

UNDERSTANDING DEMENTIA

- A guide for Singapore's patients and families •



**Khoo Teck Puat
Hospital**
Alexandra Health

TABLE OF CONTENTS

FORWARD	01
INTRODUCTION	02
MEMORY LOSS AND MILD COGNITIVE IMPAIRMENT	03
Understanding memory loss What is mild cognitive impairment?	
UNDERSTANDING DEMENTIA	04
What is dementia? Table 1: The 10 warning signs of dementia	
Types of dementia Table 2: Common types of dementia	
Symptoms in dementia Table 3: Common symptoms in dementia Table 4: Stages of dementia	
PREVENTION AND TREATMENT	09
Risk factors and prevention Medical treatment	
BEHAVIOURS IN DEMENTIA	11
Understanding behaviours Possible triggers Tips to prevent triggers Change in personality Personality changes you may see Tips to cope with personality changes	

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FORWARD

UNDERSTANDING AND CARING WELL FOR THE PERSON WITH DEMENTIA 14

- Understanding the person beyond the disease
- Planning the day for a person with dementia
- Considerations when planning activities
- Routines and reminders
- Considerations when planning daily routines
- Table 5: Daily routines

PLANNING AHEAD 19

- Driving
- Lasting power of attorney
- Advance care planning

LATE-STAGE DEMENTIA 21

- When is a person at end-stage of dementia?
- Palliative care
- Communication
- Dysphagia
- Artificial nutrition and hydration
- Functional decline
- Urinary incontinence
- Constipation
- Skin care

MUSIC IN DEMENTIA 26

- Music and us
- Music therapy
- What to expect in a music therapy session

JOURNEY AS A CAREGIVER 30

- It is okay to ask for help
- Sharing by caregivers

Dementia is fast becoming commonplace in today's world. In several developed countries with aged populations today, most people know someone with dementia or whose life has been touched by it. In the coming years, Singapore will likewise become an aged society when 14% of our population is ≥ 65 years, from the present 10%. With no cure on the horizon, we will have to learn to live with dementia as it permeates our workplace, public spaces, social circles, families and lives.



This handbook helps us come face to face with dementia, to learn, understand and accept it as a concrete reality in our lives. There has hitherto been no concise local publication that spans the entire spectrum of the condition, from prevention to diagnosis and treatment, end of life care and caregiving issues. It covers hot topics such as challenging behaviours, legal matters, advance care planning and even has a chapter on music therapy for dementia, a first for Singapore. Most importantly, the book devotes space to the philosophy of person centred care, which is widely acknowledged as the standard of care for dementia today. This comprehensive yet succinct work can be read in half a day, making it particularly attractive for busy caregivers who often have to multi-task. It is a signpost of sorts for families who are seeking direction and guidance.

The KTPH memory and dementia care team must be congratulated for working to piece the book together. In particular, nurse Koh Hui Mien deserves special mention for initiating and overseeing the publication from its inception to production. We are also deeply grateful to our caregivers Leng Chan and Elsie for sharing their personal stories. The stories provide the human touch to a subject that is close to the hearts of many families and inspire us to rise above the disease with indomitable spirit and unconditional love.

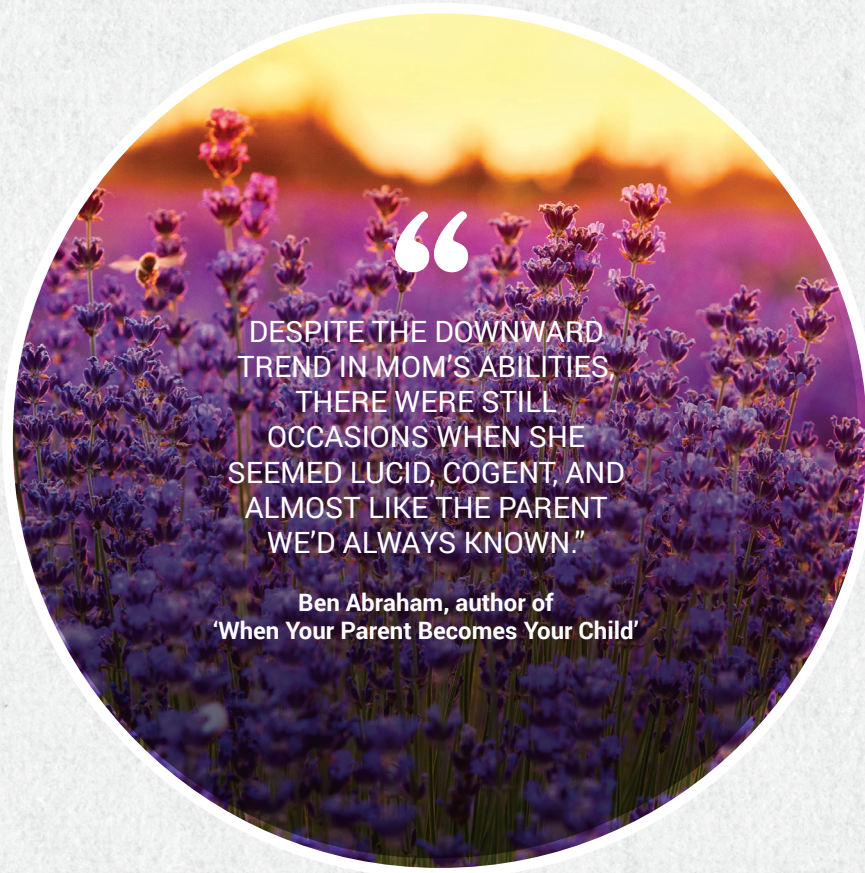
This is a must read for all whose lives have been affected by dementia. We must learn to embrace dementia and the best way to begin is by learning more about it. Let's start now!

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INTRODUCTION

The statistics surrounding dementia are staggering. Worldwide, there are now more than 36 million people living with dementia. Without a major medical breakthrough in the fight against dementia, this number could exceed 100 million by the year 2050.

It is estimated that 30,000 people suffer from dementia in Singapore today. By 2020, the numbers will increase to 50,000 and by 2050, the projected figure will exceed 180,000.



MEMORY LOSS AND MILD COGNITIVE IMPAIRMENT

Understanding memory loss

Memory is the process by which information is received, stored, and retrieved. When we first receive information, it is first encoded in a form that allows storage. Storage ensures that we maintain information over a significant period of time. Retrieval of information entails locating it from storage and bringing it back into consciousness.



Immediate memory allows recall for a period of several seconds to a minute without rehearsal. By contrast, long-term memory can store much larger quantities of information for potentially unlimited duration (sometimes a whole lifetime). Its capacity is immeasurably large.

Most dementias are characterised by abnormal forgetfulness with limited ability to recall recent events and information. Although the normal ageing process can result in difficulty in learning and retaining new material, normal ageing itself is not a cause of significant memory loss unless there is accompanying disease that is responsible for the memory deficit, such as dementia.



What is mild cognitive impairment?

Mild Cognitive Impairment (MCI) causes a modest but noticeable and measurable decline in cognitive abilities including memory and thinking skills. A person with MCI is by and large still able to function at his or her usual level but is at an increased risk of developing dementia.

UNDERSTANDING DEMENTIA

What is dementia?

Dementia is not part of normal ageing. It is a progressive decline in one's memory and other thinking skills that interferes with the ability to perform one's usual activities such as driving, shopping, cooking, managing finances, holding a job etc. Dementia can affect memory, judgment, language, planning and behaviour. Knowing the "10 warning signs" of dementia helps in early identification. (See Table 1)

10 warning signs of dementia (Table 1)

1	Memory loss that disrupts daily life A person with dementia may forget important dates or events and ask for the same information over and over again; increasingly needing to rely on memory aids.
2	Challenges in planning or solving problems A person with dementia may have trouble following a familiar recipe or keeping track of monthly bills. He or she may have difficulty concentrating and takes much longer to do things than it used to be.
3	Difficulty completing familiar tasks at home, at work or at leisure A person with dementia may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favourite game.
4	Confusion with time and place A person with dementia may have trouble finding his or her way to a familiar place or be confused about meal times such as asking for lunch at night.
5	New problems with words in speaking or writing A person with dementia may struggle with vocabulary, experiencing problems finding the right word or naming objects. He or she may have trouble following or joining a conversation and may stop in the middle of a conversation with no idea how to continue or may be repetitive.

6	Misplacing things A person with dementia may lose things and be unable to go back over his or her steps to find them again. Sometimes, he or she may accuse others of stealing. This may occur more frequently over time.
7	Poor judgment A person with dementia may exhibit poor judgment when dealing with money, giving large amount of money to strangers. He or she may pay less attention to grooming or hygiene.
8	Changes in personalities A person with dementia can become confused, suspicious, depressed, fearful or anxious. He or she may be easily upset at home, at work or with friends.
9	Withdrawal from work or social activities A person with dementia may become passive and sleep more than usual. He or she may lose interest in those activities which he or she once enjoyed. He or she may forget how to participate in a favourite hobby.
10	Changes in mood or behaviour A person with dementia can exhibit rapid mood swings with no apparent reasons or triggers.

Adapted from Alzheimer's Disease Association, Singapore

Types of dementia

There are various types of dementia. Different types of dementia may have different symptoms and care needs. Therefore, it is important to learn more about the types of dementia. Table 2 provides an overview of the common types of dementia.

Common types of dementia (Table 2)

Alzheimer's Disease (AD)
The most common type of dementia. It has an insidious onset and is a progressive disease whereby symptoms gradually worsen over a number of years. AD is irreversible and slowly impairs memory and thinking skills and eventually even the ability to carry out the simplest tasks such as eating. Currently there is no cure for this disease but treatment can help manage symptoms of AD.
Vascular Dementia (VaD)
A type of dementia that is caused by disease or injury to blood vessels in the brain, mostly strokes. The onset may be abrupt and symptoms depend on the location and size of the stroke. A person with vascular dementia may also show evidence of silent strokes on brain scan. While vascular dementia is not reversible, it is important to treat the risk factors. Controlling risk factors such as high blood pressure, diabetes mellitus, high cholesterol and smoking may slow progression and reduce stroke recurrence.
Lewy Body Dementia (LBD)
A type of dementia which has the features of Parkinson's disease. These include slowness, tremor, rigid muscles, and vivid visual hallucinations. Other prominent symptoms include problems with attention, organisation, problem solving and planning. People with LBD have higher risks for falls in view of their increased rigidity, instability and slow gait.
Frontotemporal Dementia (FTD)
A type of dementia that is characterised by marked personality changes and in some cases, language difficulties. Most people affected by FTD are younger, between 40-70 years of age. Due to the symptoms, FTD can be mistaken for Alzheimer's disease, Parkinson's disease or a psychiatric disorder like depression, obsessive-compulsive disorder or schizophrenia. There is no treatment or cure yet but medications and lifestyle changes can help to relieve the symptoms.

Symptoms in dementia

Every person with dementia is unique, thus they do not all present with the same symptoms. There is a saying, "When you see a person with dementia, you have seen just one." The needs and manifestations vary from person to person although there are some symptoms common to most people with dementia.

Common symptoms in dementia (Table 3)

MILD	MODERATE	ADVANCED
 <p>Misplacing things, repetitiveness, forgetting to pay bills, mismanaging medications, getting lost outside the home especially in less familiar places</p>	 <p>Marked problems in recent memory, difficulty in recalling an address or telephone number, resists / refuses to take shower, needing prompts and reminders to perform daily routines, say or do things that are socially inappropriate, personality and emotional changes</p>	 <p>Unable to retain any information, minimal verbal output or incoherent speech, may not be able to stand or sit up without help, may not recognise family members, basic motor skills e.g. walking, eating can be impaired</p>

PREVENTION AND TREATMENT

Stages of dementia (Table 4)

In patients with mild disease, symptoms may be subtle. In moderate disease, symptoms are more apparent and patients with severe disease are typically incapacitated.

	MILD	MODERATE	ADVANCED
MEMORY	<ul style="list-style-type: none"> • Difficulty with short-term memory • Poor attention span • Poor decision-making 	<ul style="list-style-type: none"> • Difficulty with short and long term memory • Poor orientation to day, date and/or time • Begin to forget some friends and associates 	<ul style="list-style-type: none"> • No apparent awareness of past or present
SPEECH & LANGUAGE	<ul style="list-style-type: none"> • Problems remembering the right word or name 	<ul style="list-style-type: none"> • Problems with understanding • Difficulty in expressing self and making needs known 	<ul style="list-style-type: none"> • Unable to engage in a meaningful conversation • Paucity of speech or incoherent speech. May express needs by yelling or calling out
BEHAVIOUR & MOOD	<ul style="list-style-type: none"> • May become socially withdrawn or have low mood 	<ul style="list-style-type: none"> • More easily upset and frustrated • Appear to lack emotion 	<ul style="list-style-type: none"> • Passive / withdrawn • Difficult to engage
PHYSICAL ABILITIES & SELF CARE	<ul style="list-style-type: none"> • Difficulty with planning and managing household affairs, such as cleaning and cooking • Problem with handling finances • Difficulty initiating activities • Getting lost in less familiar places 	<ul style="list-style-type: none"> • Gets lost outdoors even in familiar places • Needs reminders & prompts often in daily tasks • Requires help in: <ul style="list-style-type: none"> - Dressing <ul style="list-style-type: none"> - selecting clothing - buttoning, zipping - Grooming: <ul style="list-style-type: none"> - lack of attention to fine details - needs reminders for shaving, hair combing - Bathing: <ul style="list-style-type: none"> - forgets to shower - Bladder & bowel: <ul style="list-style-type: none"> - difficulty locating the toilet - incontinent episodes 	<ul style="list-style-type: none"> • Problems with balance and coordination resulting in gait instability and falls • Total dependence in: <ul style="list-style-type: none"> - dressing - grooming - showering - feeding • Eating & swallowing problems • Loss of bladder and bowel control

Risk factors and prevention

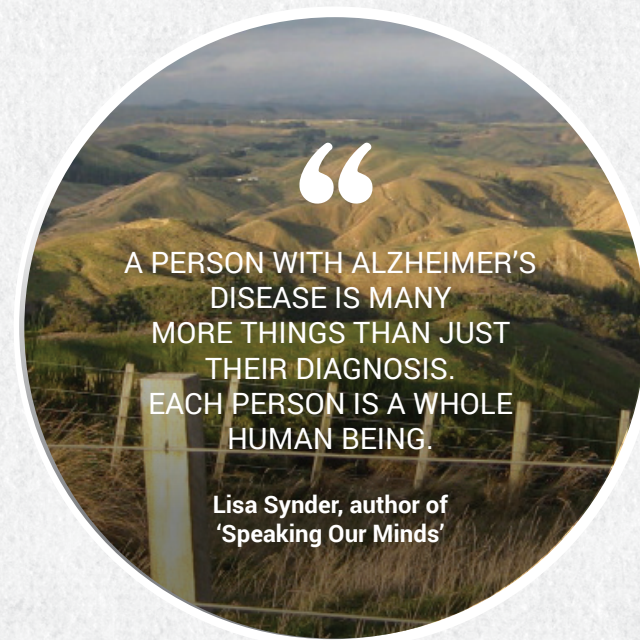
There is no certain way to prevent any type of dementia. However, adopting a healthy lifestyle can reduce one's risk of developing dementia. A healthy lifestyle can also prevent or reduce the risk of cardiovascular diseases such as strokes and heart attacks.

Risk factors for dementia include:

- Physical inactivity
- High blood pressure
- High blood cholesterol
- Diabetes Mellitus
- Excessive alcohol consumption
- Smoking
- Mid-life obesity
- Lack of mental stimulation

To lower your risk or delay the onset of dementia, you can :

- Keep physically active
- Keep your blood pressure at a healthy level
- Monitor blood glucose if you are a diabetic
- Eat a balanced diet
- Quit smoking
- Exercise regularly
- Go for regular health screening
- Refrain from heavy alcohol intake
- Be socially engaged



BEHAVIOURS IN DEMENTIA

Medical treatment

Presently, there is no cure for dementia. There are, however, drugs that may help improve mental function, mood, or behaviour and slow the symptomatic progression of the disease. Although slight improvement or stabilisation of symptoms can at times be seen, these ultimately do not prevent the disease from getting worse. The following are the medications used to treat dementia:

Acetylcholinesterase inhibitors help to maintain mental function. There are 3 in this category, namely Donepezil (Aricept), Rivastigmine (Exelon) and Galantamine (Reminyl). They are primarily licensed to treat the mild to moderate stage of the disease although there is also evidence of efficacy in advanced dementia. Generally, these medications are well tolerated but possible side effects include vomiting, nausea, diarrhoea and anorexia especially at higher doses. A transdermal patch formulation is available for Exelon.

Memantine hydrochloride is licensed to treat moderate to advanced stages of the disease. It can also be an alternative if patients cannot tolerate Acetylcholinesterase inhibitors. It has minimal side-effects generally and can be used on its own or in combination with Acetylcholinesterase inhibitors.

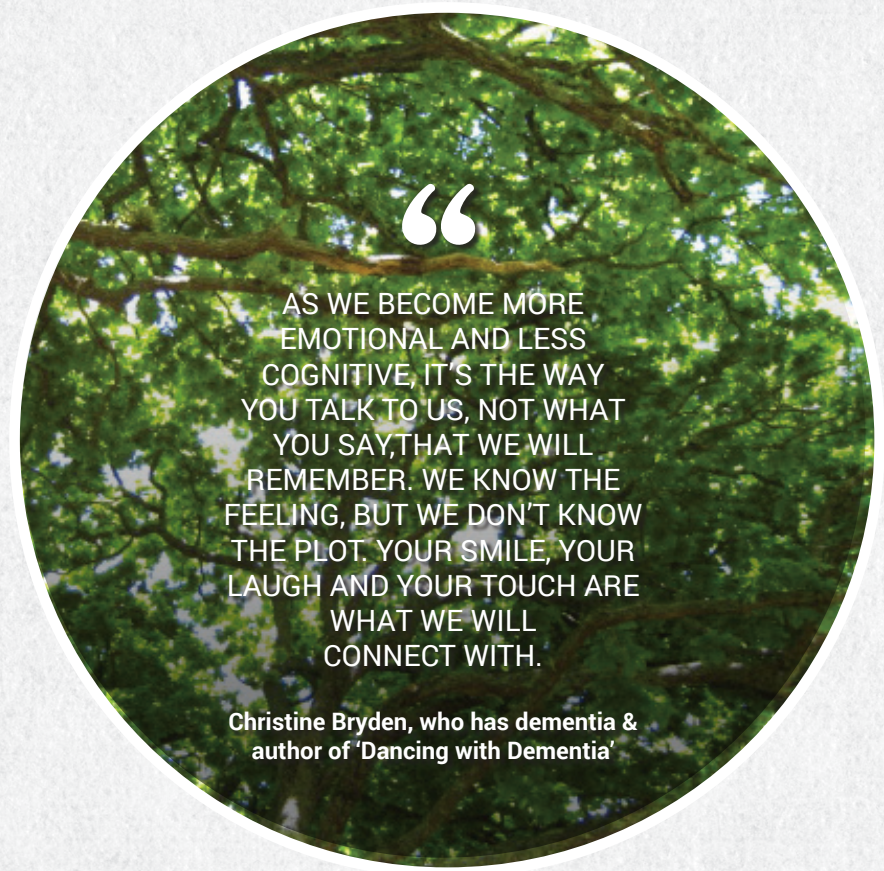
Antipsychotics, antidepressants, mood stabilisers and sedatives are at times used to treat various challenging and disruptive behaviours such as anxiety, aggression, agitation and sleep problems. Antipsychotics are used with caution and usually not for prolonged periods because they can:

- increase the risk of cardiovascular diseases, such as stroke or heart attack
- cause excessive drowsiness and impair alertness and communication
- cause slowness, rigidity, unsteady gait and falls



Understanding behaviours

All behaviours have meaning, so it is important to try to understand why the person with dementia is behaving in a particular way. Like any person, people with dementia will have their good days and bad days. Family members and caregivers play an important role in providing support and understanding, and can try to elucidate what may be triggering the behaviour. It may be easier to figure out ways to prevent the behaviour from happening again than to resolve it when it happens.



Possible triggers

- Fatigue
- Hunger or thirst
- Sleep deprivation
- Physical discomfort such as pain, fever
- Illness
- Needing to urinate or open their bowels/urinary retention or constipation
- Trying to express their emotions
- Too much noise such as TV, radio or too many people talking at the same time
- Impaired vision or hearing causing the person to misinterpret sight and sounds
- Boredom

Tips to prevent triggers

- Encourage short periods of rest in the course of the day to minimise fatigue
- Be vigilant to watch for non-verbal cues of pain and discomfort such as frowning or grimacing
- Regular toileting
- Changing or checking diapers regularly to promote comfort
- Monitor bowel habits to ensure regular evacuation
- Serve snacks and fluids in between meals
- Lower the volume of the TV or radio to minimise noise which can trigger agitation
- Too many people talking to them at the same time can be confusing
- Do not force the person to do something that he or she does not like such as bathing. The caregiver can use the soft approach by coming back to the person when he or she has forgotten about the initial event
- Reduce clutter to allow them space to move around
- Speak slowly and in short sentences especially to those with hearing impairment

Changes in personality

It is not uncommon to notice changes in the personality of a person with dementia. This is because the disease causes changes in the brain. Often, families find it difficult to accept the personality change in their loved ones. The person they once used to know may seem to have become a different person.

It is crucial for families and caregivers to understand that it is the disease that causes the changes in their loved ones and not the persons themselves.

Personality changes you may see:

- Getting upset more easily
- Suspicion towards others including family members
- Loss of interest in activities they used to enjoy
- More unkempt or pay less attention to their appearance / grooming
- Buying the same things repeatedly
- Wandering away from home
- Inappropriate social behaviour such as spitting in public
- Imagining things that are non-existent
- Physical aggression

Tips to cope with personality changes:

- Be genuine and sincere when you approach them
- Reassure them that they are safe
- Keep things simple. Say one thing at a time
- Have a daily routine and provide structured activities
- Do not argue or try to reason with your loved ones
- Step back when you are angry. If you show the person that you are angry or frustrated, they will mirror your emotions
- Try using music, songs or other activities the person used to enjoy to soothe and comfort them when they are upset
- Hold and comfort them when they appear anxious or afraid
- Try not to retort even if you are blamed or accused wrongly
- A gentle touch or hug to show the person that you really care usually helps



UNDERSTANDING AND CARING WELL FOR THE PERSON WITH DEMENTIA

Understanding the person beyond the disease

Dementia is a powerful label and marks a long journey into a world of disempowerment where human attributes and abilities are progressively lost. Indeed, many consider this disease as tragic, costly and burdensome. Dementia often affects not only the person with dementia but also brings hardship and toil to the caregiver.

However, the person with dementia remains fully human and fully alive, behind the facade of the disease. To connect with people with dementia, we need to know them and have a deep appreciation of their past, because the past is a light to what goes on in the present. It is essential and a basic prerequisite to understand the person with dementia well as we undertake the often arduous caregiving journey with them.

Generally, people with dementia are not intentionally difficult or irrational. Their behaviours can often be best understood as expressions of unmet needs and in the light of their past habits and personalities. As they have difficulties expressing themselves with words, feelings and needs are often communicated through behaviours.

Christine Bryden, a writer and a person with dementia says, “for people with dementia our behaviour is normal, considering what is happening in our heads. Try to enter our distorted reality, because if you make us fit in with your reality, it will cause us extra stress.” In order to enter into the reality of people with dementia, we need to feel with them and stand in their shoes; hence a high degree of empathy is necessary.

With good knowledge of the person and the situation, it is often not difficult to understand why the person acted and behaved in particular ways. Interpretation of behaviours may not always be straightforward, it requires patience, love and learning through trial and error. For example, agitation may sometimes be due to a noisy and unfamiliar environment triggering fear and anxiety. At other times it could be due to pain, discomfort or hunger for which the person has little means to express, short of calling out loudly.



Dementia brings us face to face with our humanity, and evokes fundamental questions about what it means to be human. Being human is not only about our human attributes and abilities, for these go away with progressive dementia. Being human is also about connecting with others and forging lasting relationships. For this reason, even as dementia takes its toll on the person, the people around him help to preserve his identity and humanity by maintaining meaningful and loving relationships with him. Only in this way can life still be worthwhile and purposeful for the person with dementia and those close to him.

Planning the day for a person with dementia

Activities are “things we do” such as daily chores, work, leisure and play. Activities help to structure time and can make the best of a person’s abilities, enhance quality of life, promote relaxation and bring pleasure. Activities need to be individualised as no two people with dementia are the same. With the progressive nature of disease, caregivers need to have realistic expectations when selecting activities. Meaningful activities promote socialisation and enhance self-esteem and well-being.

Considerations when planning activities:

Person

- Knowing the person well in terms of basic personality, significant life events, work history, hobbies, social and recreational preferences.
- Understand current cognitive and functional abilities to know strengths and limitations. Some modifications may be required to adapt to the person’s capabilities.

Activity

- Caregivers need to be sensitive and be on the lookout for the reactions of the person during activities. These include fatigue, non-verbal cues such as grimacing and frowning which may indicate pain or other physical discomfort.
- Be aware of the person’s physical limitations such as hearing, visual impairments and difficulties in performing simple movements due to medical ailments.
- Be flexible and acknowledge the person’s changing interests and abilities.
- Use age-appropriate activities and avoid materials that appear childish

Approach

- Be sincere and genuine when approaching the person with dementia. It always helps to respect and not undermine the person's decisions and preferences.
- Focus on one task at a time, break activities into simple and easy-to-follow steps. Too many instructions can be overwhelming
- It is important to communicate with the person even if he appears not to be able to respond. This can help to maintain connectedness and allow recognition and respect for the person with dementia.



Routines and reminders

With time, the ability to carry out every day routines will decline. It is therefore important for people with dementia to still maintain some independence for as long as they can. This helps to maintain confidence and enhance self-esteem. Try to think of the things that your loved ones used to enjoy doing and try to keep them involved in some way. For instance, a homemaker may still enjoy folding laundry even if they are no longer able to operate the washing machine without help.



Routines are tasks which are easily done according to a set way or method. It is easier if the person can continue the routines he/she has been used to for much of his / her life.





Reminders are helpful especially during the mild to moderate stages of the disease. It can be in the form of written notes, setting the timer alert in electronic devices or a phone call.

Considerations when planning daily routines:

- Do not rush - it will only cause more confusion, anxiety and frustration.
- Keep a sense of structure and familiarity. For instance: try to keep to consistent timings for daily routines such as waking up, shower, meal times and bedtime.
- Be flexible and allow the person to make choices.
- Break the task down into simple steps.
- Encourage rest - people with dementia can tire quickly.
- Reality orientation to keep the person aware of the date and time of day.
- Encourage performance of habitual and over-learned tasks such as drying dishes, folding clothes and watering plants.
- Help people with dementia "feel useful" by letting them help whenever and wherever possible e.g. feeding the pets, carrying shopping bags.
- Caregivers should try to avoid taking over if the person is trying to complete a task and allow him to continue at his own pace. This enables a sense of control and engenders good feelings.

PLANNING AHEAD

Daily routines (Table 5)

Common problems	Possible solutions
<p>Eating</p> <p>Little interest or initiative to eat or drink</p> 	<ul style="list-style-type: none"> • Set alerts as reminders, write notes or call them to remind them • Encourage small and frequent meals • Place cups filled with water to allow them to sip throughout the day • Eat or drink with them
<p>Eating all the time</p>	<ul style="list-style-type: none"> • Engage them in other tasks by way of diversion • Serve healthy snacks which are low in calories e.g. fruits • Serve food in small portions
<p>Grooming</p> <p>Always wearing the same clothes</p> 	<ul style="list-style-type: none"> • Lay out new clothes and help them with choice of clothes • Have more than one set of the same clothes in case the person insists on wearing the same clothes every time
<p>Problems choosing outfit</p>	<ul style="list-style-type: none"> • Allow time to let them decide & assist in promoting choice • Remove some of the clothes in the wardrobe if it appears cluttered
<p>Bathing</p> <p>Refusal to bathe</p> 	<ul style="list-style-type: none"> • Avoid coercion, be flexible and try again later. Never make a big fuss of the issue • Keep to the same bathing routine • Use soap or shower gels that the person is familiar with • Try to provide a reason that they may accept e.g. bathing before going out
<p>Toileting</p> <p>Has problems locating the toilet and / or unlocking the toilet door</p> 	<ul style="list-style-type: none"> • Use visual cues such as putting signs on the toilet door • Print the toilet door in bright colours • Set a toileting schedule • Remove the bathroom lock if necessary

Driving

Driving is a complex task that requires much concentration, split-second decision-making and good judgment. It also represents one's autonomy and independence. A diagnosis of dementia, however, does not necessarily imply the person is incapable of driving. Your doctor can arrange for a driving assessment with a healthcare professional who specialises in testing drivers with cognitive impairment. Eventually, a person with dementia will need to stop driving if it is no longer safe.

What are some signs that suggest a person with dementia may not be able to drive safely anymore?

- Getting lost while driving in a familiar location
- Violating traffic rules
- Driving at an inappropriate speed
- Taking too long to reach a destination
- Slow responses and reaction
- Repeated accidents or near accidents

Other important considerations

With time, people with dementia will lose their ability to make good decisions due to deficits in judgment and problem solving. In the later stages of the disease, the person is likely to lose the ability to make sound financial and healthcare decisions. Therefore, it is important for them to discuss such issues with their family or trusted associates



Lasting Power of Attorney

The Lasting Power of Attorney (LPA) is a legal document that a person who is at least 21 years of age can make to voluntarily appoint one or more persons to make decisions and act on his behalf should he lose the capacity to make his own decisions.

The LPA allows one to indicate a personal choice of trusted person(s) who can automatically step forward to act on one's behalf if one should lose mental capacity. It is necessary to see a certified issuer to sign as witness and to certify that the person is aware of the implications of making an LPA. A certificate issuer can be a psychiatrist, a practicing lawyer or an accredited medical practitioner.

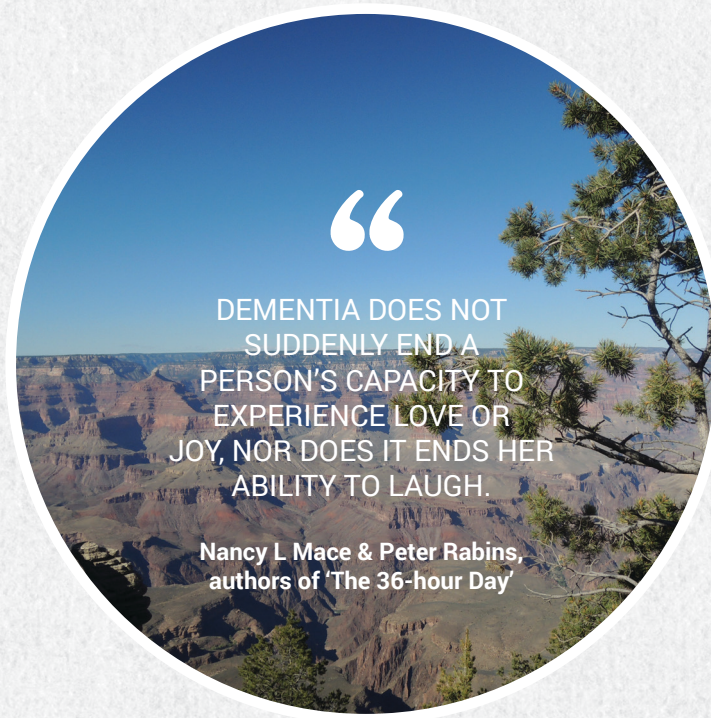
LATE-STAGE DEMENTIA

Advance Care Planning

Advance Care Planning (ACP) entails careful discussion on a person's future care preferences in the light of disease progression with careful consideration of the person's goals and values.

It includes identification of a substitute decision-maker in the event the person is no longer able to make his / her own decisions. ACP also helps in planning of care discussions which includes the Preferred Plan of Care (PPC) at the end of life.

ACP helps family members by easing the stress of making difficult decisions. The wishes of the person with dementia can be made known to them earlier so that family members can act in accordance to the expressed wishes. Ideally, discussions about end-of-life care should take place while the person with the dementia still has mental capacity to make informed choices and decisions.



Care for late-stage dementia

Making end-of-life decisions can be tough. Such decisions should respect the person's values and wishes while maintaining his comfort and dignity. Caring for persons with advanced dementia at home can be demanding. Planning ahead and knowing what to expect can make it easier.

When is a person at end-stage of dementia?

- Not being able to move on their own
- Not being able to speak or make oneself understood
- Needing help with all activities of daily living
- Progressive issues in eating / swallowing problems
- Loss of appetite
- Significant weight loss
- Sleeping excessively
- Recurrent infections often with hospitalisations

Palliative care

Palliative care is the overriding principle of care in advanced dementia. As dementia is a terminal disease, death can be expected at some time during the advanced stages. During this time, the role of a caregiver focuses on upholding dignity and quality of life for the person with dementia.



The World Health Organization (WHO), 2002 has defined palliative care as:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

The goal of palliative care is to provide the best possible quality life for the last phase of a person's life. As such, palliative care focuses on relieving symptoms such as pain, agitation, anxiety and poor oral intake, and family caregivers can play an active role in the care.

Communication

Communication is difficult for a person with advanced dementia due to their reduced ability to interact with their surroundings. Verbal expression becomes increasingly difficult and sentences tend to be shorter. Incomprehensible words may be added to the conversation.

In order to make communication easier, it is important for caregivers to understand that the person with dementia may have trouble understanding what is being said. Hence, non-verbal ways of relating through touch and one's loving presence becomes important.

Tips for effective communication:

- Always make eye contact with the person
- Call them by their preferred names.
- Use of gestures or touch whenever appropriate
- Use of pictures may be helpful
- Patient listening with interest and a cheerful disposition



Dysphagia

It is the term used to describe someone with swallowing problems. It is not uncommon for persons to have dysphagia in the later stages of dementia due to their impaired swallowing reflexes. A possible consequence of dysphagia is aspiration. Aspiration occurs when food or fluids go from the mouth into the person's windpipe (trachea) rather than the food tube (oesophagus). This can lead to choking or chest infection especially if recurrent and persistent. Some important advice includes:

- Do not feed a person who is sleepy or lying down.
- The person should be in an upright, sitting position during feeding
- Sit upright for at least 20 minutes after a meal.
- Observe closely for signs of dysphagia such as persistent cough or gurgling throat sounds after swallowing.
- Do not hurry the person. Give him time to chew and swallow before taking another spoonful.
- Do not take food in large mouthfuls.
- A speech and language therapist may recommend modifications to the diet e.g. soft, minced or pureed diet and thickened fluids.

Artificial nutrition and hydration

In very late stage dementia, the person can have severe difficulties with swallowing and may not maintain sufficient fluid and nutritional intake for bodily sustenance. Hence, caregivers are faced with the option of providing artificial nutrition. Artificial nutrition can be delivered through a nasogastric (NG) or percutaneous endoscopic gastrostomy (PEG) tube. A NG tube involves the insertion of a feeding tube via the nose into the stomach while the latter is inserted directly into the stomach through the abdominal wall via a surgical procedure.

It is important to note that artificial nutrition will not:

1. Reduce the risk of pneumonia.
2. Improve survival or prolong life in people with advanced dementia.
3. Prevent pressure ulcers.
4. Improve functional status.
5. Improve comfort or reduce suffering

However, artificial nutrition can help the person receive adequate hydration and nutrition and may help in weight gain.

Functional decline

In late stage dementia, weight loss and loss of muscle strength can be apparent. Generally, a person in the advanced stage of the disease has a low metabolic rate and is physically inactive. Prolonged immobility and bed rest can result in joint contractures and problems with skin integrity. It is useful to move the limb joints passively using range-of-motion exercises (can be taught by nurses & therapists). Regular movements not only help to prevent joint stiffness but can help to prevent pressure ulcers or bedsores.



Urinary incontinence

Urinary incontinence is a common problem in dementia. With progressive dementia, the person becomes less aware of his toileting needs and can hence wet himself without knowing. Other exacerbating factors include urinary tract infection, an enlarged prostate gland, drinking too much caffeinated beverages, impaired mobility and constipation. The following advice can be helpful:

- Bringing the person to the toilet at regular intervals (timed toileting) can help promote continence in the person. This is possible with effort and careful attention to the usual toileting habits of the person. The benefits of this include comfort and maintaining the dignity of the person in delaying the need for continence products such as diapers.
- If the person is using diapers, ensure regular diaper change to keep the area dry and clean.
- Use a skin protective / barrier cream to minimise skin irritation from soiled diapers.

Constipation

Constipation is common in older persons and especially people with dementia given their reduced awareness and relative immobility. Poor food, fibre and fluid intake are also contributory. Constipation causes discomfort and can worsen confusion and agitation. It also makes passing urine more difficult and can precipitate urinary retention.

The following advice is useful:

- Ensure adequate hydration and intake of fruits and vegetables to aid in bowel movements
- If the person is not keen to drink plain fluids, other sources of fluid include soup, melted ice cream, juices or decaffeinated coffee or tea.
- Use of laxatives if necessary
- Record and monitor bowel movements and type of stool (See Bristol Stool Chart).



Skin care

When a person is bedbound and lying in the same position for prolonged periods, the risk of developing pressure ulcers (bed sores) is high. Pressure ulcers can cause significant pain and lead to potentially life threatening infections. The following can be done to prevent pressure ulcers:

- Turn or re-position the person lying in bed at least two hourly.
- If the person is still able to sit, sit him out of bed for about 30 minutes two or more times a day.
- Provide a pressure-relieving mattress
- Perform regular skin checks for redness as a sign of impending pressure ulcer development. Areas at high risk of developing pressure ulcers include the person's ears, shoulders, elbows, hips, heels, back and buttocks.

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YOU ARE SMILING AT ME.
I SEE MY REFLECTION IN YOUR EYES.
I'VE FINALLY FOUND SOMEONE
WHO SPEAKS MY LANGUAGE.

Robert Butler, author of
'Learning to Speak Alzheimer's'

MUSIC IN DEMENTIA

Music and us

Music can touch people in profound ways. It impacts a person mentally, emotionally and even physically. There has been research on how people can respond differently to the same piece of music. It is neither surprising nor new that music can be used to improve the well-being of individuals. In fact, music has already been used as a form of therapy during the World Wars decades ago, before it was formerly established as a treatment modality.



Music therapy

Music therapy is the clinical and evidence-based use of music interventions to accomplish individualised goals within a therapeutic relationship. Goals include that of:

1. Alleviating pain
2. Managing mood
3. Enhancing memory
4. Expressing feelings
5. Facilitating communication
6. Facilitating cognitive function
7. Supporting physical rehabilitation

(American Music Therapy Association)

Music therapy reaches out to a wide spectrum of people. It can be harnessed as a therapeutic modality for the elderly who are coping with deficits in daily functioning, including physical, psychological or social functioning. It stimulates the senses and is able to evoke responses due to the familiarity, predictability, and feelings of security associated with it.

What to expect in a music therapy session

Anyone with or without music experience can be part of a music therapy session. Persons can expect to be part of different musical experiences during music therapy sessions. They include:

(i) Music listening / singing

An old song can serve as a portal to old memories, awaking the person behind the façade of physical pain and illness. A common intervention with the elderly is to sing songs that are familiar to them. Usually, the song is sung in the mood and tempo befitting the person's disposition in the moment. The person may choose to listen to the music or play an instrument / sing with the therapist. In the latter, the person and the music therapist recreate the song together, bringing about a certain sense of originality to the music, making it different from the popular recordings heard. It is often a beautiful surprise to witness how a person might forget what she has said, or done in the last hour, but remembers a song she learned and sang as a child.

(ii) Music improvisation (through singing or instrument playing)

Musical improvisation (creating music in the moment) is very often used in music therapy sessions. Most people do not have prior experience in playing instruments. The therapist receives and works with whatever musical ideas (e.g. rhythm) the person creates and together they create a larger musical work.

This process provides people the space to take charge of their musical decisions, express themselves freely and access their creative abilities. As musical improvisation is not fixed in a familiar song, persons have to be able to respond to changes (e.g. change in tempo of the music) initiated by the therapists and vice versa.

(iii) Playing of composed music

Another intervention applied would be the use of composed music that requires people to play at specific moments. This provides people with new musical experiences, and exercises their memory as they have to remember musical patterns and follow the direction of the music therapist.

(iv) **Music and movement**

Music and movement complement each other. Depending on the physical ability of the person, dancing or simple movements could be choreographed into the music. More often than not, this brings about quite a bit of laughter and fun to the session and is a non-threatening way to encourage physical exercise and expression.

Generally, the average length of a session could range anything from 30 to 60 minutes, depending on the needs of the person. Music therapists assess the individual and establish goals specific to him or her. Each session is person-centred and the therapist will constantly review the progress of each person before adjusting any of the music interventions used.

Simple musical strategies that could be used at home

Music therapy might not be accessible all the time. However, music can still be used by caregivers in dementia care. The following are some simple ideas that caregivers might explore at home with their loved ones.

(i) **Song listening**

Playing recordings of songs that the person likes or used to listen to has the potential to bring about a sense of familiarity and even memories, which could be comforting to the person. Besides, songs have structures – a beginning and an ending – which can give the person a better sense of time. Caregivers will have to do a bit of research to identify some of the songs that the person used to enjoy or the music that was popular during the person's youth.



(ii) **Singing**

Singing is the activation of a very personal and innate instrument – our voice. It connects a person to his inner self when he sings. It is also a simple exercise of the lungs and can be very expressive.

Caregivers can sing songs alongside the person. Even if the person is unable to recall the lyrics, humming the tunes of the songs is just as effective. It is important that the caregiver sings at a slower tempo, at a pace at which the person is able to comprehend the music. This means that there are times when caregivers would have to sing without the support of existing music recordings which might be too quick for the person to grasp.

(iii) **Instrument playing**

Instrument playing helps in promoting psychomotor exercise and facilitates a more physical engagement. Caregivers could invest in simple percussion instruments such as tambourines, which could be used during singing activities. Caregivers can also encourage or assist in tapping the pulse to the music that is being heard or sung.

(iv) **Music and movement**

Music can be incorporated into simple physical exercises. Caregivers should select songs that match the person's tempo. For instance, if the person is capable of slower movements, music of a slower tempo should be used.

While most people enjoy music, we have to be sensitive to the person's responses. Just like any other person, there are times when the person might just want to sit in silence, and it is important to acknowledge that as well.

It is also vital to note that through it all, the presence of the caregiver and his/her direct communication with the person during music, brings the most comfort to the person. It would not be as helpful if the caregiver simply played a recording and left the person to it. The caregiver's presence and communication provides the reassurance that the person is not alone in his / her journey.

Resources for more information

http://www.musictherapy.org/assets/1/7/MT_Alzheimers_2006.pdf

<http://www.ageuk.org.uk/health-wellbeing/conditions-illnesses/dementia-and-music/>

<http://www.alzfdn.org/EducationandCare/musictherapy.html>

JOURNEY AS A CAREGIVER

Caring for someone with dementia can be a real challenge. It entails not only personal commitment but also calls for much knowledge, patience, creativity, skills and unconditional love. Caregivers often say that they feel physically and emotionally drained. The caregiving journey can be lonely if the caregiver is isolated with no one to seek solace in. Hence, feeling sad, helpless, discouraged or frustrated are not uncommon. As important as it is to provide good care for loved ones with dementia, caregivers also need care and support.

Ways you can take care of yourself:

- Ask for help when you need it
- Join a caregiver's support group, it helps to know you are not alone
- Continue to keep up with hobbies and interests
- Meet up with friends and relatives regularly
- Eat healthily and get regular exercise

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TO TRULY UNDERSTAND
PEOPLE WITH DEMENTIA, YOU
NEED TO KNOW THAT THERE
IS ALWAYS A PERSONAL,
MEANINGFUL EXPLANATION
FOR WHAT THEY DO OR SAY,
NO MATTER HOW STRANGE IT
MAY SEEM AT FIRST.

Daniel Kuhn & Jane Verity,
authors of
'The Art of Dementia Care'

It is okay to ask for help

Always remember that it is okay to ask for help because it is unrealistic to solve all problems yourself. We all need help and support sometimes. Ask for a helping hand - it will help you care better for your loved one with dementia.

SHARING BY CAREGIVERS

My mummy dearest (The late Mdm Tan Kim Neo)

From 2000 to 2001, my family experienced the death of my brother, sister and husband. My mum could not overcome their passing and went into depression. We brought her to our family doctor and she was prescribed with an anti-depressant. To overcome her traumatic experience of losing her loved ones, we brought her out for activities such as shopping and travelling. Sadly, she started getting very agitated and this was the onset of her dementia.

My mum was very restless and kept asking for her medication, at times accusing me of giving her double dosage or bugging me the whole day for not giving her the medication. She even started going to her drawer more than 30 times a day to count her money and accused me of stealing her money. At that time I was not well versed in dementia and argued with her which made her agitated and suicidal. She even started throwing tantrums, refused to eat and cooped herself up in the room. There were times when she would wake up in the middle of the night to search for her money.

Upon the recommendation of our family physician, we consulted the doctor at Alexandra Hospital (now Khoo Teck Puat Hospital) in April 2006. He confirmed that my mum had moderate dementia and recommended medication and day care. In May, we managed to find a place at Toa Payoh New Horizon Centre managed by Alzheimer's Disease Association. Subsequently, after several visits to the doctor and trials of several medications, mum showed signs of improvement and was more alert.

There were episodes of hallucinations where she would see things eg. children around the house. She would also talk to an imaginary person.

The doctor advised us to put her on the dementia care programme. We visited the doctor many times and she finally became more manageable between 2009 to mid 2012.

In early January 2013, mum was diagnosed with advanced colon cancer. She passed away peacefully on 5 February 2013 from pneumonia.

My life as a caregiver was very stressful and I even contemplated suicide twice. On top of being a 24/7 caregiver (mum did not want any helper), I too had my own personal problems. In the beginning, I had no knowledge of dementia and was very depressed. But as time went by things became better with the help of the dementia support group. There's no social life for caregivers. Friends do not understand your sadness, anger and frustration. Through prayers and the support from my cell group, pastors and pastoral members, I pulled myself through all this.

I must confess that I had not been an angel whilst taking care of my mum. I told her white lies and shouted at her. At times I felt like strangling her. I regret that I did not take better care of her. Patients with dementia need security and love from their loved ones.

I still miss my mum very much and my advice to those with parents who have dementia is this - money cannot buy quality time with them, so treasure the moments with them whilst they are alive. Assure them that you love them.

Many thanks to the staff at KTPH Geriatric Clinic for their support, love, care and patience throughout these years for my mum and me.

Elsie Wee (Caregiver)

Alzheimer's disease. Dementia. Fourteen years ago, these were alien to me.

I heard of these terms only when the doctor diagnosed mum to have Alzheimer's disease in 2000. I did not have any knowledge about the disease then. Mum could not remember what was told to her 5 minutes ago and kept repeating the same questions. Subsequently apart from the forgetfulness, I noticed that she was unable to keep up her personal hygiene and she messed up her wardrobe.

Sometimes, she did not bath but there were times when she bathed 2 to 3 times in one day. At times, she shouted very loudly at night which made our neighbours feel uncomfortable. She often misplaced her door keys and accused my father of hiding them.

Once, she fractured her hip when she fell at home and needed to go for surgery. After discharge, she kept asking to go home when she was actually at home. When she did something wrong, I tried to explain and reason with her but she did not seem to understand. Often, I ended up yelling at her but regretted later for not respecting her as my mother.

Relatives and friends stopped coming because they felt uncomfortable seeing a once active and cheerful woman becoming a stranger to them. I became more stressed when the disease progressed with more challenging behaviour. I was drained mentally, physically and emotionally. I complained a lot about mum to my siblings who do not stay together with us, but they were unable to give good advice due to the lack of understanding of the disease and skills in dealing with the challenging behaviour.

I declined the suggestion from them to employ a helper to assist me because I was not comfortable to have a stranger in the house. Instead, I engaged a food caterer to take care of the meals and employed a part-time cleaner. I couldn't sleep well at night and when I woke up the next morning, I felt very down that I did not know what my day was going to be.

My 'new mother' was confused, fearful, insecure and full of conflicting emotions. I shed tears every day from self-pity and felt sad for my mum. On the one hand I wanted to do what was best for mum, but on the other hand I was just too frustrated. It was like entering a labyrinthine journey and losing my direction. Medical cost aside, the caregiving journey was tough. Juggling a full time job and caring for mum under a tremendous amount of stress was an uphill task.

I decided to quit my full time job. To balance my care-giving life, I enrolled myself in a part time social service related course which was a totally new area to me. I was worried that I might get depression. I sought the doctor's advice when I brought mum for her medical appointment. He suggested dementia day-care for mum and a caregiver support group which I attended and liked very much because I could vent my frustration at the sharing session and the participants could understand me. I learnt how to communicate with persons with dementia and picked up tips for dealing with challenging behaviour from other caregivers. After each session of the support group meeting, I felt fresh and rejuvenated just like after a spa. I grew from the support group and started to read more extensively on topics related to Alzheimer's disease. Mum benefited from attending the dementia day care centre too because she was an active person who liked to mingle. Some of her challenging behaviours lessened and she began to sleep well in the night because she had activities in the day. She looked happier when she returned from the day centre in the evening. Life improved for both of us as I acquired more skills.

After my 2 year course, I landed a part time job related to dementia care. I employed a helper when dad's health deteriorated drastically. Dad passed away six months after the helper came. Thank God that the helper was competent in taking care of mum despite weeping almost every night in the first year.

I am thankful for close family support as I diligently carry on my caregiver role. On my helper's day-off once a month, my brother and sister rotate to help care for mum so that I can still join my friends for weekly morning exercise and breakfast. Currently, mum has advanced dementia. She is much quieter than before and is no longer able to use words to express herself. We need to learn new ways to connect with her. In addition, she needs more physical help now and is unable to cope alone with her daily needs. She has developed problems with swallowing and can only take soft diet. I am now facing these new challenges and have to learn to cope with them. With the knowledge and skills I have gained throughout the years, I am now confident I can continue my care for mum with the assistance of my helper.

Leng Chan (Caregiver)

RESOURCES

Agency for Integrated Care

5 Maxwell Road
#10-00 Tower Block, MND Complex
Singapore 069110
Tel: 6603 6800
Website: www.aic.sg

Alzheimer's Disease Association

70 Bendemeer Road
#03-02A Luzerne Building
Singapore 339940
Tel: 6389 5121
Website: www.alz.org.sg
Email: infocsc@alz.org.sg

Khoo Teck Puat Hospital

90 Yishun Central
Singapore 768828
Tel: 6555 8828
Website: www.ktph.com.sg/geriatrics
Memory clinic email: ktph.memorycare@alexandrahealth.com.sg

