Down and Dementia
in images

an educational toolkit
with short films and teaching material

The package is for caregivers, loved ones and trainers who want to pay attention to it. You can use the whole package for free.

The Down and Dementia educational toolkit focuses on individuals with Down syndrome who are experiencing dementia. It comprises ten cases, each featuring a short film accompanied by instructional materials. Each film highlights one or two symptoms characteristic of dementia in this population.

The designation Down and Dementia is deliberate, reflecting the fact that individuals with Down syndrome have an approximately 80% lifetime risk of developing Alzheimer's dementia.

Lesson **No, that's not your name!**

Decreasing thinking ability

The film in brief

Situation 1: At Anne's work
Anne (50) walks to the front door of her apartment and enters. She moves into the kitchen, where she stands by the coffee machine and carefully inserts two pods. She places two cups underneath, presses the button, and watches the coffee pour. As she does so, she answers a question from her brother, Leendert (off-screen): "What does your day at the sheltered workshop look like?" You see and hear Anne describing her workday in a systematic, precise manner, using multiple ways of expressing time—for example, both "a quarter to ten" and "11:45."

Situation 2: Anne, clearly older and with dementia, lives in a group home
The table is being set. Like every day, the community nurse, Myriam, comes by. "Do you remember my name?" she asks. "Of course," says Anne (60 years old). Myriam helps a little: "My name is Myriam." "I don't think so," Anne responds. "What do you think?" Myriam asks. "Your name is Laurence," Anne replies. "My real name is Myriam," Myriam says. Then Anne gives Myriam a hug and says, "Sorry." A little later, she comes back to it. "I do think I am right about your first name."

All footage is authentic ***and taken from real-life situations.***

Theme

The theme of this lesson is "forgot the name."
Dementia often leads to memory loss (amnesia) and can affect a person's ability to recognize others and remember their correct names. This symptom can be especially painful for family members and loved ones. It is also referred to as disorientation in person. In addition, people with dementia may become confused in other areas, such as time and place. Disorientation in time and place is addressed in other cases.

The case "I am Anne" explores Anne's life story and the onset of her dementia, including early signs such as getting lost. It also provides important context for the other cases; therefore, it is recommended to watch **I am Anne** again.

General questions

1. What do you see and what stands out to you?
2. What could be the problem?
3. How does Myriam respond, and what do you think she is experiencing?
4. What do you notice about the physical environment?
5. How can you help Anne?

In-depth questions

1. What does it take for you to respond to a person with dementia who no longer recognizes you?
2. How might it affect group members if a person with dementia has forgotten their names, and how would you explain this to them?
3. How can you respond when a person with dementia no longer recognizes a loved one?
4. How would you explain to a colleague what you would and would not do in such a situation?
5. Have you had experiences with a resident or family member that are similar to this situation?

There are several ways to respond when a person with dementia does not know a name or uses the wrong name. You may choose to help or gently correct the person; this approach is known as reality orientation. Another option is to redirect attention and avoid correcting the mistake too strongly; this is referred to as validation.

What works—and what does not—varies from person to person and from moment to moment. The situation is often unpredictable. As a professional or informal caregiver, you are the one who must find the most appropriate response. In doing so, you will continually encounter questions, many of which have ethical implications.

Statements for Discussion

1. If a person with dementia no longer recognizes you, you should respond with understanding and help them remember, as not recognizing someone is distressing.
2. If a person with dementia has forgotten a name, relearning and practicing is the best approach.
3. It is understandable that loved ones withdraw or break off contact when a family member with dementia no longer recognizes them, as this is emotionally painful.
4. Family members and informal caregivers are more emotionally affected by these situations than professionals.
5. A person with dementia only remembers the names of people who visit regularly.