

Caring for Yourself

Living with Dementia:
A Resource Kit for Caregivers



Supported by QiC

How can this kit help you?

This kit consists of a series of 4 booklets and a listing of services. This booklet on Caring for Yourself provides essential information, practical tips, activities and resources on dementia to support you while caring for your loved one living with dementia.

It is designed for caregivers like yourself to learn about accepting and understanding the role of being a caregiver, importance of and tips on self-care, how to cope with your emotions, caregiver stress, avoiding burnout, and how and where to seek help within your home and in the community. We hope this booklet can empower you to go a longer mile in your caregiving journey, ensuring your loved one receives the best possible care. 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 enquiries@aic.sg or call 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. Role of a Caregiver and Accepting It

Are you a caregiver

A caregiver is a person who has taken on the responsibility of looking after someone who is unable to care for himself or herself fully due to illness, frailty, disability or a mental health condition. This person can be a family member, partner, relative, friend, or neighbour.



“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers.” – Rosalynn Carter

Your caregiving role may start upon your loved one’s diagnosis of a medical condition, or after an incident such as a fall or a heart attack.

Role of a caregiver

As someone who is taking care of your loved one, you may provide support to the person’s day-to-day activities, medical needs, emotional needs and may need to make key decisions on their behalf. The degree of involvement may vary according to the needs of your loved one.



The needs can be broadly categorised below.

Advance planning

Starting early conversations on care needs and arrangements with your loved one should they lose mental capacity. This includes completing an Advance Care Plan and Lasting Power of Attorney.

Visit <https://mylegacy.life.gov.sg/> or scan the QR code to learn more.



Emotional and psychosocial needs

Providing a listening ear to your loved one, and showing care and support. You and your loved one can join support groups in the community. Refer to page 26 for more information on support groups.

Financial and legal needs

Managing daily expenses, insurance, assets, and managing finances.

Visit <https://www.aic.sg/caregiving/managing-finances-and-grants/> or scan the QR code to learn more about managing finances.



Visit www.spd.org.sg/financial-planning-tips-for-caregivers/ or scan the QR code for other financial planning tips.



Health and medical needs

Ensuring your loved one is exercising, eating balanced meals and taking medication in a timely manner. Learn more about preparing simple nutritional meals for your loved one at home.

Visit www.for.sg/cookbook or scan the QR code to check out the recipes and a collection of caregiver stories in the Care.Cook.Inspire cookbook.



Physical needs

Helping your loved one in dressing up, toileting and conducting household tasks such as buying groceries and chores.

Spiritual needs

Encouraging your loved one to continue his/her practice of religious beliefs.



Accepting your role as a caregiver

You may happen to be a caregiver overnight or unknowingly. Situations such as a loved one suddenly taken ill or an accident may happen within the family, or simply whereby it may typically begin by helping a family member or a friend in need and may over time grow into something more significant. Regardless, the journey may not be that easy to begin with.

It is hence important to accept the caregiver role you play. This allows you to reframe, prepare and structure your own life differently. Many factors such as your family, your job, or your own well-being will intrude other facets of your life. Understanding that the potential stress, long caregiving hours, loneliness and exhaustion may cause lack of sleep or rest, unduly panic stresses, weight gain/loss and other health conditions. Understanding these possible effects is the key to avoiding them.

Visit www.for.sg/aic-caregiverburnout-en or scan the QR code to learn more.





2. Importance of Self-Care



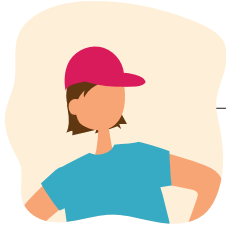
“If you can’t change your fate, change your attitude.” – Amy Tan

Caring for your loved one is important, but it is equally important to take care of yourself. Self-care means taking responsibility to care for yourself. This includes anything you do to keep yourself healthy and happy – it can be physically, mentally and spiritually.

While prioritising self-care may be common sense, it is often the first thing to be neglected when you find yourself in a challenging situation. By taking some time out for yourself as a caregiver, you may relieve the day-to-day stress and reset yourself to a point where productivity is once again optimised.



Be in control of your life



“The only control you have is over the changes you choose to make.” – Nancy L. Krisema

Ask yourself:

1

Can I see myself doing this?

Reflect on how you typically cope with stress, you can benefit only if you place your list of plans into action e.g. gardening.

2

Is cost a factor?

If yes, go for a stroll or light jog at the nearby park instead of signing up for Zumba class where you may be feeling more stressed by failing to attend it.

3

Am I trying to do too much at one go?

Do not overload your schedule with activities, you can burn yourself out on self-care on top of your caregiving tasks.

4

Is there time for this?

Best practice for self-care is having a regular routine for it. Make simple goals you can accommodate along with your caregiving duties like having a hot cup of your favourite coffee.

5

What things worked in the past?

Identify things that make you happy and positive about life, find the peace within yourself.

Looking after yourself

Learn to identify activities and practices that can support you to sustain a positive self-care in the long run.



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, develop a routine to exercise daily. 30 to 40 minutes of exercise is recommended, but regular 5- to 10-minute intervals work as well.



Nutrition

Nutrition is important. Make it a habit to read food labels and avoid food with high fat content. Learn, understand, and monitor portion sizes.

You can pick up more nutritional recipes by visiting <https://for.sg/aic-recipesvideogallery> or scan the QR code.



Sleep

Many caregivers do not get enough sleep because their loved one needs assistance during the night. Often, 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 is actually about observing and understanding things to overcome negativity and cultivate constructive thoughts. You may consider going for a massage, a facial or a swim as these activities may serve as a way to relax and meditate.

Practising mindfulness also helps you to focus on the present moment. Learn more through online courses and resources at www.brahmcentre.com or scan the QR code.



Managing emotions

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

Respite and support are coping techniques; every caregiver needs to build up a support network.

When to seek help – “Why doesn't anyone ask how I am doing?”

It is easy to feel invisible next to a person living with dementia. Many caregivers say that nobody asks about their situation as everyone else is focused on the person living 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 ways to seek help when needed.

Seek professional help if you:

- Drink alcohol more frequently than usual, and often drink more than you intended.
- Often take prescription drugs without a doctor's advice.
- Suffer from skin rashes, backaches, colds, or a flu that does not 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 loved one.

Managing negative emotions

Have you faced these problems as a caregiver?





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. These 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 is always a good idea to remind yourself:

- How much support you are providing to the person you are caring 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 is natural to feel frustrated, trapped and angry at your state. However, showing this emotion to your loved one or others is not an ideal way to improve the situation; just as it is unhealthy to keep these feelings to yourself.

Support and understanding are essential. Join a support group for caregivers to seek advice and solace from other caregivers who may be going through similar experience, chat with a therapist, or keep a journal to express your feelings.



Depression

Caregiving can be emotionally stressful and trigger negative emotions. Sometimes unknowingly, these negative emotions may lead to depression which 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 make time for yourself, get some respite, and talk to a care professional, family, or friend.



3. Dealing with Caregiving Stress

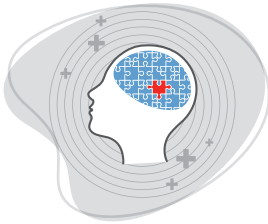
Tips to relieve stress

If you feel stressed, here are some simple tips to help you.



Change your mindset

- Remind yourself that you are doing something important for the person in your care.
- Know your limits, take care of your self-esteem.
- Do not give in when your loved one is too demanding.
- Live one day at a time.



Manage your emotions

- Do not feel guilty about your emotions. They are natural and very human.
- Express your anger and frustration by sharing with a friend or writing down your feelings.
- Allow yourself to cry if you need to.



Manage your stress through mindfulness

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



Manage your tasks

- Set realistic goals – remember that you may not be able to do everything like before.
- Make a list of important tasks.
- Think of ways to make your work easier, allow some things to be left until a better time.
- When handling a difficult task, make it easier by calming down or listening to music.



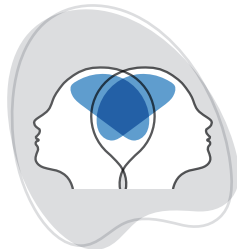
Take care of your health

- Take short breaks in-between activities or errands.
- Focus on getting quality sleep instead of more sleep.
- Set aside time for meditation, reflection or prayer.
- Have a balanced diet, and find time for regular exercise.



Do things you enjoy

- Make time for yourself.
- Treat yourself to a coffee break or massage.
- Keep in contact with friends and join in fun activities.



Do not shoulder it all

- Speak completely, openly and honestly to people who can understand and help you.
- Join a support group or start one to share ideas and resources.
- Talk to the doctor about your caregiving responsibilities, which are just as important as talking about your loved one's needs.

Hear from former caregiver Richard Ashworth on how he managed his caregiver stress. Visit www.for.sg/asktheexpertsep6 or scan the QR code to watch the video.



Taking a breather

Pace yourself from the start to avoid overwhelming yourself. 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 difficult to think of your own needs when caring for a loved one, but if you do not, 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 take care of 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 living 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 eldersitting services which helps to care for your loved one for a few hours per week or per month.
- Hire a pre-trained foreign domestic worker who has undergone comprehensive training through the ElderCarer Foreign Domestic Worker Scheme. Alternatively, you can tap on the Migrant Domestic Worker (MDW) Levy Concession for Persons with Disabilities to offset the cost of hiring one.
- Help your loved one join a support group.

Seeking support

Caregiver Support Network (CSN) which started as an initiative under Dementia-Friendly Singapore (DFSG), aims to support and connect with caregivers caring for persons living with dementia, mental health or physical health conditions.

The goal of CSN is to empower caregivers through a Peer Support Network focusing on self-care, mindset change and recognition. See page 28 for more details.



Respite zone

A respite zone is an area set aside just for you to relax while your loved one rests or is taken care of. This space could be anywhere you feel comfortable at such as your bedroom, a spare room, or an office.

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

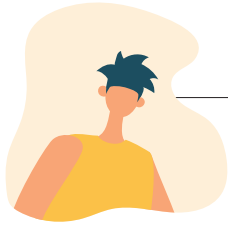
- Find a suitable space in your home, such as a spare room.
- Use a screen or a curtain for privacy if you cannot close the door.
- Keep in mind what you want to do there, such as read, paint or write.
- Modify the space according to your needs. Keep whatever is necessary for your respite activity.
-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

You may 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 caregiving 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 is not selfish to set aside space and time for yourself.



Activities & relationships outside the house



“Caregivers do not have to entirely change their usual routine and activities.”



Social support can help alleviate the stresses of caregiving. Keep a list of the family members, neighbours and friends whom you can go to for help.

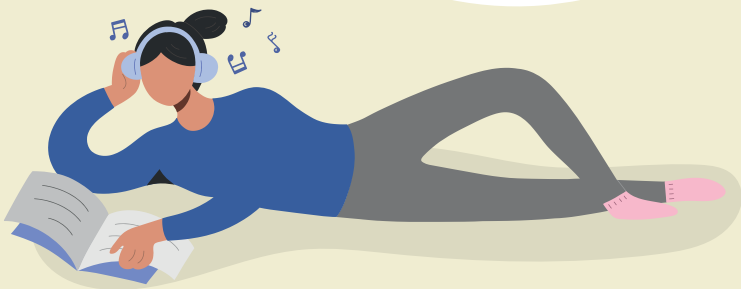
If your friends want to know how they can ease your burden, ask them to:

- 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 clipping.
- 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.
- Know and 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. Consider a care routine for yourself, like how you plan care for your loved one.
- Knowledge is empowering. Get information about your loved one's condition.
- Share your feelings with someone.
- Keep a journal or turn to daily prayers – note three new things you are grateful for every day.
- Memorise an inspiring poem.
- Pick up meditation or do breathing exercises when you are stressed.



Resources and references

Use available resources to better care for yourself in various aspects of health and well-being such as the Caregiver Well-being Tool, take reference from We Care Toolkit. Visit www.ncss.gov.sg/caregiving or scan the QR code.



Use respite care services that can lighten your caregiving load. Visit www.for.sg/aic-respitecare or scan the QR code to know more about respite care in Singapore.



Visit www.for.sg/aic-daycare or scan the QR code to find out more about centre services.



Visit www.for.sg/aic-nursinghome or scan the QR code to find out more about nursing home respite care.





4. Managing Grief & Loss

Dealing with loss

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

Grief is our way of reacting when we lose someone important to us. 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.

Here are some common grief reactions that you and your other family members may experience:

	Examples
Behaviour	Agitation, tenseness, restlessness, fatigue, over-activity, searching, crying, sighing, social withdrawal, loss of interest, low energy, dreams of the deceased, attach to/avoid items of the deceased etc.
Physical/Body reactions	Loss of appetite, sleep disturbances, energy loss, exhaustion, complaints of 'hollow' stomach, tightened chest, constricted throat, breathlessness; hyper-sensitivity to sight/smell/sound, physical complaints similar to deceased, lower immunity etc.
Thoughts	Preoccupation with thoughts of deceased, sensing the presence of the deceased, disbelief, denial, helpless, hopeless, difficulties with memory and concentration, absent-minded, disorganised thoughts etc.
Feelings	Depressive, despair, distress, anxious, fearful, guilt, self-blame, angry, irritable, lonely, sad, longing, shock, numb, liberated, relief etc.

Coping with grief

- Get enough rest and sleep: If you cannot sleep well at night, take naps, have some quiet time and read a book or listen to music.
- Carry on with your usual activities as much as possible, these will help you to adapt better and take your mind off your loss for a while.
- Surround yourself with loved ones: Share memories about the deceased.
- Avoid quick fixes: Many people turn to alcohol, overeating or other addictions during grief. Although they may seem to help for a short while, they will actually make life more difficult in the long term.
- Try to be open and accept help: It will help you to avoid becoming too tired.
- Take comfort in a support group or in your faith: Attending support group sessions can help you communicate with others in the same situation. Prayer and meditation can help you feel better.
- Get creative. Write a poem or create a painting to express your feelings and you will be able to cope with your loss in a healthier way.
- Rediscover or participate in activities on your own or with a group.
- Find time to review your finances. Some caregivers left work to provide care, you may feel uncertain about re-entering the workforce, here are some initiatives available to assist you in this transition.

Adapt and Grow helps Singaporeans in job seeking and exploring new career opportunities. Visit www.wsg.gov.sg/ or scan the QR code.



SkillsFuture is a national movement to provide you with the opportunities to develop your potential through skills mastery and lifelong learning. Visit www.skillsfuture.gov.sg or scan the QR code.



e2i's Career Trial is part of the suite of career services to strengthen the employability of Singaporeans, through a short-term stint with an employer. Visit www.e2i.com.sg/businesses/manpower/career-trial/ or scan the QR code.



Anticipatory grief

Anticipatory grief refers to a feeling of grief occurring before an impending loss and may happen at any point during the progression of your loved one's condition. This may be difficult to accept, especially if you had a special bond with them; but remember that it is a normal process for caregivers.

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. Conditions such as dementia 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 keep 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 is 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 know who may be able to help you out.

Seeking professional help

People need a place to process complicated, human emotions and have some time for themselves.

Sharing your grief and communicating how you feel is an essential part of healing. Do not let the fear of letting it out or doing the wrong thing stop you from reaching out. You may start within your home where you may feel comfortable speaking to a family member or a trusted friend. For other caregivers, they may feel more at ease not involving familiar faces and to seek professional help, such as speaking to a counsellor.

Relief is normal

When someone has passed on, 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.

Don't assume you would not 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 feelings of guilt.
- Your speech functions and body movements have become slow and tired.

Counselling

Counselling services are available for caregivers looking after persons living with dementia. All information is kept strictly private and confidential. Face-to-face consultation is also available by appointment, to provide an avenue to discuss the issues further and explore options available that may aid in coping with the challenging situation faced.

You may also approach the Community Intervention Teams for counselling. Visit www.for.sg/sgwcomit or scan the QR code to look for the services.





5. Seeking Help



Caregiver support groups

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

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 condition as your loved one. Caregiver support groups exist in hospitals, in the community, and even online.

Finding support groups

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

Hospital support groups

Support groups for Dementia

- Dementia support groups at Khoo Teck Puat Hospital and National Neuroscience Institute
- Dementia support groups at Singapore General Hospital

Support groups for Parkinson's Disease

- Monthly support groups at Singapore General Hospital, Tan Tock Seng Hospital and National University Hospital



Caregiver Support Network (CSN)

Caregiver Support Network (CSN) which started as an initiative under Dementia-Friendly Singapore (DFSG), aims to support and connect with caregivers caring for persons living with dementia, mental health or physical health conditions.

The goal of CSN is to empower caregivers through a Peer Support Network focusing on self-care, mindset change and recognition. They are available in the following Dementia-Friendly Communities (DFCs) and nationwide to enable caregivers to care for themselves and to become pillars of support for one another. Look for the CSN near you.

Allkin Singapore Ltd (Teck Ghee)	Tel: 6385 0260
AWWA (Yio Chu Kang)	Tel: 6511 6690
AWWA (Woodlands)	Tel: 9784 9247
Caregivers Alliance Limited (Nationwide)	Tel: 6460 4400
Care Corner Seniors Services Ltd (Toa Payoh East and Toa Payoh West-Thomson)	Tel: 6258 6601
Club HEAL (Nationwide)	Tel: 6899 3463
Dementia Singapore (Nationwide)	Tel: 6377 0700
Fei Yue Community Services (Queenstown)	Tel: 6011 7651
Montfort Care (Bedok)	Tel: 6312 3988
NTUC Health (Taman Jurong)	Tel: 9455 2308
REACH Community Services (Hong Kah North)	Tel: 6801 0878
WeCare@MarineParade (Marine Parade)	Tel: 6493 7353

*Information is accurate as at September 2024. Visit www.for.sg/dh-csn for the latest updates.



Online community

Many private community groups are active on social media sites such as Facebook.

These groups can take the form of:

1. Online community where caregivers can interact with one another and acquire relevant information. Visit www.facebook.com/DementiaFriendlySingapore or scan the QR code.



2. Community Networking Projects, such as Project We Forgot Community Network. Visit www.projectweforgot.com or scan the QR code to learn more.



3. Visit www.for.sg/aic-csn or scan the QR code to find out more about caregiver support groups.



4. If you are keen on setting up a Caregiver Support Network, visit www.for.sg/csntoolkit to watch a step-by-step video, or download the CSN toolkit at www.for.sg/csntoolkit which provides you with useful timelines and templates to use. You can also scan the QR codes to learn more.

Video



Toolkit



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.