

# Living with Dementia

## *A Resource Kit for Caregivers*

### CARING FOR YOURSELF

A Dementia Friendly Singapore Initiative



# 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](mailto:careinmind@aic.sg) or at the Singapore Silver Line at 1800 6506060.

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# CARING FOR YOURSELF

## LOOKING AFTER YOURSELF

**Always remember that part of your duty to your loved one is to take good care of yourself.**

Most caregivers feel that all their time, energy and care should be given to their loved ones. However, your loved one may suffer too, if you do not look after yourself.

Consider these tips:

### **Exercise**

A lifestyle that lacks physical activity is a risk factor of all major diseases. Moderate exercise, such as walking, helps as an easy way to exercise. Regular exercise not only improves your mood and appearance, but also gives you opportunities to meet new people. As much as possible, find a way to have an exercise in your day.

30 to 40 minutes of exercise is recommended, but regular 5- to 10-minute intervals is great as well.

### **Nutrition**

Nutrition is important. Make it a habit to read food labels and avoid foods with high fat content. Learn, understand, and monitor portion sizes so that you'll know how much nutrients your body needs.

### **Sleep**

Many caregivers do not get enough sleep because their care recipient needs help during the night. Oftentimes, the best solution for this is to draw up a roster so that you can take turns with other family members to stay awake.

### **Relaxation Techniques**

Most people think relaxation is only about clearing your mind, but it's actually about observing and understanding things to overcome negativity and

cultivate constructive thoughts. One can even go for a massage, a facial or out for a swim as these activities can also serve as a way to relax and meditate.

**Here are seven easy steps to manage stress through meditation in 5 to 10 minutes:**

1. Sit up straight on a chair or a big, firm pillow.
2. As you inhale, tense up your entire body – arms, legs, buttocks, fists. Scrunch up the muscles on your face too.
3. Hold for two to three seconds.
4. Exhale and relax (repeat twice).
5. Take a deep breath. Let your belly expand.
6. Exhale and relax (repeat twice).
7. Breathe normally and be aware of your thoughts for five minutes. Do not give in to your thoughts or resist them.
8. Think of each thought as bubbles floating up to nothingness – e.g. sad thought, happy thought, angry thought.

## **MANAGING NEGATIVE EMOTIONS**

**Have you faced these problems as a caregiver?**

Grief	Fear of the future
Financial problems	Feelings of being unable to cope

### **Guilt**

Even if things are going well, you may think that you are not doing enough. Feeling guilty happens when your expectations are not met. They may include feelings of not wanting to be a caregiver in the first place or lack of free time for yourself.

In such instances, **it's always a good idea to remind yourself** at least once a day:

- How much help you are providing a person you care for
- Your intentions come from love, care, and compassion for your loved 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

## Anger

It's natural to feel frustrated, trapped and angry at your state. However, showing this emotion to your loved one or other persons in your life is not an ideal way to improve the situation; just as it's unhealthy to keep these feelings to yourself.

Consider **joining a support group for caregivers** for advice and solidarity, **making an appointment with a therapist**, or **keeping a journal** to express your feelings. Support and understanding are essential, and it might be useful to seek advice and solace from other caregivers going through the same experience.

## Depression

Caregiving can be emotionally stressful and trigger negative emotions such as the ones mentioned above. Sometimes, these negative emotions can lead to depression that will then put you and your loved one's well-being at risk.

Depression can also increase the risk of developing illnesses such as heart disease. so it's a healthy idea to make time for yourself, get some respite, and talk to a professional, family, or friend for you to express your emotions.

## MANAGING YOUR EMOTIONS

You might feel alone and that you are the only one dealing with these feelings. As people with dementia become more dependent on their caregivers, **families of care recipients sometimes fear being isolated from the community.**

More than ever, **respite** and **support** are coping techniques every caregiver needs to **build up an emotional support network.**

### **When to Seek Help – “Why doesn't anyone ask how I am doing?”**

It's easy to feel invisible next to a person with dementia. Many caregivers say that nobody asks about their situation as everyone else is focused on the person with dementia. **These feelings should not be allowed to build up**, as mental health experts advise.

**Support groups**, religious and spiritual advisers, or mental health counsellors can always advise caregivers on the many positive ways to seek help when needed.

**Also, immediately seek professional help if you:**

- Drink more alcohol than usual
- Often take prescription drugs without a doctor's advice
- Suffer from skin rashes, back aches, colds, or a flu that doesn't go away
- Find yourself unable to focus or think clearly
- Feel tired and do not want to do anything
- Feel worthless, guilty, or sad most of the time
- Have fear and anxiety
- Feel depressed for two weeks or longer
- Have thoughts of inflicting harm on yourself or your care recipient

**Dealing with Caregiving Stress**

If you feel like you're buried under burdens that you can't escape from, here are some simple tips for catching a breather.

<b>Change Your Mindset</b>	<b>Manage Your Emotions</b>	<b>Manage Your Tasks Better</b>
<ul style="list-style-type: none"> <li>● <b>Remind yourself that you are doing something important</b> for the person in your care.</li> <li>● Know your limits, take care of your self-esteem.</li> <li>● Do not give in when your care recipient is too demanding.</li> <li>● Live one day at a time.</li> </ul>	<ul style="list-style-type: none"> <li>● <b>Do not feel guilty about your emotions.</b> They are natural and very human.</li> <li>● Express your anger and frustration by writing down your feelings.</li> <li>● Allow yourself to cry.</li> </ul>	<ul style="list-style-type: none"> <li>● <b>Set realistic goals</b> – remember that you may not be able to do everything like before.</li> <li>● Make a list of important tasks.</li> <li>● Think of ways to make your work easier, allow some things to be left 'till a better time.</li> <li>● When handling a difficult task, make it easier by listening to music.</li> </ul>
<b>Take Care of Your Health</b>	<b>Do Things You Enjoy</b>	<b>Don't Shoulder It All</b>

<ul style="list-style-type: none"> <li>• Take short rests in-between activities or errands.</li> <li>• Focus on getting relaxing sleep instead of more sleep.</li> <li>• Set aside time for meditation, reflection or prayer.</li> <li>• Eat a balanced diet, and find time for regular exercise.</li> </ul>	<ul style="list-style-type: none"> <li>• Make time for yourself.</li> <li>• Treat yourself to a massage.</li> <li>• Keep in contact with friends and join in fun activities.</li> </ul>	<ul style="list-style-type: none"> <li>• Speak completely, openly and honestly to people who can understand and help you.</li> <li>• Join a support group or start one to share ideas and resources.</li> <li>• Use respite care services that can lighten your caregiving load. Looks for a service that suits you from the AIC E-care locator.</li> <li>• Talk to the doctor about your caregiving responsibilities, which are just as important as talking about your loved one's needs.</li> </ul>
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## **TAKING A BREATHER**

Pace yourself from the start so that you won't be overwhelmed throughout the years. More importantly, ask for help and take occasional breaks so that you can refuel yourself for the next leg of the journey.

### **Respite Time**

Respite time gives you a break from your responsibilities. It can help you to **relieve stress, making it a necessity in your role as a caregiver**. It may be hard to think of your own needs when caring for a loved one, but if you don't, your life will be taken over by your duties and exhaustion.

### **Here are some care options that you can alternate your time with:**

- Ask a family member or friend to stay with your loved one for an hour or more so that you can take a break.
  - Family members or friends may attend courses subsidised by the Caregivers Training Grant to learn more about how to care for your loved one with dementia.
- Take your loved one to a day care centre. This will give you a break during the day or on some days.
- Get home care services like Eldersitter services to help care for your loved one for a few hours per week or per month.
- Hire a foreign domestic worker. There is a Foreign Domestic Worker Grant that can help you offset the cost of hiring one.
- Help your loved one join a support group.

### **Seeking support will allow you the time to care for your personal needs too.**

## **Respite Zone**

A respite zone is an area set aside just for you to relax. This space could be your bedroom, a spare room, or an office. **It should be a place for you to take a break while the senior or elderly rests or is taken care of by someone else.**

Here are some things to note while creating your respite zone:

- Find a suitable space in your home, such as a spare room.
- Use a screen or a curtain for privacy if you cannot close the door.
- Keep in mind what you want to do there, such as read, paint or write.
- Modify the space according to your needs. Keep whatever is necessary for your respite activity.
- Set aside the time to use it, such as during your loved one's naptime, or when someone takes over your caregiving duties.

You can consider surfing the Internet or indulging in leisure activities like sewing and writing, **as long as they allow you to take your mind off your responsibilities.**

**You need to feel secure in your respite zone.** It is important for the people you live with to understand that this space is yours. **It's not selfish to set aside space and time for yourself.**

## Activities & Relationships Outside the House

**Caregivers do not have to entirely change their usual routines and activities.**

There are **support services** that can give caregivers a break. Keep a list of the family members, neighbours and friends whom you can go to for help.

If your friends want to know how they can ease your burden, ask them to:

- Call and be a good listener as you may voice strong feelings
- Offer words of appreciation for your efforts
- Share a meal
- Help you find useful information about community resources
- Show genuine interest
- Stop by to visit, send cards, letters, pictures, or humorous newspaper clippings
- Share the workload if they can

## Other Ways to Take a Break

Here are some other suggestions to help you take a mental or physical break:

- Learn to say 'no' as setting limits can improve relationships.
- Change your mindset. Try not to think about what you do not have or cannot change.
- Appreciate what you have and can do.
- Find simple ways to have fun – play a board game, organise family photos, listen to music, read about an inspiring person.
- Learn ways to better manage your time and your leisure activities.
- Knowledge is empowering. Get information about your loved one's condition.
- Share your feelings with someone.
- Keep a journal – write down three new things you are grateful for every day
- Memorise an inspiring poem.
- Pick up meditation or do breathing exercises when you are stressed.

## **CAREGIVER SUPPORT GROUPS**

In most support groups, you will be able to share your problems and listen to others as well. **This will not only get you the help you need but also give you the chance to help others.**

You will understand in caregiver support groups that **you are not alone in your caregiving journey.** The people in your support group may have relevant knowledge and advice – especially if they are caring for someone with the same illness as your loved one. Care support groups exist in hospitals, in the community, and even online.

### **Finding Support Groups**

You can speak to the medical social workers in any hospital or you may ask fellow caregivers to learn more about support groups for you and your loved one.

Here are some support groups to consider.

<b>Hospital Support Groups</b>	<b>Community Support Groups</b>	<b>Online Community</b>
<p><b>Support Groups for Dementia:</b></p> <ul style="list-style-type: none"> <li>Alzheimer Disease Association Dementia Caregiver Support Group</li> <li>Dementia support groups at Khoo Teck Phuat Hospital and National Neuroscience Institute</li> <li>Dementia support groups at Singapore General Hospital</li> </ul>	<ul style="list-style-type: none"> <li>Alzheimer's Disease Association (Tel: 6593 6440)</li> <li>Project Angels (Tel: 6274 6904)</li> <li>TOUCH Caregivers Support (Tel: 6258 6797)</li> <li>Caregivers Alliance Limited (Tel: 6753 6578)</li> <li>Filos Community Services (Tel: 6242 5978)</li> <li>Caregiving Welfare Association (Tel:</li> </ul>	<p>Many private community groups are active on social media sites like Facebook.</p> <p>These groups can take the form of</p> <ol style="list-style-type: none"> <li><b>Online support groups</b> wherein caregivers interact with fellow caregivers;</li> <li><b>Interest groups</b> in which caregivers and the interested public join to acquire</li> </ol>

Hospital Support Groups	Community Support Groups	Online Community
<p><b>Support Groups for Parkinson’s Disease:</b></p> <ul style="list-style-type: none"> <li>• Monthly support groups at Singapore General Hospital, Tan Tock Seng Hospital and National University Hospital</li> </ul> <p><b>Support Groups for Cancer:</b></p> <ul style="list-style-type: none"> <li>• Colon Cancer Support Group at Tan Tock Seng Hospital and Singapore General Hospital</li> <li>• Prostate Cancer Support Group at Tan Tock Seng Hospital</li> <li>• Breast Cancer Support Group at National Cancer Centre, Singapore General Hospital and Tan Tock Seng Hospital</li> </ul> <p><b>Support Groups for Other Medical Conditions:</b></p> <ul style="list-style-type: none"> <li>• Singapore National</li> </ul>	<p>6466 7957)</p>	<p>relevant information.</p> <p>3. Community Networking Projects, such as <b>Project We Forgot Community Network</b></p>

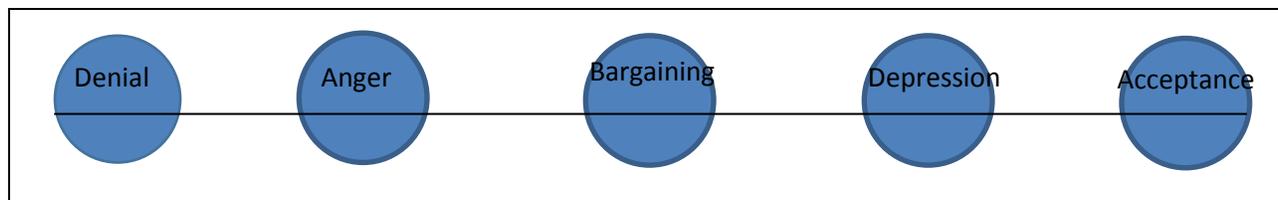
Hospital Support Groups	Community Support Groups	Online Community
<p>Stroke Association</p> <ul style="list-style-type: none"> <li>• Stroke Club at Singapore General Hospital @ Bright Vision Hospital</li> <li>• Cardiac Rehabilitation Support Group at Tan Tock Seng Hospital</li> <li>• Wish Bone: Osteoporosis Support Group at Singapore General Hospital</li> <li>• Asthma Support Group at Changi General Hospital (including sufferers of Chronic Obstructive Pulmonary Disease)</li> <li>• Stroke Support Group at Tan Tock Seng Hospital</li> </ul>		

## **MANAGING GRIEF & LOSS**

Dealing with loss is a part of life and **it's okay to feel sad when a loved one passes on.**

Grief is a reaction to any form of loss. While it is a universal experience, responses to it vary from person to person, depending on countless factors such as one's relationship with the beloved.

The grieving process usually takes place over five stages. Each stage brings with it different emotions to work through. However, the five stages may not be experienced in the same order, and not everyone may even experience some of the stages shown below.



### **Stage One: Denial and Isolation**

The first stage of grieving is denial. **It is normal and common to deny, ignore or reject the loss to subconsciously avoid the accompanying pain and sadness.** People at this stage often wish to be alone to avoid dealing with others.

#### **Ways to cope:**

Keep on reminding yourself of what you've gone through to let it sink in. Communicate with your family and friends as much as possible.

### **Stage Two: Anger**

At this stage, people begin to **blame others or themselves for the loss.** They might argue with parties involved, such as healthcare professionals and other family members who were responsible for the wellbeing of the loved one.

#### **Ways to cope:**

As early as possible, find out as much as you can about your loved one's condition and his/her remaining days. Ask the doctor to explain it to you and understand the options available. Give yourself time to accept what is happening.

### **Stage Three: Bargaining**

Also known as the 'if only' stage, bargaining happens due to feelings of regret and helplessness. Caregivers often **want to know if there was something that could have been done differently or better for their loved ones.**

#### **Ways to cope:**

Bargaining is a natural process of grief. Avoid evaluating your life based on feelings; it is more important than ever now to communicate and share your thoughts with your family and friends.

### **Stage Four: Depression**

People at this stage feel overwhelming sadness about everything as they start to accept the reality of loss. The fact that this has happened will start weighing heavily on you. **It may feel like you will never be able to move past it or find something to feel that gap.**

#### **Ways to cope:**

Take as much time as you need to grieve your loved one. There is no fixed duration; **everyone has different periods of mourning.** Spend some time remembering your moments with them and talk about it with your family and friends. Allow yourself to feel sad without the need to hide it. **Live one day at a time and take small steps forward.**

### **Stage Five: Acceptance**

At this last stage, you may still feel upset about your loss, but in some way, you have made your peace with this part of reality. You can now accept and embrace the idea of reaching a new point in your life.

#### **Ways to cope:**

Take more interest in everyday activities. Sign up for enrichment courses and social gatherings. You may find that it is helpful to immerse in a hobby, meet someone new, or get counselling.

**The entire grieving process may take anywhere between 6 to 12 months, although some people may take a shorter or longer time.**

## Anticipatory Grief

Dementia may gradually change the personality of your loved one.

**Anticipatory grief** is questioning if this “stranger” is the same person we know and love. This could be difficult to accept, especially if you had a special bond with them; but remember that **your loved one is still the same person despite all the challenges they now have in communicating and expressing themselves.**

Here are some things to remember when dealing with anticipatory grief:

### 1. **Accept that anticipatory grief is normal.**

You are allowed to feel this type of grief when an eventual loss is approaching. This is a common phenomenon that has been documented for nearly a century. You are not alone.

### 2. **Acknowledge your losses.**

It is okay to grieve even though your loved one is still alive and there are other things going well for you. Consider having a creative outlet to express emotions of resignation, fear and depression. Explore mindfulness as a way of being present and aware of the many emotions going through you. **Connect with others.**

Anticipatory grief is common among caregivers; unfortunately, you may feel alone and isolated if you had devoted all your time to caregiving. Seek out caregiver support groups either in your area or online, so you can connect with others who understand the challenges you are facing.

### 3. **Remember that anticipatory grief doesn't mean you are giving up.**

As long as you are there to support and care for your loved one, you are not giving up on them. Terminal illnesses are not within our control. Instead, focus on what you are doing and shift your energy towards creating peaceful and meaningful moments together.

### 4. **Reflect on the remaining time.**

Spend your remaining time together in a way both parties would find meaningful and fulfilling. This is the time to really do something together that you will never be able to do with them again. If your loved one is open, you

may also want to discuss practical matters, like advanced directives and funeral arrangements to ensure that you are able to honour their wishes.

## **5. Communicate.**

Anticipatory grief is different for everyone. Expect that everyone in your family may be experiencing and coping with anticipatory grief in different ways, so keeping an open line of communication to support and understand one another. Consider involving close family and friends in your loved one's remaining moments.

## **6. Take care of yourself.**

It's easier said than done, but it's true. Remember the old cliché: You can't take care of others if you don't take care of yourself.

## **7. Tap on your support network.**

Caregiving and anticipatory grief can be a long and difficult road. Assess and map out your support network so you'll know who may be able to help you out.

## **8. Seek professional help if you need it.**

Normal, everyday people need a place to process complicated, human emotions and have some time for themselves. If ever you feel overwhelmed with the feelings of anticipatory grief and other emotions, just say 'Yes'.

## **9. Relief is normal.**

When someone dies, experiencing a sense of relief is a normal response. Although this can also create feelings of guilt, remember that feelings of relief arising from an anticipated death does not mean you love the person any less. It is a natural reaction after a stressful and overwhelming time in your life.

## **10. Don't assume you won't grieve.**

Just because losing someone was anticipated, do not assume this will either speed up or slow down your grief after the death. Remember that everyone grieves differently.

**Do not hesitate to see your doctor or visit a counsellor if you continue to experience five or more of these symptoms 12 months after your loved one has passed on:**

- ✓ You feel that your grief is making you unhealthy or sick
- ✓ You feel that you have been grieving for much longer than you want to
- ✓ You keep thinking about harming yourself or ending your life
- ✓ You are worried that you might hurt others
- ✓ You are hallucinating about things that aren't really there
- ✓ Your behaviour or routine suddenly changes
- ✓ You have felt hopeless and unable to cope with life for more than two weeks at a stretch
- ✓ You cannot function at home, work or school
- ✓ You just cannot get over a feeling of guilt
- ✓ Your speech functions and body movements have become slow and tired