Flashcards *Dementia*



- **These flashcards contain information about working with people with dementia in low resource areas.**
- **These Flashcards are made for the use by fieldworkers.**
- **These flashcards are based on the information about dementia from the RehApp.**

rehapp

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What can you do with these flashcards:

- To help guide your visits to families that have a family member with dementia.
- Make an inventory of the needs of the person with dementia and his/her family.
- Learn about the implications of a disability for the person and their family.
- Use them to do an assessment.
- Use them to set goals for a person with dementia.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you monitor process.

Introduction

The number of people with dementia is expected to rise to 152 million by 2050, particularly in low middle income countries (LMIC) where two-thirds of people with dementia live. There is growing pressure on family members to support people with dementia. Caregiving roles are normally assumed by family members as well in some countries as volunteers or community workers within communities. These volunteers, or community workers, are also referred to as fieldworkers.

Enablement developed an application called RehApp which aims to provide practical, easy-to-understand knowledge to fieldworkers about various health-related impairments. These flashcards are for fieldworkers that don't own a smartphone or prefer a hardcopy version to take with them.

Index:

Note: These flashcards contain information about ASD. *The content is organised according to the International Classification on Functioning, Disability and Health domains of the World Health Organization (2012). These cards don't replace the knowledge and skills of health professinals. We advise you to seek their advice first.*

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Dementia

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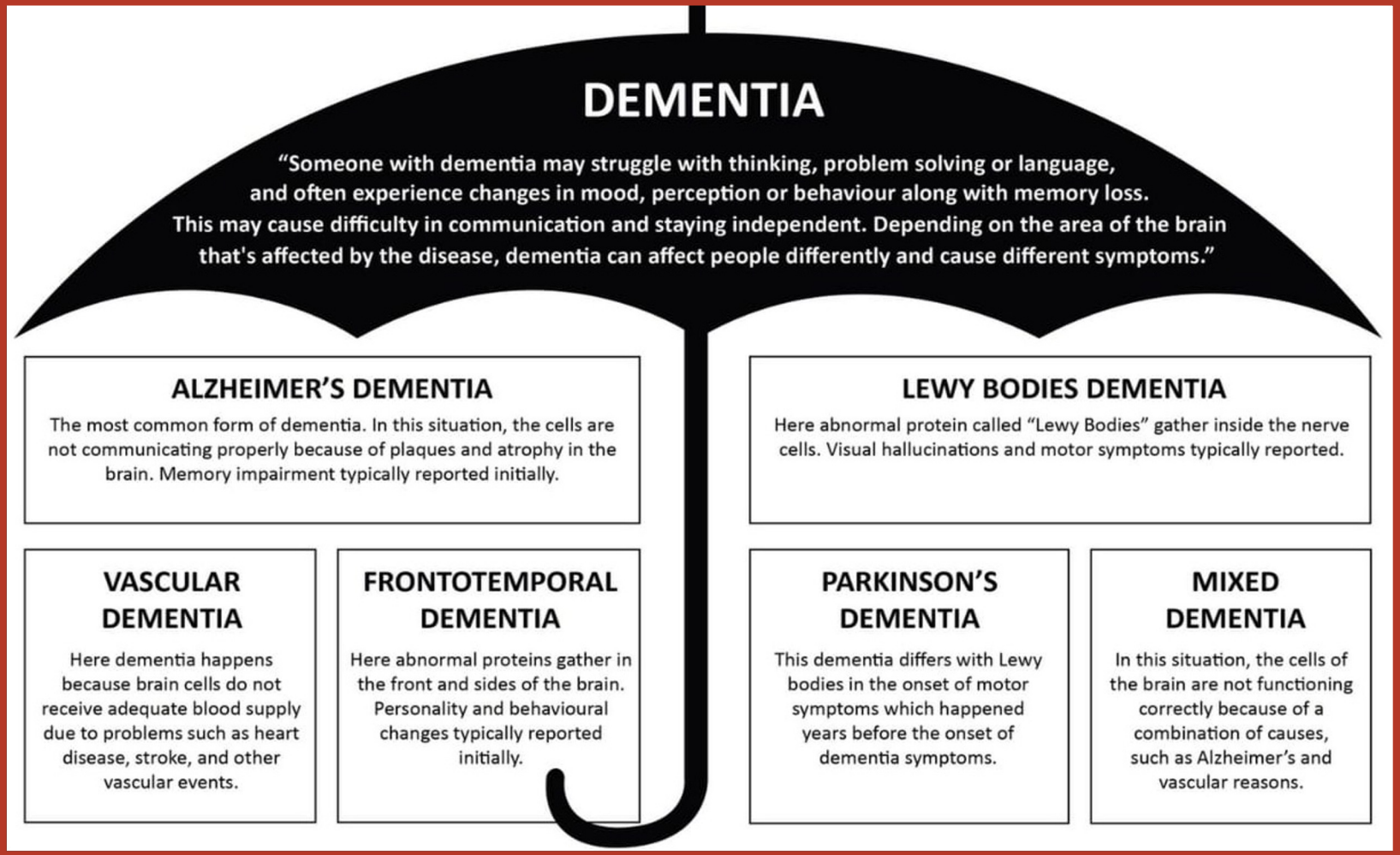
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Card 1

Introduction

What is dementia?

Dementia is an umbrella term for different diseases that involve a **reduction in mental abilities, severe enough to interfere with activities of daily living, which becomes greater over time.** Worldwide, around 50 million people have dementia, and there are nearly 10 million new cases every year. These numbers are expected to almost triple by 2050. Although there is no cure for dementia, **it is certainly manageable.** A family member can support the person with dementia in many ways, especially in their daily activities and maintaining their identity. **Family members who look after people with dementia may experience great physical, emotional, and economic challenges. The guidance offered in these flashcards aims to provide valuable support.**



Card 2

Introduction

Stages of dementia

Early Stages

- Forgetting details of recent events.
- Having difficulties with having a conversation, such as struggling to find words and repeating themselves.
- Behaving in ways that seem odd and misplacing things around the house.
- Showing personality or mood changes.
- Becoming less good at making decisions or plans.



Middle Stages

- Being very forgetful of recent events but remembering events from long ago.
- Needing support with personal care, such as washing and getting dressed.
- Becoming angry, upset, or distressed very quickly.
- Doing things that may be unsafe, such as leaving on a gas cooker.
- Forgetting and mixing up the names of friends or family.
- Being confused about the concept of time and place, e.g., forgetting to eat or drink.
- Losing motivation or interest in people, hobbies, and skills.



Late Stages

- Not being able to remember what they did a few minutes ago or recognize familiar people or objects.
- Problems with controlling bowels and bladder or recognizing when they need to use the toilet and where.
- Sleeping problems and night-time disturbances, e.g., wandering at night.
- A higher risk of harming oneself, especially when agitated, e.g., tripping over objects, grabbing a hot kettle, or sharp objects.
- Need lots of attention and full support in (self) care.



Flow Chart of Early Dementia Detection

Actions to take

Talk with family members. If they notice any signs of dementia (see stages card 2), seek the help of a doctor.

Early detection can make a big difference!



Go to a doctor or general practitioner, as they will perform a clinical assessment, take a medical history, perform physical examinations, and order any needed additional tests.



After suspicion of dementia, the doctor may refer the patient to a dementia-specific specialist, such as a geriatrician, neurologist, psychiatrist, or psychologist, for further advice on medication, lifestyle, safety, etc.



Card 3

Introduction



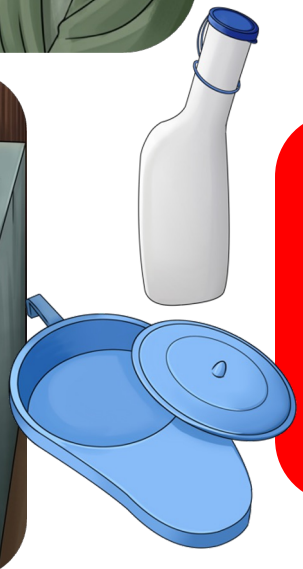












Body functions and structures:

Information and actions to take









Card 5

Body functions and structures

Brain Functions (Memory, Attention, Orientation, and Language)

- **Memory impairments** may be the first common complaints noticed by people with dementia and their families: → Mixing up or forgetting (events, topics, people, or objects), struggling with familiar tasks and finding the right words, and getting lost in the neighbourhood.
- **Attention difficulties** in focusing on tasks or information → Person with dementia may experience their daily routine and complex information becoming stressful and making them feel pressured.
- **Orientation problems** in seeing, hearing, and with time and place → A person with dementia may have difficulties understanding objects and become confused about the real time (day or night, date) and place (where they are now).
- **Language/speech problems** → People with dementia may find it difficult to start or follow an ongoing conversation. They might easily forget the words or the earlier discussed topic or get distracted by others or things around them.



Card 6

Body functions and structures

Actions to take

Coach the person and family members in applying the following actions in daily life. Practice with them if needed.

- Try not to force the person with dementia to remember, as this can make them feel embarrassed and frustrated. Try to support them by giving helpful reminders of the events, person, or object they forget.
- Leave reminders on paper in places they regularly visit and write a daily checklist with them (cross items off as they complete).
- Set a regular daily routine. Double-check whether they remember and understand the information or how to do the task, asking them to re-tell it in their own words.
- Repeat important information regularly and explain things in a simple manner.
- Look at memory books or photo albums together or do other meaningful past activities such as storytelling using photos, objects, videos, music clips, books, tablets, or other digital devices.
- Engage them in arts-based activities such as drawing, painting, book clubs, or singing.
- Help recall memories or things to do, using rhymes or songs to make them easier to remember.
- Adjust the environment for them **(see card 38).**
- Always have a calm, patient, friendly, and two-way conversation.
- Ask the person with dementia what things bother them and solve the problems (e.g., noise or music, too much light, room temperature, and distracting colours or furniture).





Card 7

Body functions and structures

Heart and Blood Vessels

Heart and blood vessels have a vital role in making sure the brain gets enough oxygen and nutrition.

A decline in function, such as heart failure, high blood pressure, and any other heart and blood vessel-related disease, such as diabetes mellitus, can influence dementia. Refer to a doctor immediately when the family or you think something is wrong.

Blood Pressure Categories

American Heart Association | American Stroke Association

BLOOD PRESSURE CATEGORY	SYSTOLIC mm Hg (upper number)		DIASTOLIC mm Hg (lower number)
NORMAL	LESS THAN 120	and	LESS THAN 80
ELEVATED	120 – 129	and	LESS THAN 80
HIGH BLOOD PRESSURE (HYPERTENSION) STAGE 1	130 – 139	or	80 – 89
HIGH BLOOD PRESSURE (HYPERTENSION) STAGE 2	140 OR HIGHER	or	90 OR HIGHER
HYPERTENSIVE CRISIS (consult your doctor immediately)	HIGHER THAN 180	and/or	HIGHER THAN 120

Actions to take

Coach the person and family members in applying the following actions in daily life:

- Do a **routine health check and follow the doctor's medication prescription.** The family member can do **blood pressure checks at home or in the local health clinic.** In the beginning, twice a day (once in the early morning before breakfast and once in the evening) is advisable, but the family member should seek the doctor's opinion.
- Support a **healthy body weight and diet** for the person with dementia**:**
  - Eating a diet high in fruits, vegetables, and whole grains (oats).
  - Lean (less-fat) meat, fish, poultry, and low-fat dairy products.
  - Low salt and sugar intake will help. It is wise to stop smoking and drinking alcohol.
- Adjust **routines and lifestyle** if needed**:** Keep active and exercise for at least 20-30 minutes a day or 150 minutes a week. Some exercise examples are brisk walking, cleaning, dancing, and gardening. It also depends on what the person enjoys.



Card 8

Body functions and structures

Movement Related Functions

Balance - A person with dementia may feel unsteady on their feet. It may also be that they have **less leg strength** due to a lack of movement. A person with dementia can experience their environment as confusing. This can all impact their **coordination** negatively. A person with dementia can, therefore, lose their ability to walk, stand, or get themselves up from the chair or bed. This can limit their independence and increase the risk of infections and blood clots.

Make sure the family members observe if the person with dementia is experiencing challenges during activities that involve standing and walking. A warning sign is that they are shuffling their feet instead of lifting them with each step. To maintain functional independence, the family member can encourage the person with dementia to move more, lead, and be active during the day.



Actions to take: Coach the person and family members in applying the following actions in daily life:

- **Exercise -** A great way to help maintain strength and balance is through seated exercises: sit down on a chair and do different movements with the person with dementia, e.g., raising the arms and legs, sit-to-stand repetitions, and marching on the spot. The family member should also try to go walking with the person with dementia. Use mobility aids if needed, e.g., walkers and canes. The family members can play music and dance with the person with dementia.
- **Make the home safer -** It is important to pick up and remove things from the floor that people may trip over, such as shoes or tools. Remove rugs or secure them with double-sided tape. If possible, keep the house well-lighted, even at night, so the person with dementia can see their surroundings when, for example, having to go to the toilet. Make sure to also have a correct chair height for the person with dementia so it is easier for them to stand up and sit down.
- **Safe footwear—**The family member should ensure that the person with dementia wears shoes that do not cause the person to slip. It is important to pick shoes that fit properly without being too loose or tight. The shoes should have a good grip on the soles and a low heel for maximum contact with the ground.

Card 9

Body functions and structures

Vision

As a person ages, they may experience difficulty with their vision and should have their eyes tested. This is especially true for people with dementia. People with dementia combined with sight loss can experience increased disorientation and isolation. They are also at an increased risk of falls and may have difficulties moving between light and dark spaces. Vision difficulties can also lead the person with dementia to misperceive and misidentify people and things.



Actions to take

Coach the person and family members in applying the following actions in daily life:

- Ensure the person has **regular eye checkups** and **tell the eye doctor that the individual has dementia.**
- Look out for signs of visual impairment, such as lack of eye contact during interaction.
- **Provide glasses and ensure good lighting** to reduce the risk of falls.
- **Keep furniture and other objects in familiar places** and away from walking pathways**.**
- **Use contrasting colors,** such as a dark plate for serving mashed potatoes, a white toilet with a black toilet seat, or a color to identify a bathroom door.
- Help the person with dementia to **identify people by asking others to say their names.**
- **Avoid arguing or saying too much i**f the person does not understand the object they want or the topic you are talking about. If possible, **give the item to them and calmly explain its name and use.**

Card 10

Body functions and structures



Hearing

As a person ages, they may experience difficulty with hearing and should have it tested. Hearing impairment, especially in a person with dementia, can cause an increased struggle in carrying out daily activities and is likely to cause distress.

Actions to take

Coach the person and family members in applying the following actions in daily life:

- Find a **suitable place** to talk, with good lighting and away from noise and distractions.
- **Get the attention** of the person with dementia before starting to speak, by waving or tapping them on the arm.
- Make sure **not to cover your mouth** and have **face-to-face contact** with the dementia person.
- **Speak clearly** but not too slowly, not exaggerating lip movements, as this can make it harder to lipread. Use **friendly facial expressions and body language.**
- Be careful **not to shout.** This can be uncomfortable for hearing aid users, and it looks aggressive.
- Be mindful **not to keep repeating something** if the person with dementia does not understand. Instead, try to **say it differently.**
- Check that the person with dementia is following the conversation. You should **use plain language** and **slowly and clearly.** A**void difficult and technical terms and unfamiliar words.**

Card 11

Body functions and structures

Pain and Sores

People with dementia may experience **chronic pain** (long-term) and **Sores** (a break in skin). Their limitation in brain function and abilities make them less able to communicate their pain and to move actively.

Pain can make the person with dementia feel aggressive and difficult to help. Lack of communication can result in under-treatment and reduce quality of life. A sore may develop over bony areas close to the skin due to sitting or lying in one position for a long time without moving.



Actions to take

Coach the person and family members in applying the following actions in daily life:

- **Assess any sores or pain regularly** by **checking their body and observing** for unusual face expressions, moaning, or restlessness. The lack of desire to move can indicate that the person with dementia is in pain.
- **Ask for help from a doctor** so they can receive the correct treatment. Chronic pain may require regular medication, and sores may require treatment.
- Provide **non-medicinal care, such as massaging with hands and applying a hot or cold pack,** but consult a doctor or therapist first**. Don't** massage sores.
- Be careful to **avoid conditions that cause pain such as infections, fractures and bedsores** by preventing the person from falling and regular movement, also when the person cannot walk**.**
- Prevent bedsores by helping the person with dementia eat healthily (this prevents the skin from drying) and addressing **problems with incontinence (moisture from leaks can damage the skin).** Keep the buttocks dry and clean.
- Be **mindful of underlying health conditions** such as diabetes and high blood pressure, which can increase the risk of bedsores. The family member should **consult the doctor and manage these with regular medications.**
- **See card 20** for additional advice.

Card 12

Body functions and structures

Digestion

Persons with dementia can develop problems with **eating, drinking, and swallowing** at any stage of their illness. A person with dementia may lose interest in eating or drinking. They may forget to put food into their mouth and even to chew or swallow it. The person with dementia may also talk with their mouth full, which can increase the risk of choking.

Eating and swallowing require complex skills in the mouth and throat area. When these skills become more difficult, they require extra attention. The family members should be extra careful; otherwise, **these problems can bring dangerous risks like poor nutrition, choking, and lung infections.**



Actions to take

Coach the person and family members in applying the following actions in daily life:

- Keep in mind that **independence in eating or drinking** is the best approach. Family members should not prefer using a feeding tube (nutrition taken through a tube in the nose) unless recommended by the doctor.
- **Follow the eating flow** of the person with dementia by feeding at the appropriate speed (not too fast, giving the person time to swallow) and the right mouthful size (not too large).
- Place your hands on the hands of a dementia person to **help the movement** to complete eating.
- Use interestingly coloured eating tools, like a spoon with a colourful handle (this **makes eating more appealing**), and arrange a familiar place to eat in the house (this can **relax the person and may encourage them to eat more**).
- **Position the person with dementia correctly** (not lying down, but using supportive pillows in the chair if needed) to improve the speed and safety of swallowing.
- Deliver **good mouth care,** like brushing the teeth twice a day.



Card 13

Body functions and structures

Urinary and Fecal Incontinence

Persons with dementia can experience difficulties with going to the toilet, as they don't recognize the sign to go or forget where the toilet is. Incontinence is the involuntary (not on purpose) leakage of urine or feces. Sometimes, this is because of a medical condition that may be treatable. In other cases, this condition could lead to medical conditions such as infections or bedsores if not properly cleaned.

Some possible reasons for incontinence:

- Natural aging, especially with decreased brain function from dementia, leads to less control of the bladder and bowels. The dementia person may be unable to react fast enough to the sensation of needing to use the toilet.
- The person with dementia may not be able to undress.
- The person with dementia may have a urinary tract infection, prostate problems, constipation, or other gut conditions (irritable bowel syndrome). If suspected, the family member can consult a doctor for advice.





Examples of urinal device for men (top) and women (bottom) to use

Actions to take

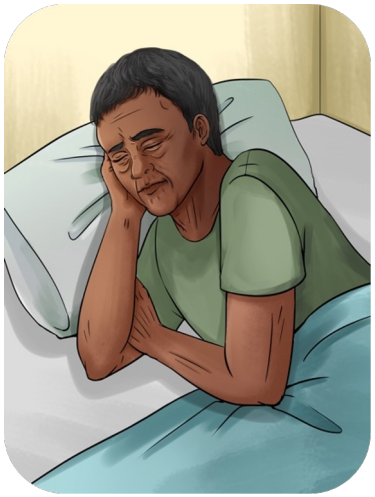
Coach the person and family members in applying the following actions in daily life:

- **Consider using incontinence products**, such as waterproof mattress covers, pads on the person's bed, or adult (self-made cotton or pamper) napkins in the underwear.
- **Give the person plenty of time** in the bathroom to empty their bladder and bowels.
- **Check** the toilet to see if the person with dementia has finished their business on the toilet.
- **Be aware to not limit their drinking except before bedtime**. This can otherwise cause dehydration, leading to a urinary tract infection, increased incontinence, and agitated behavior.
- When a person cannot or has difficulty walking and needs to use the toilet at night, you can consider using urinal devices in the bed for easy access. See pictures on the right.



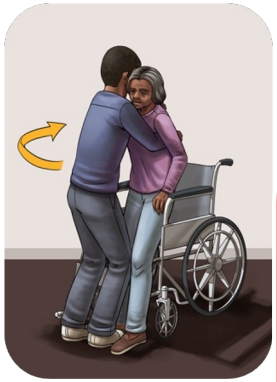












Activities and participation:

Information and actions to take

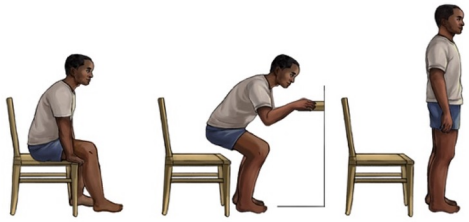


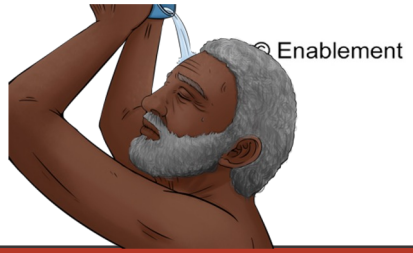
















The Importance of Activities

PROMOTING INDEPENDENCE

Independence is important at all stages of dementia (early-middle-late). Dementia can limit a person's ability to live independently, which can be very distressing for the individual and family members.

Promoting independence is a way to:

- to keep control of their own life;
- stay healthy;
- play a role in society;
- feel valued and valuable.

The role of family members

It is important for family members and field workers to use a person-centered approach to care. This allows people with dementia to maintain as much autonomy and control as possible over their well-being.

One of the greatest challenges for family members is how much assistance they need. The person with dementia should not overstrain themselves or do too little. The family members should encourage people with dementia to perform activities that they can already do well, which are also called **strengths**.

Actions to take

- Discuss the amount of encouragement needed with the family members.
- Look for the right level of challenge (not too much, unsafe, difficult, boring, or easy) and stimulation for the individual to maintain active and involved participation in personal, family, and community life.
- Discuss with the family member which activities, on a normal day, the person with dementia can still do to provide enough challenge and stimulation.





Card 15

Activities and participation

Card 16

Activities and participation

Actions to take continued

Coach the person and family members in applying the following actions in daily life:

- Encourage participation in daily activities
  → Such as household activities and getting dressed, as well as helping in the kitchen e.g. let the person indicate what to wear, help by pulling a shirt over the head, help with washing the dishes.

- Focus on the person's abilities
  → If preparing meals is no longer possible, ask the person to set the table instead. Some days will be better than others.

- Encourage physical activity
  → Family members should encourage some physical activity every day, whether it is stretching or walking around. Keep in mind that doing self-care activities themselves is also physical activity.

- Provide opportunities for social engagement
  → Facilitate activities that promote self-esteem, such as arts and crafts, music, theater, and meeting other people.

- Create a safe, comfortable environment that reflects the person's preferences and personality
  → Reduce factors that can trigger behavioral and psychological symptoms of dementia, such as crowds, bright lights, and loud noises. For example, it can be difficult for a person with dementia to follow and engage in a conversation with a group of people who talk fast and extensively.

***Note: The person-centered** approach adapts care to the person with dementia's interests, abilities, history,* and personality.







Card 17

Activities and participation

Activities of Daily Life

Activities of daily living are tasks that are done regularly, such as preparing a meal, dressing, brushing teeth, leisure, and social interaction. It is important to help the person with dementia stay involved. The family member can adjust many activities to the dementia person's ability by, for example, having them do parts of the activity with instruction and making sure all needed materials are nearby.

Independence in activities like toileting, washing, dressing, eating, drinking, and caring for the body is important for a person with dementia. The following sections describe these activities.



Actions to take

Coach the person and family members in applying the following actions in daily life:

- Encourage involvement in daily life, like setting the table or washing the dishes.
- Pay special attention to what the person with dementia enjoys.
- Keep the person's skills and abilities in mind. The family member should consider any physical impairments (seeing, hearing, and mobility) of the person with dementia and adjust the activities where needed.
- Relate the activity to the work that the person with dementia did in their life. For example, a past farmer may enjoy working in the garden.
- Adjust activities to the person's stage of dementia. As the disease progresses, introduce simpler tasks such as folding dish towels.
- Focus on enjoyment in activities, not achievement and doing the activity the best way possible.



Card 18

Activities and participation

Communication

Good communication and the ability to communicate can help a person with dementia cope better with their abilities and challenges. It helps to express their needs and reduce anxiety.

Elderly people with dementia are likely to have sight or hearing problems. This makes it harder to communicate. This can be uncomfortable and frustrating for people with dementia. In some cases, the family member can use non-verbal communication to communicate with them, such as by pointing to what you mean.

Communication is an important part of establishing a relationship. It helps to promote activities and participation.

Relationship

Dementia can affect all aspects of a person's life, including relationships with friends and family. **Relationships help to sustain the identity and well-being of the person with dementia.**

As the condition progresses, relationships and roles will change over time. This means that the person with dementia can become more dependent on the family member, friends, and family while having difficulty recognizing people.

It can be difficult for the person with dementia and the people around them to adjust to increasing challenges in daily life. This process will take some time.

Actions to take

Coach the person and family members in applying the following actions in daily life**:**

- Speak clearly and slowly.
- Use short sentences.
- Make eye contact and get down to eye level.
- Listen carefully to what the person wants to say or express attentively.
- Observe closely what the person wants.
- Give the person time to respond.
- Encourage the person to join in conversations.
- Let the person speak for themselves during discussions.
- Give the person simple choices: ask yes or no questions.
- Use other ways to communicate if needed (non-verbal communication), such as hugging, touching, and holding hands.

Note: Remember, every person is an individual and should be treated differently



Card 19

Activities and participation

Moving around

Dementia is likely to have a significant physical impact on the person in all stages of dementia. Progressively, they can lose their ability to walk, stand, and get themselves up from the chair or bed. They may also be more likely to fall. In later stages, a person with dementia may stay in one position for a long time without moving. Therefore, they are at higher risk of getting:

- bedsores
- pneumonia (lung infection)
- constipation
- thrombosis (blood clots)
- contractures (tightening of muscles)

This can be prevented by remaining active, such as moving positions regularly, with help if needed. It improves blood circulation, prevents body stiffness, and improves overall well-being.

Help the family member to become familiar with preventive information and exercises and integrate movement into daily life **(refer to card 20)**.

Wandering

Anyone who has memory problems and can walk is at risk for wandering. This is moving around without knowing exactly where you are or where to go. **It is important to be aware of** this type of situation. Help to recognize signs to look out for:

- The person with dementia may have difficulty locating familiar places like the bathroom, bedroom, or dining room.
- The dementia person may try or want to "go home", even when they are at home.
- The person can be restless, pace, or make repetitive movements.
- The person might not find his/her way home when outside.







Card 20

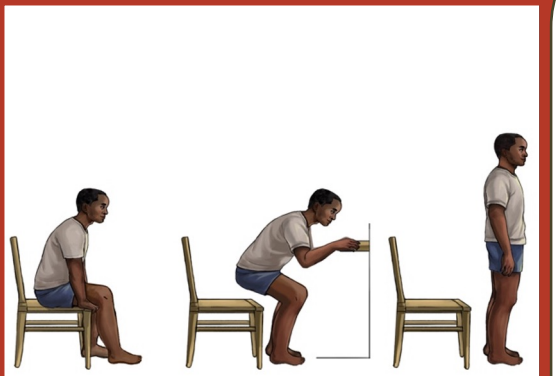
Activities and participation

Action to take for mobility

Coach the person and family members in applying the following actions in daily life where possible:

- Encourage walking around the house, the yard, going to the grocery store, or outside for any amount of time. Do it together if needed.
- Do regular (daily) sit-to-stand exercises (see picture below) with the person with dementia. This helps strengthen muscles needed for essential physical activities like using the toilet.
- Help the person with dementia maintain good balance in a standing position. This improves balance and posture. For example, you can include them in washing dishes or brushing teeth in a standing position.
- Encourage the person with dementia to stretch while lying in bed by moving various body parts and stretching stiff muscles.
- Ask the person with dementia to help with for example gardening – something simple like raking, watering plants or pulling weeds gives a sense of accomplishment and is a great workout.





© Enablement

Preventing Bedsores

Coach the person and family members in applying the following actions in daily life:

- Arrange a referral to a health professional in case of a breakdown of the skin.
- Keep the skin of the person with dementia clean and dry.
- Ensure the person with dementia eats nutritious food and drinks enough liquids (around 1.5L of water daily); consult your doctor if this is a problem.
- Change the position (at least every 2 hours) of the dementia person by using aids like pillows and blankets between parts of the body that press against each other.

→ *Risk areas: under your tailbone, shoulders, heels and elbows, between knees and ankles*

Preventing Wandering

Coach the person and family members in applying the following actions in daily life:

- Identify the most likely times of day that wandering may occur and facilitate physical activities at those times.
- Clearly mark interior doors, and use colors and signs for easier recognition.
- Reassure the person with dementia when they feel lost, restless, or disoriented and guide them back to a familiar place.
- Avoid going to busy places with the person with dementia that are confusing and can cause disorientation.

Card 21

Activities and participation

Action to take for transferring

When a person with dementia has difficulty moving from one sitting or lying position into another position, they might need help. When helping to change positions, keep the following measures in mind to prevent back pain. Teach the family to do the same:

- Stand with your head up, shoulders back, chest high, and back straight.
- Place your feet hip-width apart.
- Shift so one foot is in front of the other.
- With your knees bent, lift the person using your leg muscles rather than pulling them with your arms.
- Do not turn from the waist.
- Do not reach out while lifting. The weight needs to be close to your body.
- Allow the person you assist to do as much of the moving as possible.
- Count to three out loud before lifting so the person knows what to expect.



How to Assist with Walking and Sitting

Coach the person and family members in applying the following actions in daily life:

- Check if the person with dementia wears supportive footwear, which helps to stand and walk stably.
- Always provide a walking aid if recommended by a health professional.
- When guiding the person, position yourself alongside the person's weaker side.
- If the person with dementia has problems with balance, you can use a belt around the person's waist to hold and guide the person.
- While going from stand to sit, make sure to have the person with dementia turn fully and stand against the chair before attempting to sit.
- The family member should remind the person to return to the armrests with one or both arms before sitting.



Card 22

Activities and participation

How to turn or position an elderly person with dementia:

Coach and advice the family member

1. When a family member is moving a person with dementia in bed, they need to be aware of the person's abilities. If the person can physically help, let them help. Communicate what you are doing and when.
2. Provide privacy, e.g., close doors or curtains when helping with dressing, washing, or going to the toilet.
3. Allow the person with dementia to do all or most of the work. Pulling the person only with the upper body is likely to cause injury to the family member or the person with dementia.
4. Ensure that the person with dementia has enough room to roll to the side of the bed. If needed, have the person bend both legs and put feet on the bed to allow them to assist with scooting over.
5. Ask the person with dementia to help roll to the side by reaching in the direction of the roll or holding onto the side of the bed if possible. Bending their legs will make the roll easier.
6. Put one hand under their shoulder. Put the other hand on their hip, then gently roll him or her toward the other side of the bed.
7. Make sure the person with dementia is comfortable. Count to three before each step to prepare them for what is coming.

How to safely transfer someone with dementia from a bed to a wheelchair:

See pictures below

1. When lifting a person from a bed, the family member should be aware of abilities and limits. A clear communication is necessary.
2. The wheelchair should be brought close to the bed and positioned on the stronger side of the person with dementia.
3. The wheelchair footrests need to be folded out of the way and secure the brakes.
4. Using proper movements (rolling to the side, helping to move up, guiding to the stand, turning to the chair, and seeing the picture) can make the process easier for the family member or for yourself.
5. Holding onto a person's belt or pants can help control the step-by-step movements needed to stand and sit.
6. While seated in the wheelchair, ask the person to push themselves up from the seat to help move them to the back of the chair.



Card 23

Activities and participation

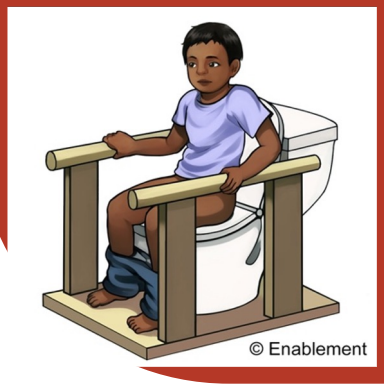
Toileting

A person with dementia may need support in toileting. Keeping a sense of dignity is important, and **this should be supported in a way that promotes independence.** A person with dementia is more likely to have problems with toileting or incontinence than a person of the same age who does not have dementia.

Actions to take

Coach the person and family members in applying the following actions in daily life**:**

- Encourage the person with dementia to indicate when they need to use the toilet in time.
- Otherwise, learn to notice when the person gives a sign about needing to use the toilet (agitation, fidgeting).
- Have a routine and take the person to the bathroom regularly, for instance, every two hours.
- Make environmental adjustments to help the person find and use the toilet easily and safely. For instance, use a picture on the door, signs, raised toilet seats, and grab bars (for examples, see pictures below).
- Consider putting a toilet chair or urinal in the person's bedroom in case of nighttime accidents.





Washing

In the later stages of dementia, the person will need more help with everyday activities such as washing and bathing. **The family member should be sensitive and gentle and respect the dignity of the dementia patient.**

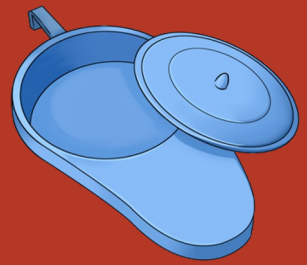
Personal routines and preferences of the dementia person should be considered wherever possible. Independence should be maintained by assisting the person.

Actions to take

Coach the person and family members in applying the following actions in daily life**:**

- Prepare the room by gathering bathing supplies and placing them within reach.
- Encourage independent washing by breaking the process of washing down into small steps.
- Always respect the person's dignity and privacy, e.g., close doors/curtains.
- Involve the person in decision-making e.g., the family member can ask if the person wants a bath/wash at the basin or a shower.





Examples of urinal device for men (left) and women (above) to use



Card 24

Activities and participation

Sleeping

Sleeping more (even during the day) and feeling tired fast are common features of people with dementia. Fatigue can also be described as a feeling of constant exhaustion. **A person with dementia may begin to find simple tasks tiring.** Tasks such as communicating, eating, or trying to understand what is going on can be quite exhausting.

This state of constant fatigue or feeling low in energy may also be caused by sleeping problems, medication side effects, and/or poor nutrition.



Actions to take

Coach the person and family members in applying the following actions in daily life:

- Make a daily schedule for the person with dementia. Keep them active during the day with a routine of activities, as it will ease them into a good bedtime routine at night.
- Ensure that the person is eating enough nutritious food and drinking enough (about 1,5 liters water per day).
- Monitor the amount and quality of sleep a person gets. People in later stages of dementia gradually start sleeping more, which may be due to the dementia progressing.

Note: If the excessive sleeping started suddenly or they do not seem to be feeling well, it may have another cause and it is better to seek advice from a doctor first.









Personal factors:
Information and
actions to take









Card 26

Personal factors

Lifestyle of a person with dementia

To preserve brain function as long as possible, family members should help the person with dementia engage in meaningful activities throughout the day to lead an active lifestyle. This will help to promote a feeling of importance and well-being. Also, helping the person with dementia maintain and engage in their social relationships, e.g., with friends, family, and community members, can greatly improve their quality of life.

Actions to take

Coach the person and family members in applying the following actions in daily life. The family member should try to support the person with dementia in **continuing their hobbies, meeting supportive friends, and spending social time with community members**. Some activities the family member can encourage, depending on the activities the person likes or used to do him-/herself and what the person is still able to do:

- Getting out of the house (together if needed) , such as visiting a beach, going for a walk in a park, or around the village. Do it regularly if possible.
- Gardening: watering plants, weeding, planting flowers.
- Bringing the person along when shopping at a store or market, at a quiet time of the day.
- Including the person in kitchen activities: preparing food, setting the table, washing dishes and putting away dishes.
- Play a (e.g., card) game with friends and family.
- Including them in family meetings and activities. Involve the person in conversations.
- Throwing and catching a ball with grandchildren.
- Keep doing their own hobbies: drawing, playing with a pet, playing a game, reading a book, or other.





Card 27

Personal factors

Managing emotions

All people can experience and respond to situations differently. A family member must consider that a **person with dementia can often feel upset, anxious, confused, and act impulsively**. In the early stage of dementia, a person may feel embarrassed that they have acted strangely or forgotten something.

Also, a person with dementia may feel they are not understood. These situations may cause the person to feel shame or anger. The family member should try to **figure out what triggers these emotions, comfort the person, and solve the problem.**



Actions to take

Coach the person and family members in applying the following actions in daily life:

- The family member should always **stay calm and patient** when a person is experiencing overwhelming emotions.
- **Give the person one-on-one time**. Go to a quiet area and speak about what may be bothering them; comfort them.
- In the early stage of dementia, support the person in accepting their condition and not make them feel insecure. Try telling them things such as, "**It's okay to forget things**".
- The family member should try to always comfort and **give the person peace of mind** when they are upset. Try saying something like, "**It is ok to worry about it, let us find the way to figure it out**".
- The family member should try to **put themselves in the person's shoes**. Try to imagine and understand what has caused the person to be upset; this can help to solve the problem - **be empathetic.**
- The family member can try to promote positive feelings by **changing the topic or suggesting an activity** when the person is upset. For example, suggest "**Would you like to have a cup of tea?**".

Card 28

Personal factors

Activities to help with managing emotions:

Coach the person and family members in applying the following actions in daily life:

- The family member can listen to the person's favorite music.
- Look at familiar (family) photographs with the person (**consider if the memory will make them upset or happy**).
- The family member can play an instrument and sing songs with the person.
- Encourage the person to talk more about subjects they enjoyed in the past, such as **achievements and adventures**.
- Go for a walk and enjoy the scenery.
- Smell something nice or that reminds the person of past experiences: perfume, coffee beans, tea leaves.
- The family member can give the person thoughtful attention (massage, hug, rubbing).









Card 29

Personal factors

Lifestyle and Mental Health of family members

Explain to family members that, besides taking care of their loved ones, they may still have their own daily tasks and responsibilities. Regardless of their busy schedule, **maintaining their own healthy lifestyle is fundamental** to preventing physical illness and fatigue. **Giving attention to their own needs** can prevent mental health problems like depression and anxiety.

Never underestimate the importance of self-care. Taking care of oneself can greatly benefit personal mental health and improve the quality of caregiving. With a healthy mind and body, one can fully and effectively care for loved ones with dementia.



Actions for maintaining a healthy lifestyle

Coach the family members in applying the following actions in daily life:

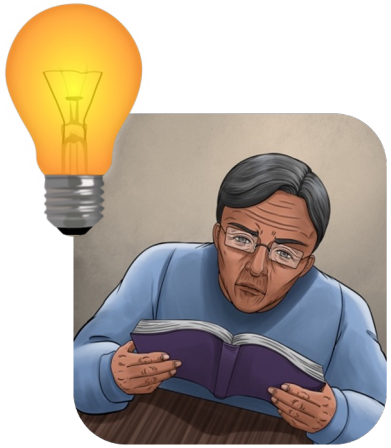
- Maintain their health by exercising regularly and eating healthy foods (vegetables, fruits, less fast food, etc.).
- Have enough sleep (6 to 8 hours).
- **Do not hesitate to ask for help.**
- Making time for own hobbies.
- Keep in touch with friends and other family members.
- Help get more information about dementia.

Actions for maintaining mental health (self-care)

- Give themselves a 'me time' by doing things that make them happy.
- **Do an activity to relax oneself,** such as a simple breathing exercise, meditation, or massage.
- Find comfort in spiritual beliefs by praying.
- Sharing feelings with friends and family.
- **Find social support** by joining a family members' support group if available.
- Get professional help for mental support, if needed, such as a counselor, psychologist, or psychiatrist.









Environmental factors:

Information and
actions to take





Card 31

Environmental factors

Community Stigma

Dementia affects not only individuals with the condition but also the family members. People with dementia are often **stigmatised (treated differently)** due to their impairments, such as a decline in brain function, personality change, disruptive behaviors, poor self-care, and incontinence. **Family members or fieldworkers may also experience stigma** through their association with people with dementia, and society may treat them alike.

It can be an additional burden for family members who already bear the emotional, physical, and financial burdens that come with caring for a person with dementia.



Actions to take

There are many beliefs concerning dementia in communities. Some people believe dementia is something metaphysical linked to supernatural or spiritual beliefs. These beliefs can restrict a dementia person and their family's participation in the community, for instance, access to a house of prayer.

Support the person and family members with addressing community stigma:

- **Increase awareness** in the community by correcting wrong understandings about dementia. The fieldworker and family member can inform the community that people with dementia have a right to well-being and can still participate, contribute, and maintain dignity in a community setting.
- **Involve a person with dementia in activities or conversations.** Without someone starting the conversation, the person with dementia may become isolated. Involvement in some activities like art and physical activity provides an opportunity to reconnect with their communities. This shows that an active life after a diagnosis of dementia is possible.
- Gain more knowledge and mental support by **joining a dementia family members' support group** to share similar experiences.

Card 32

Environmental factors

Support Group

Help a person with dementia and their direct family members to join a support group. By joining a support group, family members **develop social and mental well-being**. Family members can also improve knowledge related to dementia, gain ideas to help with caregiving and **learn ways to better take care of themselves.**

Family members can search for support groups for family members of people with dementia **via national self-help groups or doctor's references.** Help the family contact the support group and get access to it.



Using Technology

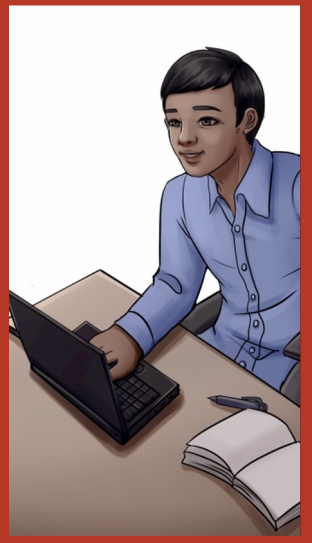
Several technologies are currently available to support family members and people with dementia in rural and urban areas.

Telemedicine helps family members to keep improving health care in remote areas by breaking geographical barriers and reducing unnecessary travel. **The family members can make use of different technologies, such as:**

- Basic telephone
- Web or video-based conferencing and networking
- Websites
- Videophones
- Videos

Help explore any available opportunities in your community, province, district, or at the national level.





Card 33

Environmental factors

Home Modifications

The home of the dementia person should be **suitable for their abilities and needs.** The family member can make changes to the home to support the dementia person's limitations, maximise their independence, and promote personal identity. The home should enhance self-esteem and welcome relatives and the local community. Making changes to the home environment can help the person maintain their independence and stay safe.

Action to take

Support the person and family members with analysing and making home modifications where needed**:**

- Remove anything that may cause the person to trip or fall, such as rugs.
- Keep important items in the same place.
- **Use plain furniture and materials of which the colours contrasts** with the walls and floor.
- **Improve lighting** and make the most of natural light.
- Leave the bathroom door open and a light on at night.
- **Enhance visual access** by ensuring that the person with dementia can see what they need to see (for example, objects and persons) from wherever they spend most of their time.







Card 34

Colophon

This was made possible with the support of:



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Sightsavers

In collaboration with colleagues from the Atma Jaya Catholic University of Indonesia, an endeavour was made to create flashcards that contain information about dementia. This is for field workers to support people with dementia and their family members in ensuring their well-being and providing quality care.

With appreciation to:

- Family members from Indonesia, Ireland, Germany, and The Netherlands
- Medical and Psychology students-advisors from the Atma Jaya Catholic University Indonesia
- Physiotherapy, Nursing, and Health Care Management students-advisors representing Amsterdam University of Applied Sciences

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Card 35

Colophon

When drafting the content of these Flashcards, these resources were particularly helpful:

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