



A Caregiver's Top 20 Questions

(For Caregivers of Persons with Dementia)

Developed by:
Agency for Integrated Care
Dementia-Friendly Community – A Caregiver’s Top 20 Questions
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A Caregiver's Top 20 Questions

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1. What is Dementia?

Dementia is an illness that affects the brain and is not a natural part of ageing. It's an illness that makes a person lose the ability to:

- think, reason, remember new information
- recall past events
- care for one's self
- learn new information and skills
- problem-solve; *and*
- make sound judgement calls

Dementia can affect adults of any age, but is more common in those aged 65 and above.

2. I think my loved one might have dementia. What can I do to help him / her?

If you suspect your loved one is suffering from dementia, you should get them properly diagnosed and treated. However, starting a conversation with someone on the issue of memory loss and possible dementia can be a difficult thing to do. They may feel worried, helpless, or be in denial.

Have the conversation in a familiar and relaxing place, and ask questions like, “*You seem worried; how can I help?*” There is no need to convince your loved one to visit a doctor in one session.

You can bring your loved one to a memory clinic in the hospital (CGH, IMH, NUH, NTF, TTSH) and approach a General Practitioner (click [here](#)), or call the following hotlines for more information.

a) HealthLine by Health Promotion Board (HPB) - 1800-223-1313

b) Singapore Silver Line 1800-650-6060

c) Dementia Helpline by Alzheimer's Disease Association - 6377 0700

3. How do I involve my family in my loved one's care?

If your loved one is newly diagnosed, gathering the family to discuss the care needs of your loved one can be helpful. The objective of the family discussion is about how your loved one's care needs can be honoured.

Different family members will cope with the diagnosis and communicate their thoughts and emotions differently, possibly leading to some tension. Set an agenda for discussion, delegate support roles and have some ground rules in order to have a fruitful discussion.

4. Can dementia be prevented and cured?

Here are some tips on how one can keep their mind active and lower the risk of dementia:

- Regular exercise
- Mental stimulation
- An active social life
- Healthy diet
- Maintain a healthy lifestyle

There is no cure for dementia at present. There are, however, drugs that may help improve mental function, mood, or behaviour, and slow the symptomatic progression of the disease. Although slight improvements or stabilisation of symptoms can at times be seen, these ultimately do not prevent the disease from getting worse.

5. How do I keep track of my loved one's appointments?

Date	Time	Questions for the doctor	What was discussed / Treatment option recommended / Follow-up required	Other notes

Refer to the table shown above as an example of an appointment log for your loved one. Each entry into the appointment log should note what was discussed with the doctor, the treatment options recommended, and any other notes from your doctor.

Keeping a symptom diary for your loved one is also useful, and it will ease your mental burden of having to remember too many things. You can use it to communicate to the doctor any symptoms or behaviours of concern that your loved one is experiencing. You may also consider customising your log so that it is easy for you to keep track of unique circumstances.

6. What services are available for my loved one with dementia?

There are many services available for persons with dementia and their caregivers. They include:

1. Emergency numbers
2. Helplines
3. Government Hospitals
4. Support and services for dementia
5. Nursing homes
6. Respite care services
7. Senior care centres
8. Caregiver support group
9. Caregiver training
10. Resource guides
11. Services to make the home environment dementia friendly

Refer to the Resources Tab on the website for a list of services.

7. What are the financial subsidies that I can apply for?

There are many financial subsidies available for persons with dementia and their caregivers. These include:

1. Community Health Assist Scheme (CHAS)
2. Seniors' Mobility and Enabling Fund (SMF)
3. Pioneer Generation Disability Assistance Scheme (PioneerDAS)
4. Caregivers Training Grant (CTG)
5. Foreign Domestic Worker (FDW) Levy Concession for Persons with Disabilities
6. Foreign Domestic Worker (FDW) Grant

8. What are the advanced preparations that we have to make?

Early planning can help in caring for your loved one with dementia. Some families may think that it is inappropriate to discuss these topics, but it is important to make clear that this will enable your loved one's preferences to be honoured. Early planning is also good because as dementia progresses, it may be more difficult for your loved one to communicate their wishes to you.

Advanced preparations that can be made include:

- Advanced Care Planning
- Advanced Medical Directive
- Lasting Power of Attorney
- Will
- Home modifications

9. How can I communicate with my loved one?

Dementia can affect the language skills of your loved one to communicate with you. Keeping up can be upsetting and frustrating for both them and yourself. When communicating with a person with dementia, it is important to keep in mind that conversations may become more disjointed, repetitive and absent altogether.

Practice active listening, reading body language, asking questions to clarify and seek common ground.

Here are some communication tips you can use:

- Speak slowly and clearly.
- Sometimes, expressed emotions are more important than what they say. Look for the intentions behind words or sounds. Observe their body language.
- Give your loved one time to respond. Do not interrupt or finish sentences unless he/she asks for help finding a word or finishing a sentence.
- Avoid lengthy conversations that require complex thinking. Instead, break down tasks with clear, step-by-step instructions.
- Ask one question at a time. Multiple questions can be overwhelming.

10. What are some meaningful activities that I can carry out with my loved one?

Caregivers often have to design a daily routine that works for a loved one. Structured and enjoyable activities can be encouraging in reducing agitation and improving your loved one's mood, keeping them mentally and physically active in the community.

Here's a list daily activities to consider:

- Household chores
- Creative activities (music, art, or crafts)
- Intellectual activities (reading, or solving puzzles)
- Physical activities

However, before proceeding to these activities, consider the following:

- Likes, dislikes, strengths, abilities and interests of your loved one
- How your loved one used to go about his or her day
- What times of the day your loved one functions the best
- Setting aside ample time for meals, bathing and dressing your loved one

11. Why is my loved one like a different person?

As dementia progresses, your loved one may feel like a different person and exhibit behaviours of concern. Some commonly seen behaviours are:

- Agitation
- Aggression
- Anxiety
- Apathy or indifference
- Delusions
- Depression
- Night time behaviour
- Wandering behaviour

These may be a result of the condition, but are often due to unmet needs. Oftentimes, they may have difficulty communicating that they are in distress or have a desire to do something, and that results in “behaviours of concern”. Try your best first to find out the root cause of the behaviours before you address them.

12. How do I get my loved one to enjoy their meals?

As eating is also a social activity, creating a comfortable dining atmosphere can help boost your loved one's appetite. Try these tips:

- Eat with your loved one
- Reduce unnecessary distractions
- Ensure that you have a variety of food in various colours
- Avoid the use of patterned plates, cutlery and furniture to prevent confusion
- Let him/her choose what they want to eat
- Provide regular snacks or small meals rather than setting designated mealtimes
- Make the look and smell of the food appealing and appetising
- Do not overload the plate with too much food; small and regular portions work best
- Encourage your loved one to get involved at mealtimes; they could help to prepare the food and utensils on the table

13. How can I allow my loved one to wander safely?

To address this behaviour, let's first understand the reasons behind it. Wandering behaviour may be due to:

- A conditioned habit or routine
- Boredom
- Restlessness or a need to burn up energy
- Confusion
- Looking for something or someone
- Trying to get away from something

These are some strategies to help reduce your loved one's need to wander:

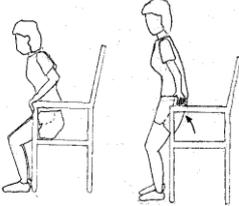
- Carry out daily activities within a safely structured routine
- Plan activities during the most likely times of day that wandering may occur
- Reassure and gently redirect them if they feel lost, abandoned or disoriented
- Ensure all basic needs are met
- Avoid busy places that are confusing and can cause disorientation
- Install door locks out of the line of sight
- Use devices or bells that signal when a door or window is opened
- Provide supervision anywhere and everywhere
- Keep car keys out of sight

For more information, please refer to the Caregivers Guide for Persons with Dementia that Wander, available on the website.

14. What fitness activities are available for my loved one who has difficulties with mobility?

When mobility is affected or difficult, it may be difficult to find exercise activities that are suitable. Here are some activities and exercises that can be done at home.

If your loved one feels pain at any time, please stop the activities immediately.

	<p>Sit-to-stand</p> <ol style="list-style-type: none"> 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 __ times
	<p>Leg lift</p> <ol style="list-style-type: none"> 1. Sit with the back well supported in a chair. Lift the affected leg up. 2. Do not allow the thigh to rotate outwards or the body to arch backwards. 3. If necessary, use the hand to assist. 4. Repeat __ times for each leg.
	<p>Knee extension</p> <ol style="list-style-type: none"> 1. Sit well supported on a chair. 2. Straighten the knee one, at a time, then bend it slowly. 3. Repeat __ times for each leg.
	<p>Ankle exercise</p> <ol style="list-style-type: none"> 1. Lift alternate foot off the ground (with the heels remaining on the ground). 2. Repeat __ times for each leg.

Playball

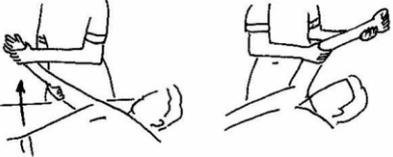
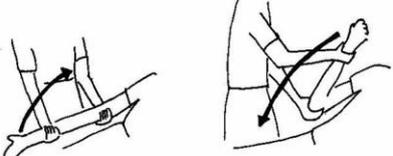
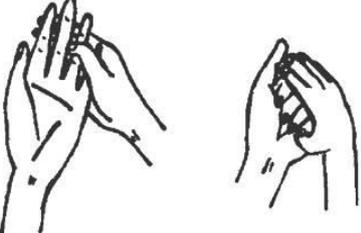
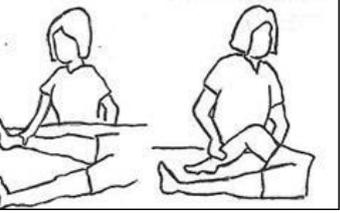
Throw a soft ball to your loved one and invite him / her to hit it back to you. This helps with hand-eye coordination. This activity can be done standing or seated and you may adjust the distance between you and your loved one to match his strength.

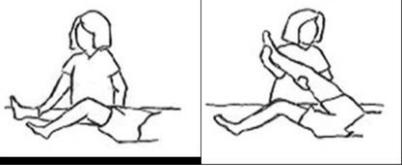
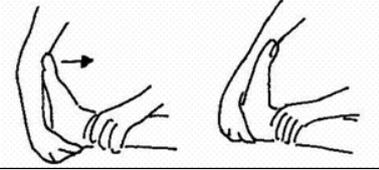
Walking

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

If your loved one is not able to do any of the exercises given above, encourage them to continue with their daily routine (e.g. walking to the toilet and sitting out of bed in a chair) to prevent deconditioning.

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 putting on the clothings for your loved one.

	<p>Shoulder flexion and extension</p> <ol style="list-style-type: none"> 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 __ times for each arm.
	<p>Elbow extension</p> <ol style="list-style-type: none"> 1. Bend and straighten elbow. 2. Repeat __ times for each arm.
	<p>Wrist flexion and extension</p> <ol style="list-style-type: none"> 1. Support the top and bottom of the wrist joint. 2. Bend the wrist forward and backward. 3. Repeat __ times for each arm.
	<p>Finger flexion and extension</p> <ol style="list-style-type: none"> 1. Bend the fingers to make a fist, then straighten fully. 2. Repeat __ times for each hand.
	<p>Hip, knee flexion and extension</p> <ol style="list-style-type: none"> 1. Place one hand below the knee and the other hand below the heel. 2. Slide the foot towards the buttock. 3. Repeat __ times for each leg
	<p>Hip adductor stretch</p> <ol style="list-style-type: none"> 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 __ times for each leg
	<p>Hamstring stretch</p> <ol style="list-style-type: none"> 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 __ times for each leg
	<p>Calf stretch</p> <ol style="list-style-type: none"> 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 __ times for each leg

15. How can I ensure my loved one can keep going to the toilet independently?

Bringing the person to the toilet at regular intervals (i.e. timed toileting) can help promote independence. This is possible with the effort and careful attention to the usual toileting habits of the person.

16. Where can I meet other caregivers who are going through the same thing?

Caregiver support groups are available in hospitals, the community and even online. They can be made up of care partners, spouses, family members, and friends of those caring for persons with dementia. It offers caregivers support and information targeted at managing dementia. It also encourages caregivers to share information, give and receive support, and exchange practical suggestions with one another.

17. How can I manage my own feelings and stress?

It is not uncommon for caregivers to feel guilty, angry and depressed. Things may be going well, but some caregivers feel that they could be doing more. Sometimes, caregivers may feel trapped, angry and frustrated. The emotional stress could also lead to depression.

Some ways to manage negative emotions include:

- How much help you are providing a person who is unable to function by themselves
- Your intentions come from love, care, and compassion for your dear one
- Doing this will not only motivate you to improve your caregiving skills; *but also*
- Give you a sense of fulfilment as an individual, for the present and future

Be mindful that situation you are in is because of the illness, not your loved one.

18. How do I take breaks for myself?

It is important to take breaks or respite so that you can refuel yourself for the next leg of the journey. The key to get respite is to ask for and accept help from as many places as possible.

1. Respite time

- Ask a family member or friend to stay with your loved one for an hour or more so that you can take a break.
- Take your loved one to a day care centre.

2. Respite zone

- A respite zone is an area set aside just for you, to take a break whilst your loved one is resting or being taken care of by someone else.
- In this zone you may engage in activities that you enjoy, play light music, and simply relax.
- Modify and furnish the space according to your needs.

3. Activities outside the house

- As much as possible, try to keep up with your own activities and interests.
- Get as much involvement as possible from family and friends in the care of your loved one.
- Consider support services.

4. Other ways to take a mental or physical break

- Appreciate what you have and can do.
- Change your mindset – do not think about what you do not have or cannot change.
- Limit coffee and caffeine intake so that it does not interfere with your sleep.
- Keep a journal on your thoughts, feelings, and what you are grateful for.
- Pick up meditation or do breathing exercises when you are stressed.

19. Where can I find a caregiver support group?

In most support groups, you will not only get useful knowledge and support from others on the same caregiving journey, but you'll be able to help them as well. Most importantly, you will find out that you are not alone.

Support groups exist in hospitals, in the community, and even online. Here's a list you can consider:

Hospital support groups for dementia

- Alzheimer Disease Association Dementia Caregiver Support Group
- Dementia support groups at Khoo Teck Phuat Hospital and National Neuroscience Institute
- Dementia support group at Singapore General Hospital

Community Support Groups

- Alzheimer's Disease Association (Tel: 6593 6440)
- Project Angels (Tel: 6274 6904)
- TOUCH Caregivers Support (Tel: 6258 6797)
- Caregivers Alliance Limited (Tel: 6753 6578)
- Filos Community Services (Tel: 6242 5978)
- Caregiving Welfare Association (Tel: 6466 7957)

Online Communities

You can find active **online support groups** on social media like Facebook to interact with fellow caregivers or an **interest group** which you can join to gain more relevant information and tips.

20. I cannot accept the idea that my loved one has dementia and may leave me one day. What should I do?

This is called anticipatory grief. It's possible to experience this when you first come to know of your loved one's condition, or through the caregiving journey until their final days.

Here are some things to remember when dealing with grief:

1. Accept that anticipatory grief is normal
2. Acknowledge your losses
3. Connect with others
4. Reflect on the remaining time
5. Take advantage of your support networks
6. Consider counselling