

A photograph of two women dancing joyfully in a home setting. The woman on the left is older, with short blonde hair, wearing a blue polka-dot headband and a green long-sleeved shirt. She has her arms raised and is smiling broadly. The woman on the right is younger, with dark hair, wearing a blue and white striped turtleneck. She is also smiling and has her arms raised, holding hands with the older woman. The background is a warm, slightly blurred interior space with wooden shelves and various items.

**volkshilfe.**

# LIVING AN ACTIVE LIFE DESPITE DEMENTIA

**WHAT RELATIVES CAN DO IN EVERYDAY LIFE**

# LIVING AN ACTIVE LIFE DESPITE DEMENTIA

## **DEMENTIA TURNS A LIFE UPSIDE DOWN.**

The important thing is to adjust to the different life situation. Help the person with dementia to maintain their independence and joy of living for as long as possible.

On the following pages, we have tried to explain how that can be successful, despite all the uncertainties and challenges. Our aim is to offer encouragement to relatives and persons affected. Despite dementia, it is still possible to lead a good, happy and active life.

**Yours sincerely,  
Volkshilfe**

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# SELF-DETERMINATION

At the very beginning, people with dementia are just as active as they used to be. They are able and willing to plan and shape their lives and they should do so as well. However, after some time, it becomes increasingly difficult for them to occupy themselves. At this point, it is useful to actively encourage them to do things that give them pleasure. The important point is not to expect too much of them.

## MAINTAINING INDEPENDENCE

The home environment has one distinct advantage: it is where many things are familiar. Things that can still be done independently should be continued so that these abilities are not lost. With calm, patience and empathetic support, many people with dementia can certainly still go to the toilet, wash themselves, comb their hair and get dressed. The important thing is to provide encouragement and motivation.

## REMAINING ACTIVE

Physical exercise is good for the brain, helps the person to relax, makes them happy and leaves less room for fear and aggression. For people with dementia, regular exercise is of great importance because it enhances their perception of their environment.

If physical exercise becomes virtually impossible, it has to be handled by the carer. Elevating the person in bed for a different perspective or providing a gentle massage with a hedgehog ball creates closeness and enables the person with dementia to feel their own body. One common side effect is inner restlessness. Simply place your hand on the person's arm and breathe in unison—that's usually the best way of eliminating restlessness.

## FEELING THEIR OWN BODY

The more a person's radius of movement is restricted, the fewer their sensory impressions. And when these impressions are severely diminished, the person gradually loses connection with reality.

### TIPS

- Criticism and scolding only lead to withdrawal or aggression. Give more praise.
- A favourable scenario would be a relaxed atmosphere without any hectic or sensory overload.
- Time pressure and performance pressure only lead to disappointment.
- Questions that persons affected are unable to answer only make them feel insecure.
- Laughter and humour are always helpful.

# WHAT CAN I DO IN EVERYDAY LIFE?

In everyday life with a person suffering from dementia, hurdles and questions keep cropping up. These useful tips provide answers to the most common questions that arise.



## AVOID WHY QUESTIONS.

Persons affected are quickly overburdened, especially at an advanced stage of dementia. Ask simple questions ("Would you like some cake?" instead of "Would you like chocolate cake or strawberry cake?") and avoid questions beginning with why ("Would you like to have lunch with me?" instead of "Why don't you want to have lunch now?").



## CREATE ORIENTATION.

If the person with dementia no longer remembers the way home, don't just tell them the way but assist their recollection process. Also, decide together where to put important things, e.g., keys.



## TAKE THEM SERIOUSLY.

For those affected, many everyday things can become a burden. Talk to each other calmly and patiently. Being taken seriously is an important feeling.



## ENCOURAGE PHYSICAL ACTIVITY.

Physical exercise has a positive impact and helps to avoid aggression. Encourage the person to go for walks, participate in gymnastics or do sports.



## PROVIDE THE RIGHT NUTRITION.

The sense of taste often changes significantly, causing food to be rejected. Strong seasoning can help. People suffering from dementia often forget to drink. Make sure they do because not enough fluids can lead to more confusion.



## MEMORY TRAINING.

Depending on the interests of your family member, there are ways to train his or her memory. Continuing hobbies for as long as possible will help.



## PROMOTE INDEPENDENCE.

As long as your relative can bathe, get dressed or do certain things in the home on their own, he or she should continue doing so. Helping out is good, but doing everything for the person is bad.



## ROUTINES HELP.

A clear daily structure is of enormous importance for people with dementia. Small daily routines help, e.g., listening to a familiar radio station, placing the newspaper next to the coffee cup, having lunch punctually at 12 noon or going for a walk in the afternoon.



## BE CALM.

Don't be discouraged if something doesn't work out properly. Whether a task is being regarded as too difficult at the moment also depends on how the person is feeling that day. The important thing is to treat each other calmly.

# STRUCTURE IN EVERYDAY LIFE

## PERSONAL HYGIENE

People with dementia should look after their own personal hygiene for as long as they can. It's important not to be impatient and not to pressure the person if something doesn't work out as quickly as it used to. Personal hygiene should not be regarded as a necessity but as one way of allowing sensory experiences.

## CLOTHING

If people with dementia can choose their outfit every day, it promotes their independence. If the clothing happens to be unsuitable for the time of year, don't criticise their choice but suggest something appropriate. Say, for instance, that the red jacket would match very well.

## GROCERY SHOPPING

Involve the person with dementia. At the same time, it is a little memory exercise.

- Would you like to eat noodles today? What is your favourite sauce?
- Shall we buy the ingredients for pancakes? What will we need?
- Are we short of flour? What do we need it for?

## COOKING

Food can be smelled, seen, tasted and felt; few things are perceived so intensely with all the senses. But above all, you can do the preparing, cooking and baking together.

## MEALS

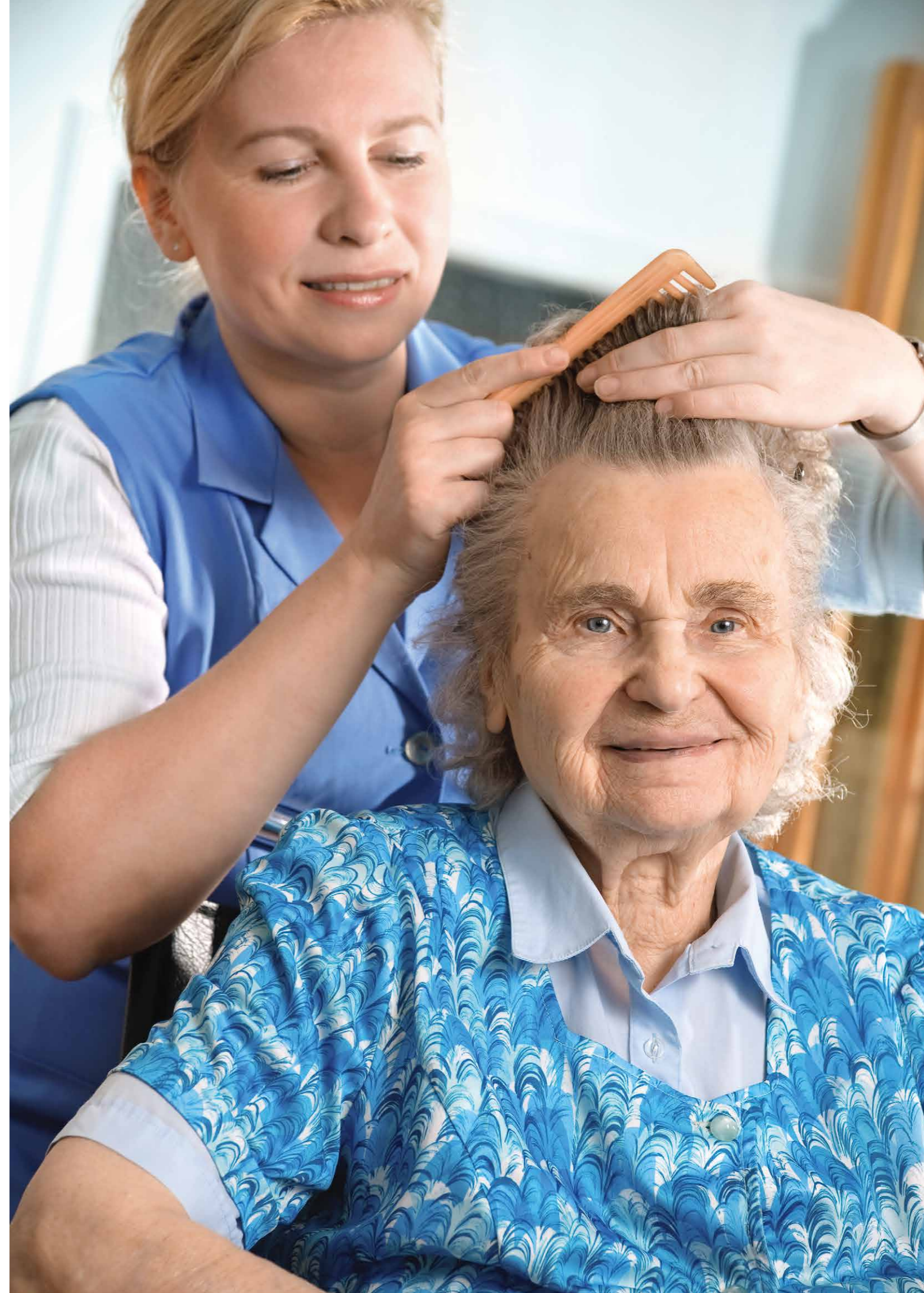
Meals give the day some structure. For as long as possible, you should have meals together, as an enjoyable ritual that gives a sense of security. Share the tasks involved:

- Lay the table together
- Fold the serviettes
- Divide the cake between the plates

In everyday situations, you should often make a request of the person you are taking care of. That gives them a feeling of being needed. As a result, the other person's opinion is appreciated and taken seriously.

- Can you help me, please?
- Do you remember what ingredients we need?
- Shall we invite the neighbour over for coffee tomorrow?

All these little activities achieve great things!



# WEEKLY SCHEDULE

Drawing up a weekly schedule can help to structure everyday life. Simply detach the schedule from the brochure and fill it with the scheduled appointments and activities for a particular week. It might look like the example below:

## Weekly schedule



Morning/midday			
Day	What?	Where?	What to take with us?
Monday	<i>Foot care with Ms Mayer, street address</i> <i>Purse, key</i>		
Tuesday	<i>Shopping, supermarket</i> <i>Purse, shopping list, key, carrier bag</i>		
Wednesday	<i>Day Centre, Haus Regenbogen</i> <i>Purse, key, ticket for public transport</i>		
Thursday	<i>Dr [insert name], Medical Centre, street address</i> <i>Chip card, purse, key, ticket for public transport</i>		
Friday	<i>Shopping, supermarket</i> <i>Purse, key, shopping list, bag</i>		
Saturday	<i>9 a.m. Hairdresser, street address</i> <i>Purse, key, ticket for public transport</i>		
Sunday	<i>Walk</i> <i>Key</i>		



Afternoon/evening			
Day	What?	Where?	What to take with us?
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			



Day	Morning/midday			Afternoon/evening		
	What?	Where?	What to take with us?	What?	Where?	What to take with us?
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						



Day	Morning/midday			Afternoon/evening		
	What?	Where?	What to take with us?	What?	Where?	What to take with us?
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						



# COMMUNICATION MADE EASIER

Humans are social beings. One of the tools we use to communicate is speech. With it, we can express states of mind, wishes and ideas, and we can also clarify misunderstandings.

People living with dementia often have difficulty communicating. They have difficulty finding the right word, can only concentrate on listening for a short period and can easily be distracted by background noise. They are often no longer able to reflect on their own behaviour. This can easily lead to conflicts:

- The persons affected don't recognise who they are looking at. The result is a defensive attitude.
- Persons affected become anxious and behave irrationally.
- Frustration arises owing to the lack of ability to articulate themselves.
- The persons affected behave aggressively.
- There may be unfounded accusations, such as claiming that you have stolen something.

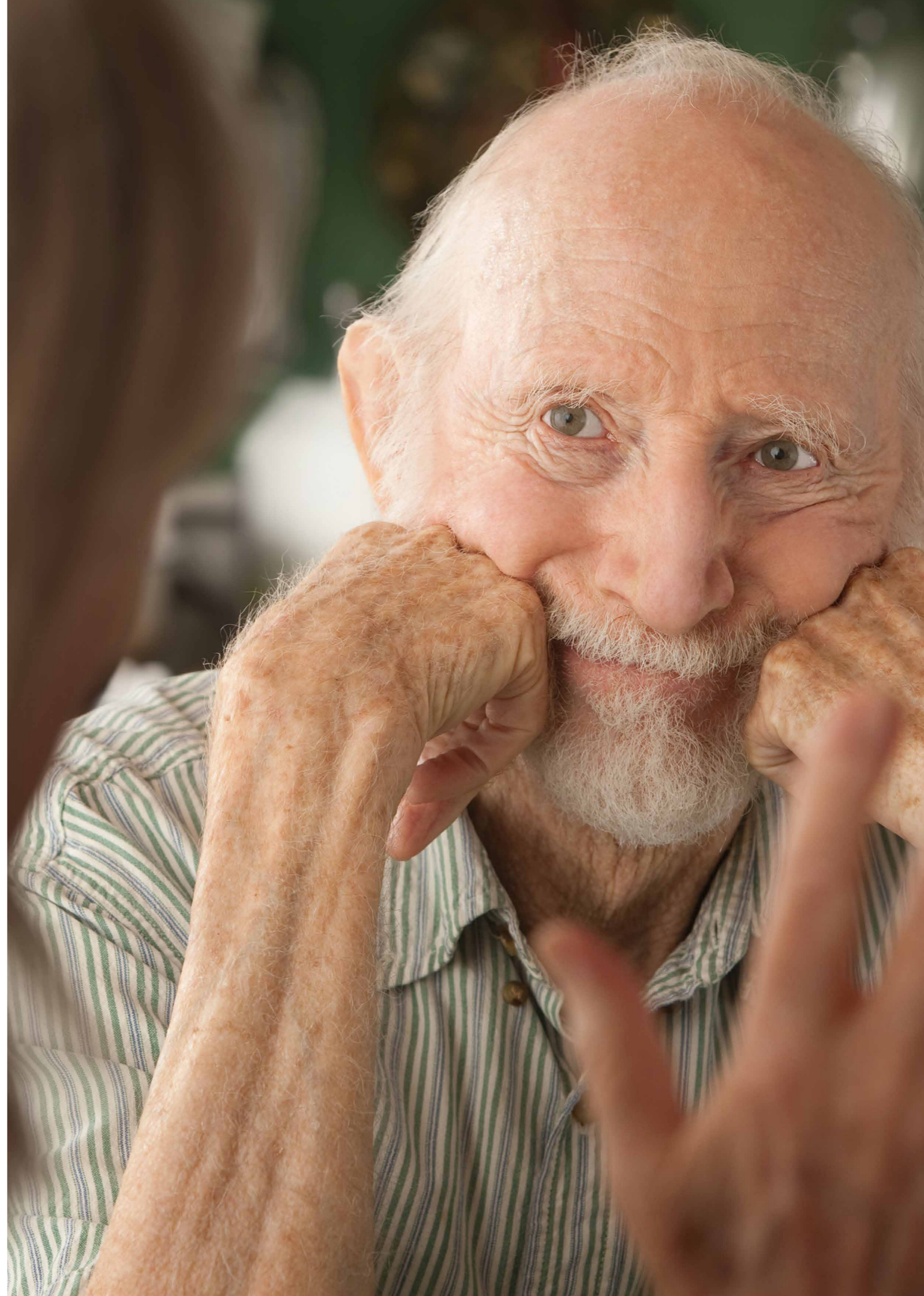
## TIPS

To facilitate communication with a person who has dementia, there are practical aids available:

- Touching them can create trust.
- Photographs and videos constitute a visual reminder (e.g., memory album).
- Music brings back memories and evokes feelings.
- Art can help to express emotions.

## REALISE THAT DEMENTIA IS A DISEASE, SO DON'T TAKE IT PERSONALLY.

- Always treat the other person with respect.
- Don't take mood swings personally.
- Take into account the psychological needs of people with dementia, for example, their state of mind. Is he or she in a good or bad mood? Does he or she need rest?
- Don't criticise mistakes but give praise when something has been done correctly (e.g., "Today you've combed your hair nicely again.").
- Don't overburden them: If possible, only ask closed questions (e.g., "Would you like to have a meat sandwich?" and not "What would you like to eat?").
- Repeat important information a number of times using the same formulations.
- Avoid distracting background noise (e.g., television).
- Speak slowly and clearly in short and easy sentences.
- Accompany what you say with facial expressions, gestures and body language.
- Have their glasses and hearing aids checked and adjusted if necessary.



# ROLE REVERSAL

Couples where one partner suffers from dementia must first find a new rhythm. There is often a role reversal if, for example, one of the two is no longer capable of accomplishing his or her tasks in their life together. These new roles must first be tried out. Don't let yourself be discouraged if something doesn't work out properly first time.

## TIPS

- **Time:** Take your time and start the day without rushing.
- **Pleasure:** It's not about perfection but about pleasure in doing something with one another. Often it is useful to say: "I need your help, please." and "Thank you for assisting me."
- **Respect:** People with dementia want to be taken seriously. Criticism discourages and demotivates them.

# SHARING MEMORIES TOGETHER

It is possible to share memories for a long time to come. There are numerous ways of doing it. You can ask simple questions:

- What was your favourite food when you were a child?
- Who was your best friend? What did you do together?
- What did you really want to become?

If the person with dementia can no longer answer these questions, it is helpful to remember together: "I still remember how proud you were of the first money you earned for yourself. You spent it on a trip to Lake Traunsee."

At the beginning of the disease, there is still an opportunity to capture life, literally. Labelling photos is an easy method of jogging the memory. That way, it is possible to create memory islands. Photos are a help to both of you. They continue to narrate a person's life even when he or she can no longer do so.

## TIPS

- Shared trips down memory lane are important and enjoyable.
- The past is not always full of positive recollections. Photos that evoke sadness or anger should not be shown.
- A jointly compiled "biography folder" with documents and photos is also a nice memory island for later. It can also accompany the person with dementia to a care home, if that should become necessary, to make it easier for the person to remember themselves, their family, friendships and their own past.



# MEMORY TRAINING

People with dementia are often absent-minded because their memory for names and recent events gradually fades. In the course of the disease, the person's perception of time and place is lost. The internal clock that tells people roughly when it's time to have a meal or go to sleep is disrupted.

## TIPS

- Apply memory aids: Use large lettering, colours and symbols to label doors and boxes, for example.
- Use memory aids and notes: use a large calendar for all appointments and write down important telephone numbers and make notes.
- Incorporate dates and times into daily routine: To maintain the perception of time, use aids such as large clocks or automatic alarm clocks.
- When going for walks, casually mention or ask about the following: This is the baker. That's where Ms Huber lives. What colour is the traffic light? How much does the newspaper cost? It is important to casually incorporate these questions into a conversation. Under no circumstances should going for a walk be perceived as a test situation.
- Talk frequently about upcoming events.
- Have extra keys made.
- Store documents, money and jewellery in a safe place.
- Organise the day according to a fixed schedule and try to create plenty of routine.
- Mark clothing with written notes or sewn-in labels bearing the name, address, telephone number and a reference to the dementia. It may also be useful if the person wears a bracelet or necklace bearing that information.
- Remain in the familiar environment.
- Inform neighbours of the disease.

# HOBBIES

Painting, crafting and collecting are good for the mind and hands. What hands have been happy to do for decades is not so easily forgotten. The same also applies to the mind and legs. One person used to be a long-standing member of a model railway society, whilst another always attached priority to reading the latest books. After a diagnosis of dementia, and especially as the disease progresses, many people withdraw from their societies and clubs. However, only those who continue to participate recall dance steps or are capable of handling minor roles in a drama group. It's important to repeatedly encourage persons affected to continue their activities because as the disease progresses, they often lose motivation. Anyone who does not have a hobby should be encouraged to try out something new.

Hobbies keep dementia patients physically and mentally active, train them and, above all, are a source of pleasure.

People with dementia often remain committed to their long-standing hobbies, even though they may take a completely different attitude towards them because some abilities are lost.

## TIPS

- Leisure activities should be fun and not overwhelming.
- To provide orientation and avoid stress, hobbies should be integrated into a fixed daily schedule.
- There is strength in repetition. Always do things the same way, slow down and adjust to the speed of the other person.
- Instead of reading conventional books full of text, use magazines with plenty of photos or audio books.
- For all those who used to enjoy dancing but no longer master any step sequences, swaying to the music can also be fun.
- Those who can no longer hold a power drill may be able to smooth a piece of wood with sandpaper as an alternative.

# CULTURE

## MUSIC

For many people, music plays a key role in their life. Persons with dementia can be reached particularly well through music. Memories come alive, and people become more active and more cheerful. In addition, music promotes a sense of community – especially if it is listened to or played together.

### TIPS

- The music should not be too loud or be too disturbing.
- It's not a good idea to have the radio on all day. Breaks are also necessary.
- A customised playlist of favourite songs that are easy to play is ideal for integrating the therapeutic effect of music into everyday life.

## THEATRES AND MUSEUMS

Those who have always enjoyed going to the theatre should be allowed to continue this passion. Museums are good because you can leave at any time if the person becomes tired or overburdened. However, it is important to note that in most cases you are not allowed to touch anything, something people with dementia sometimes find difficult to understand.

### TIPS

- The choice of seat for a visit to the theatre should be considered carefully. The most suitable seats are ones at the side if you have to leave the performance early. Some theatres have special seats for people with disabilities.
- The use of panty liners or adult nappies may be necessary to provide a sense of security and relaxation.

## FILMS

For people with dementia, many films are difficult to understand, have pictures that change too quickly and are generally too hectic. Films with calm camera work and simple narration are always more suitable.

### TIPS

- The film should not be too long. Thirty minutes are often sufficient.
- Films and television should not run in the background.
- It must be possible to stop the film at any time if it causes unrest. Therefore, always stay close by.
- A short "cinema event" together at home can give lots of pleasure.



# SPORT

It has long been known that sport is healthy not only for the body but also for the mind. A study has shown that just half an hour of weekly endurance training in people with incipient dementia contributes to a significant improvement in their well-being and memory. Physical exercise and sport not only invigorate but also combat depression and the fear of falling.

## TIPS

- Someone who is particularly unathletic can perhaps be motivated by a group. Moving together and doing simple gymnastics in a senior citizens' group is definitely a good form of physical exercise. Dancing is also sport; it promotes strength, coordination, balance and agility but also stimulates breathing and circulation.

# NATURE

## WALKS

Going for walks should remain part of everyday life for as long as possible. Not only is it good to be out in the fresh air, but it also stimulates the senses, often more intensively than at home. Meeting neighbours and acquaintances also plays a key role. How long the walk lasts and where it takes you can, of course, be decided individually.

## TIPS

- Even a walk round the house together can have a positive effect. However, longer outings that take up more time should also be organised now and then, if feasible. But always consider the possibility of leaving early.
- Keeping the same pace on a walk has a calming effect and conveys a sense of harmony.
- You shouldn't be afraid to ask friends or family members to come along.

## THE GARDEN

For many people, their own garden is a familiar place they have become fond of over the years. The longer it can be used the better because a garden offers a person many ways of occupying him or herself:

- Sowing seeds and weeding;
- Harvesting fruit and vegetables;
- Cutting flowers;
- Mowing the lawn.



# FREQUENTLY ASKED QUESTIONS

## WHEN DO WE SPEAK OF DEMENTIA?

Dementia is a general term for those diseases where deposits in the brain lead to a gradual loss of memory, thinking, recollection, orientation or the linking of thought content. The word dementia comes from the Latin "demens", which when translated means "out of one's mind". That is misleading because a person's "mind" still exists during dementia; it merely changes occasionally.

## WHAT IS THE DIFFERENCE BETWEEN DEMENTIA AND ALZHEIMER'S?

Dementia is a collective term for a set of symptoms that result in cognitive impairment. There are curable and non-curable forms. Alzheimer's disease, the most common form of dementia, mainly occurs in people over the age of 70. It cannot be cured, but its course can be positively influenced by treatment.

## HOW IS THE DIAGNOSIS MADE?

Thorough diagnosis comprises a conscientious examination of the person's physical and mental condition. Psychological tests can be carried out to examine memory, thinking ability, speech and perception. It is also important to rule out other diseases by means of various laboratory tests and examinations. When making a diagnosis, it is particularly important to talk to those affected and their relatives.

## WHICH DOCTOR SHOULD YOU GO TO AND WHEN?

Even prior to diagnosis, people often have the feeling that something is not quite right. If a suspicion of dementia proves to be correct, an early diagnosis can help to ensure that the medical condition will progress positively. Consult your family doctor first. Discuss your concern in peace and quiet. A family member can also be present. The family doctor then decides, together with all those affected, whether further measures would be useful and necessary, and if so, which ones.

## WHAT TREATMENT OPTIONS ARE AVAILABLE?

The earlier a dementia disease is diagnosed, the better the response can be. People can lead an independent life for longer if treatment commences as early as possible. Every type of treatment must always be adjusted to suit the individual. That is the only way treatment successes can be achieved. There are drug and non-drug therapies (music, exercise, gardening, art and occupational therapies, etc.) that can help to maintain mental and physical abilities and quality of life for as long as possible.

# HOW DOES VOLKSHILFE HELP?

Many people want to lead a largely self-determined life for as long as possible if support and care should become necessary. That is possible with professional aid.

## THIS IS HOW VOLKSHILFE SUPPORTS YOU:

- Mobile services for care and support at home: Home nursing, home help;
- Arrangement of emergency telephones;
- Meals at home;
- Long-term and short-term care in care homes and senior citizen centres;
- 24-hour personal support;
- Day centres;
- Assisted/supervised living arrangements;
- Support, relief and accompaniment of caring relatives;
- Visiting services.



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