutes. Participants are provided hand-outs on paper. Participants have to follow the hand/figure/the curves with their finger, corresponding with their breathing. Give all participants the chance to practice and reflect on/share their experiences
- **Tools:**

  Figures hand/figure/curves (see picture above)

  Hand/flower: inhale and exhale by following the arrows

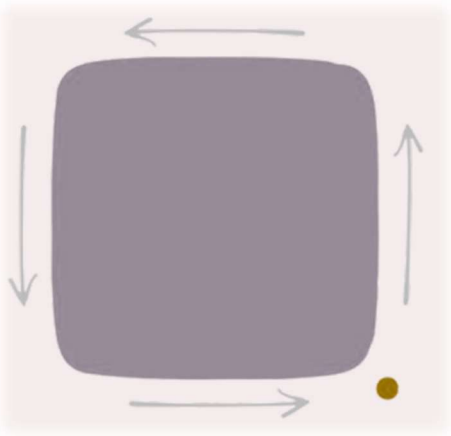
  Curves: Inhale when the curve is going up, exhale when the wave is going down
- **Experience:** the combination between looking at the paper, breathing and following with one hand can be challenging for some (hand-eye coordination)

Additional breathing exercises suitable for people with Young Onset Dementia

Pursed Lip Breathing

- Sit comfortably with your back straight
- Inhale slowly through your nose for a count of four
- Purse your lips as if you were going to whistle
- Exhale slowly and gently through your pursed lips for a count of six
- Repeat for several breaths, focusing on the controlled exhalation

Square Breathing (Box Breathing)



- Sit comfortably and close your eyes if you prefer to do so
- Inhale deeply through your nose for a count of four
- Hold your breath for a count of four
- Exhale slowly and completely through your mouth for a count of four
- Hold your breath for a count of four before beginning the next cycle
- Repeat the cycle for several rounds, focusing on the rhythmic pattern

AlternatingNostril Breathing (Nadi Shodhana)

- Sit comfortably with your back straight and eyes closed
- Use your right thumb to close your right nostril and inhale slowly through your left nostril
- Close your left nostril with your ring finger, and exhale slowly through your right nostril
- Inhale through your right nostril
- Close your right nostril and exhale through your left nostril
- Continue alternating nostrils for several breaths, focusing on the smooth transition between inhaling and exhaling

Guided Imagery Breathing

- Sit or lie down comfortably in a quiet space
- Close your eyes and imagine a peaceful and relaxing scene, such as a serene beach or a tranquil forest
- As you inhale deeply, visualize yourself absorbing the calmness and tranquility of your chosen scene
- As you exhale slowly, release any tension or stress, allowing it to dissipate into the environment
- Continue breathing deeply and visualizing the calming scene for several minutes

Breathing: assignments

Basic: Quiz

1. What is the primary purpose of breathing? (only one answer is possible)
    - To release carbon dioxide from the body
    - **To supply the body with oxygen**
    - To regulate body temperature
    - To expel excess water from the lungs

2. Which of the following muscles is primarily responsible for breathing? (only one answer is possible)
    - Biceps
    - Hamstrings
    - **Diaphragm**
    - Deltoid muscles

3. Which of the following is NOT a benefit of deep breathing? (only one answer is possible)
    - Improved oxygenation
    - **Increased stress levels**
    - Enhanced focus and concentration
    - Better digestion

4. Which breathing technique involves inhaling deeply through the nose, using the belly capacity and exhaling slowly through the mouth? (only one answer is possible)
    - Chest breathing
    - Shallow breathing
    - **Diaphragmatic breathing**
    - Hyperventilation

5. How can breathing exercises benefit young people with dementia? (more than one answer possible)
    - **To promote relaxation**
    - **To improve respiratory function**
    - To increase muscle strength and flexibility
    - **To get in to a calmer state**

Advanced: Case study

Read the following case study and answer the accompanying questions:

Sarah is a 45-year-old woman who has been diagnosed with Young Onset Dementia. She has recently started experiencing difficulties with breathing, according to her family and caregivers. Sarah's dementia has progressed to the point where she requires assistance with daily activities, including eating and personal care.

Questions:

Question 1: **Explain** how stress can affect the breathing?

Question 2: **Identify** the potential risks associated with untreated breathing difficulties in individuals with dementia?

Question 3: **Summarize** which non-pharmacological interventions can be implemented to help manage Sarah's breathing difficulties?

Question 4: **How** can you, as Sarah's caregiver, ensure proper monitoring of her breathing and respiratory status?

Question 5: **Illustrate** some strategies for communicating with Sarah effectively about her breathing difficulties, considering her dementia diagnosis?

Standardised answers

Answer to question 1: People with Young Onset Dementia may experience anxiety, agitation, or panic attacks, which can lead to rapid, shallow breathing or hyperventilation. These breathing patterns can disrupt the balance of oxygen and carbon dioxide in the blood, causing respiratory distress.

Answer to question 2: Untreated breathing difficulties can lead to complications such as respiratory infections, pneumonia, hypoxia (low oxygen levels), and respiratory failure, which can further exacerbate cognitive decline and decrease quality of life.

Answer to question 3: Non-pharmacological interventions for managing breathing difficulties focus on techniques and lifestyle changes that can improve respiratory function without relying on medication.

These interventions can include:

(1) **Breathing exercises:** Techniques like pursed lip breathing, diaphragmatic breathing, and paced breathing can help regulate breathing patterns, reduce shortness of breath, and improve oxygen exchange efficiency.

(2) **Postural adjustments:** Maintaining proper posture, especially during activities that require exertion, can optimize lung function by allowing for maximum expansion of the lungs.

(3) **Air quality and Temperature regulation:** Minimizing exposure to pollutants, allergens, and irritants in the environment can prevent exacerbation of breathing difficulties. This includes avoiding smoking, using air purifiers, and ensuring adequate ventilation indoors. Keeping indoor environments at a comfortable temperature and avoiding exposure to extreme heat or cold can help manage symptoms.

(4) **Relaxation techniques:** Stress and anxiety can exacerbate breathing difficulties. Practices such as meditation, progressive muscle relaxation, and guided imagery can help reduce stress levels and promote relaxation, thereby improving breathing function.

(5) **Hydration:** Maintaining adequate hydration is crucial for thinning mucus secretions, preventing airway obstruction, and supporting overall respiratory function.

Answer to question 4: Caregivers can monitor Sarah's breathing by regularly observing her respiratory rate, rhythm, and effort, as well as looking out for signs of respiratory distress or changes in mental status. They should also report any concerns to healthcare providers promptly.

Answer to question 5: Communication strategies may include using simple and clear language, providing reassurance and support, using visual aids or gestures, and involving Sarah in decision-making.

Breathing: advanced further reading and references

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3. Mindfulness

Mindfulness: rationale and learning goals

Mindfulness is the practice of **awareness at the present moment** by experiencing **thoughts, feelings, bodily sensations and the surrounding environment**.

It can be explained as being fully present and having awareness of senses and feelings by blocking out the surroundings. An important aspect is to **experience the present now without judgement and interruption**.

Paying more attention to the present moment could improve mental wellbeing and support cognitive capacity.

Mindfulness in Young Onset Dementia can:

- alleviate worries
- enable the focus on the present
- provide relaxation and distraction

Teaching mindfulness is feasible, particularly in early stages of dementia and can be adapted in a dementia friendly manner by evaluating and adjusting it to the individuals' current state.

Learning goals: After completing this part, participants can…

Basic

- Explain the definition of mindfulness
- Identify the effect/ impact of mindfulness
- Illustrate how mindfulness can be applied for people with Young Onset Dementia (OSD)
- Describe what is needed to practice it (conditions)

Advanced

- Apply tips and good practices in mindfulness
- Prioritize which tips and good practices can be used in specific situations

Mindfulness: theory

Mindfulness is awareness of the present moment without judgement. Mindfulness is a holistic intervention for reducing stress through cultivating present awareness, emotional regulation, and positive thinking.

Regular practice of mindfulness has been described to:

- lower heartrate and decreases blood pressure
- reduce cortisol levels and experienced stress/distress
- activate regions of the brain associated with attention emotional regulation and empathy
- foster overall mental and physical health
- decrease anxiety, depression and pain
- improve mental health-related quality of life
- improve quality of sleep and relaxation
- support personal accomplishment and self-compassion

Mindfulness practice is proven to have an effect on three specific immune system processes:

- inflammation
- cell-mediated immunity
- biological ageing

Mindfulness can be practiced in various contexts:

- during a meditation session
- during daily activities like walking or eating to enhance focus
- as a part of therapy or a training session

Practicing mindfulness may also help individuals **to notice signs of stress or anxiety** earlier and to deal with them better. Mindfulness can be seen as an ongoing trait and practice of **awareness** leading to **acceptance of thoughts** which can lead to (new) **actions**.

Mindfulness based interventions can also support **informal caregivers** in dealing with similar feelings when confronted with a family member showing symptoms of dementia. Therefore it should be considered to involve informal caregivers when mindfulness-based interventions are being introduced to people with Young Onset Dementia.

Mindfulness: interventions and exercises

Exercise 1: Storytelling

- **Description:** explaining what mindfulness is by telling a story
- **Goal:** telling a story can bring the group together and can provide rest in the group. It provides an opportunity for meaningful interaction, stimulation and enjoyment in the moment.
- **Method:** let everyone take a seat quietly. Read the story and explain what mindfulness is. Combining storytelling with mindfulness can really help people with dementia feel better. It makes them more focused, helps them feel present in the moment.
- **Tools:** a quiet environment. Sit in the middle of the group so that everyone sees and hears you.
- **Experience:** the participants were relaxed during the reading. The participants said it was nice to listen and to being read to aloud.

Exercise 2: Mindful walking

- **Description**: mindful walking, being outside and focus on one point
- **Goal**: by focusing on one point you practice your ability to consciously focus and maintain your attention. It helps you to be more aware of the present moment and your surroundings. It helps to keep your mind from wandering. By focusing on one point you can calm yourself and reduce stress. it gives you the opportunity to feel a deeper connection with yourself and the nature around you
- **Method**: plan a walk in the neighborhood. Try to get people to pay attention to sounds, different colors, shapes that they encounter. Then stop at one place. Ask the participant(s) to observe the area. Ask them to pick up something out of the landscape and look at it for one minute. All participants are invited to share what they choose and they are invited to elaborate on why they have chosen this. The following instructions can help to guide the exercise:

  "Think of mindful walking as a slow walk without a destination or a purpose. All you have to do is walk and focus on the experiences that occur in the here and now. You can focus on the here and now by focusing your attention on the way you walk while walking. Notice how your feet touch the ground, how you roll and lift them. Then also pay attention to your body. How does your body feel while walking? You can also focus alternately on your different senses. What do you see around you? What do you smell? What do you hear? What do you feel?"
- **Tools**: it's important to find quiet and safe outdoor locations. Ensure that people with dementia feel comfortable while going outside. The nice thing about mindful walking is that you can do it

anywhere, anytime. It is most pleasant to walk in nature as there you have an extensive view. That makes it easier to pick up something out of the landscape and look at it for one minute

- **Experience**: some participants discovered new things in the landscape and this also stimulated them to talk about this

Exercise 3: Imagery

- **Description**: choosing cards with nature scenes
- **Goal**: choosing a nature picture as a focal point can help you focus attention, reduce stress, develop a sense of connection with nature and stimulate the imagination. It can help to calm down and relax
- **Method**: gather the participants around a large table. Spread the cards with nature scenes on the table. Let each participant choose a card. Ask to look closely at the card and think about why they chose that card. Ask additional questions such as: what do you like about the image? Does the image remind you of anything? Which colours do you like?
- **Tools**: you can easily make the cards (A5 format) with free to use images of nature
- **Experience**: the images enabled the participants to talk about what they liked. It promoted communication and focus. The participants themselves experienced it as something very positive

Mindfulness: assignments

Basic: Quiz

1. What is the core focus of mindfulness (only one answer is possible)
    - Actively avoiding thoughts and emotions
    - Letting go of all feelings of discomfort
    - **Observing thoughts and feelings without judgement**
    - Strive for perfect concentration on one objective

2. What is the definition of mindfulness? (only one answer is possible)
    - It is a general technique of breathing
    - **It is a practice of awareness of senses and feelings**
    - It is a form of intense concentration on a particular object
    - It is a reflection moment of what just happened

3. What could be seen as a goal of mindfulness practice? (only one answer is possible)
    - Learning to ignore negative feelings
    - **To create a feeling of calmness and acceptance of yourself**
    - Avoiding all forms of stress and discomfort

4. How does mindfulness affect physical conditions of a person? (more answers possible)
    - **It improves sleep quality**
    - **It boosts immunsystem and could reduce inflammation**
    - It enhances digestion and causes weight gain
    - **It lowers heartrate, deceases blood pressure and reduces cortisol levels**
    - It accelerates ageing

5. **How can mindfulness benefit individuals with an early stage of dementia?** (only one answer is possible)
    - It improves memory retention
    - **It reduces stress and anxiety**
    - It increases confusion and disorientation
    - It enhances physical strength

Advanced: Case study

Read the case study below and answer the following questions. Write down your answers or discuss the answers with others.

Marc is 58 years old. He used to work as an IT specialist. A few years ago, he had to stop working due to his diagnosis of Young Onset Dementia. Marc lives with his wife An. An works fulltime in an office, her career is in the IT sector as well. They have 2 children who visit them regularly. Marc manages tasks at home using lists they made together. Marc becomes increasingly anxious when handling tasks such as using the dishwasher, vacuuming or baking bread. He notices that some actions don't go as smoothly as they used to. This makes him very nervous and agitated. Sometimes, he also feels anxious as his daily activities don't always go as planned.

Questions:

Question 1: How can practicing mindfulness help Marc to reduce his feelings of nervousness and restlessness when handling tasks?

Question 2: Which specific mindfulness exercises could help Marc experience more calmness and focus during daily activities?

Question 3: What would be important to consider before introducing exercises/interventions or activities?

Question 4: How can you measure that the intervention mindfulness has worked as it was meant to be?

Question 5: How could the local environment be involved in supporting Marc?

Standardised answers

Answer to question 1 (How can practicing mindfulness help Marc to reduce his feelings of nervousness and restlessness when handling tasks?): mindfulness can help Marc to become more aware of his thoughts, emotions and physical sensations in the moment, without judging them. By practicing mindfulness, Marc can learn to recognize and accept his anxiety and nervousness without becoming overwhelmed. This can help him respond to challenging situations with more calmness and clarity.

Answer to question 2 (Which specific mindfulness exercises could help Marc experience more calmness and focus during daily activities?): some mindfulness exercises that can help Marc are:

Breathing exercises: becoming aware of his breathing and focusing on calm, deep breaths can help Marc calm his nerves.

- **Body scan:** a guided meditation in which Marc focuses his attention on different parts of his body can help him release physical tension and feel more relaxed.
- **Mindful walking:** as Marc walks, he can become aware of every step he takes, the sensations in his body and the environment around him, which can help calm his mind.

Answer to question 3 (What would be important to consider before introducing exercises/ interventions or activities?): before introducing mindfulness exercises, it is important to consider Marc's current cognitive abilities and emotional state. The exercises should be adapted to his capacity and comfort level. Marc's family should also be involved to ensure they are aware of the proposed interventions and to provide support where necessary.

Answer to question 4 (How can you measure that the intervention mindfulness has worked as it was meant to be?): the effect of mindfulness interventions can be measured by several factors, such as the level of anxiety and nervousness Marc experiences while performing tasks, his ability to concentrate and his general well-being. This can be followed by regular reviews and conversations with Marc and his family to note any changes.

Answer to question 5 (How could the local environment be involved in supporting Marc?): the environment can be involved in supporting Marc through various initiatives. Simple mindfulness exercises can also be done together with his wife. This gives confidence and ensures that Marc and his wife can focus on something other than what is going wrong. Local organizations can also be engaged to provide information and support to Marc and his family, and to connect them with other people in similar situations for social support and sharing experiences.

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- https://www.eoswetenschap.eu/psyche-brein/welke-wetenschap-zit-er-achter-mindfulness

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- Danish Center for Mindfulness: https://mindfulness.au.dk/en/about-us
- https://mindfulness.au.dk/en/get-started
- Danish research articles: https://mindfulness.au.dk/en/research/publications
- Manglende systematik af stresstiltag, men dokumenteret effekt af mindfulnessbaseret stressreduktion. *Ugeskrift for Læger 2019*, Emilie Hasager Bonde, Lone Overby Fjorback & Lise Juul
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- "God effekt af mindfulness ved symptomer på stress, angst og depression". *Ugeskrift for Læger* (2013) Af Lone Overby Fjorback, Benita Holt Rasmussen og Tua Preuss.
- Rapport: "Mindfulness af danske veteraner – et pilotstudie". Af Tua Preuss, Karen Johanne Pallesen og Lone Fjorback.
- "Mindfulness -baseret kognitiv terapi" – Psykolog Nyt. Af Jacob Piet
- Mindfulness og kvalitet? – Psykolog Nyt. Debatindlæg af Anne Maj van der Velden.

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Other links related to dementia and mindfulness in Denmark:

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German

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- Deutsche Alzheimergesellschaft: https://www.deutsche-alzheimer.de/publikationen and https://www.deutsche-alzheimer.de/fileadmin/Alz/pdf/factsheets/infoblatt6_nichtmedikamentoese_behandlung.pdf
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4. Sleep

Sleep: rationale and learning goals

A good qualitative sleep contributes to several bodily functions such as:

- Recovery and energy
- Cognitive functions
- Both physical and mental health
- Hormonal balance an immunity

Although evidence on sleep problems and insomnia is scarce among **people with Young Onset Dementia** it can be concluded that cognitive decline and late onset dementia have a negative effect on sleep.

Sleep problems such as **sundowning, disrupted sleep and daytime sleepiness** often occur in dementia. Furthermore, people with dementia tend to report a higher number of **experienced nightmares**.

Being aware of **good quality sleep** and gaining insight in **healthy sleep habbits (sleep hygiene)** can contribute to the **prevention and management of sleep problems** in people with Young Onset Dementia.

Learning goals: After completing this part, participants can…

Basic

- Understand sleep cycles
- Understand the importance of sleep
- Give suggestions to improve sleep hygiene/sleep habbits

Advanced

- Know challenges and techniques to explain sleep hygiene to people with Young Onset Dementia

Sleep: theory

Sleep is an essential function that allows your body and mind to recharge, leaving you refreshed and alert when you wake up. Healthy sleep also helps the body remain healthy.

Good sleep provides rest and recovery, supports physical and mental health and facilitates the hormonal and immune system. Furthermore, good sleep aids cognitive functions such as the ability to concentrate, think clearly, and process memories.

How much do we (preferably) sleep?

- Between the ages of 18 and 64 years: 7-9 hours per night
- 65 years and older: 7-8 hours per night

(Sleepfoundation.org)

Our sleep is composed out of several **sleep cycles.** During each cycle you go through different **sleep stages**: the NREM sleep with light sleep (N1, N2) and deep sleep (N3) followed by REM (dream)sleep.

The composition of each cycle, how much time is spent in each sleep stage, changes as the night proceeds.

Figure by Sleep foundation (https://www.sleepfoundation.org/stages-of-sleep)

Healthy sleep habits/behaviour or sleep hygiene

- Stick to regular bedtimes
- Wind down from a busy day
- Take the time to relax before bedtime
- No alcohol before bed
- No caffeine after 3 PM
- No daytime napping longer than 30 min or later than 3 PM
- Don’t exercise too intensively before bed time
- Taking a bath or warm shower can help you relax before bed time (avoid hot temperatures)
- Practicing a breathing exercise before bed time can help you find sleep more easily
- Stop smoking or don’t smoke before bedtime
- Don’t eat too heavy before bedtime
- Keep negative thoughts out of the bedroom: time for renumeration is preferred during the day
- Keep your bedroom for sleep only
- Keep your bedroom tidy, dark and cool

8 TIPS TO IMPROVE YOUR SLEEP HYGIENE

SET A SCHEDULE

Maintain a consistent sleep-wake cycle

CREATE A PRE-SLEEP ROUTINE

Wind down with calming activities before bed

LIMIT DAYTIME NAPPING

No longer dan 30 minutes

LIMIT SCREEN TIME

Reduce exposure to screens, especially before bedtime

OPTIMIZE BEDROOM

Make your bedroom dark, quiet, and cool

WATCH YOUR DIET

Avoid heavy meals, caffeine, and nicotine close to bedtime

STAY ACTIVE

Regular exercise can improve sleep, but avoid vigorous activity close to bedtime

MANAGE STRESS

Practice breathing exercises to ease your mind before sleep

How can poor sleep be treated?

- **Cognitive behavioural Therapy for insomnia (CBT-i)** is a widely used evidence-based treatment for insomnia. The basic components of CBT-I include: 1) sleep restriction, which involves limiting time in bed to consolidate sleep and increase the sleep drive; 2) stimulus control, which involves restricting the behaviors that occur in the bedroom to promote a strong association between sleep and sleep related stimuli; and 3) cognitive restructuring, which addresses maladaptive thoughts and beliefs about sleep in order to decrease sleep-related anxiety. The use of CBT-i has already been shown effective in improving sleep onset latency, sleep efficiency and wake after sleep onset
- **Acceptance and Commitment Therapy (ACT)** is a more evolved version of CBT and also shown useful in treatment of insomnia. ACT is known as a psychological intervention based on modern behavioral psychology in which individuals change their relationships with physical thoughts and feelings such as their sleep. Although there are several parallels between CBT-I and ACT, ACT includes six treatment processes (Hexaflex): Acceptance, Cognitive defusion, Being in the present moment, Self as context, Values, and Committed action

- **Sleep hygiene (or Healthy sleep behaviour/habbits)** is an important addition to CBT-i. Sleep hygiene consists out of general knowledge about sleep (or healthy sleep behaviour) such as nutrition and substance use, regular exercise and bedroom arrangement, sleep-wake regularity and avoidance of daytime naps as well as stress management

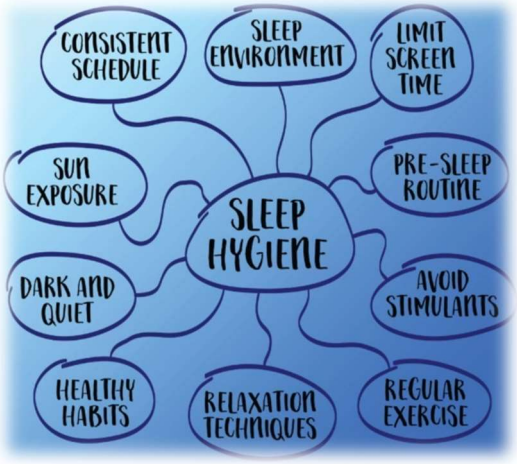
- **Relaxation techniques** such as Breathing exercises and mindfulness

Sleep: interventions and exercises

Exercise 1: Sharing experiences on sleep

- **Description**: a discussion (in group) or conversation/dialogue (in a one-on-one context) on sleep habits can help people with Young Onset Dementia to open up about experiences they have faced/are facing about their sleep
- **Goal**: to talk about experiences, fears regarding (future) sleep and (dis)beliefs about (not) sleeping well
- **Method**: the participants are asked a few questions regarding sleep. There is no right or wrong answer. The goal is merely to reflect on own situations and to listen to other participants.
- **Tools**: questions this exercise can be found in the toolbox of the manual
- **Experience**: not all participants experienced sleep problems, although talking about sleep in general can help understand the importance of sleep

Exercise 2: Discussing sleep hygiene/healthy sleep behaviour



- **Description**: pictures about sleep habits/behaviours are being shown to initiate expression of the participants by means of reflective questions (goal: insight in sleep hygiene)
- **Goal**: to gain insight in good sleep behaviour/habits (sleep hygiene)
- **Method**: all participants are shown a picture or participants get to choose a picture. On the backside of the picture, a reflective question/statement about good/poor sleep behaviour/habits is written. The participants can reflect on their answer. After answering the questions, more information about these sleep behaviours/habits can be discussed.
- **Tools**: pictures and questions/statements about sleep can be found in the toolbox of the manual
- **Experience**: talking about sleep habits helped participant to open up and share about their experiences

Exercise 3: Breathing exercise before bed time

- **Description**: a breathing exercise
- **Goal**: the goal is to teach participants how to focus on their breathing and to have participants experience the relaxation response while performing the exercise
- **Method**: participants are advised to perform these breathing exercises before bedtime (relaxation) and when they are lying awake at night
- **Tools**: more examples of breathing exercises can be found in the chapter 'Breathing exercises' of this e-learning and in the manual
- **Experience**: the participants found the breathing exercises during every session very relaxing. It was difficult for some of them to have a good abdominal breathing while sitting down. Doing these exercises in a reclining position (in bed) could improve abdominal breathing

Sleep: assignments

Basic: Quiz

1. How much sleep does an adult need? (only one option possible)

    - A.5-8h
    - **B.7-9h**
    - C.7-10h

2. How many sleep phases do we have and in what sequence do they occur? (only one option possible)

    - **4 sleep stages going from Awake to light sleep to deep sleep to REM sleep**
    - 4 sleep stages going from Awake to REM sleep to light sleep to deep sleep
    - 3 sleep stages going from deep sleep to REM sleep to light sleep

3. Why is it important to stick to regular bedtime hours? (only one option possible)

    - To keep your biological clock in sync
    - To maintain good sleep behaviour/habits in order for your biological rhythm to be able to help you fall asleep and awake more refreshed
    - In order to increase the change to get enough sleep
    - **All of the above**

4. What are good sleeping habits? (more options are possible)

    - **Take the time to relax before bedtime**
    - No cafeine after 7 PM
    - No daytime napping longer than 90min or later than 3 PM
    - **Don't exercise too intensively before bed**
    - Taking a cold bath or shower can help you relax before bed
    - **Practicing a breathing exercise before bed can help you find sleep more easily**
    - **Stop smoking or don't smoke before bedtime**
    - **Don't eat too heavy before bedtime**
    - **Keep negative thoughts out of the bedroom: time for renumeration is preferred during the day**

5. How can poor sleep be treated? Give two examples of evidence based treatment options for insomnia in general.

Examples of evidence-based treatment options for insomnia in general are:

- Cognitive behavioural Therapy for insomnia (CBT-i)
- Acceptance and commitment therapy (ACT)
- Sleep hygiene/sleep habbits
- Relaxation techniques such as breathing exercises, mindfulness

Advanced: Case study

Read the case study below and answer the following question:

Case study: Peter is 53 years old and living with Alzheimer´s disease. Peter lives with his wife, Luisa and their teenage daughter, Sarah. Peter tells you that he has difficulties falling asleep in the evening. He also wakes up during the night and finds it hard to fall asleep again because he has a lot of worries about the future and he feels stressed about his situation. He often wakes up multiple times during the night and starts walking around the house. Peter and Luisa enjoy their evenings when they drink coffee and see movies. Peter goes to bed at different hours each night and he likes to look at his phone in bed before trying to go to sleep. When Peter doesn´t get his sleep during the night, Peter often takes naps during the day and he tells you that he often gets bored during the day and doesn't know what activities he can do.

Question: What could you suggest to Peter to improve his sleep? Or what could you suggest to Peter to prevent sleep problems?

Standardised answers

Advice you could give Peter to help him sleep better:

- Decrease caffeine consumption after 3 PM
- Alternative activities to replace/decrease screen time in the evening and in bed (smartphone?)
- Stick with regular bedtime hours (in the evening and in the morning)
- Avoid naps during the day or to limit naps to a 30min timeframe. Replace naps by a meaningful activity/think together about meaningful activities (hobbies, voluntary work,…)
- Wind down from the day
- Reduce negative thoughts in the bedroom by offering relaxation techniques (such as mindfulness, breathing exercise,…)
- Discuss with Peter how to cope with awakenings during the night (by offering relaxation techniques, make a crossword puzzle, …)

Sleep: advanced further reading and references

English

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- https://worldsleepsociety.org/
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Dutch

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Danish

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German

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