

Trainers' manual



YOUNG-D

A behavioural program for people with young onset dementia in order to cope with anxiety, stress and sleep problems

Odisee
UNIVERSITY OF APPLIED SCIENCES

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Foreword

This trainers' manual is a product of the overarching **project YOUNG-D**. The YOUNG-D program 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.



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**").



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. This manual can also serve as a fundament for further research or trainers that aim to integrate YOUNG-D in their own setting. However, nothing from this publication may be duplicated, as a whole or in part, by whatever means, without properly citing it's original source.

The following citation should be used to refer to this original work

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

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

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Finally, we would like to give recognition to **all people with young onset dementia** who were involved during the implementation and consultation of this young-D programme.

“Nothing about us without all of us” (Alzheimer Europe)

Background

Late onset dementia (LOD) and young onset dementia (YOD)

Dementia is characterized by a decline in cognitive functions and an occurrence of behavioral abnormalities which may interfere with an individual's activities of daily living. Dysfunctions such as memory loss or dysfunctions of executive functions, language, praxis and gnosis are often present when living with dementia. Dementia usually affects older adults (late onset dementia or LOD), but may also occur in people under the age of 65. This is called young onset dementia (YOD) (Fadil et al., 2009) or young onset dementia (YOD). In order to ensure consistency in this work, the abbreviation YOD will be used.

YOD is often misdiagnosed or diagnosed in a timely manner due to the fact that it has a more varied differential diagnosis than LOD (Fadil et al., 2009). Therefore, clinicians face major diagnostic challenges in YOD. Nevertheless, a prompt diagnosis is essential for adequate counselling and management of the patient (Carter et al., 2018; Pawlowski et al., 2020).

The psychosocial and economic consequences of YOD are often severe. YOD can have a significant impact on an individual's career and productivity, which can result in financial consequences for both the patient's family and society (Fadil et al., 2009). Furthermore, as YOD progresses more aggressively when compared to LOD, and as patients are often diagnosed at a younger age, the age-related psychosocial needs of patients with YOD may differ from those with LOD (Mendez, 2017). Although in practice, the management of YOD is similar to that of LOD, special attention should be given to targeting the specific cognitive areas involved and more age-appropriate psychosocial support and education (Mendez, 2017).

YOD in Europe

The Alzheimer Europe organization has published the prevalence of dementia in Europe in its yearbook for 2019, but it does not include figures for people with YOD. Alzheimer Europe has stated that there is a lack of research and available data on YOD. Therefore, it is currently impossible to publish prevalence estimates for this specific group.

Alzheimer Europe has published an estimated prevalence of young onset dementia for people aged 60-65 years of 0,6% overall, with a specific prevalence of 0,9% for women and 0,2% for men. The prevalence estimate should be interpreted with caution due to the limited age group considered, as it may result in an underestimation (Alzheimer Europe, 2019).

Hendriks et al. (2021) conducted a meta-analysis of reported prevalence of YOD in Europe and the United States, summarizing the results as follows:

“The global age-standardized prevalence was 119.0 per 100 000 population in the maximum age span of 30 to 64 years, 159.4 per 100 000 population in Europe, and 114.7 per 100 000 population in the US. This corresponds to an absolute number of 3.9 million people living with YOD worldwide, of whom 0.5 million live in Europe and 200 000 live in the US.”

(Hendriks et al., 2021)

In 2022, Hendriks et al. published another systematic review and meta-analysis on the global incidence rates of YOD, stating that the global age standardized incidence rate of YOD for people aged 30 to 64 was 11 per 100,000 person-years worldwide, which corresponds to ≈370,000 (95% confidence interval [CI] 230,000- 660,000) new cases each year worldwide. In 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 (Hendriks et al., 2022).

The YOUNG-D EU consortium consists out of partners from four European countries, i.e. Belgium, the Netherlands, Germany and Denmark. Each of these countries has published the prevalence of young onset dementia:

- In **Belgium**, the most recent estimates show that there are currently 1.800 people with YOD living in Flanders (Alzheimer Liga, 2023). According to the Flemish center of Expertise for Dementia, it is estimated that in 2025, there will be 4.464 people with YOD in the Flemish region of Belgium (Expertisecentrum Dementie, 2023). However, it is important to note that these figure should be interpreted with caution, as there are currently no national statistics available.
- In **the Netherlands**, an estimated 15.000 people of the Dutch population are living with YOD (Alzheimer Nederland, 2023).
- In **Germany**, The Deutsche Alzheimer Gesellschaft estimated that currently up to 20.000-24.000 of the Germans are living with YOD. (The Deutsche Alzheimer Gesellschaft, 2023). However, this is likely an underestimation, as the German Center for Neurodegenerative Diseases (DZNE) estimated there were around 73.000 people with dementia between the ages of 30 and 64 in 2018 (Alzheimer Europe, 2019; DZNE, 2023).
- In **Denmark**, 3.000 of the Danish are registered with the diagnosis of YOD (Danish Dementia Research Center, 2023).

Although the prevalences of YOD have been published, all included sources indicate 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 may be outdated and underestimate the real prevalence of YOD. However, it is clear that individuals with YOD or individuals in a prodromal stage of YOD (Stella et al., 2014) have different needs compared to those with late onset dementia (LOD). Therefore, care and interventions for individuals with YOD should be adjusted accordingly.

Alzheimer Europe has expressed a clear and urgent need for further research into the prevalence of dementia in people under the age of 65. Specifically, community-based studies should include this age group (Alzheimer Europe, 2019).

The psychosocial impact of YOD

The prodromal stage of dementia is often accompanied by symptoms such as depression, anxiety, apathy, irritability, agitation and sleep disorders (Stella et al., 2014). Additionally, the behavioral and psychological symptoms of dementia (BPSD) include agitation, aggression, depression, apathy agitation and sleep changes (Cerejeira et al., 2012; Cloack and Al Khahili, 2023). Given that YOD is accompanied by increased anxiety, stress and sleep problems, specific needs arise in the treatment of young onset dementia (YOUNGD.eu, 2023).

Although the symptoms of YOD often impact the quality of life of both the person with YOD and their informal caregiver, current care interventions for people with YOD often fail to address the management or maintenance of healthy stress levels, decreased anxiety and healthy sleep patterns (Vanderlinden and Musch, 2022). Due to the fact that the group of individuals with YOD is often understudied, there is a lack of evidence regarding the effects of programs that address anxiety, stress and sleep in YOD.

Van Vliet et al. (2017) conducted a qualitative study which highlighted the importance of experienced loss, coping, adaptation and available external support in the context of individuals with YOD trying to engage in daily life. Therefore, it is crucial to focus on developing coping mechanisms for people with YOD to manage anxiety, stress and sleep problems.

Draper and Withall (2016) also discussed the impact of YOD on family members. According to Draper and Withall (2016), caregivers such as partners, children and other informal carers often experience unmet needs, feel burdened by care and are at high risk of physical and emotional consequences.

Anxiety, stress and sleep problems in YOD

As previously mentioned, the available care for people with YOD often lacks psychosocial interventions or activities in daily care to help them cope with anxiety, stress and sleep problems. In response to that, Odisee University of Applied Sciences in Belgium initiated a research project in 2019. In the JONG-D research project, Dr. Julie Vanderlinden and Drs. Liza Musch aimed to identify the needs of individuals with YOD in relation to anxiety, stress and sleep (Vanderlinden and Musch, 2019).

Using this needs assessment and working in collaboration with care partners in Flanders (“Familiezorg Oost-Vlaanderen”), a six-week psychosocial program was developed and implemented on a weekly basis. The JONG-D program aims to improve health literacy and coping skills for individuals with YOD who experience stress, anxiety and sleep problems. The program consists of six weekly one-hour sessions held at day care centers for individuals with YOD. The program has been piloted in multiple day care centers for individuals with YOD.

Due to the rising prevalence of YOD in Europe, the JONG-D program will now be translated into a European program known as YOUNG-D. Odisee University of Applied Sciences has formed an EU consortium consisting of seven partners from Belgium, The Netherlands, Germany and Denmark in 2022. The consortium’s objective is to translate, revise and implement the YOUNG-D program in these countries. The Erasmus+ Programme of the European Union is co-funding this consortium.

Psychosocial programs for YOD

Richardson et al. (2016) conducted a review study summarizing the impact of psychosocial interventions for people with YOD and their family carers. The final review included only three studies, highlighting the scarcity of research conducted in this area. The interventions involved participants performing gardening tasks, voluntary work or work tasks alongside an allocated buddy. Although the interventions primarily focused on meaningful activities and physical stimulation, none of them addressed emotions, feelings or sleep. However, participants reported improved self-esteem, a sense of value, purpose, self-worth and social inclusion. Additionally, carers reported benefits for the participants, such as improved sleep, mood and orientation (Richardson et al., 2016).

Similarly, a scoping review by de Mettelinge et al. (2021) concluded that coping and (non-pharmacological) treatment strategies for YOD are non-existent, despite the growing attention for YOD. Richardson (2016) also emphasized the importance of tailored interventions to support individuals with YOD and their specific needs.

According to a research guide published by Dementia Enquirers, it is recommended to offer sessions to people with dementia in small groups of 6-10 people. Additionally, the duration of each session should be limited to 1 hour-1,5 hours to maintain the participants’ concentration and attention span (Dementia Enquirers, 2019). The suggested method is to conduct group discussions. A group

discussion is a conversation among a group of people who respond to questions or statements from the trainer. It provides an opportunity for participants to share their ideas or opinions with others in the group. These discussions are a simple way to hear about other people's perspectives. As the group size is limited, these discussions are not too intense or individualized. During discussions, a facilitator is typically present to guide the discussion, take notes and request clarification when necessary (Dementia Enquirers, 2019).

Considering the gap in literature and the suggested recommendations for future research in YOD, it is recommended that future interventions focus on non-pharmaceutical methods to enhance the coping mechanisms of individuals with YOD. These interventions should aim to counteract the psychosocial impact of YOD and require further extensive research.

A program to reduce anxiety, stress and sleep problems in YOD: the YOUNG-D program



Overall aim of YOUNG-D

This YOUNG-D program is part of the overarching YOUNG-D project. The overall aim of this **project** is to increase awareness and coping skills on anxiety, stress and sleep problems in YOD for (1) people with YOD and (2) (future) health care providers in YOD in the included EU-partners.

- The **YOUNG-D program** aims to enhance the competences of individuals with YOD to cope with anxiety, stress and sleep problems.
- The **trainers' manual** aims to enhance the competences of trainers to offer the YOUNG-D program to individuals with YOD in their own setting.

Additional information about this project can be found at: <https://www.youngd.eu/>

Rationale for the composition of the YOUNG-D program

The young-D program consists out of several sessions that cover effective methods, including breathing exercises, mindfulness and Cognitive Behavioral Therapy for insomnia (CBT-i), sleep hygiene and Acceptance and Commitment Therapy (ACT).

Breathing exercises

Deep breathing exercises are a simple and time-efficient technique that does not require specialized equipment, making it accessible in a wide variety of settings (Tavoian et al., 2023). Additionally, literature has described the positive effects of deep and slow breathing on anxiety and stress levels:

- Diaphragmatic breathing (DB) is a slow and deep breathing technique that affects the brain and various bodily systems (the cardiovascular, respiratory and gastrointestinal system) by influencing the autonomic nervous functions (Hamasaki, 2021). DB exercises have been shown to reduce stress, treat eating disorders, chronic functional constipation, hypertension, migraine and anxiety and improve quality of life (Hamasaki, 2021).
- Another study by Dass et al. (2022) also describes the positive effects of synchronized and controlled breathing in asthma patients. This type of breathing can reduce stress, strain and anxiety and change behavior, as well as improve the immune system and the strength/endurance of the respiratory muscles (Dass et al, 2022).
- Naik et al. (2018) conducted a study which demonstrated that a 12-week intervention of slow breathing exercise training significantly reduced perceived stress levels in healthy males.
- Tavoian et al. (2023) also reported positive effects of deep breathing at work on employee stress levels .

Although breath work and deep breathing have been reported to reduce anxiety and stress and improve sleep outcomes, there is currently no research on the effect of deep breathing in dementia. James et al. (2021) conducted a small powered study on the effects of breathing on informal caregivers of people with dementia. Additionally, Min et al. (2023) reported on the preventive value of breathwork in the etiology of Alzheimer's' disease. Slow-paced breathing, via heart rate variability (HRV) biofeedback, stimulates vagus-nerve pathways that counter noradrenergic mechanisms in stress and arousal pathways. This can influence the production and clearance of Alzheimer's disease (AD)-related proteins (Min et al., 2023). While breathing exercises have been proven effective in reducing anxiety and stress, as well as in improving sleep, further examination is needed to determine the effectiveness of breathwork as an intervention for people with dementia. Given the limited research on breath work in dementia, it is possible to extrapolate the importance and potential health benefits of breath exercises from previous studies conducted on the general population (Dass et al., 2022; Hamasaki, 2021; Naik et al., 2018; Tavoian et al., 2023).

YOUNG-D includes breathing exercises in every session. **Session 1** provides a general introduction to breathing and exercises are tried out in a group setting, either self-guided or with audio. **Session 4** is entirely devoted to breath work, where several exercises are introduced to participants providing an opportunity to experience and exercise. Additionally, a short breathing exercise (3-5 minutes) is provided at the beginning and the end of **sessions 2-6**.

Mindfulness

Mindfulness is the practice of gently focusing awareness on the present moment by experiencing thoughts, feelings, bodily sensations and surrounding environment through a gentle nurturing lens. Paying more attention to the present moment – to thoughts and feelings and to the world around – can improve mental wellbeing (NationalHealthService).

- Mindfulness-based stress reduction programs (MBSR) have been researched as a potential holistic intervention for reducing stress by cultivating present awareness, regulating emotions and promoting positive thinking (Green and Kinchen, 2021).
- The effects of mindfulness were also described in a review study of Janssen et al. (2018). It was found that implementing mindfulness-based interventions in employees reduced levels of emotional exhaustion, stress, psychological distress, depression and anxiety. Additionally, improvements were observed in terms of personal accomplishment, self-compassion, quality of sleep and relaxation (Janssen et al., 2018).
- Mindfulness meditation programs showed moderate evidence of improving anxiety, depression and pain and low evidence of improving stress/distress and mental health-related quality of life (Goyal et al., 2014).

Research has been conducted on the use of mindfulness-based interventions (MBI) in dementia, but evidence is limited (Berk et al., 2018). According to the review study of Berk et al. (2018). MBI did enhance well-being, resilience and autonomy in the participants with dementia in the included studies. A more recent study by Giulietti et al. (2023) found that MBI training is effective in improving the quality of life and preventing deterioration in patients with early-stage Alzheimer's dementia (Giulietti et al., 2023).

“Some people with dementia and carers find mindfulness helpful as a way of relaxing and reflecting.”

(Livingwithdementiatoolkit.co.uk)

In **YOUNG-D**, mindfulness is primarily covered in **session 5**, during which several mindfulness exercises are performed. Additionally, mindful breathing exercises will be included in **sessions 2-6**.

Cognitive Behavioral Therapy for insomnia (CBT-i), sleep hygiene and Acceptance and Commitment Therapy (ACT)

Cognitive Behavioral Therapy for insomnia (CBT-i) is a widely used evidence-based treatment for insomnia. The three main components of CBT-i are: 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 (Koffel et al., 2014). Additionally, sleep hygiene is an important addition to CBT-i. Sleep hygiene comprises knowledge about sleep, including nutrition and substance use, regular exercise, bedroom arrangement, sleep-wake regularity, avoidance of daytime naps and stress management (Chung et al., 2018).

CBT-i has been demonstrated to be effective in improving sleep onset latency, sleep efficiency and wake after sleep onset (Geiger-Brown, 2015; Koffel et al., 2014). In conclusion, CBT-i is an effective and durable treatment for comorbid insomnia (Geiger-Brown, 2015).

In addition to CBT-i, Acceptance and Commitment Therapy (ACT) is a more advanced version of CBT and has also been shown to be effective in treating 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 similarities between CBT-i and ACT, ACT includes six treatment processes (Hexaflex). Salari et al. (2020) identified six key components of ACT: Acceptance, Cognitive defusion, Being in the present moment, Self as context, Values, and Committed action (See Figure 1).

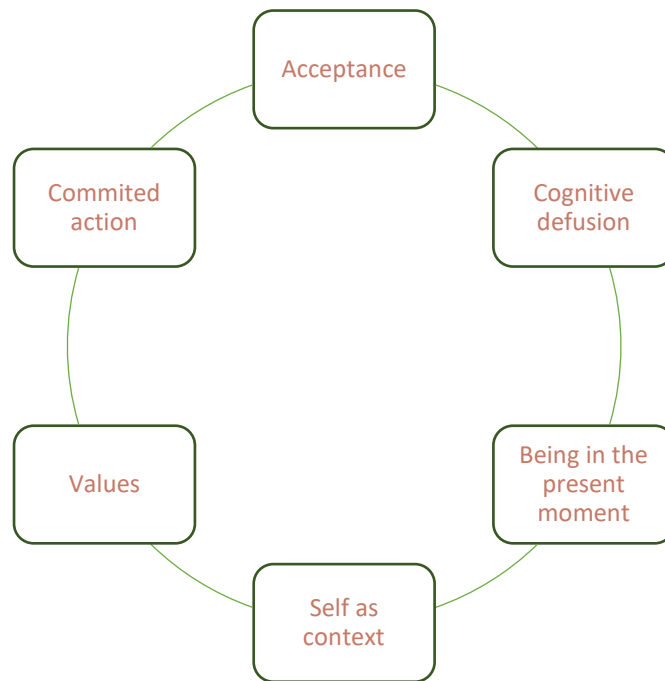


Figure 1: The hexaflex model (ACT)

Although evidence on CBT-I and ACT in dementia is limited and often inconclusive, a few studies have examined the effect of CBT-i in people with mild cognitive impairment and dementia (Jin et al., 2021; Kraus et al., 2008; O’Coaimh et al., 2018; , Robinson et al., 2023). Jin et al. (2021) conducted a review of the evidence on the effects of CBT-i. They concluded that CBT-i is associated with improvements in anxiety (Kraus et al., 2008), depression, and quality of life in people with mild cognitive impairment and dementia. The study found that CBT-i showed a reduction in insomnia and improvements in sleep quality (Jin et al., 2021).

YOUNG-D integrates aspects of both CBT(-i) and ACT to address anxiety, stress and sleep problems. **Session 2** covers general education on healthy sleep habits (sleep hygiene and stimulus control), as well as acceptance, cognitive defusion and cognitive restructuring. In **session 3**, group discussions focus on reflections on emotions, stress and sleep and their impact on daily life, using self as context and values. **Session 4** includes mindfulness as part of ACT (Being present in the moment).

The YOUNG-D program: considerations for implementation

YOUNG-D is a six-week (weekly) program offered in (day care) centers for people with young onset dementia.

Basic requirements

- The ideal **group size** varies between **4 and max. 8** people with YOD;
- **Each session** will have **two facilitators** available per center, one trainer and one support person;
- The program is designed for individuals with YOD. It is recommended that informal caregivers/care partners are informed about the program to encourage individuals with YOD to continue performing the exercises they learned during the program at home.
 - *It is important to note that the YOUNG-D program is being piloted for the first time in the EU-partners. The main objective of the program is to provide sessions and exercises in centers for YOD. After completing the program, all centers are advised to consider methods to motivate participants and informal caregivers to continue their exercises at home.*
- The program lasts for **six weeks**;
- The **trainer** for this program should be a professional with a background in YOD and is preferably already familiar with the participants. During the YOUNG-D program, the trainer receives information on each session and takes part in the meetings;
- Ideally, the sessions should take place in a **separate room** within the center;
- The materials used during each session are specified per session. The trainer should ensure that all necessary materials are available on site;
- Each center should provide **follow-up** for participants after each session.

Information for organizations that offer the YOUNG-D program

- Each organization is free to conduct an intake with the person with YOD before the program begins;
- Each organization may set additional exclusion criteria in line with a non-discrimination policy. The overall inclusion criteria are people with YOD;
- Each organization may also provide separate (parallel) sessions for informal caregivers/care partners;
- Each organization has the freedom to choose whether to extend the program's duration in terms of the number of weeks or the frequency of sessions per week, depending on their practical organization;
- Each organization has the option to develop and provide handouts or program information to the participants or informal caregivers/care partners.

Information for participants

- Participation in YOUNG-D is voluntary and free for all participants;
- All participants are welcome to contribute their input/reflections during the sessions, but it is not mandatory;
- It is important that all participants respect each other's input/reflections and the trainer on site should ensure this during the sessions;

Evaluation of the program

- In order to evaluate the YOUNG-D program upon completion of the pilot, a redefinition will be carried out. The evaluation of the YOUNG-D program will be conducted using:
 - Attendance of participants and trainers;

- Impressions of the participants through an informal, low-threshold inquiry at the end of each session.
 - E.g. Is there anything you liked/disliked in this session? Did you have any positive or negative feedback about this session? How did you feel about the exercises? Are you capable of performing this exercise independently, or do you require further guidance? Is there someone available to provide this guidance?
- Impressions of the trainers through an online survey. The survey included questions about the strengths of the program, as well as any difficulties, pitfalls or challenges encountered during the implementation of the program.

The YOUNG-D program: content per session

Session 1: Getting to know each other and the program

Rationale of the session

During the first session, participants are welcomed to the group and have the opportunity to become acquainted with the trainers and other group members. Following this, participants are introduced to the YOUNG-D program.

The initial task involves a group discussion on the current mood of the participants. A group discussion is an excellent way to become acquainted with other group members. All participants are asked to express how they are currently feeling. The trainer can record the responses on a flipchart or a paper in the middle of the table (mood board). It is crucial to provide all participants the opportunity to speak and share their thoughts if they wish to do so. Participants who choose not to share are free to abstain. The rationale for the program has already explained that expressing emotions and feelings can contribute to coping (Giulietti et al., 2023; Goyal et al., 2014; Green and Kinchen, 2021; Janssen et al., 2018).

Secondly, the participants are introduced to breathing exercises. The trainer can choose between a self-guided breathing exercise or an audio recording, depending on what the participant finds more comfortable. The exercise can be introduced in the following way: “Our breathing often provides insight into our emotions or stress levels. When we feel tense or stressed, our breathing often becomes shallow or superficial. Focusing on our breathing and increasing our awareness of it can lead to a slower breathing pace, which promotes deeper and more profound breathing. This, in turn, can help to reduce bodily tension, anxiety and stress. The exercise described can help individuals become more aware of their own breathing.” (Dass et al., 2022 ; Hamasaki, 2021, ; Naik et al., 2018 ; Tavoian et al., 2023). It is important for the trainer to emphasise that there is no failure in this exercise. Participants cannot fail when performing the exercise. They are welcome to observe before performing the exercise if they wish.

Session goals

- Participants are welcomed to the program and the group (welcome word)
- Participants are given an overview of the YOUNG-D program (introduction)
- Participants are introduced to the trainers and other group members (getting to know each other)
- Participants are given the opportunity to share their current mood with the group, if desired (mood board)
- Participants are then introduced to a breathing exercise (breathing exercise)
- Participants are encouraged to attend the next session

Session methods

This session is expected to last between 60 and 90 minutes (Dementia Enquirers, 2019).

- **Introduction** of the general **theme/aim/program**
- **Getting to know each other**/introduction
- **Mood board** check in (group conversation/picture mood board)
 - Goal: to initiate a group conversation and assess the current mood of the group members
 - Method: ask the participants: “How are you feeling at the moment?”
- End the session with a first **breathing exercise** (audio or self-guided by trainer)
 - Goal: Breathing awareness; short introduction (see rationale)
 - (Session 4 will explore breathing in more depth)
 - Method: Select the most appropriate method for the group:
 - Breathing with hand
 - Breathing with waves / heart
 - In real-time with the trainer or audio tape:
 - Audio recording for mindful breathing
 - Audio recording for abdominal breathing

Evaluation at the end of each session

- The trainer asks open and accessible questions at the end of each session.
- Examples of questions that can be asked:
 - Is there anything you liked/disliked about this session?
 - How did you feel about the exercises?
 - Do you feel confident performing these exercises on your own, or do you need further guidance?
 - Is there anyone available to provide you this guidance?
 - ...
- The trainer welcomes answers from all participants and notes down their reflections after each session.

Follow up

After each session:

- The trainer takes the time to check in with each participant
- The trainer checks if the participant has any questions, comments or concerns they would like to discuss privately
- The trainer records any additional (anonymous) feedback from participants

Toolbox

- Each center may provide an information/flyer for the participant/caregiver
- Breathing exercises
- Audio breathing exercise

Session 2: Sleep

Rationale of the session

Although there is limited evidence on sleep problems and insomnia among people with YOD, existing literature suggests that cognitive decline and LOD have a negative impact on sleep (Cipriani et al., 2015). Promising interventions for preventing and managing sleep problems in people with and without dementia include CBT-i, sleep hygiene and ACT (Chung et al., 2018; Geiger-Brown et al. 2015; Jin et al., 2021; Koffel et al., 2014; Salari et al., 2020,). In addition, regular performance of breathing exercises can also improve sleep (Jerath et al., 2018).

This session introduces participants to the theme of sleep. The trainer begins by inviting all participants to join a breathing exercise. Next, sleep habits are discussed through a group discussion. The trainer poses several general sleep-related questions to the group and invites all participants to share their own experiences. Participants who do not wish to share, may refrain from doing so. Next, the trainer will place several association cards related to sleep on the table/ground. Participants are free to choose a card. The trainer will then ask each participant which card they have chosen and will link it to a few reflective questions on sleep hygiene. The session will conclude with a brief breathing exercise.

Session goals

- Participants are asked a few questions on sleep in general
- Participants are introduced in sleep hygiene (healthy sleep habits)
- Participants are asked to reflect (and share) on their own sleep habits
- Participants are asked to join a breathing exercise

Session methods

- **Start** the session with a three-minute **breathing exercise**

- **Sleep habits**
 - Goal: discussion of sleep habits. It is important for trainers to keep in mind that the goal of this session is not to tackle any sleep problems, but more to create a forum to discuss used sleep habits among participants
 - Method: Use a group discussion (peer-to-peer) or an individual dialogue. Alternatively, consider using a taking jar or group discussion to facilitate the group discussion
 - Examples of questions for the group discussion on sleep:
 - What is sleep? (restful stage)
 - How much sleep does an adult need? (7-9 hours)
 - How is your sleep currently?
 - How much sleep do you get during the night?
 - Do you sleep during the day?
 - What helps you sleep?
 - What interferes/challenges your sleep?
 - Do you sleep throughout the day?



- **Sleep hygiene**

- Goal: to gain insight into sleep hygiene/healthy sleep habits (see figure 2). It is important for the trainer to be prepared and read through background information on healthy sleep habits/sleep hygiene prior to the start of the session.
 - <https://www.thensf.org/>
 - <https://sleepeducation.org/healthy-sleep/healthy-sleep-habits/>
 - <https://www.sleepfoundation.org/sleep-hygiene>
- Method: participants are shown pictures related to sleep and are asked reflective questions to elicit their responses.
 - Examples of pictures and reflective questions (see figure 3):
 - a bed: what makes a good bed/bed room?
 - a cup of coffee: before going to bed, what do you usually eat/drink?
 - a person who is relaxing: how do you unwind after a busy day? What helps you relax?
 - a clock: what time do you usually go to bed and wake up?
 - ...

- **End** the session with a **three-minute breathing exercise**

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 than 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

Figure 2: Infographic on healthy sleep habits/sleep hygiene



Figure 3: pictures to help discuss good sleep habits/sleep hygiene

Evaluation at the end of each session

- The trainer asks open and accessible questions at the end of each session.
- Examples of questions that can be asked:
 - Is there anything you liked/disliked about this session?
 - How did you feel about the exercises?
 - Do you feel confident performing these exercises on your own, or do you need further guidance?
 - Is there anyone available to provide you this guidance?
 - ...
- The trainer welcomes answers from all participants and notes down their reflections after each session.

Follow up

After each session:

- The trainer takes the time to check in with each participant
- The trainer asks if they have any questions, comments or feelings they would like to express privately
- The trainer records any additional (anonymous) feedback from participants

Toolbox

- Audio breathing exercise
- Pictures or pictograms about sleep

Session 3: Emotions and feelings

Rationale of the session

Vandekerckhove and Wang (2017) found that unexpressed emotions or feelings can lead to stress and sleep problems in the general population. Therefore, it is important to be aware of experienced emotions and feelings to promote emotional regulation. Mindfulness (Goyal et al., 2014; Green and Kinchen, 2021; Janssen et al., 2018) and breathing techniques (Hamasaki et al., 2021; Naik et al., 2018; Tavoian et al., 2023) have been shown to be effective in experiencing feelings in the present moment without judgement or the urge to change them. Additionally, CBT and ACT are evidence-based methods for exploring ideas and beliefs about feelings and emotions. These therapies can aid in cognitive restructuring, which can contribute to emotional regulation (Chung et al., 2018; Geiger-Brown et al., 2015; Koffel et al., 2014; Salari et al., 2020).

During this session, participants will be invited to take part in a breathing exercise. Following this, the trainer will present cards with real facial expressions representing basic emotions such as happiness, sadness, anxiety and anger. Participants will then select a card that reflects their current emotional state. The trainers will then lead a group discussion on these facial/emotional expressions, during which coping strategies can be discussed. The session will conclude with another breathing exercise.

Session goals

- Participants are invited to join the breathing exercise
- Participants gain insight into basic human emotions
- Participants are encouraged to reflect on their own current feelings
- Participants are encouraged to share about their coping strategies for managing emotions
- Participants will be able to learn (and be aware about) from each other's experiences with feelings

Session methods

- **Start** the session with a **three-minute breathing exercise**
- **Talking jar/game** with questions about emotions/feelings (group discussion)
 - Goal: to invite participants to reflect on their emotions and feelings
 - Method: the jar/board game contains several cards with questions regarding feelings and emotions.



- Examples of questions for the talking jar
 - How are you feeling today?
 - Can you define the words happy, sad, angry, scared?
 - How do you want to feel?
 - Do you have someone in your network whom you can talk to when you experience emotions such as happiness, sadness, anger or anxiety?
 - ...

Alternative methods: showing association cards (what image reflects your current emotional state?), listening to music (what music makes you happy?/sad?), poems about emotions, art works

- **Cards with emotions**
 - Goal: participants gain insight into different emotions
 - Method 1: all emotions (pictures of real faces) are placed on the table/floor. Participants are then invited to select a picture (see figure 4).
 - Examples of questions for the emotion cards
 - Please share with the group which card you have chosen?
 - What can you see in this picture?
 - Why do you feel this way at the moment?
 - What can help you when you experience this feeling?
 - ...

- Method 2: all emotions (pictures of real faces) are placed on the table/floor. The trainer selects a card with an emotional expression (all emotions are being discussed) and initiates a group discussion.
 - Examples of questions for the emotion cards
 - Do you recognize this emotion?
 - Have you felt like this lately?
 - What sensations do you experience in your thoughts or body when you feel this emotion?
 - What helps you when you feel this emotion?
 - Is there someone you can talk to when you experience this emotion? ...
 - The trainer should inform the participants that it is normal to experience certain emotions. It is possible to feel happy and sad simultaneously, and sometimes we may experience emotions such as anger or anxiety for an extended period. The trainer can reassure participants that it is not necessary to feel happy all the time and that it is important to experience a variety of emotions. Therefore, it is crucial to acknowledge emotions and to learn to accept, to live with and to manage them. The trainer can question the participants how they currently deal with their emotions and who they turn to in their network when they need to discuss these emotions.
 - At the end of this session, the trainer should ensure that all participants have had the opportunity to express/share their feelings, if they wish to do so. Participants who choose not to share are welcome to refrain from doing so. If a participant chooses not to share anything in the group, it may be useful for the trainer to inquire about it informally during an individual meeting with the participant.
- **End** the session with a **three-minute breathing exercise**



Figure 4: Pictures to discuss emotions

Evaluation at the end of each session

- The trainer asks open and accessible questions at the end of each session.
- Examples of questions that can be asked:
 - Is there anything you liked/disliked about this session?
 - How did you feel about the exercises?
 - Do you feel confident performing these exercises on your own, or do you need further guidance?
 - Is there anyone available to provide you this guidance?
 - ...
- The trainer welcomes answers from all participants and notes down their reflections after each session.

Follow up

After each session:

- The trainer takes the time to check in with each participant
- The trainer checks if the participant has any questions, comments or feelings they would like to discuss privately
- The trainer records any additional (anonymous) feedback from participants

Toolbox

- Audio breathing exercise
- Jar with questions/or board game
- Pictures of real faces (with emotional expressions)

Session 4: Breathing

Rationale of the session

Breathing or breath work, also known as deep breathing or focus breathing, can increase awareness of breathing and help control or slow down the pace of breathing. This can stimulate the vagal nerve (parasympathetic nervous system) and is known to reduce anxiety and stress (Dass et al., 2022; Hamasaki, 2021; Naik et al., 2018; Tavoian et al., 2023).

In this session, the trainer provides various methods to begin breath work. Firstly, the trainer begins with a brief breathing exercise (similar to those in previous sessions). The trainer can choose to use a self-guided breathing exercise or an audio recording if it feels more comfortable.

The exercise can be introduced by stating that: “Our breathing can often indicate our feelings or stress levels. When we are tense or stressed, our breathing may feel shallow or superficial. By focusing on our breathing and by becoming more aware of our breathing patterns, we can slow down our breathing pace, which can help us breathe more deeply and profoundly. Slow and deep breathing can help to slow down the body and the brain and reduces bodily tension, anxiety and stress. This exercise can increase awareness of your own breathing. It is important for the trainer to note that there is no failure in this exercise which means that participants can’t fail when performing the exercise. Participants are welcome to observe the exercise being performed by the trainer/the other participants, if that makes them more at ease.

Session goals

- Participants are welcomed to join the breathing exercises
- Participants are informed on breathing, and the effects of slow/awareness breathing
- Participants are offered different breathing techniques and exercises
- Participants are invited to share their experiences about their breathing exercises

Session methods

- **Start** the session with a **three-minute breathing exercise**

- Introduction of the **visual breathing tool** (or an app on own device)
 - Examples of visual breathing tools
 - <https://www.grc.com/breathe.htm>
 - https://www.youtube.com/watch?v=bF_1ZiFta-E
 - <https://www.youtube.com/watch?v=5DqTuWve9t8>
 - <https://words.jamoe.org/46-breathing/>
 - Individual exercise (in group) for 3-5 minutes
 - Introduce a 'tour de table' after the session (give all participants the opportunity to reflect and provide their answers)

- Introduction of **visual breathing exercises**
 - Examples of visual breathing exercises
 - Hand: follow the curves of the fingers (see figure 5)
 - Waves: follow the curves of the wave/curve (see figure 6)
 - Individual exercise (in group) for 3-5 minutes
 - Introduce a 'tour de table' after the session

- **End** the session with a **three-minute breathing exercise**

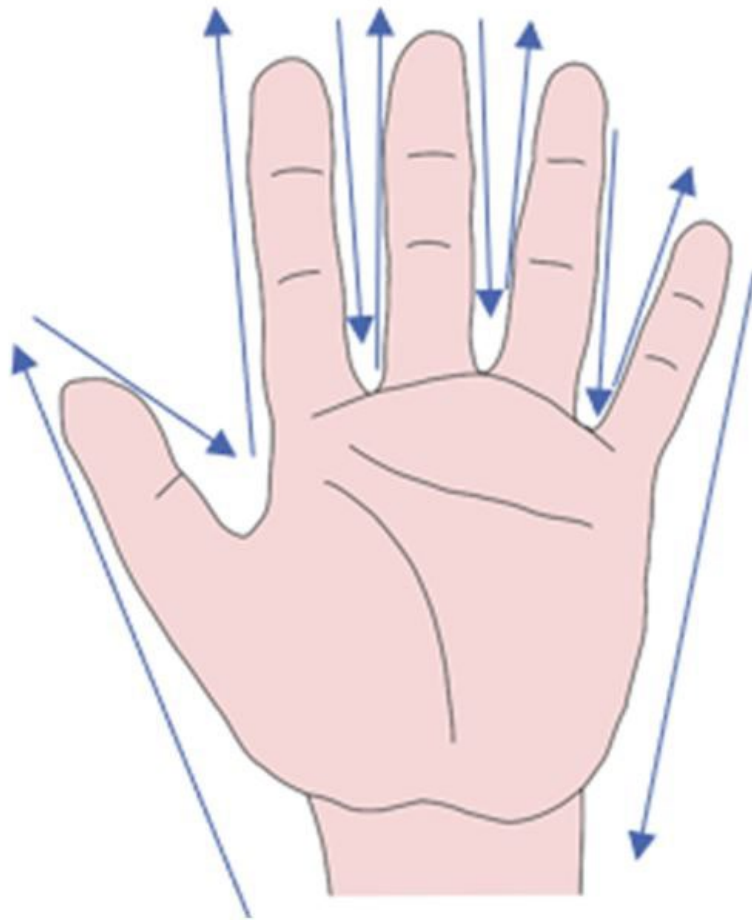


Figure 5: visual breathing exercise (hand)

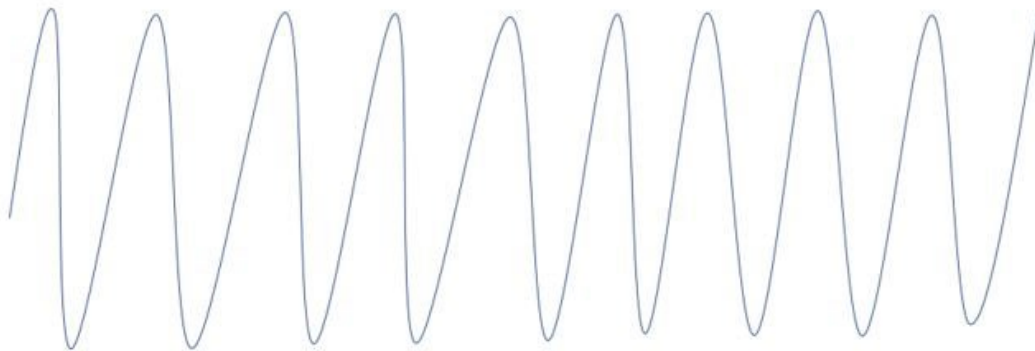


Figure 6: visual breathing exercise (wave/curve)

Evaluation at the end of each session

- The trainer asks open and accessible questions at the end of each session.
- Examples of questions that can be asked:
 - Is there anything you liked/disliked about this session?
 - How did you feel about the exercises?
 - Do you feel confident performing these exercises on your own, or do you need further guidance?
 - Is there anyone available to provide you this guidance?
 - ...
- The trainer welcomes answers from all participants and notes down their reflections after each session.

Follow up

After each session:

- The trainer takes the time to check in with each participant
- The trainer checks if the participant has any questions, comments or concerns they would like to discuss privately
- The trainer takes notes on any additional (anonymous) feedback from participants

Toolbox

- Audio breathing exercise
- WIFI connection
- Visual breathing app on a tablet/own device (free)
- Information on breathing exercises

Session 5: Mindfulness

Rationale of the session

Mindfulness and mindfulness-based interventions have been shown to effectively reduce anxiety, stress and sleep problems (Goyal et al., 2014; Green and Kinchen, 2021; Janssen et al., 2018). Additionally, mindfulness has been suggested as a preventive technique for Alzheimer's' disease (Giulietti et al., 2023). The rationale for including mindfulness in the YOUNG-D program was previously explained in this document.

During this session, participants are invited to engage in a breathing exercise. This will be followed by a mindful movement activity led by the trainer. This can take the form of a (short) walk outdoors or an indoor movement activity if necessary due to the participant's mobility, weather conditions or safety concerns). The trainer may choose to incorporate natural elements or association cards into the activity. During this exercise, the trainer invites participants to select an element from nature during the walk or choose an association card they like. The participants will then be asked to observe the chosen item for one minute, adopting a curious researcher's perspective without judgement or the urge to alter the item. Afterward, participants are encouraged to share their experiences by answering reflective questions. Finally, the trainer could introduce a mindfulness exercise using a raisin or piece of chocolate.

An example of such an exercise can be found at:

https://universitycollege.okstate.edu/lasso/site_files/documents/the_raisin_method.pdf

Session goals

- The participants are welcomed to join the breathing exercise
- The participants are introduced to a mindful movement/exercise
- The participants are invited to share their experiences on these mindful exercises

Session methods

- **Start** the session with a **three-minute breathing exercise**

- **Mindful movement**
 - Goal: introduction of mindfulness in their daily walk
 - Method 1: the participants are taken outside by the trainer
 - Plan a short walk (taking into account the physical level of the participants)
 - Choose a resting place (preferably in a natural or green area/park)
 - Ask the participants to focus on one thing (such as an object, a tree, a bench,...) and practice mindfulness by looking at it for one minute
 - Ask them to share which object they chose and why
 - Ask them to describe the object
 - End the exercise with a brief guided breathing exercise and return to the day care center/original location
 - Method 2: if walking outdoors is not possible, the trainer will invite participants to engage in a mindful movement exercise indoors
 - The trainer should start the session with a short warm-up. This should include stretches for the arms, hands, upper body, neck, legs and feet
 - The trainer places several association cards about nature on the table (e.g. sea, mountains, sun, flowers, sand, lavender, grass, fields, moss, birds, farms,...) (see figure 7)
 - Each participant is invited to select an association card they like and spend one minute looking at it
 - Then, participants are invited to describe what they saw/noticed
 - The exercise should end with a short guided breathing exercise

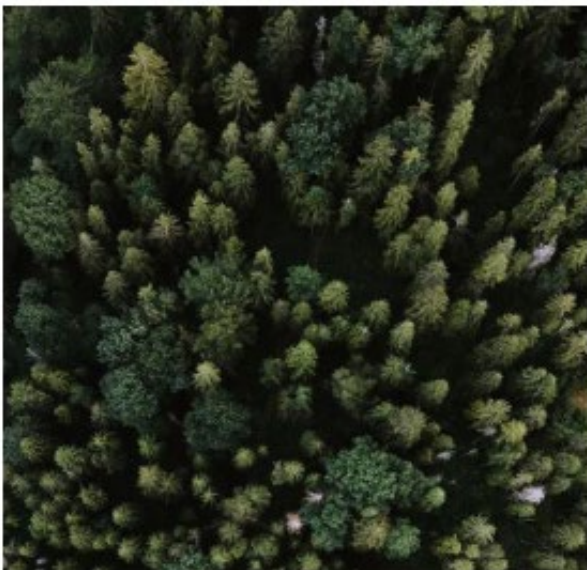


Figure 7: association cards about nature

- **Mindful exercise**
 - Goal: an alternative exercise to introduce mindfulness into daily life situations
 - Method: the trainer distributes a raisin or piece of chocolate to each participant, with prior consideration for any dietary intolerances of participants
 - The trainer instructs the participants to observe the object using their senses (watch it, listen to it, feel it, smell it, taste it, ...) for one minute
 - The trainer invites the participants to share their experiences with the group, including any unexpected experiences
 - Examples of questions that can be asked:
 - What did you see when holding the raisin/piece of chocolate?
 - What did you hear when holding the raisin/piece of chocolate?
 - What did you feel when holding the raisin/piece of chocolate?
 - What did you smell when holding the raisin/piece of chocolate?
 - What did you experience when tasting the raisin/piece of chocolate
 - ...
- **End** the session with a **three-minute breathing exercise**

Evaluation at the end of each session

- The trainer asks open and accessible questions at the end of each session.
- Examples of questions that can be asked:
 - Is there anything you liked/disliked about this session?
 - How did you feel about the exercises?
 - Do you feel confident performing these exercises on your own, or do you need further guidance?
 - Is there anyone available to provide you this guidance?
 - ...
- The trainer welcomes answers from all participants and notes down their reflections after each session.

Follow up

After each session:

- The trainer takes the time to check in with each participant
- The trainer checks if the participant has any questions, comments or concerns they would like to discuss privately
- The trainer records any additional (anonymous) feedback from participants

Toolbox

- Audio breathing exercise
- Scheduled walk around the center
- Cards with themes of nature on it
- Piece of chocolate or a raisin per participant

Session 6: Wrap up of all sessions/integration

Rationale of the session

During this session, the trainer and group will review all items covered in previous sessions. The aim of this final session is to reinforce important concepts and provide additional opportunities for discussion and exercises. Participants can also reflect on how to implement what they have learned at home.

Session goals

- Participants are welcomed to join the breathing exercise
- Participants are invited to share their experiences of the exercises
- Participants are invited to share their experiences of program YOUNG-D
- Participants are invited to share their experiences with peers/caregivers

Session methods

- **Start the session with a three-minute breathing exercise**

- **Moodboard:** how do you currently feel? (group discussion)
 - Goal: exploration of current emotions
 - Method: jar of questions or board game
 - Examples of questions for the talking jar
 - How do you feel today?
 - Can you describe what happiness/sadness/anger/anxiety means to you?
 - How do you want to feel?
 - Do you have someone in your network whom you can talk to when you experience emotions such as happiness, sadness, anger or anxiety?

- ...
- **Breathing exercise**
 - Goal: repetition of breathing exercises
 - Method: the participants are free to choose what exercise they wish to perform. The trainer may provide additional explanations of the techniques if necessary.
 - Pick one exercise and perform it in a group. The available exercises are: audio-exercise, breathing by hand curves, breathing with waves and the visual breathing guide.
- **Revision of the program**
 - Goal: reflection on the program
 - Method: group discussion (peer-to-peer discussion)
 - Examples of questions for the group discussion
 - What did you like and what did you dislike in the program?
 - Which exercise helped improve your sleep?
 - Which exercise helped you relax or to wind down?
 - Did you also exercise at home?
 - What exercise/behaviour do you wish to continue?
 - What is required to continue with these exercises? Or what do you want to continue?
 - Why do you want to continue these exercises?
 - How can you introduce this as a new (daily) behaviour?
- **Show and tell**
 - Display the images/brief summary of the activity (with/without the presence of caregivers/care partners)
- **End the session with a three-minute breathing exercise**

Evaluation at the end of each session

- The trainer asks open and accessible questions at the end of each session.
- Examples of questions that can be asked:
 - Is there anything you liked/disliked about this session?
 - How did you feel about the exercises?
 - Do you feel confident performing these exercises on your own, or do you need further guidance?
 - Is there anyone available to provide you this guidance?
 - ...
- The trainer welcomes answers from all participants and notes down their reflections after each session.

Follow up

After each session:

- The trainer takes the time to check in with each participant
- The trainer checks if the participant has any questions, comments or concerns that participants would like to discuss privately
- The trainer takes notes on any additional (anonymous) feedback from participants

Toolbox

- Audio breathing exercise
- Jar with questions for board game
- Pictures that were taken during the program (on the wall of fame/show and tell moment)
- Toolkit for home use: each center is free to provide all participants with exercises to continue performing at home

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List of used abbreviations

- DZNE: Deutsches Zentrum für Neurodegenerative Erkrankungen
- EOD: early onset dementia
- LOD: late onset dementia
- MBI: mindfulness based interventions
- MBSR: Mindfulness-based stress reduction
- NHS: National Health Service
- YOD: Young Onset Dementia
- PI: Principal Investigator