

Living with Dementia

A Resource Kit
for Caregivers



**Planning
Care**



"It is important to make clear that the family discussion is about honouring your loved one's wishes."

How can this kit help you?



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

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

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

CAREGIVING ARRANGEMENTS

Gathering the Family

A family discussion can be very helpful when your loved one has been diagnosed with dementia and needs care. Some families may think it is taboo to discuss concerns revolving around dementia, but it is important to make clear that the **family discussion is about honouring your loved one's wishes.**



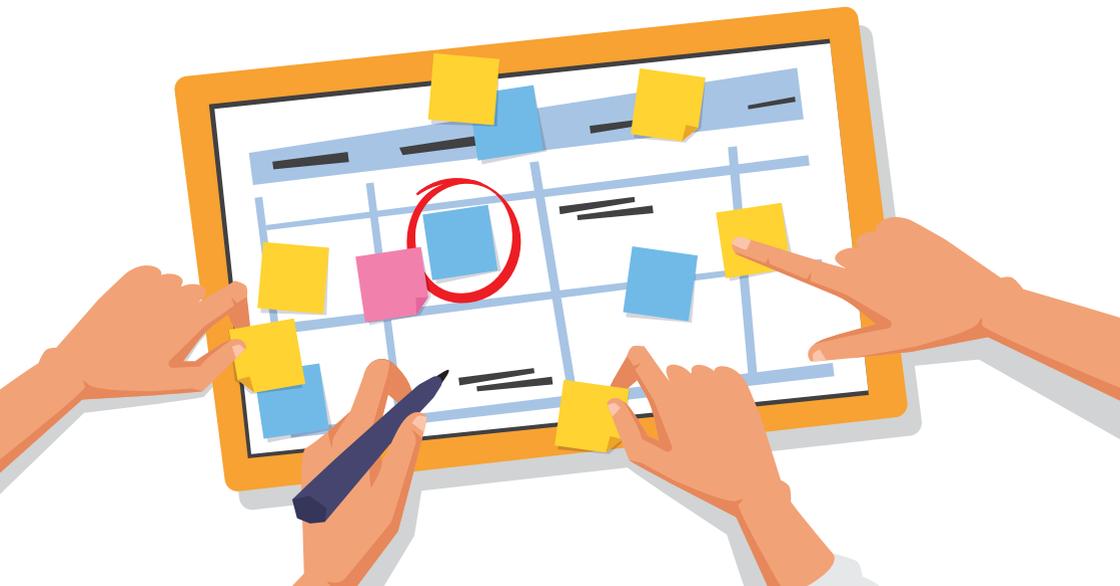
Different family members will cope with the diagnosis differently and communicate their thoughts and emotions in their own ways. Sometimes, this might lead to unintentional friction within the family. Some disagreements that may arise from caregiving are:

- The type of care given
- Financial responsibilities
- Roles of each family member in caregiving responsibilities
- Struggles with managing work, personal responsibilities and caring for loved one
- Clashing emotions that come with the caregiving journey

It is important that these issues are identified and managed efficiently. **Preparing for them can reduce the stresses and strains of caregiving,** and in the process, enhance and strengthen family relationships.

Set some ground rules to help you and your family members have fruitful discussions on caregiving concerns:

- Keep your loved one's needs and wants at the centre of the discussion. To have a clearer picture of what their wishes are, you can consider Advance Care Planning as early as possible.
- Set aside time for regular meetings and discussions regarding your loved one's care and the various caregiving responsibilities. Care needs can and will change with time.
- Have a roundtable discussion so that everyone will have a turn to speak and raise their concerns.
- Respect each other's views and needs. Try to see things from all perspectives. Everyone has personal responsibilities that they need to consider – e.g. children, work, spouse, finances, etc.
- Focus on one issue at a time before moving onto the next.
- Consider which method you can use to come to a family consensus – e.g. through majority voting, seeking doctor's opinion, etc.
- Be open to discussion and possibly adapting your point of view to the priorities at hand.



Who Should Attend the Meeting?

If you have a big family, there may be instances in which certain members will be unable to attend. In such a case, **it is important that family members who are in a position to finalise key decisions are there.** This may not necessarily mean the eldest relative or the person paying the bills.

Whether your loved one with dementia should be part of the meeting depends on the following:

- 1 Is your loved one able to think clearly and express his/her wishes?
- 2 Do you think he/she would be comfortable sitting in on the discussion?
- 3 Can the family have a frank discussion if your loved one is present?

Setting an Agenda

In a meeting that reflects deep feelings and opinions from every individual, **putting the situation in perspective helps the family focus on the main issue.** This can be done by:

- Explaining the condition so that everyone understands what is happening. If you have been talking to the doctor or healthcare professional all this time, then you may be the best person to explain what you know.
.....
- Laying out the possible healthcare options and costs involved with each choice.
.....
- Making someone in the family the decision-maker on behalf of the senior or elderly.
.....
- If your loved one already has a caregiver, or has a foreign domestic worker providing care, the family must assess if the caregiver has the ability to take care of these new and developing needs.

Deciding Who Does What

The best way to choose the decision maker is to ask your loved one while he or she is able to make decisions on their own. If a decision maker has not been appointed, the family will need to nominate a decision maker everyone is comfortable with.

The meeting is also a good time for everyone to figure out the part they can play to help. Some of the key roles we suggest include:



Main caregiver

This should be the person who has been living with the senior or elderly the most



Finances

Someone in the family could bear care costs, while the rest of the family chips in however they can



Transport

Family members who own vehicles may help to ferry the senior or elderly to and back from appointments



Support for main caregiver

When the main caregiver needs a break, extra help, or has to leave the country for a period, some family members may volunteer to step in to provide ongoing care



Liaison with healthcare professionals

Someone who can communicate and relay important healthcare information, if the main caregiver is unable to

Should the Family Meeting Be Done In a Healthcare Setting?

Some families may prefer to hold the meeting in a hospital as they prefer to consult healthcare professionals directly when questions arise. Care professionals such as counsellors and medical social workers are also trained to help guide a family towards making decisions that benefit their loved one.

Every family has its own circumstances. You may ask a medical social worker or healthcare professional at your institution of choice to provide more advice on holding the discussion. Outside the healthcare setting, you may also approach a Family Service Centre.

Visit <https://www.caregiver.org/holding-family-meeting> for tips on holding a family meeting.

Keep the Family Involved

After the discussion, the family should stay in touch with one another. Social media makes it easy for people to contact each other quickly, and messaging apps like WhatsApp are very useful for families to send updates on the loved one's condition. This can also be a good way for members of the family to show their support for the main caregiver.

Giving the caregiver emotional support can be just as powerful as lending a hand with everyday duties.

Tips on Holding a Family Meeting
<https://www.caregiver.org/holding-family-meeting>

Helping Your Loved One Who's Living Alone

Persons with dementia in the early stage may choose to live alone so as to maintain their independence for as long as possible, or simply to remain in a familiar place. As the dementia progresses to moderate and advanced dementia, it is likely that alternate living arrangements have to be made.

Here are some tips for caregivers on how they can offer care to their loved ones who live alone.

1

Your loved one may forget to shower, change their clothes and have their meals. Our loved one may forget to perform housekeeping duties, or forget to feed pets, etc

Make your loved one's self-care easier

Arrange for meal delivery services and housekeeping services. Write reminders and stick them on places they will see (fridge, bedroom, living room, etc). Eg feed the pets, remember to turn off the stove, sweep the floor. Large and easy to read clocks and calendars will help your loved one to orient.

2

Your loved one may lack judgment in dangerous situations such as hazardous electrical appliances, slippery floors, etc

Improve safety in your loved one's home

Install non-slip mats and grab bars in the bathroom. Remove hazards from the house such as faulty kitchen appliances, clutter, fire hazards and broken furniture. Use technology in the form of monitoring systems to help track your loved one's mobility in the house.

3

A person with dementia may exhibit behaviour that is hard to understand or accept. This may lead to unfriendliness or trouble with the neighbours, police and community.

Involve others in your loved one's care

Involve other family members in the caregiving and take turns to visit your loved one regularly. If regular visiting is not possible, communicate regularly with your loved one via phone call or text.

Explain your loved one's situation to neighbours and local shopkeepers, so that they can help keep an eye out for your loved one in the community.

Adapted from Alzheimer's Society

Making Your Home Dementia-Friendly

Preparing your home to make it a safe place for your loved one is also part of early planning. Persons living with dementia may experience difficulty performing routine tasks such as:

- **Eating**
- **Bathing**
- **Dressing**
- **Walking; and**
- **Going to the toilet**

This increases the risk of falling down. To allow seniors to feel more confident and live independently at home, it is important to create a safe and comfortable environment that can minimise risks of falling.

An Occupational Therapist can help to assess your home, identify potential safety hazards, and recommend simple home modifications and assistive equipment to enhance your loved one's freedom of mobility.

Additionally, it is beneficial to know your loved one's preferences, habits and routines. Discuss them with other family members to plan the most appropriate changes. It is advisable to implement the changes gradually, because any sudden change may disrupt your loved one's routine and cause them stress instead.

General Fall Prevention Tips for Homes

Ensure the physical home space is appropriately equipped

- Adequate lighting
 - use bulbs with a minimum of 100 watts
- The height of chairs are not too low
- The nightlight switch is within easy reach



Remove clutter and potential safety hazards

- Clear and keep walkways dry
- Keep away or remove loose wires
- Avoid rugs and loose carpets

Be attentive to your loved one's attire

- Ensure he/she wears proper shoes with non-slip soles

Be attentive to your loved one's movements

- Place frequently used items within reach
- Ensure floors are not wet and slippery before they walk on it
- Pace all activities; do not rush to do things
- Change their positions slowly when getting them up from the bed

You may also consider the installing the following features:

- Grab bars inside the toilet
- Ramps over kerbs
- Anti-slip flooring

For more ideas on how to modify each room in your house for a dementia-friendly home, you may check out these links:

Adapting a House

www.enablingenvironments.com.au/adapt-a-house.html

How and What to Modify in your Home

www.silverpages.sg/caregiving/active-caregivers/Home%20Modifications

View a Virtual Care Home from Your Screen

dementia.stir.ac.uk/design/virtual-environments/virtual-care-home

Tips on Creating an Elder-Friendly Home

<http://www.patientsengage.com/conditions/elder-friendly-homes>

Home Safety Tips to Protect Your Loved Ones from Falls and Injuries

www.ktph.com.sg/hllibrary/display/650/home_safety_tips__general

Other Useful Resources

For Dementia-Friendly mock-up apartments

The Alzheimer's Disease Association has developed a guide to Designing a Dementia-Friendly Environment using a mock-up apartment for understanding key dementia-friendly principles.

You can obtain a copy from professional_trg@alz.org.sg or call 6293 9971.

For knowledge on vendors for home modifications

The Able Studio can help you select a vendor to make modifications.

You can visit their website at www.theablestudio.com.sg or call 6602 2253.

For subsidies as part of the Home Improvement Programme (HIP)

HDB provides subsidies under the Enhancement for Active Seniors (EASE) scheme as part of the Home Improvement Programme (HIP). It looks at improving the comfort and enhancing the mobility of seniors living in HDB flats through slip-resistant treatment to floor tiles of a bathroom or toilet, installation of grab bars and ramps.



For occupational therapist home visits

Occupational therapists from TOUCH Community Services make home visits to make customised recommendations based on assessing the caregiver's needs, care recipient's function and care environment. They can also provide assistance in following up with contractors.

*Note that individuals who are under Public Assistance will be fully subsidised, while those who require financial assistance will undergo an eligibility evaluation.

You can refer to http://www.caregivers.org.sg/articles/home_mod.pdf for more information on making your home senior-friendly

*Dementia-Friendly Singapore does not have any financial interest in any of the enterprises.

Tips for Relatives & Friends When Visiting

1

Understand Dementia

Understanding how dementia develops will allow you a window into what your loved one is going through. It will help you to understand some of the behaviours or feelings your loved one is experiencing. Refer to Book 1 on "Knowing Dementia and Building a Dementia-Friendly Community" to understand dementia.

2

Always Introduce Yourself

Greet your loved one by introducing of your name and how you are connected to them. Sometimes your loved one may have forgotten, and they may develop anxiety from trying to recall who you are.

3

Make the Visit Fun!

Make the visit fun by taking something with you: an old photo, a memento from a past trip together, or an item from olden days. Reading from a magazine or newspaper also helps to engage your loved one and gives both of you something to do together.

Use music to lift your loved one's mood. Music can create an atmosphere of relaxation or fun whether it is played from a CD or on an instrument. It can help your loved one recall past memories, or simply to have a good time!



4

Acknowledge Your Loved One's Feelings

Have an open mind and be flexible: Your visit may not go according to how you have planned, but that is all right. Have an open mind on how your visit with your loved one goes, adapting to your loved one's energy levels, mood, etc.



Dementia can cause your loved one to experience feelings of anxiety, anger and agitation. Acknowledge how your loved one feels to provide some assurance.

5

Adapt Your Communication Style

Explore other methods of communication other than talking. Hold your loved one's hand, give him/her a hug, a shoulder rub or hand massage to complement or replace conversation.

Communicate clearly by asking closed ended questions instead of open ended questions. Listen patiently and allow him/her time to respond. With dementia, your love one's ability to express himself/herself may be affected. Try not to finish his or her sentence. Instead, listen patiently as he/she speaks and searches for the right words.

6

Keep in Touch

Often, it is assumed that with memory loss, interaction with loved ones and friends holds little or no purpose. However, offering your loved one your time and presence helps to sustain their emotional wellbeing! Be comfortable with silence as it is not a bad thing. Savour each other's presence and your time with each other.

Employment for Persons with Young-Onset Dementia



Work plays a central role in our lives, providing us with a sense of fulfilment and personal development. For persons with dementia, there are many decisions to make about employment including whether or not to tell the employer, what changes could be made to the workplace and how long to continue working.

The issues related to deciding whether or not to tell an employer about a diagnosis of young-onset dementia can be very complex. There are no set rules that will work for everyone. For many people it will depend on the extent to which symptoms affect their ability to do their job, the pace at which symptoms are progressing, and the support that may be required of (or that's likely to be offered by) the employer.

Young-onset dementia may have no impact on a person's ability to do their work at the early stages, although it is likely to do so over time. It is important for people with young onset dementia to consider a number of options before making a decision about continuing with on-going employment and/or informing their employer.

Assessing the Work Situation

- Consider possible safety risks associated with dementia symptoms (for example, if operating machinery, being responsible for financial matters or driving work vehicles) and if there is a duty of care to inform an employer or clients receiving a service.
- Allow time to absorb the diagnosis and don't rush into any decisions.
- Fully review all aspects of the situation before telling an employer.
- Talk to family, health professionals and where appropriate, a union representative or anti-discrimination advocate about working conditions and health issues.
- Before considering resignation from employment, seek consultation and advice about employee entitlements and rights.

It may be useful to consider:

- Job satisfaction or work performance in the current role.
- Access to staff counselling.
- The number of years of service to the company.
- The nature of the work you do, and whether changes associated with young onset dementia may affect others.
- The ability of the company to provide support.
- Relationships with peers and management.
- Whether it may be possible to change or reduce duties or put in place supports that may assist in carrying out the job.
- Available superannuation, death or disability insurance.
- The availability of an advocate when interacting with the employer.



Tips for Festive Cheer



Festivities are typically a time for joy and celebration across all cultures. However, it might present as a stressful time for both caregivers and persons with dementia due to a disruption in their usual routine. Here are some practical tips on how you can make the time an enjoyable one for all family members.



1. Consider the food

Food is often a highlight in family get-togethers. Ensure that the food being served can also be savoured by your loved one. Try to serve softer food in smaller portion sizes for easier swallowing and digestion.

2. Planning the day

Try to keep to your loved one's usual routine as much as possible. Schedule in some rest time for your loved one if an entire day of bustle might be overwhelming. Stagger the timings for visiting if you have many relatives coming as it might be overwhelming for your loved one.

3. Preparing for the festivities

What are the usual routines you do with your loved one during the festivities? Try to involve them with simple activities, such as rolling the dough when baking festive goodies, or folding paper decorations.

The preparation process can also

help to orientate your loved one and get them excited for the upcoming celebrations.

4. Communicate with your relatives

Try to get your relatives to spend some one-on-one time with your loved one with dementia.

5. Prepare some reminiscence materials

Get your relatives involved by putting together a scrapbook with old photos and mementos from the past. This will serve as a conversation starter between your relatives and your loved ones with dementia.

6. Enjoy the festivities too!

Get a relative to help out with your caregiving duties so that you will have some time off for yourself to enjoy the festivities and celebrations too!





Taking Public Transportation

Public transportation is a common mode of transport for all Singaporeans. This does not change even with the onset of dementia. Having an easily accessible transportation system enables persons with dementia to stay connected to their friends, families, and community. It also provides access to healthcare.

Tips for travelling on public transport with your loved one

Plan the route before you make the journey

Allow enough time for travel

Take note of any situations that may make your loved one with dementia feel uncomfortable

Bring along a friend or relative for extra support if needed

Challenges faced by persons with dementia

Dementia can make it challenging for people to access transport. Some reasons are:

- Memory loss of transport routes
- Disorientation to time and place
- Mislacing items whilst travelling (eg ezlink card, bag)
- Decreased judgement and difficulty planning and organising transport
- Difficulty in communicating to transport operators where they want to go
- Changes in mood or behaviour whilst using public transport

A person with dementia should be aided by a caregiver as they may not feel comfortable travelling alone. Not allowing a person with dementia to go out may make them socially isolated and depressed.

Initiatives by local transport providers

Grab has introduced their GrabAssist programme, where drivers are trained in helping out passengers with different accessibility needs. On top of wheelchair transfer and handling of mobility devices, these drivers know the basic signs and symptoms of dementia and basic communication skills.

Advance Care Planning

**Main Source: Living Matters - A website in Singapore that focuses on Advance Care Planning*

Advance Care Planning (ACP) is the process of planning for one's future health and personal care. Having ACP conversations will allow your loved one with dementia to:

- Share their personal values and beliefs with the family
- Explore how his/her values and beliefs influence their healthcare preferences in difficult medical situations
- Delegate a trusted member/relative to make healthcare decisions on their behalf, should he/she be unable to one day

Ideally, **discussions about your loved one's care should take place as early as possible**, while your loved one with dementia still has the capacity to make informed choices and decisions.

4 Simple Steps to Advance Care Planning

1. Think about it

- Consider what your loved one needs to live meaningfully and what would be important to him/her at the end of life
- Understand the prognosis and treatment options

2. Talk with loved ones and caregivers

- Discuss wishes and goals for care with close family and friends to help them better understand the situation
- Your loved one with dementia may have one or two trusted loved ones who can be his/her voice

3. Put wishes into a plan

- Record and share decisions and wishes with appropriate persons
- Share and discuss these future healthcare choices with the attending doctor

4. Review your preferences

- Your loved one can always change his/her mind after the plans are made
- If that happens, be sure to update the ACP documents and make new copies for the trusted parties involved



A guide on preparing an ACP document in 4 different languages, can be downloaded from the Living Matters website.

For more information visit:

www.livingmatters.sg

Lasting Power of Attorney

As dementia progresses, persons with this condition will have increasing difficulty with judgment and problem solving. You may notice that they might be less able to make sound financial and healthcare decisions.

The Lasting Power of Attorney (LPA) is a legal document that confers one or more persons the authority to make decisions and act on the signee's behalf. The signee must be at least 21 years of age to voluntarily make this appointment, should he/she lose the capacity to make his/her own decisions.

It is necessary for a certified issuer to sign the LPA as a witness and to certify that your loved one is aware of the implications of making an LPA. A certificate issuer can be a psychiatrist, a practicing lawyer or an accredited medical practitioner.

There are two types of LPA Forms

Form 1: This is a standard version that individuals use to grant general powers with basic restrictions to their donee(s).

Form 2: This is for those who have non-standard requirements and wish to grant customised powers to their donee(s). It is typically chosen by those who have larger and more complicated assets.

If you are interested or feel that an LPA is important for your loved one, please visit the website for the Office of the Public Guardian at <https://www.msf.gov.sg/opg/Pages/Home.aspx>

For more information, you may also call 1800-226-6222, or email enquiry@publicguardian.gov.sg

Advance Medical Directive

**Main Source: Ministry of Health*



An Advance Medical Directive (AMD) is a legal document signed by your loved one in advance, informing their doctor that they do not want any extraordinary life-sustaining treatment to be used, in the event that your loved one becomes terminally ill and unconscious.

.....

Making an AMD is a voluntary decision by your loved one. As medical technology advances, there are many ways of extending a person's life. This means that he or she can live longer even under a terminal illness. Extraordinary life-sustaining treatment is any medical treatment which serves only to prolong the lifespan of terminally ill patients; but does not cure the illness, e.g. a respirator connected to a patient to assist with breathing does not contribute to healing or treatment

Your loved one may not be able to express his or her wishes to continue or stop treatment. Some people may prefer to pass away naturally in peace and not extend treatment. In the situation that your loved one is not able to communicate their wishes to the doctor in the future, the doctor will be guided by his or her AMD.

To make an AMD:

- Patients must be above the age of 21 and of sound mind.
- Three doctors (including the hospital doctor) must all certify that patients are terminally ill.* Two of the doctors must be specialists.
- Patients need to complete and sign the AMD form in the presence of two witnesses – the doctor in-charge and someone who is above 21. Both witnesses cannot stand to gain anything from the patient's passing.

*If there is disagreement between the doctors,

- The doctor-in-charge will review the AMD.
- If there is still no agreement, the Ministry of Health will appoint three additional specialists to review your loved one's case.
- If all the three appointed specialists are unable to certify that your loved one is terminally ill, the AMD cannot take effect.

More information can be found on the Ministry of Health's website.

An AMD can be cancelled at any time. Your loved one can do this by completing a form or writing a letter to the Registrar of AMDs, and having a witness who can testify to their cancellation. You may opt to be a witness.

If he or she is unable to write, they may communicate their wishes to cancel the AMD by speaking or using sign language. The witness will have to submit the notice and explain why they are unable to submit it themselves.

Making a Will

Planning a will is important to carry on the wishes of a loved one after he/she passes on. The will should contain clear instructions about what one wants to do with his/her money and the assets they own. It will also ensure that your loved one's legacy and future generations are taken care of accordingly.



About A Will

A will takes effect after death. It is a legal document that describes your loved one's estate, which includes their money, savings and assets.

It also states how your loved one's estate will be distributed among their beneficiaries.

Wills differ from person to person. It can be a simple one-page document to a complex one, depending on your loved one's estate. It also contains instructions about the care of young children, special needs children, gifts to charity, and so on.

A will normally enlists the following:



- A list of all of your loved one’s assets
.....
- A list of all your loved one’s liabilities and debts, stating how your loved one wants to pay his/her debts off before assets are distributed to the beneficiaries
.....
- The beneficiaries and guardians, and how much each one is to receive
.....
- The executors to carry out your loved one’s will. A beneficiary may also be the executor.
.....
- The advisors (such as your loved one’s lawyers and accountants)
.....
- A revocation clause: This is to cancel out any wills your loved one planned previously.
.....
- A residuary clause: This gives your loved one a say in how they want to distribute the rest of their estate. For example, if a beneficiary dies before your loved one, the intended assets will be a part of this remainder.

Why Make A Will?

If your loved one does not have a will, the Public Trustee, an office under the Ministry of Law, will decide who receives his/her property based on the law. What this means is that people to whom your loved one wants to pass on their money or belongings may not get them.

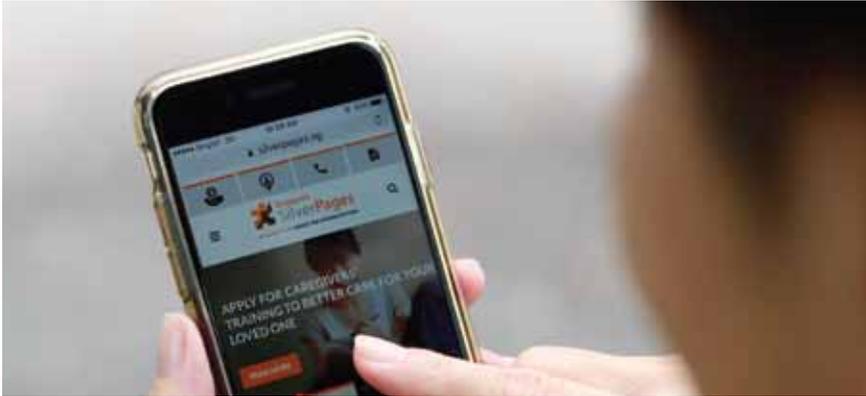
Help your loved one ensure that their money goes where they want it to go by planning a will. They may appoint:

- An executor, someone trusted to make sure their wishes are carried out;
or
- A guardian to take care of the property or money they are leaving for their children.

If you and your loved one need legal advice, you might want to consider visiting a free legal clinic. Keep in mind free legal clinics are staffed by volunteer lawyers so not all of them may be experts in this area. You should call the clinic before you visit to make sure they can give you and your loved one the necessary advice. Free legal clinics are offered at some community clubs.



Resources



There are also guides available online containing specific insights for dementia planning and support for various circumstances. You'll be able to find more information at Agency for Integrated Care's resource library or caregivers' resource found in the Singapore Silver Pages (<https://www.silverpages.sg/>) for a collation of comprehensive information and resources about caregiving.

Useful Links

1. e-Care Locator for dementia support and services

You can use this to locate nearby services that can cater to your specific needs and concerns.

2. Alzheimer's Disease Association

Alzheimer's Disease Association (ADA) is a voluntary welfare organisation that provides day care services for people with dementia, including counselling, education talks, trainings and workshops for caregivers.

3. Mind Matters – Resource Directory on Community Mental Health

Look for dementia-related services using this directory

<https://www.silverpages.sg/resourcelibrary/publications/Community%20Mental%20Health%20Resource%20Directory>

Financial Assistance Schemes



Being diagnosed with a medical condition such as dementia is not only emotionally painful, but can also present itself as a financial challenge to families.

AIC has several financial assistance schemes that cater to persons living with dementia, as well as their caregivers and loved ones. Find out more about these schemes and their eligibility criteria from <https://www.silverpages.sg/financial-assistance>.

Caregiver Training

There may be times when you find that you do not have adequate skills to provide care for your loved one. Caregiving training can equip you with relevant skills and useful tips on providing a safe, healthy and supportive environment for your loved one.

To know about how you can apply for a Caregivers Training Grant and the caregiver courses available, please visit <https://www.silverpages.sg/financial-assistance> and <https://www.silverpages.sg/caregiving/training>.

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