

Providing Care



Living with Dementia: A Resource Kit for Caregivers



Supported by aIC

How can this kit help you?

This kit consists of a series of 4 booklets. This booklet on Providing Care provides you with essential information, practical tips, activities and resources on dementia to support you in caring for your loved one living with dementia.

It is designed for caregivers like yourself to pick up tips on having effective communication with your loved one, how to design a daily routine with engaging activities, and managing dementia as it progresses by stages etc. This in turn enables you to 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 ccmh@aic.sg or the Agency for Integrated Care (AIC) hotline at **1800 650 6060**.

We appreciate your feedback on this kit and hope you can take a few minutes to share your comments by scanning the QR code. Thank you!



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1. Understanding Communication Challenges

“ 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. It is important to adopt a KIND and CARE approach (refer to page 30 of Knowing Dementia) when you come across a person living with dementia. It is not a condition that he or she chooses to be in.

Early Stage



- 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.
- May feel overwhelmed by excessive stimulation.

Moderate Stage



- Able to follow simple one-step instructions.
- May understand written information in a word-by-word process.
- Having a hard time following conversations.
- Repeating oneself.
- If interaction is demanding, persons living with dementia may withdraw from the interaction.
- Personality and behavioural changes, suspiciousness and delusions may hinder meaningful conversations.

Advanced Stage



- Face difficulty with verbal communication as vocabulary may be reduced.
- Verbal expression may be in patches or strings of words and sounds.
- Conversations may be disconnected.
- Communication and words may be interpreted in unconventional ways.
- Vocabulary consists of basic and simple language.
- Interaction may be sparse.
- They may not be aware of conversations directed at them. May lapse into a familiar language used in their native country or their mother tongue.



2. Communication Tips

Interaction can be challenging between you and your loved one. As such, it is important to practise active listening, read their body language, ask questions for clarity, and seek common ground when you communicate. Non-verbal communication through different senses will become more significant 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.



Non-verbal Communication

Sight

- Choose a quiet room with sufficient natural light. Use soft lighting so that shadows and glares can be reduced.
- Give visual cues and provide context. Point at or touch the item you want them to use or explain.
- If you do not understand what your loved one means, ask them to point or gesture instead. Written notes can be helpful.
- 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.

Always introduce yourself to them

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

Hearing

Music can trigger memories, improve mood and encourage engagement. You may play light, soothing and relaxing music, but it is best to understand your loved one's music preference.



Verbal Communication

Treat your loved one with dignity and respect

- Consider bending down to speak when your loved one is seated.
- 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.
- Offering comfort and reassurance can encourage them to open their thoughts to you.

Simplify what you say

- Speak slowly and clearly. Keep your tone of voice calm and patient when conversing.
- Avoid lengthy conversations that require complex thinking. Ask one question at a time as multiple questions can be overwhelming.
- Ask close-ended questions answerable with a “yes” or “no.”- Ask, “Would you like some coffee?”- Avoid asking, “What would you like to drink?”.



Non-verbal Communication

Smell

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

Touch

- Never underestimate the power of a loving touch. Namaste Care is a way to connect with your loved ones by showing your love and concern through the form of a gentle hand massage.

To find out more about Namaste Care, visit aic.buzz/NamasteCare or scan the QR code.





Verbal Communication

Ensure that their physical space is comfortable and quiet

Engage with them in one-to-one conversations in a surrounding with minimal distraction.

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

Be patient

- Take time to listen and observe your loved one's gestures, facial expressions and body language to better understand how he or she is feeling, thinking, or needs.
- Give them time to respond. Do not interrupt or finish sentences unless they ask for help to complete a sentence.

Visit www.nhs.uk/conditions/dementia/communication-and-dementia/ or scan the QR code for more information.



Visit www.dementia.org.sg/wordshurt/ or scan the QR code to learn more about Dementia Language Guidelines.





3. Designing a Daily Routine

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:



Household Chores



Mealtimes



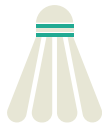
Personal Care



Creative Activities



Mental Activities



Physical Activities



Social Activities



Spiritual 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

Visit www.aic.buzz/CG-CareRoutine or scan the QR code to learn more about managing a care routine.



Here is an example of a daily routine suitable for early to moderate stage of dementia:

Morning 	Afternoon 	Evening 
Wash up, brush teeth, get dressed to visit the market or coffee shop	Assist in meal preparation (e.g. plucking or washing vegetables, shredding potato skin)	Take a bath 
Prepare and eat breakfast, and clean up the kitchen	Eat lunch and wash the dishes 	Prepare and eat dinner, and clean up the kitchen
Have coffee, and engage in a conversation	Socialise with other people	Play cards, watch their favourite TV programme or get a massage 
Try a craft project (e.g. folding origami), or relieve memories by browsing through old photos	Listen to music, do crossword puzzles, and watch TV 	Socialise with other people
Participate in simple chores together (e.g. folding clothes, or wiping the table after meals)	Do some gardening, take a walk, or visit a friend	Get ready to sleep 
Take a walk, or play an active game	Take a nap	



4. Activities to Engage Your Loved One Living with Dementia

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



1 Choose activities that are similar to what they have always enjoyed.



2 Emphasise on their strengths. Focus on what your loved one can do and not on what they cannot do.



3 Communicate with them verbally and non-verbally. Always allow time for response and minimise options if it could cause distress or confusion.



4 Make sure the area is **comfortable and conducive** – take note of adequate lighting, allow ample space to move around, and minimise background noise.



5 **Keep an eye for signs** of fatigue or being overwhelmed – check with your loved one if he/she needs to rest frequently.

Visit www.dementiahub.sg or scan the QR code for more information.



Engaging them in home management

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:

Early Stage



- Planting seedlings
- Transplanting small plants into larger pots
- Folding clothes
- Cleaning windows
- Arranging cutlery
- Sorting recipes and finding pictures for illustrations
- Making familiar, simple dishes
- Sorting and arranging photos in a photo album
- Making a scrapbook

Moderate Stage



- Folding towels
- Rinsing clothes
- Sorting nail polish and lipsticks by preference of colour
- Sorting containers by size and/or colour
- Washing fresh produce and preparing them for later use
- Pulling weeds
- Watering plants
- Making a photocollage

Advanced Stage

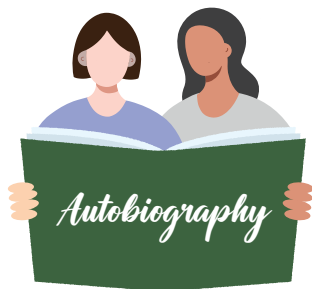


- Looking at old photos
- Observing and making conversation
- Enjoying the garden through sight, smell and touch

Autobiography – Looking into their experiences

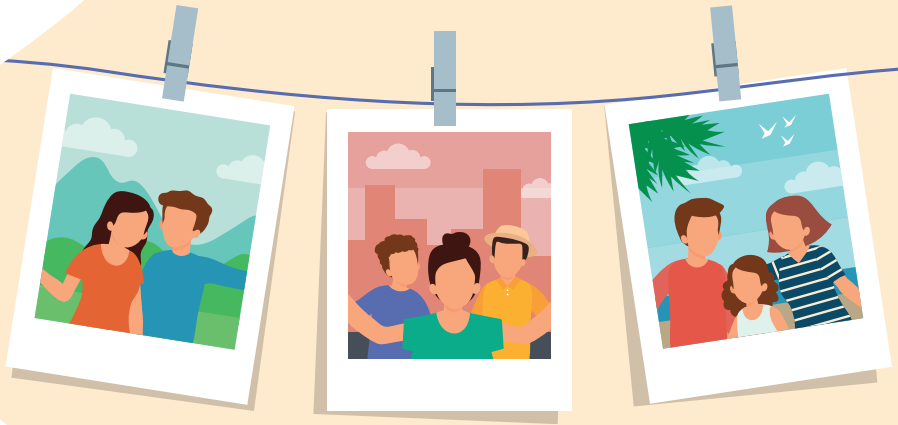
Early Stage and Moderate Stage

Often, 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.





Tips

- Choose the format of the autobiography e.g diary, scrapbook, video, audio recording.
- This activity may only be suitable for persons living with mild to moderate dementia.
- Use the autobiography to remind the person living with dementia about who they are.
- Use photos and pictures for the autobiography when necessary.
- Suit the activity to your loved one's pace.

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.
- 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. Here are guiding questions, consider going 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?



Working Life

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?



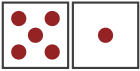
Relationships

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?



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)



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?



People who are important to me now

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

Reminiscence activities

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.

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 and cooking



Childhood games and pastimes



Favourite things / food / songs



Dreams and aspirations



Achievements



Music



During the war



Love and marriage



Work



Friends



Regrets



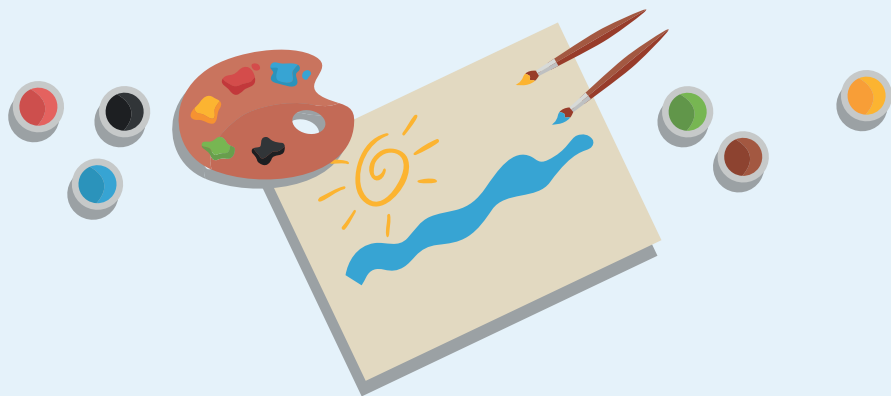
Holidays

Art & Craft – Continue the drawing

Early Stage and Moderate Stage

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 or her feelings about it.

Art & Craft – Stringing beads bracelet

Early Stage and Moderate Stage

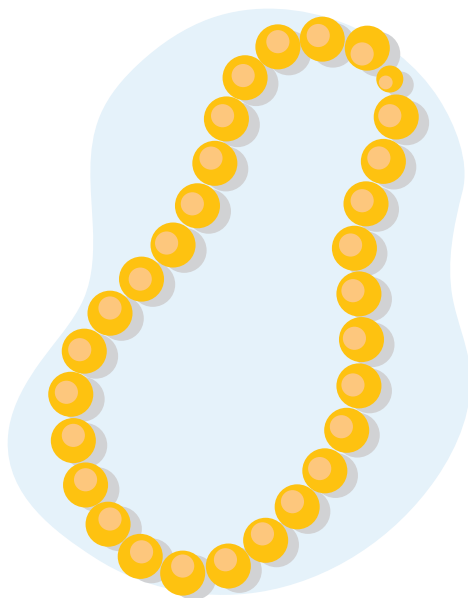
Stringing beads into bracelets improves hand and eye coordination. The use of coloured beads stimulates the visual senses, in addition to a sense of achievement when your loved one can wear and take ownership for these creations.

Items required

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

Steps involved

1. Show your loved one a completed bracelet.
2. Measure and cut out the length of string required.
3. 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.

Exercises

Be physically active

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, and maintain their cognitive function and cardiovascular health.

The Health Promotion Board (HPB) recommends all individuals to participate in activities such as walking. Consult your loved one's physiotherapist for an exercise programme that can be suited to his or her needs.

Walk

Encourage or accompany your loved one for a 30-minute walk two to three times per week. This helps to keep them physically and mentally healthy.

Play ball

Gently throw a soft ball 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. Adjust the distance between you and your loved one to match his or her strength.

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 may provide discomfort or pain for them.

Safety is important!

- ✓ Do the exercises with supervision
- ✓ Do not hold your 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 or 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 the 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:

Exercises for moderate stage



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.



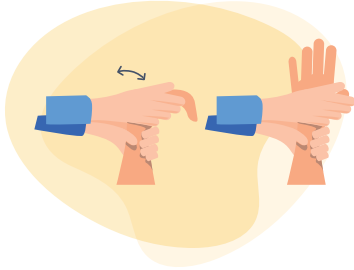
Shoulder flexion and extension

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

1. 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.*



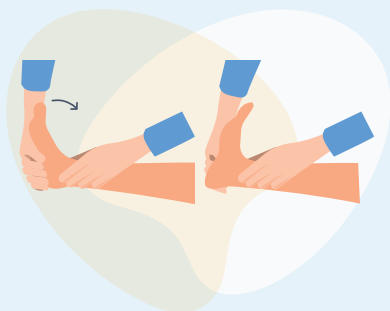
Hip adductor stretch

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.

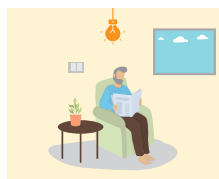
Multi-sensory Care Session

Engage your loved one living 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. There are four components of a Care Session:

1 Create a safe and comfortable space

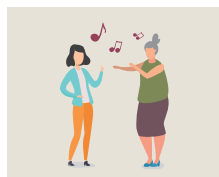
Ideally, there should be a safe, designated room for your loved one. If there is no designated room, you may create a screened-off area in your living or dining room.

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 for a sensory experience:



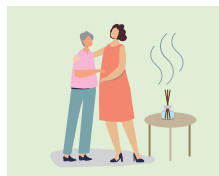
Lighting

Choose a quiet room or space with sufficient natural light and ventilation. Strong lighting can be glaring and uncomfortable, so use soft lighting. If possible, choose a comfortable 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 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.



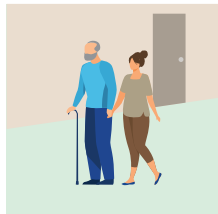
Suitable furniture

Provide a comfortable chair for your loved one to recline, and a light blanket for a cosy feel.

2 Choose meaningful activities

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, for a more positive response.

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



Multi-sensory activity

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.

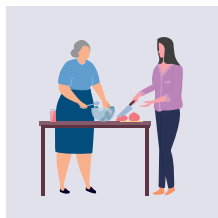
Watch for changes in expression and massage their hands gently. Touch is a fundamental way of communicating love and a light massage does just that.



Activities of Daily Living (ADL)

ADLs can take on meaningful experiences. 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.

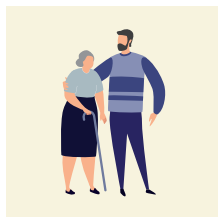
You may also include reminiscence elements such as the use of their favourite scents or playing old songs to liven up the atmosphere.



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 persons living 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.

Visit aic.buzz/NamasteCare/ or scan the QR code to learn more about Namaste Care.



You may also download the Namaste Care Toolkit for Caregivers at www.aic.buzz/namaste-toolkit-caregivers or scan the QR code.



3 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.

Visit www.aic.sg/caregiving/family-support or scan the QR code to learn more on family discussion to better care for your loved one.



4 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:

Face cloths	To wipe and clean the face of your loved one
Aqueous cream	To moisturise the skin of your loved one
Cotton buds	To softly clean areas of your loved one's face
Hypoallergenic oil for massage	To gently massage and rub your loved one's hands
Soap dispenser/ hand sanitiser	To wash and clean the relevant areas of your loved one
Hairbrush and comb	To keep your loved one kempt and tidy
Nail clippers	To trim the nails of your loved one and maintain nail hygiene
Face cream	To keep your loved one's face fresh and moisturised <small>*Note: Traditionally sold creams may evoke memories for seniors</small>
Lip balm	To keep your loved one's lips moisturised
Shaver and shaving cream (For males)	To keep your loved one's face kempt and shaven



5. Diet and Nutrition



As dementia progresses, your loved one may lose weight and become malnourished due to reduced appetite, cognitive and behavioural issues.

Diet - Healthy eating

Eating a balanced diet and drinking sufficient fluids are important for maintaining physical and mental well-being. Adopting a Mediterranean diet may lower the risk of cognitive decline. 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?

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

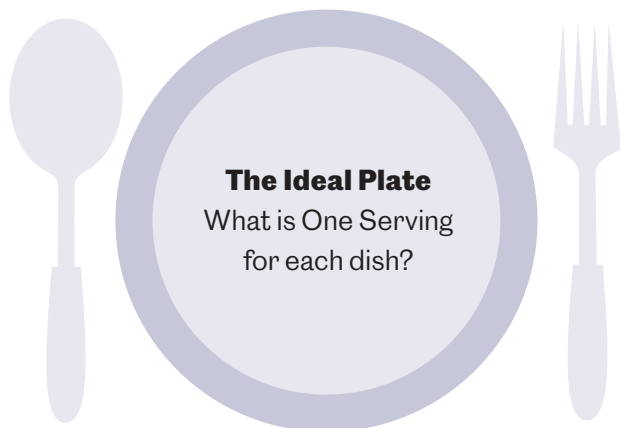
How can you improve your loved one's appetite?

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

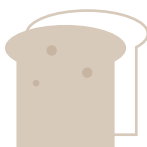
Eating well

Eating a well-balanced nutritious meal is important for overall health. The key to the ideal meal for persons living 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 diet.

How much to eat?



1/2 bowl of rice



2 slices of bread



1 medium banana



4 pieces of biscuit



2 cubes of tofu



3/4 cup of vegetables

Drinking enough fluid



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



Offer water frequently throughout the day and at mealtimes.



Offer help to those who can't drink independently.



Offer barley, milk, soy milk, tea, coffee, juice, juicy fruits and soups for variety.

Visit www.dementiahub.sg or scan the QR code for more information about Diet and Nutrition.





6. Managing Behavioural Change

Dementia is often accompanied by behavioural changes, which affect your loved one living with dementia and all around him or her. Behavioural changes can be one of the most difficult effects of dementia.



Persons living with dementia who experience behavioural changes are often described to have a “completely different personality” from their old self. Different behavioural changes occur at different points in mild and moderate stages of dementia, and vary between people and across different types of dementia.

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

Early Stage

- Forgetfulness
- Occasionally repeating himself or herself
- Isolating themselves from others
- Feeling tired all the time
- Easily irritated

Moderate Stage

- Getting lost in familiar places
- Repeating what he or she has said
- Problems with communication
- Neglecting personal hygiene and self-care
- 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

Agitation and aggression

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
 - Easily upset
 - Easily irritable
 - Frequent arguing
 - Inappropriate screaming, crying, disruptive sounds
 - Refusal to shower, bathe or be groomed
 - Running away from home
- ✓ Anxiety or excessive worry
- ✓ Apathy or indifference
- ✓ Delusions / hallucinations
- ✓ Depression

Disinhibition

- ✓ Sexually inappropriate behaviour
- ✓ Socially inappropriate behaviour
- ✓ Hoarding
- ✓ Regular night-time activity
 - Getting up at night
- ✓ Repetitive Behaviours
- ✓ Resistance to Activities of Daily Living
- ✓ Sundowning
- ✓ Wandering behaviours

Causes of behavioural changes

As dementia affects the brain that controls everything from thoughts, emotions, behaviours, to speech; dementia may make your loved one less able to recognise his or her needs and how to communicate. In addition, these behaviours also manifest due to changes in the brain caused by dementia – the type of behavioural changes exhibited depends on the area of the brain affected by dementia as well.

It is important to understand the meaning underlying the behaviours, from the perspective of your loved one living with dementia. 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:

Physical Needs

Your loved one living with dementia may be experiencing pain or discomfort, or suffering from other illnesses at the same time.

Psychological or Cognitive Needs

Your loved one may be depressed or have other mental health conditions, or feeling confused or threatened in an environment that does not seem right or familiar.

Social Needs

Your loved one may be feeling lonely, isolated or bored.

Environmental or External Needs

Your loved one may be in an overstimulating environment (loud noises or busy environment) or experiencing a different and unfamiliar routine.

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 or 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.

Management of behavioural changes

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

✓ **What triggers the behaviour**

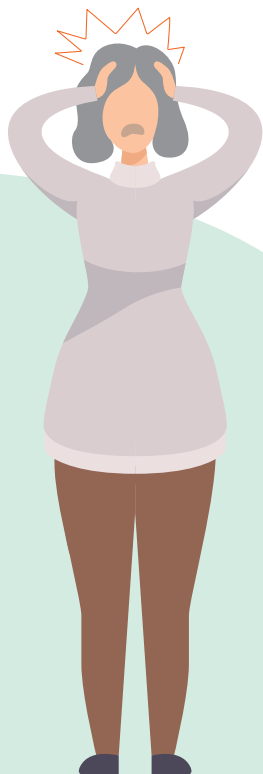
Consider their unmet needs such as constipation, pain, and toileting needs.

✓ **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 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. Below are some examples:

1. Revise your approach. Tasks may need to be simplified and your loved one may need some help with the task. Remember that it is about simply engaging your loved one in an activity. It will help them to focus on their abilities, rather than 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.

Managing behaviours during mealtime

Is your loved one experiencing difficulties with eating?

People living with dementia can develop difficulties in swallowing as 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 fluids 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	<ul style="list-style-type: none"> ✓ 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	<ul style="list-style-type: none"> ✓ 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 living 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:

- ✓ Dislike 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	<ul style="list-style-type: none"> ✔ Check their mouth 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 look and smell 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	<ul style="list-style-type: none"> ✔ 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 meal time/not attentive to eating	<ul style="list-style-type: none"> ✔ 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 meal time ✔ Ensure appropriate and adequate lighting

Managing wandering behaviour

How to address wandering behaviour in your loved one living with dementia?

Many persons living with dementia feel the urge to walk about and in some cases leave their homes. Persons living with dementia may simply not remember where they had set out to go, or what they had intended to do. Wandering may be concerning when persons living with dementia may meet with dangerous situations while wandering about the neighbourhood. This is due to lack of orientation, causing difficulties in finding their way back home.

Continuing with a habit or routine

They say old habits die hard, so if a person living with dementia had a very specific routine or habit that they used to follow, they may want to carry on with it. They may want to go shopping or go 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 to look 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 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 or 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 a person living 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 do not understand that they are supposed to be asleep.



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

- ✔ Carry out routine activities – having a routine can provide structure. Try to create a daily routine for your loved one living 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 your loved one 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 your loved one gone to the bathroom? Is he or she thirsty or hungry?
- ✔ Avoid busy places such as shopping malls, grocery stores or other busy venues that are confusing and can cause disorientation
- ✔ 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.

Visit www.aic.buzz/ATE-ep5 or scan the QR code to watch the “Ask the Expert” video on how to manage your loved one’s behavioural changes.



Visit www.aic.buzz/dementia-brochures or scan the QR code for other useful resources on dementia.



Visit www.dementiahub.sg/living-well-with-dementia/managing-wandering-behaviour/ or scan the QR code to learn more about understanding and managing loved ones living with dementia who wander.



Sundowning

If your loved one living 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 in the evening and at night e.g. night-shift job.
- ✓ 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, e.g. shadows on the wall or floor that occur around evening time.

Adapted from www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/sundowning or scan the QR code.



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.

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



Services

Caregiver Training

There are knowledge and skills which you can learn to create a safe and supportive environment for your loved one. Training can be conducted at your home or at training facilities.

Visit www.aic.sg/caregiving/caregiver-training or scan the QR code to learn more.



Caregiver Support Groups

You may also speak to and learn from other caregivers who may have similar experiences.

Visit www.aic.sg/caregiving/caregiver-tips or scan the QR code to learn more.



Care Services

Counselling, Respite Care, Home Care, Senior Activity Centre, Senior Care Centres, and nursing homes.

Visit www.aic.sg/care-services or scan the QR code to learn more.





7. 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 active 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 your loved one 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 seniors' 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 and drinking too much caffeinated beverages may lead to urinary tract infection, an enlarged prostate gland, 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 living with dementia.

Is your loved one experiencing constipation?

Constipation is common in older persons, especially person living 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.

For more information on other care services, you may refer to Page 43.

End-of-Life care

Caring for a loved one at the end of his or her life can be a challenging experience as most of us do not know what to expect and have to juggle with multiple responsibilities. As End-of-Life care can last between days and months, you should work closely with your healthcare providers to approach the changing situation in a collaborative manner. With their support, you can remain focused on caring for your loved one while attending to your own needs as a caregiver.

Palliative care

Palliative care at the end of life refers to whole-person-care that focuses on the physical, emotional, social and spiritual needs of the persons approaching end of life, where a cure or reversal of the disease is no longer possible.

Palliative care focuses on improving a person's quality of life by relieving pain, discomfort or distress. It is delivered through a multidisciplinary medical team consisting of doctors, nurses, pharmacists, social workers and counsellors, to address your loved one's holistic needs.

- ✓ Physical
- ✓ Psychological
- ✓ Social
- ✓ Financial
- ✓ Spiritual concerns of patients and families

The purpose of palliative care is to improve the quality of life of the dying person including the relief of pain. As a caregiver, you should discuss palliative care options with the doctor, together with your loved one. End-of-Life care may last for weeks, months or occasionally years. It is often difficult to know exactly when a person living with dementia is approaching the end of their life.

Visit www.singaporehospice.org.sg/palliativecare/ or scan the QR code to learn more.



You can also enroll for training courses to manage the needs of your loved one. Visit www.hca.org.sg/Caregivers-Training-Videos or scan the QR code to watch the videos.



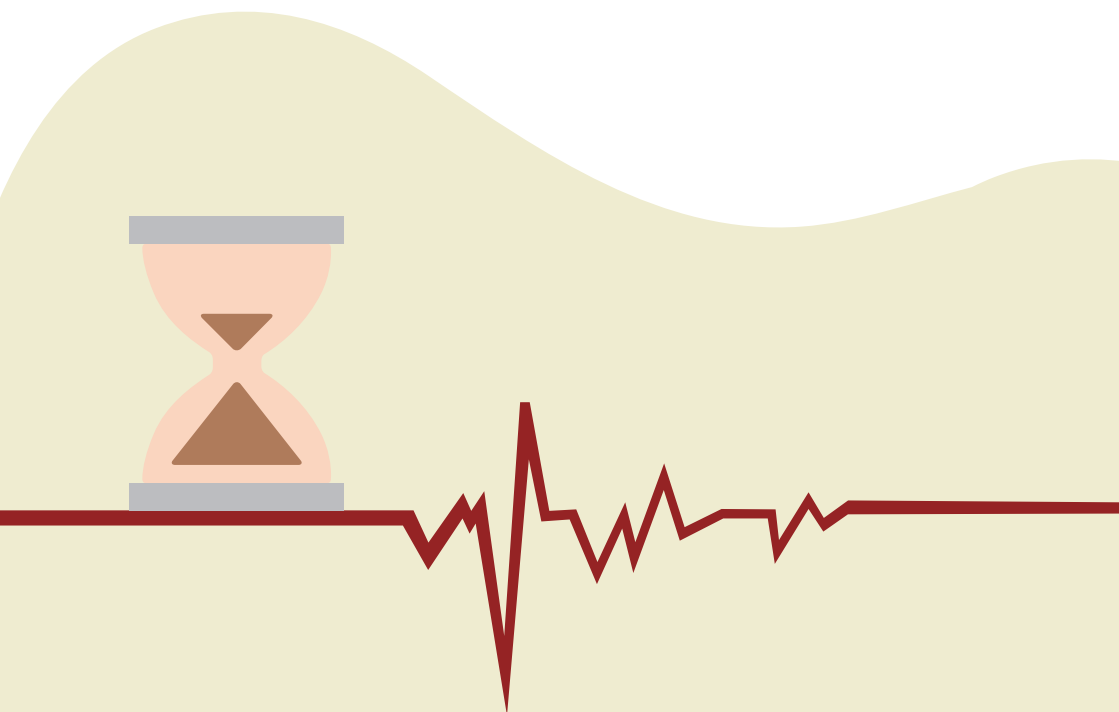
Nearing the end of life

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.

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.



Visit www.singaporehospice.org.sg/dialogue or scan the QR code for more tips on talking about dying.



Visit www.griefmatters.org.sg/planning-ahead/ or scan the QR code to learn more on grief matters.



Visit www.dyingmatters.org or scan the QR code to learn more on dying matters.



Professional care

End-of-life care for a person living 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 your loved one's condition changes and involve you in any decisions. He or she 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 living 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 with your loved one or reminisce about things from the past, even if you don't think he or she can follow what you are saying. He or she may respond to the tone of your voice and feel a level of connection with you even if he or 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 www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care#content-start or scan the QR code.



Pay Attention to Your Own Needs

Managing your emotions and responsibilities as a caregiver can become overwhelming. Do remember to take care of your own needs. Eat balanced meals and take time to rest. Reach out to others to ask for practical help and emotional support for yourself. Let the healthcare team know when you have difficulties coping with the demands of caregiving so that they can put in additional support for you.

Find out more about self-care tips and resources from Book 2 – Caring for Yourself.

The Heart of Care



Click
www.aic.sg



Call
1800 650 6060



Visit
AIC Link

The Agency for Integrated Care (AIC) aims to create a vibrant care community for people to live well and age gracefully. AIC coordinates and supports efforts in integrating care to achieve the best care outcomes for our clients.

We reach out to caregivers and seniors with information on staying active and ageing well, and connect people to services they need.

We support stakeholders in their efforts to raise the quality of care, and also work with health and social care partners to provide services for the ageing population.

Our work in the community brings care services and information closer to those in need.