Living with Dementia

A Resource Kit for Caregivers





"Dementia can affect your loved one's ability to communicate. They may communicate or interact with people differently than before."

How can this kit help you?



This kit, written in four parts, compiles information, practical tips, activities and resources on dementia to support you in caring for your loved one with dementia. It is designed to address challenging concerns and issues to help you better cope with your caregiving journey, ensuring your loved one receives the best possible care.

While dementia may not be curable, it is possible to slow down the progression with activities, therapies and medication. Remember that you are not alone in this caregiving journey.

If you know of someone who might need help or would like to find out more about the support and services for dementia, contact us at careinmind@aic.sg or Singapore Silver Line at 1800 650 6060.

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How to communicate with persons with dementia

Interaction can be challenging between you and your loved one. As such, it is important to practise active listening, reading their body language, asking questions for clarity, and seeking for common ground when you communicate. Non-verbal communication through different senses will become more significant as well, as time passes by.

Verbal Communication

Approach them with care

It is thoughtful to knock on the door or ask for their permission before you enter.

Always introduce yourself to them Speak directly to your loved one. Approach them from the front so they are aware of your presence.

Communicate with them at eye level Consider bending down to speak when your loved one is seated.

Ensure that their physical space is comfortable and quiet

Engage with them in one-on-one conversations in a surrounding with minimal distractions.

Optimise your loved one's vision and hearing

Ensure that their glasses are properly worn and the lighting is sufficient; their hearing aids are in good working condition, and; that dentures are put on for clearer speech.

Non-Verbal Communication

SIGHT

Choose a quiet room with sufficient natural light. Use soft lights so that shadows and glaring brightness can be reduced. If possible, choose a colour that your loved one likes for the surroundings.

HEARING

Music can trigger memories, improving mood and allowing engagement. It's a good idea to play light, soothing and relaxing music, but it's best to understand your loved one's music preference.

SMELL

Scent the room with essential oils of lavender and lemon. These fragrances have been shown to reduce anxiety and agitation for people with dementia.

TOUCH

Never underestimate the power of a loving touch. Hold your loved one's hands or give them a light hand massage.

"I have dementia.
I may snooze in the middle of the day
I may respond in an unusual way
I ask you to try very hard to see
This is my new reality.
Live in my moments,
The ones that remain
Focus on me, not my fading brain."

Dementia can affect your loved one's ability to communicate. They may communicate or interact with people differently than before.

Early Dementia

Able to participate in meaningful conversation with difficulty in articulating certain words.

Able to communicate in brief social interactions with difficulty functioning in prolonged social settings.

Difficulty with following lengthy conversations.

May follow what is said, but forget it after a brief period.

Jokes and sarcastic remarks can be confusing, and may provoke sensitive feelings towards context.



Moderate Dementia

Able to follow simple one-step instructions.

May understand written information in a word-by-word process.

Conversations are hard to follow.

Repetitive.

If interaction is demanding, people with dementia may withdraw from the interaction.

Personality and behavioural changes, suspiciousness and delusions may hinder meaningful conversations.

Advanced Dementia

Difficulty with verbal communication as vocabulary may be reduced.

Jse of non-verbal communication methods is recommended.

Verbal expression may be in patches or strings of words and sounds.

Use of non-verbal communication methods is recommended.

Conversations may be disconnected.

Use of non-verbal communication methods is recommended.

Communication and words may be interpreted in unconventional ways.

Use of non-verbal communication methods is recommended.

Vocabulary consists of basic and simple language.

Interaction may be sparse.

They may not be aware of conversations directed to them.

Heavier reliance by loved ones on visual cues, context, tone of voice and touch.

May lapse into a familiar language used in their native country or their mother tongue.

Consider these tips when communicating with them:

Use different senses as a form of communication with your loved one

- Give visual cues. Point at or touch the item you want them to use or explain.
- Gently touch your loved one to maintain attention if he/she is easily distracted.
- If you do not understand your loved one, ask them to point or gesture as well. Written notes can be helpful when a spoken word seems confusing.

Simplify what you say

- Avoid lengthy conversations that require complex thinking. Break down tasks with clear, step-by-step instructions.
- Ask one question at a time as multiple questions can be overwhelming.
- Ask close-ended questions answerable with a "yes" or "no."
 - I. Ask, "Would you like some coffee?"
 - II. Avoid asking, "What would you like to drink?"

Be patient

- · Speak slowly and clearly.
- Take time to listen to what your loved one feels, thinks, or needs.
- Give them a time to respond. Do not interrupt or finish sentences unless they ask for help to complete a sentence.
- Use positive and good-natured humour to lighten the mood.

Be supportive

- Offering comfort and reassurance can encourage them to open their thoughts to you.
- · Sometimes, the emotions expressed are more important than what they say. Look for the intentions behind words or sounds. Observe their body language.
- It is okay if you do not know what to do or say; your presence is the most important indication of support to your loved one.

Treat your loved one with dignity and respect

- Avoid talking down or facing away as if they are not there.
- · Keep eye contact as much as possible and acknowledge your understanding of their expression and words.
- · Do not exclude your loved one from conversations with others.



Need more information? Here are some useful links for more details:

National Health Service (UK) - Communicating with someone with dementia http://www.nhs.uk/Conditions/dementia-guide/ Pages/dementia-and-communication.aspx



Your loved one may have difficulties in performing their usual tasks as dementia progresses, so designing a daily routine is a good way to provide them with some structure. Planning activities they enjoy can be helpful in reducing agitation and improving your loved one's mood.

Here are some daily activities to consider:

Creative Household Personal **Mealtimes** activities chores care Physical Mental Spiritual Social activities activities **Activities** activities

Before designing a daily routine, consider the following:

- · Their likes, dislikes, strengths, abilities and interests
- · How your loved one used to plan his or her day
- · Times of the day when your loved one feels more alert
- · Ample time for meals, bathing, and dressing your loved one
- · Practicing good sleeping habits by waking up and going to bed at regular timings

Daily Routine Example Suitable for early- to moderate-stage dementia



Wash up, brush teeth, get dressed to visit the market or coffee shop

Prepare and eat breakfast, and clean up the kitchen

Have coffee, and engage in a conversation

Try a craft project (e.g. folding origami), or relieve memories by browsing through old photos

Participate in simple chores together (e.g. folding clothes, or wiping the table after meals)

Take a walk, or play an active game

-☆- Afternoon

Assist in meal preparation (e.g. plucking or washing vegetables, shredding potato skin)



Eat lunch and wash the dishes

Socialise with other people



Listen to music, do crossword puzzles, and watch TV

Do some gardening, take a walk, or visit a friend

Take a nap

Evening



Prepare and eat dinner, and clean up the kitchen

Play cards, watch their favourite TV programme or get a massage



Get ready to sleep

Activities To Engage Your Loved One

Daily routines may include:

Chores:

Dusting, sweeping, doing laundry. Mealtime:

Preparing food, cooking, eating. Personal care:

Bathing, shaving, dressing.

Other activities may include:

Creative:

Painting, playing the piano.

Intellectual:

Reading a book, doing puzzles.

Physical:

Taking a walk, playing catch.

Social:

Having coffee, talking, playing cards. Spiritual:

Praying, singing a hymn.

Spontaneous:

Visiting friends, going out to dinner.

Work-related:

Making notes, fixing something

More info can be found in the Alzheimer's Association website https://www.alz.org/national/ documents/brochure_activities.pdf

Selecting activities across these categories can help keep your loved one mentally and physically active. Too much free time alone may make them feel lonely and unproductive, increasing the risk of depression, agitation, and anger.

In addition, people respond differently to various activities, so you should try them out and see which works best.

The important thing is to give them an enjoyable experience. The outcome and product of the activity come second.

Here are some tips on how you can engage your loved one with dementia through an activity:

- · Choose activities that are similar to what they have always enjoyed.
- Emphasise on their strengths. Focus on what your loved one can do and not on what they cannot do.
- Communicate with them verbally and non-verbally. Always allow time for response and minimise options if it could cause distress or confusion.
- Make sure the area is comfortable and conducive – take note of adequate lighting, allow ample space to move around, and minimise background noise
- Keep an eye for signs of fatigue or being overwhelmed - check with your loved one if he/she needs to rest frequently

In Advanced

Stage

Here are some activities that you can consider to engage your loved one living with dementia.

Home Management

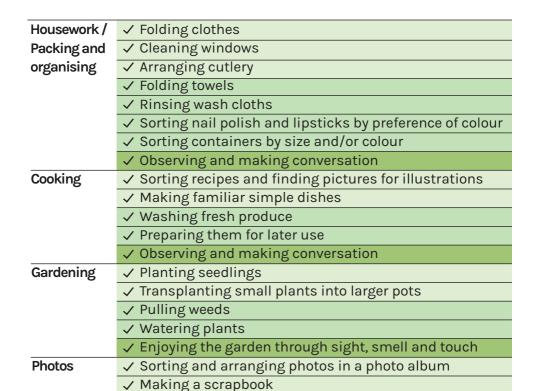
In Early

Stage

Persons living with dementia often spend a lot of time in the home environment. Allowing them to play a role in home management gives them a sense of purpose. Here are some examples of how they can help out at home.

In Moderate

Stage



✓ Making a photo collage ✓ Looking at old photos

Autobiography - Looking into their Experiences (Early to Moderate Dementia)

Oftentimes, we only know our loved ones as they are today, failing to understand that they have their own unique and individual memories.

An autobiography is useful for cognitive stimulation in persons living with dementia. While it personalises their sense of identity, it also helps the caregiver to understand the person beyond their condition, allowing care to be provided in a way that is positive and person-centred. It captures their history, likes and dislikes, and also helps you to understand your loved one better. It is also a great opportunity to involve other family members in this project to strengthen their bonds.

Below are some basic tips on how to capture stories from your loved one:

- · Ask questions clearly and slowly with short sentences and simple words. Repeat questions if necessary.
- · Have a natural conversation; it's not an interrogation.
- · Maintain eye contact and show interest by leaning forward and nodding.
- · Do not interrupt them or correct what they say.
- · Avoid topics that might cause distress.
- · Keep the interview short and simple, conducting it in a familiar environment. You may gradually find out more information over time, instead of trying to complete everything in a single session.
- · At the end of the conversation, thank your loved one to show that you value what they have shared.

Possible questions for the autobiography may revolve around their past and key moments in their lives. These are only guide questions, so please go with the flow of the conversation as much as possible.



Childhood

- 1. Can you tell us about your childhood?
- 2. What are your memories from school?
- 3. What was your favourite subject?
- 4. What were you good at?
- 5. What were your favourite activities or games?
- 6. What are the most exciting memories from your childhood?



- 1. What was your first job?
- 2. Where did you work (including working at home)?
- 3. What was it like? Did you move on to different jobs?
- 4. If you had your time again, would you do the same job or something else?
- 5. What are your valuable memories of work?

(C) Relationships

- 1. Who means a lot to you? Who were you closest to? (Prompt: friends and family)?
- 2. How many family members do you have? What are their names and relationship to you?
- 3. Did you have any pets?

a **Places**

- 1. Where would you say has given you the greatest feeling of "home"?
- 2. What memories do you have of the place you spent your happiest or longest times? (Prompt: the buildings, countryside, local people and communities.)
- 3. Are there any other places that hold a special importance to you? (Prompt: holiday places, places where certain events took place, etc. Include any pictures or postcards.)
- e Social **Activities** and Interests
- 1. What do you like to do in your spare time?
- 2. What types of music do you like to listen to? (Include some favourite songs/pieces of music.)
- 3. Do you have any favourite radio channels or TV programmes?
- 4. What is your favourite food and drink?



1. Who are the important people in your life at the moment? (Include name and relationship to you.)

Tips

- Choose the format of the autobiography diary, scrapbook, video, audio recording according to the mental ability of your loved one to communicate and interact with them.
- This activity may only be suitable for persons with mild to moderate dementia.
- Use the autobiography to remind the person with dementia about who they are.
- · If the person has difficulty communicating with words, use photos and pictures for the autobiography.
- · Suit the activity to your loved one's pace.

Reminiscing with Photos

Many people enjoy telling stories about their experiences to the younger generation. Telling their life story helps them give meaning to the time spent in their lives.

This is not so different for your loved one with dementia. The added benefit of reminiscing gives them a positive brain workout from recalling the details of past events.

Reminiscence can be done in many ways. It can be through conversations, looking through photos or family videos, or a visit to their favourite places. No matter how this activity is done, it is important to give your loved one the time and patience to recall.

Be genuinely curious about their story and show your interest. If they are recalling some events that you are part of, you can also share your perspective and add more dimensions to the story.



Here are some photos related to early Singapore life that may trigger their memories. We have also included some discussion topics that you can ask your loved ones.

Suggested topics to talk about:

| Date and place of birth | Family life and grandparents | Food & Cooking | Childhood games & pastimes |
|---------------------------------|------------------------------|-------------------|-------------------------------|
| Favourite things / food / songs | Dreams & aspirations | Achievements | Music |
| During the war | Love & marriage | Work | Friends |
| | Regrets | Holidays | |

Art & Craft - Continue the Drawing

(Early to Moderate Dementia)

The activity of arts and crafts is beneficial to your loved one as it promotes the use of mental creativity.

The ability to learn about creation through the freedom of verbal and visual expression is a powerful stimulation and release for the brain.

While this requires co-planning to create a shared piece of art, it also encourages thinking, in case the initial drawing process did not lead to the outcome desired.

Items required:

Drawing paper

If your loved one is not used to drawing, a large piece of paper may be intimidating. You can start by using a smaller piece of paper.

Markers

To promote creativity, you can offer markers of a variety of colours.

Steps involved:

- 1. Request for your loved one to sit on a chair at a table.
- 2. Explain that the game is to create a picture by taking turns to draw on the paper.
- 3. Each person is allowed 3 strokes. If necessary, you may start the drawing first before passing it to your loved one to continue.
- 4. At the end of the drawing, invite your loved one to share about his/her feelings about it.



Art & Craft - Stringing Beads Bracelet

(Early to Moderate Dementia)

Stringing beads into bracelets improves hand and eye coordination. The use of coloured beads stimulates the visual senses, in addition to a sense of achievement when your loved one can wear and take ownership for these creations.

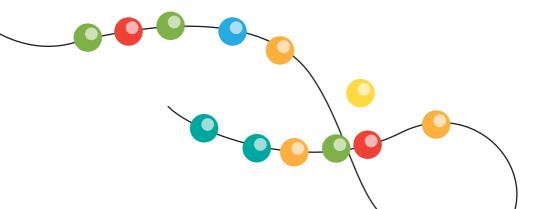
Items required:

- Large beads, preferably brightly coloured
- String, preferably with elasticity
- Large bowls with beads sorted out

Steps involved:

- Show your loved one a completed bracelet.
- 2. Measure and cut out the length of string required.
- Tie a knot at one end of the string.
- 4. Thread beads through the string. Your loved one could choose their own colour(s) and order in which they would like to string them.
- 5. Tie both ends of the string upon completion.

You can engage your loved one to first sort out the beads by colours to increase the difficulty of the task. Be mindful about their vision and beads chosen should have a hole large enough to thread the string in easily. Always consider demonstrating in case they have difficulties in following instructions.



Game - Fisherman Treasure

This game helps your loved one recognise objects in the environment. It also promotes sensory experience, enjoyment, and hand-eye coordination, while enhancing motor control for accuracy.

Items required:

- 1. Plastic tub
- 2. 10-15 floatable rubber fishes
- 3. 1 small fishing net
- 4. 1 plate

Steps involved:

- 1. Fill the tub with water.
- 2. Place the fishes into the water.
- 3. Distribute the fishing net.
- 4. Invite your loved one to sieve out the fishes then place them on a platform.

You can do this activity in a group to enhance social interaction. Consider sitting down in case your loved one cannot stand for too long or has poor balance. You may also provide bigger nets and less fishes for those with specific physical conditions.

Game - Rummage Box

Relying on the use of sensory stimulation to discern between objects, this activity lets your loved one practise their other senses through an engaging process. This gives them an alternative source of self-support in the event that their sight becomes impaired.

Items

- 1. Box
- required:
- 2. Blindfold or dark scarf
- 3. Items that can be differentiated easily with touch, e.g. ping pong ball, eraser, orange

Steps involved:

- Place the items in the box.
- 2. Invite your loved one to reach for the items in the box.
- 3. Let him / her hold it for 5 seconds.
- 4. After which, let him / her guess the items held.

You can also consider using objects which carry a distinct smell or even sound to assess how well your loved one functions with his/her other senses.

Game - Remember the Cooking Ingredients

Recalling recent conversations helps your loved one to practise memory skills and mental cognition. One way is to talk about dishes and ingredients to prompt your loved one to recall recipes he/she has known or cooked with before. Identifying the correct cooking ingredients will be a balance between focus and memory work.

Items required:

- 1. 20-30 pieces of common ingredients
- 2. Table

Steps involved:

- 1. Start by chatting about dishes that your loved one used to cook for the family or eat regularly.
- 2. Place pictures of common food ingredients on the table.
- 3. Invite your loved one to pick out pictures of ingredients mentioned in the earlier conversation.

Talking about the dishes with picture cards may be helpful if your loved one requires more clues and prompts. You can also revisit the earlier conversation and mention these ingredients. A more complex variation would be to ask if your loved one is able to estimate the prices of the ingredients.



Exercise

Being physically active not only helps your loved one to look good and feel good, it also helps them maintain their current abilities to function, reduce fall risks, as well as maintain their cognitive function and cardiovascular health.

According to the recommendation given by the Health Promotion Board (HPB), all individuals are encouraged to participate in aerobic activity, like walking, for at least 2 and a half hours every week. Consult your loved one's physiotherapist for an exercise program that can be suited to his or her needs.



Safety is important!

- · Do the exercises with supervision
- Do not hold breath while exercising
- Wear proper shoes when exercising
- · When doing the exercises in a seated position, sit on a steady chair, preferably with an arm rest
- · When doing the exercises in a standing position, place a stable chair behind your loved one so that he/she can have something to hold on to
- · Stop the exercise immediately if it causes pain and consult a doctor or physiotherapist
- · Do not exercise if your loved one feels unwell

At early stage, you may encourage your loved one to continue with their current exercise regime, or encourage them to go for classes such as a Tai Chi or dance.

At the moderate stage, it may be difficult to continue going for classes. Here are some exercises that can also be done at home.

Sit-to-stand

- 1. Sit on a chair with the feet supported on the floor. The ankles should be positioned slightly behind the knees.
- 2. Push gently through the heels, bend at the hips, keep the head up and stand up.
- 3. Share the weight between both legs.
- 4. Repeat 10* times.

Leg lift

- 1. Sit with the back well supported in a chair.
- 2. Lift the affected leg up.
- 3. Do not allow the thigh to rotate outwards or the body to arch backwards.
- 4. If necessary, use the hand to assist.
- 5. Repeat 10* times for each leg.

Knee extension

- 1. Sit well supported on a chair.
- 2. Straighten the knee one, at a time, and then bend it slowly.
- 3. Repeat 10* times for each leg.

Ankle exercise

- 1. Lift alternate foot off the ground with the heels remaining on the ground.
- 2. Repeat 10* times for each leg.











^{* 10} is a general guide. Check with your loved one's physiotherapist on what is the suitable level of physical activity.

Playball

Gently throw a softball to your loved one and invite them to throw it back to you. This helps boost hand-eye coordination. The activity can be done either while standing or seated. You may also adjust the distance between you and your loved one to match his/her strength.

Walking

Encourage your loved one to continue with a 30-minute walking exercise two to three times per week. This helps to keep them physically and mentally healthy.

Passive Exercise

If your loved one is not able to do any of the exercises given above, encourage them to continue with their daily routine to maintain their ability to be independent.



In advanced dementia, the caregiver may have to conduct passive exercises for the loved one. These exercises with your loved one can be done two to three times a day to prevent their joints and muscle from becoming stiff. Stiff joints and muscles can cause pain when you are dressing your loved one.

Shoulder flexion and extension

- 1. Support the elbow and wrist.
- 2. Raise the arm
- 3. Do not flex or extend the arm further if pain occurs.
- 4. Be careful not to pull on the arm.
- 5. Repeat 10* times for each arm.

Elbow extension

- Bend and straighten elbow.
- 2. Repeat 10* times for each arm.

Wrist flexion and extension

- 1. Support the top and bottom of the wrist joint.
- 2. Bend the wrist forward and backward.
- 3. Repeat 10* times for each arm.

Finger flexion and extension

- 1. Bend the fingers to make a fist, and then straighten fully.
- 2. Repeat 10* times for each hand.

Hip, knee flexion and extension

- 1. Place one hand below the knee and the other hand below the heel
- 2. Slide the foot towards the buttock.
- 3. Repeat 10* times for each leg.



















Hip adductor stretch

- 1. Support below the knee and heel.
- 2. Bring the entire leg to the side.
- 3. Hold for 30 seconds or less.
- 4. Keep your loved one's foot as straight as possible.
- 5. Repeat 10* times for each leg.





Hamstring stretch

- 1. Support below the knee and heel.
- 2. Bring the entire leg up, keeping knee straight.
- 3. Hold for 30 seconds or less.
- 4. Repeat 10* times for each leg.

Calf stretch

- 1. Cup the heel with forefoot resting on the forearm of the person assisting with the exercise.
- 2. Hold the leg down with other hand.
- 3. Push the forefoot up gently (avoid pushing only the toes) without causing pain.
- 4. Hold for 30 seconds.
- 5. Repeat 10* times for each leg.



^{* 10} is a general guide. Check with your loved one's physiotherapist on what is the suitable level of physical activity.

Engage your loved one with moderate or advanced dementia by creating a comfortable space for meaningful activities. In this space, family and friends can engage your loved one through a multi-sensory Care Session.

These are the four components of a Care Session:



Create a safe and comfortable space

Ideally, there should be a safe, designated room for your loved one. If there is no designated room, you may create a screened-off area in your living or dining room.

The space or room should be a sensory experience for your loved one, providing a multi-sensory experience every time they step inside. There are four further components caregivers should consider for this sensory experience:

- Lighting: Choose a quiet room or space with sufficient natural light and ventilation. A strong light can be glaring and uncomfortable, so use soft lights to reduce shadows. If possible, choose a colour your loved one likes for the walls, curtains, screens, etc.
- **Music:** Play soothing and relaxing music. Understand what kind of music your loved one prefers as a way to meet their needs wherever possible. Music can also trigger memories and improve their mood, allowing further engagement.
- Scent: Scent the room or space with essential oils of lavender and lemon, which have been shown to reduce anxiety and agitation for persons living with dementia.
- Suitable furniture: Provide a comfortable chair for your loved one to recline, and a light blanket for a cosy feel.

No.

Choose meaningful activities

It's a good idea to choose meaningful activities for your loved one as verbal communication becomes difficult for them. When introducing an activity, take time to explain and demonstrate to your loved one what the activity is about, as this is more likely to result in a positive response.

It is also important to determine a suitable activity based on their abilities and preferences. Here are some examples:

Welcome your loved one into a peaceful and private space - The multi-sensory activity can commence when your loved one enters the space. Let them feel welcomed by holding their hand and assisting them to sit comfortably in a chair.

This can also be followed with simple questions about their day to start a meaningful conversation.

Watch for changes in expression and massage their hands gently. Touch is a fundamental way of communicating love and a light massage does just that.

Activities of Daily Living (ADL) - ADLs can take on meaningful experiences within this room. For example, your loved one may usually resist having their nails clipped. However, in this safe and comfortable space, your loved one is calm and is more likely to cooperate as they enjoy the experience.

You may also include reminiscent elements such as the use of their favourite scents or playing old songs to liven up the atmosphere.

Preparation of appropriate food and drink - Prepare food and drinks that your loved one likes as these will stimulate their sense of sight, smell and taste.

Use the safe and comfortable space as an opportunity for your loved one to drink sips of water between activities, thereby ensuring hydration and a multi-sensory experience. The power of a loving touch – Physical touch is known to be the most powerful stimulus in engaging someone with advanced dementia. It is a fundamental means of human communication and part of our lifelong need to be cared for, nurtured, valued, and loved.

It may involve just holding your loved one's hand, offering a hand rub, or a massage; even gently brushing your loved one's hair can be a pleasurable and meaningful experience.

No.

Involve caregivers, family and friends

Involve your loved one's family and friends in these activities. Having different people to engage with them adds variety to their social interaction. Family and friends can take turns to conduct meaningful activities progressively.

Everyone involved can also meet regularly to discuss how to meet the evolving needs of your loved one.

No.

Essential equipment and supplies

Personalise this Care Session with supplies that could facilitate meaningful activities for your loved one. For example, the application of traditional creams and ointments used regularly in the past that may evoke their memories. Here are some other suggestions:

| Supplies | Purpose | |
|-----------------------|--|--|
| Face cloths | To wipe and clean the face of your loved one | |
| Aqueous cream for | To moisturise the skin of the senior or elderly | |
| moisturising the skin | | |
| Cotton buds | To softly clean areas of the senior's face | |
| Hypoallergenic oil | To gently massage and rub your loved one's hands | |
| for massage | | |
| Soap dispenser/ | To wash and clean the relevant areas of the senior or elderly | |
| hand sanitiser | · | |
| Hairbrush and comb | To keep your loved one kempt and tidy | |
| Nail clippers | To trim the nails of the senior or elderly and maintain nail hygiene | |
| Face cream | To keep the senior's face fresh and moisturised | |
| | *Note: Traditionally sold creams may evoke memories for seniors | |
| Lip balm | To keep the your loved one's lips moisturised | |
| | To keep the senior's face kempt and shaven | |

Preparing For Doctor's Visits

No.

Keep a symptom diary for your loved one

A diary helps you keep track of signs and symptoms experienced by your loved one. Note the symptoms or behaviours exhibited - when and how they started and how frequently they happen - and use it to communicate any concerns you may have when it comes to caring for your loved one.

This will also help the doctor in keeping track and administering a more tailored treatment plan.

Example of a symptom diary log:

| г | | | |
|---|------|------|--|
| | Date | Time | Changes in Mood / Behaviour / Memory / Health (For easy tracking, you can add a remark column for noting when they started, how frequently they happen, what the triggers are) |
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Maintain an appointment log of your loved one's medical appointments

This will help you keep track of your loved one's medical appointments, especially if they have several doctors. Get the most from a doctor's visit by having a clear objective or by preparing questions.

Each entry into the appointment log records the discussion such as the treatment options recommended and any other notes from your doctor. This will also be helpful when caregiving arrangements are shared among family members, ensuring continuity of care for your loved one.

Example of an appointment log:

Appointment Date

Appointment Time

Questions for the doctor

Main Discussion & Recommendations

Other Notes



Plan for the actual trip to the doctor

Most public transportation officers are trained to support persons with mobility issues. Private hires like GRAB Assist can also help with your loved one's trip to the doctor. Choose the most comfortable schedule for you and your loved one, keeping the time around you're your scheduled trip free from appointments to ensure a comfortable travel. They may also experience stress and anxiety from being in an unfamiliar environment, so always prepare for emergencies by bringing:

- ✓ a change of clothes
- ✓ toiletries
- ✓ towels
- ✓ mobility aids
- ✓ snacks and water

Diet & Nutrition

As dementia progresses, your loved one may lose weight and suffer from undernutrition due to reduced appetite, and cognitive and behavioural issues.

Diet - Healthy Eating

Eating a balanced diet and drinking plenty of fluids are important for maintaining physical and mental well-being. Adopting a Mediterranean diet may lower the risk of cognitive decline and dementia. This means eating higher proportions of cereals, fruits, fish and vegetables.

While it is essential to provide regular, healthy and balanced meals, you must also take note of the eating environment. As eating is a social activity, creating a comfortable dining atmosphere can help boost your loved one's appetite.

How can you improve the eating environment?

- a. Eat with your loved one.
- b. Reduce unnecessary distractions.
- c. Ensure that you have a selection of various foods.
- d. The colours of the food, plate, and table should be different and contrasting.
- e. Avoid the use of patterned plates to prevent confusion.

How can you improve your loved one's appetite?

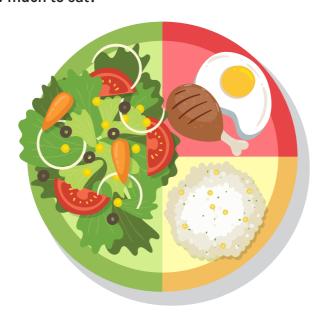
- a. Let them choose what they want to eat.
- b. Provide regular snacks or small meals rather than setting designated mealtimes.
- c. Make the look and smell of the food appealing and appetising.
- d. Do not overload the plate with too much food. Small and regular portions work best.
- e. Encourage your loved one to get involved with mealtimes, such as asking them to help in preparing the food.
- f. Invite familiar people to join the meal and provide some company.

Eating Well

Eating a well-balanced nutritious diet is important for overall health. The key to the ideal meal for seniors or the elderly with dementia is not necessarily providing a special diet, but providing variety, balance and moderation. As they tend to eat less, they will require more vitamins and minerals to support their diets.

How much to eat?

The Ideal Plate



What is One Serving for each dish?

| ½ bowl of rice | 2 slices of bread | |
|---------------------|---------------------|--|
| 4 pieces of biscuit | 2 squares of tofu | |
| 1 medium banana | ¾ cup of vegetables | |



The fluid requirements for older adults are similar to younger adults'. Older adults, however, tend to drink less than what their bodies need for a number of reasons

With age, the body loses its ability to detect thirst. Some older adults also suffer from poor memory, immobility, or illness - all of which can result in decreased fluid intake.

In addition, certain medications can also interfere with feelings of hydration and/or the thirst mechanism. Dehydration can be a serious health problem in older adults as it can be associated with other illnesses

Prevent dehydration by providing your loved one with adequate fluids throughout the day.

Tips to increase fluid intake

- a) Offer water frequently throughout the day and at mealtimes.
- b) Offer help to those who can't drink independently.
- c) Offer barley, milk, soy milk, tea, coffee, juice, juicy fruits and soups for variety.

Managing Early And Moderate Dementia

These are some common behaviours exhibited in early and moderate stages of dementia. It will vary from person to person.



In Early

- Forgetfulness
- Dementia Occasionally repeating him/herself
 - · Isolating themselves from others
 - · Feeling tired all the time
 - · Easily irritated

In Moderate Dementia

- · Getting lost in familiar places
- · Repeating what he/she said
- · Problems with communication
- · Neglecting personal hygiene and self-fare
- · Losing track of time & events
- Misplacing items more frequently
- · Behavioural disturbances
- · Forgetting the names of common objects and familiar people
- · Forgetting important events, i.e. birthdays of their children
- · Confused about timings and places
- · Poor or decreased judgement
- · Problems with abstract thinking
- · Swallowing problems

Sometimes, behavioural changes during early and moderate stages of dementia can cause concern. Some examples of behaviours of concern that are commonly seen include:

- Aggression
- Agitation
 - o Easily upset
 - Easily irritable
 - Frequent arguing
 - o Inappropriate screaming, crying, disruptive sounds
 - o Refusal to shower, bathe or be groomed
 - o Running away from home
- · Anxiety or excessive worry
- · Apathy or indifference

- Delusions / hallucinations
- Depression
- Disinhibition
 - Sexually inappropriate behaviour
 - Socially inappropriate behaviour
- Irregular Night-time Activity
 - o Getting up at night
- · Wandering behaviours

In managing behaviours of concern, it is important to ascertain-

- what the trigger is. Consider commonly unmet needs, such as constipation, pain, and toileting needs.
- whether the behaviour is causing distress to your loved one if so, prompt treatment may be necessary.
- whether the safety of your loved one is compromised if so, some modifications to the home setting may need to be made to ensure that the environment is safe.

In reality, it is the daily, non-drug methods and techniques that turn out to be effective in the long-term.

Non-drug measures are usually the first-line approach before medication treatment is considered.

- Revise your approach. Tasks may need to be simplified and your loved one may need some help with the task. Remember that it's about simply engaging your loved one in an activity. It will help them to focus on their abilities, rather on their inabilities.
- 2. Validate how your loved one feels. Acknowledge your loved one's feelings and experience. Do not confront or argue – it is not necessary to always correct your loved one when they are in the wrong.
- 3. Direct their attention elsewhere. Identify the cause behind the behaviour and address it through engaging your loved one in meaningful activities.

Is your loved one behaving aggressively? Sometimes your loved one may behave aggressively if there are unmet needs which cause them discomfort. Such behaviour may be the result of an unmet need such as:

| BIOLOGICAL | SOCIAL | PSYCHOLOGICAL |
|---|---|---|
| Pain, illness, or physical discomfort Misunderstandings due to poor eyesight / hearing Hallucinations and delusions | Lack of social contact and loneliness Boredom, inactivity and sensory absence Changing of established routine | Frustrations at not being able to complete tasks Possibility of depression Perception that personal space is invaded Feeling ignored |

What can you do if your loved one behaves aggressively?

- Try to stay calm and take a deep breath. Avoid any potential for confrontation.
- · Try not to show any fear, alarm or anxiety as this may make him / her more agitated.
- · Validate your loved one's feelings reassure your loved one and acknowledge their feelings.
- · Listen to what they are saying.
- Maintain eye contact and try to encourage communication.
- · Redirect their attention elsewhere to get them to focus on something else
- · Seek support for yourself from family, friends, counsellors or support groups.



How to address wandering behaviour in your loved one with dementia

· Continuing with a habit or routine

They say old habits die hard, so if a person with dementia had a very specific routine or habit that they used to follow, they may want to carry on with it.

They may tend to go shopping or back to their old office, because they have conditioned themselves to think they should be there.

Reasons for that may be caused by:

Boredom

Someone who is lacking in mental and physical stimulation may simply decide that they'll go looking for something to do. This means they could wander off or simply fancy going for a walk to look for a sense of purpose.

Restlessness or a need to burn up energy

If your loved one used to have an active life and is suddenly stuck at home, they may simply have the urge to get out and about.

Confusion

Sometimes your loved one may tend to wander and forget how he/she got into that room in the first place. This can happen a lot with dementia, so your loved one may be trying to 'retrace' their steps.

Likewise, if they don't remember an area, they may wander off until they find something familiar.

Looking for something or someone

Wandering may occur because they've suddenly decided they need to find an old friend they haven't seen for a long time, or they're wondering where they parked their car, even if they haven't driven for quite some time.

An attempt to get away from something

If the situation or place they're currently in is painful, stressful or unpleasant in any way, they may simply walk off to get away from it all.

Likewise, if the environment is very noisy, they might walk off to find somewhere more quiet and peaceful - and who can blame them?

Night wandering

Always be aware that wandering can happen at any time, including the middle of the night. If someone with dementia gets easily confused with what time of the day it is, you may find them wandering at 2 a.m. because they think they have to be somewhere and don't understand that they're supposed to be asleep.

The tendency to wander is common to persons living with dementia. Use the following strategies to help your loved one understand there is no need to wander:

- · Carry out daily activities having a routine can provide structure. Try to create a daily routine for your loved one with dementia.
- · Identify the most likely times of day that wandering may occur plan activities at that time. Activities and exercise can reduce anxiety, agitation and restlessness.
- · Reassure the person if they feel lost, abandoned or disoriented - if the person with dementia wants to leave to "go home" or "go to work", use communication focused on exploration and validation, and refrain from correcting them.
- Ensure all basic needs are met has the person gone to the bathroom? Is he or she thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation - shopping malls, grocery stores or other busy venues.

- Install locks out of the line of sight
- install either high or low exterior doors and consider placing slide bolts at the top or bottom.
- Use devices that signal when a door or window is opened - this can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.
- Provide supervision do not leave someone with dementia unsupervised in new or changed surroundings. Never lock them at home or leave them in a car alone.
- Keep car keys out of sight if the person is no longer driving, remove access to car keys - a person with dementia may not wander on foot. If the person is still able to drive, consider using a GPS device to guide them if they get lost.

Sundowning



If your loved one with dementia displays behaviour changes particularly in the evening time, it is wise to consider that it may not simply be a symptom of dementia. These behaviour changes may be agitation, aggression, confusion and restlessness. This is known as sundowning and often occurs in the moderate to severe stages of dementia.

Possible causes of Sundowning

- Changes in the physical brain may affect the sleep cycle and cause wakefulness in the evening and at night.
- · Your loved one may have previously been occupied and busy at a particular time of the day
- Little or disturbed sleep that may cause restlessness, or napping during the day time
- · Side effects of medication that can cause confusion, agitation or wear off during the evening time
- · Environments that cause discomfort may precipitate sundowning, eg shadows that occur around evening time

Tips for Caregivers

Sundowning may cause some distress to caregivers. Here are some tips which may be helpful in reducing sundowning symptoms in your loved one.

- 1. Implement a daily schedule.
- 2. Occupy your loved one with a familiar activity that will bring them comfort, eg listening to favourite music, looking at old photographs
- 3. Reduce environmental discomforts such as loud noises and bright lights

Adapted from

https://www.alzheimers.org.uk/about-dementia/symptomsand-diagnosis/symptoms/sundowning



Is your loved one experiencing difficulties with eating?

People with dementia can develop difficulties in swallowing as their dementia progresses with their age.

Parts of the brain that control swallowing may affect and weaken the muscles involved, affecting various parts of the feeding process. Difficulty in swallowing also increases the risk of food or drinks entering the lungs. This can lead to a serious lung infection.

Watch out for these signs and symptoms of difficulties with swallowing:

- Coughing during or after meals
- Frequently clearing the throat
- Feeling breathless while eating
- Holding food in the mouth and refusing to swallow
- Having difficulty swallowing
- Spitting lumps of food out

If your loved one has any of the symptoms above, have an assessment with a speech therapist. They will provide advice on the safest dietary options, including changes in diet texture and liquid consistency where appropriate. They may also provide strategies on feeding your loved one safely. This may minimise their risk of aspiration.

| What you may observe | Suggested strategies |
|--------------------------------|--|
| Coughing/choking | Ensure that your loved one sits in an upright position when eating Prepare food and liquid that are of the correct texture Engage in a slow feeding rate Control the amount being fed Avoid offering mixed textures of liquid and solid food (e.g. milk with cereal, or noodles with soup), as it can increase the risk of choking |
| Holding food in their mouth | Offer food that does not require much chewing Give verbal reminders to swallow Present an empty spoon near or in their mouth to prompt them to perform the swallowing action again |

Currently, there is no strong evidence that tube feeding helps at this stage. It may even prolong their suffering.

Common behavioural difficulties during feeding

People with dementia may also refuse to eat. They may become angry, agitated, or challenging to feed during mealtimes. This can happen for a variety of reasons:

- · Disliking the food
- Feeling rushed
- · Feeling uncomfortable with the environment or people
- Feeling frustrated with the difficulties they are having

It can be challenging to identify what the actual problem is, particularly if they have difficulties communicating. It is important to remember that these reactions are not deliberate.

Try not to rush your loved one or put pressure on them to eat and drink quickly. Instead, look for non-verbal cues such as body language and eye contact as a means of communication. Wait until they are calm and less anxious before proceeding with the meal.

| What you may observe | Suggested strategies |
|--|---|
| Refusing feeding attempts/ spitting out food | Check their mouths for ulcers or poor dental health as these can be painful Encourage independence when eating or drinking; gently place your hand over theirs to guide the cutlery to their mouth if they are unable to self-feed Offer familiar or favourite food and drinks Make the food looks and smells appealing — prepare food with different tastes, colours and aromas Use familiar utensils Ensure that the temperature of the food served is appropriate |
| Eating very quickly | Supervise the meal and use prompts, e.g. chew before swallowing Gently place your hand over theirs to control their feeding rate Cut up their food into smaller pieces to reduce the risk of choking |
| Distracted during mealtimes/ not attentive to eating | Have a minimalistic table set-up Ensure that there are minimal distractions, e.g. quiet and calm environment, or fewer people Play calm and soothing music in the background during mealtimes Ensure appropriate and adequate lighting |

For alternative care solutions and support for caregivers, these are some services which can provide some relief and help.

| PEKAICE2 | Ca |
|----------|----|
| | Ca |
| | _ |

Caregiver Training Caregiver Support Group Counselling Respite Care Home Care Senior Activity Centre Senior Care Centres Nursing Homes

Managing **Advanced Dementia**

These are some common behaviours exhibited in the advanced stage of dementia:

- Losing mobility and ability to perform daily tasks
- Losing ability to communicate
- Food refusal
- Swallowing problems

Is your loved one experiencing difficulties with eating?

Food plays a very important part in our lives, so it can be difficult for caregivers when they see their loved one losing interest in food and consequently losing weight.

This tends to happen towards the advanced stage of dementia. It may seem as though your loved one is being starved. However, the reality is that their metabolic rate goes down and they use up less energy too.

Your loved one may not be as active or mobile as before and may not require the same amount of calories they had when they were more active. In fact, having a reduced interest in food or fluid intake can be a part of "natural progression" as we age.

Here are some strategies that may help you deal with this issue:

- Look for opportunities to encourage your loved one to eat. If they are mostly at night, night-time snacks may be a good idea.
- Encourage your loved one to get involved in preparation during mealtimes where possible.
- · Encourage your loved one to enjoy a snack.
- Offer familiar or favourite food and drinks.
- Choose the most flavourful food for mealtimes.
- Offer small amounts of food and drinks throughout the day.

In advanced dementia, when swallowing is weakened, your loved one may have an increased risk of food and fluid entering their lungs. Offering food and drinks may no longer be safe when signs of choking or aspiration occur.

The priority may then shift to making the senior or elderly feel comfortable. Caregivers can:

- · Moisten their loved one's lips
- Continue to let them have a little taste of their favourite food

This is part of comfort and pleasure feeding as it allows your loved one to maintain some dignity and retain the enjoyment of certain tastes. It is important to never force feed or make them eat when they are drowsy.

Alternative sources of artificial nutrition such as tube feeding have not been proven to increase patients' lifespan. It does not eliminate or reduce the risks of aspiration either as supervised oral feeding is as effective as tube feeding. On the contrary, having a feeding tube may add discomfort to your loved one and they may need to be restrained, especially if there is a tendency to pull out the feeding tube.

Is your loved one experiencing urinary incontinence?

Urinary incontinence is a common problem in dementia. As the disease progresses, your loved one may become less aware of their toileting needs and urinate unconsciously. Deterioration may lead to urinary tract infection, an enlarged prostate gland, drinking too much caffeinated beverages, impaired mobility, and constipation.

It can be helpful to:

- · Take them to the toilet at regular intervals (timed toileting) to foster continence. This is possible with effort and careful attention to their usual toileting habits. This gives them a chance to maintain comfort and self-esteem, and postpones the need for continence products such as diapers.
- · Ensure regular diaper changes to keep the nether regions dry and clean.

 Use a skin protective cream to minimise skin irritation or breakdown from soiled diapers.

The need to use diapers is a result of your loved one's inability to control their urinary motions.

- Note that it is important to check and change diapers frequently for hygiene purposes.
- Turn your loved one at regular intervals if he/she is bedbound to prevent development of pressure sores.
- · Skin, which is hot from constantly being in the same position and moist from urine or faeces, can become macerated and be prone to bed sores, resulting in infections. Serious infections can affect the deep tissues or bone underneath the skin and be difficult to treat.

Good skin hygiene, together with adequate fluid intake and regular bowel clearance, prevents urinary tract infections which are also common in people with dementia.

Is your loved one experiencing constipation?

Constipation is common in older persons, especially people with dementia, given their reduced awareness and relative immobility. Poor food, fibre and fluid intake may also cause constipation.

Constipation is a source of discomfort, and can worsen confusion and agitation. It also makes passing urine more difficult and can cause urinary retention.

Consider the following advice:

- Ensure adequate hydration and intake of fruits and vegetables.
- · If the person is not keen on drinking plain fluids, other sources of fluids include soup, milkshakes, juices or decaffeinated coffee or tea.
- Use laxatives if necessary
- · Record and monitor bowel movements and type of stool

SERVICES

Caregiver Training Caregiver Support Group Counselling Respite Care

Home Care Senior Activity Centre Senior Care Centres **Nursing Homes**

End of Life Care



End of life care aims to support someone in the later stages of a life-limiting condition to live as well as possible until they pass on. It also aims to support family and caregivers during this time and after the person passes on. End of life care may last for weeks, months or occasionally years - it is often difficult to know exactly when a person with dementia is approaching the end of their life.

Nearing the End of Life

There are symptoms in the later stages of dementia that can suggest the person is reaching the final stage of their illness, but this may be difficult to predict as well. These include:

- · Speech limited to single words or phrases that may not make sense
- · Needing help with most everyday activities
- · Eating less and having difficulties swallowing
- Bowel and bladder incontinence
- · Being unable to walk or stand, problems sitting up and controlling the head, and becoming bed-bound.

A Good Death

For many people, a 'good death' means:

- · Being treated with compassion and respect
- · Being kept clean, comfortable and free from distressing symptoms
- Being in a familiar place surrounded by those close to them

End of Life Care seeks to support all aspects of your loved one's wellbeing, especially:

- · Physical needs (including pain relief and management of other symptoms)
- Emotional health
- Social health their relationships with others
- · Spiritual beliefs



Professional Care

End of life care for a person with dementia can involve a number of different professionals working together, including the doctor, nurses, social workers or care home staff. Palliative care professionals at a local hospice or hospital may give specialist input if this is needed. This team of professionals should keep you updated as the person's condition changes and involve you in any decisions. The person should always have an up-to-date care plan that includes end of life plans and is shared with those involved in the person's care.

It is likely that a person with dementia is nearing the end of their life if they have these symptoms, along with other problems such as frailty, infections that keep coming back, and pressure ulcers.

Tips for Caregivers:

How to better communicate with your loved one

- Maintain eye contact as much as possible.
- Talk about things of interest to your loved one or reminisce about things from the past, even if you don't think he/she can follow what you are saying. He/she may respond to the tone of your voice and feel a level of connection with you even if he/she does not understand what you are saying.
- Use appropriate physical contact such as holding hands or a hug to reassure your loved one that you are there for them.
- Take your time and look for non-verbal signals from your loved one
- Non-verbal communication gestures, body language, facial expression and touch - can help facilitate communication

Adapted from

https://www.alzheimers.org.uk/get-support/help-dementia -care/end-life-care#content-start





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