SingHealth DukeNUS ACADEMIC MEDICAL CENTRE

Memory & Cognitive Disorder Centre

A Caregiver's Easy Guide

Supporting Persons with Dementia

SingHealth

Healthy Living Series

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3,700
Doctors

40
Medical Specialties

150
Sub-specialties

SingHealth provides tertiary medical care across a comprehensive spectrum of over 40 medical specialties with the in-depth expertise of 150 sub-specialties.

Supported by a faculty of 3,700 doctors and well-equipped with medical diagnostic and treatment technology to provide quality care for our patients, the group has earned a strong reputation for setting standards in healthcare.

As an Academic Medical Centre, we seek to transform patient care by integrating clinical services, teaching and research. Patients at SingHealth enjoy the benefit of treatments with a focus on quality and holistic medical care in an integrated and multidisciplinary setting.

SingHealth DukeNUS
ACADEMIC MEDICAL CENTRE

- Singapore General Hospital
- Changi General Hospital
- Sengkang General Hospital
- KK Women's and Children's Hospital
- National Cancer Centre Singapore
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SingHealth DukeNUS
ACADEMIC MEDICAL CENTRE

Memory & Cognitive Disorder Centre

The **SingHealth Duke-NUS Memory & Cognitive Disorder Centre** was established in March 2020 to meet the varying needs of patients throughout their dementia journey. The virtual Centre is a network that brings together the strengths and expertise of healthcare professionals from different specialties across SingHealth institutions, to help patients access multidisciplinary treatments and support at all stages of their dementia journey.

Our Centre's members are also looking beyond today's dementia care needs to plan for the future. The Centre collaborates with researchers and educators from SingHealth institutions and Duke-NUS Medical School to deepen knowledge in the causes of dementia and cognitive impairment, drive innovation to find better ways to prevent, diagnose and treat conditions, and ensure healthcare professionals have the skills they need to provide the best care for patients.

The Centre also serves as a hub to promote closer collaboration with various community partners, to provide holistic and financially viable dementia services.

Our Services

The Centre manages a wide range of patients with cognitive impairment, providing multidisciplinary dementia assessment and management services.

Conditions seen include:

- **Alzheimer's Disease**
- **Frontotemporal Dementia**
- **Mild Cognitive Impairment**
- **Vascular Dementia**
- **Lewy Body and Parkinson Disease Dementia**

Services provided include:

- **Cognitive Education**
- **Dementia Counselling**
- **Neuroimaging**
- **Pharmacological Treatment**

Find out more about the
SingHealth Duke-NUS Memory & Cognitive Disorder Centre at
www.singhealth.com.sg/memory-and-cognitive-disorder-centre

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Foreword

Dementia can affect anyone, from working adults to the very elderly. The disruption it causes is unique to each patient depending on their circumstances. For example, a father in his 40s with a young family to support faces different physical, emotional and social challenges to an 80-year-old widow who lives alone and also suffers from other health problems. Hence, there is no 'one-size-fits-all' treatment for dementia.

Every patient requires care tailored to their specific needs which often change over time as their dementia gets worse.

This booklet is compiled to help in understanding dementia, which can be a complex condition. The challenges are faced not just by the persons with dementia but also their caregivers, and the impact can be physical, emotional and psychological. We hope this awareness will help support and prepare anyone for the caregiving road ahead.

We would like to give special mention to Adj Assoc Prof Lim Si Ching who initiated this booklet and dedicated her time in putting it together. Prof Lim is a Senior Consultant Geriatrician at Changi General Hospital and has a special interest in dementia care, particularly in patients with behavioural and psychological symptoms of dementia.

Similarly, we are grateful for the care team at the SingHealth Duke-NUS Memory & Cognitive Disorder Centre for their shared commitment to improving care for persons with dementia and their families.

Let's walk this journey together!

Dr Simon Ting
Head, SingHealth Duke-NUS Memory & Cognitive Disorder Centre;
Senior Consultant, Department of Neurology,
National Neuroscience Institute

Contents

The Facts on Dementia

Information contributed by:

SingHealth DukeNUS Academic Medical Centre

Memory & Cognitive Disorder Centre

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What is Dementia?

Dementia is a term used to describe impairment of brain function involving memory, thinking and concentration thus affecting the ability to process new information, problem-solve and make judgements.

To debunk the common misconception, dementia is actually not part of normal ageing.

How Common is Dementia?

- It is estimated that 1 in 10 people aged 60 and above may have dementia in Singapore.
- In the year 2020, we have an estimated 53,000 people living with dementia in Singapore. This figure will increase to 187,000 by 2050.
- Neurological disorders (e.g., Alzheimer's disease*, vascular dementia, Parkinson disease, etc.) are now the fifth leading cause of disability according to the Singapore Burden of Disease report.

DEMENTIA

60-80%
Alzheimer's disease

20%
Vascular dementia

10%
Dementia with Lewy bodies

Other types
- **Frontotemporal dementia**
- **Normal pressure hydrocephalus**
- **Creutzfeldt-Jakob disease**

***Alzheimer's disease is the commonest type of dementia.**
The various types of dementia shall be mentioned in passing in this publication, but for the most part, Alzheimer's disease represents all the common features of dementia.

Who Gets Dementia?

Dementia can affect anyone regardless of their culture and education background. There are a number of diseases which can cause symptoms of dementia, all of which cause gradual death of brain cells.

Risk factors

The following factors may increase the risk of developing dementia:

Modifiable risk factors	Non-modifiable risk factors
Diabetes Having diabetes, especially if poorly-controlled, may increase the risk of dementia.	**Family history** Having parents or siblings with dementia increases one's risk of developing it themselves.
Poor heart health Hypertension (high blood pressure) and hypercholesterolaemia (high blood cholesterol) increase dementia risk if not well-controlled.	**Age** Most cases of dementia occur in those aged 65 years and above.
Repeated head injury The risk is greater especially if the head injury is severe.	**Parkinson disease** Patients with Parkinson disease may develop dementia as the disease progresses.
	Stroke A history of stroke increases dementia risk.

Causes of Dementia

The commonest causes of dementia are Alzheimer's disease (60-80%), vascular dementia (20%), and mixed dementia with Alzheimer's disease and vascular dementia.

Alzheimer's disease and vascular dementia are not mutually exclusive. They can frequently occur together, especially among the elderly.

Diseases causing dementia are generally not reversible. However, cognitive problems caused by certain diseases may improve with treatment of the underlying condition. These include autoimmune disorders, thyroid disorders, folic acid and B12 deficiency, calcium disorders and infective causes such as syphilis and HIV.

Alzheimer's disease

Alzheimer's disease is a condition in which there is deposition of amyloid plaques and tau protein, with deficiency of neurotransmitters (acetylcholine) in the brain.

The disease **usually progresses over an average span of eight years** from the onset of symptoms.

It is a leading cause of death behind cardiovascular disease and cancer.

Vascular dementia

Vascular dementia is caused by the disruption of blood flow to the brain. One type of vascular dementia is multi-infarct dementia, which occurs when **blood vessels in the brain are blocked leading to a reduced supply of oxygen to the brain**. When oxygen supply is interrupted, a series of mini strokes (infarcts) occurs causing death of brain cells.

These mini strokes that result in vascular dementia are often so small that they present no immediate symptoms. However, the damage accumulates over time and ultimately leads to vascular dementia.

With vascular dementia, **mental status decline may have a clearer time of onset, compared to Alzheimer's disease**. Symptoms also tend to get worse in a series of 'steps' with stable interim periods, suggesting that small strokes have been occurring.

Do Young People Get Dementia?

Although the elderly are more prone to dementia, the young are not immune.

Young-onset dementia (YOD) is a relatively new phenomenon observed in Asia. Although it typically affects those aged 45-65 years, it can also affect people in their early 40s or even late 30s.

More aggressive than dementia in the elderly, YOD results in a **faster loss of cognitive abilities** as the progression of brain cell death in younger people is usually more rapid.

In recent years, there has been an increasing number of YOD cases attended to by specialists at the National Neuroscience Institute (NNI). YOD accounts for a third of all dementia cases seen at NNI.

Though the increase in numbers could be due to rising public awareness resulting in more being diagnosed, it could also be due to higher prevalence of vascular risk factors.

Can Dementia Be Prevented?

While there is no known method to prevent dementia, it is possible to lower dementia risk with the following measures:

Stay mentally active

Learning new hobbies, engaging in games and learning a new skill can improve cognitive reserve by improving the structure and dynamics of brain circuits, which can compensate for when certain parts of our brains malfunction. Selecting an activity which you find enjoyable will increase the likelihood of sustainability.

Be socially engaged

This reduces the risk of depression, reduces stress and improves cognitive reserve.

Staying socially active in the community, such as through joining the various activities in local community centres or simply connecting with friends and family, are relatively simple and low cost, yet support physical and brain health.

Eat healthily

A Mediterranean diet in combination with a low salt diet is beneficial for the brain and heart.

Keep physically active

Exercise of moderate-to-vigorous intensity 3-4 times a week, for at least 30 minutes, is helpful in lowering the risk of cognitive decline among seniors.

For seniors with mild cognitive impairment, exercise (aerobic and resistance training) slows down the progression of cognitive decline.

Ensure regular visits to the doctor, and take good care of medical conditions like diabetes, hypertension and hypercholesterolaemia

These diseases increase the risk of blockage of blood vessels, which predisposes one to develop vascular dementia.

Symptoms of Dementia

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Try the Memory Checklist on

HealthBuddy

Scan the QR code to assess if your or your loved one's forgetfulness is 'normal', or if you should see a doctor for further assessment.

Forgetfulness – Is It Dementia?

Dementia can sometimes be mistaken for simple forgetfulness, which is a normal part of ageing. Here are some key differences between normal ageing and dementia.

Normal ageing

- Able to function independently, such as managing housework and finances, cooking, and taking public transport and medications independently
- Occasional forgetfulness such as missing appointments
- Occasionally forgets what day or date it is, but is able to remember later or look for sources to check
- Loses things from time to time
- Occasionally forgets a word or uses the wrong word, but is able to rectify it
- Makes a bad decision once in a while

Dementia

- Makes frequent and major mistakes which lead to the inability to live independently
- Frequently forgets important appointments and to pay bills
- Loses track of the time and day, or even what year it is
- Misplaces items, sometimes putting valuables in strange places and being unable to find them
- Has difficulties understanding what is said and answers questions incorrectly
- Has poor judgement and makes bad decisions frequently

Stages of Dementia

Dementia usually begins subtly and progresses for two to three years before family members notice the change.

EARLY

Mild Impairment

(1-5 years from onset of symptoms)

- Forgets names
- Misplaces familiar objects
- Shows decreased work performance
- Shows signs and symptoms of depression
- Has slight difficulty concentrating
- Takes longer to accomplish daily tasks with mistakes in between
- Has problems managing finances

MIDDLE

Moderate Impairment

(5-10 years from onset of symptoms)

- Shows major memory deficits
- Neglects hygiene
- Requires assistance for activities of daily living (ADLs)
- Unable to recall names of children
- Unable to recall date, time and place
- Displays aggression or agitation

LATE

Severe Impairment

(10-15 years from onset of symptoms)

- Suffers from incontinence
- Lack of motivation with usual hobbies or activities
- Exhibits diminishing remote memory
- Bedridden / unable to perform basic ADLs like eating, walking, toileting, etc.
- Some may refuse food or drink
- Uncommunicative and has difficulty understanding spoken language

In the **early stage**, it may be hard to tell if something is amiss with your loved one.

Although family members may suspect that something is wrong, people affected by Alzheimer's disease (one of the causes of dementia) are usually not aware that they have a problem, hence deny or disagree when their mistakes are pointed out.

In the **middle stage**, supervision for certain ADLs is required.

Mood and personality changes may become more prominent and problematic for persons with dementia. They may frequently become agitated on and off with or without being provoked. They may wander and lose their direction, become overly friendly towards strangers, undress in public or make inappropriate sexual advances.

The **late stage** of dementia is marked by a severe decline of cognitive ability.

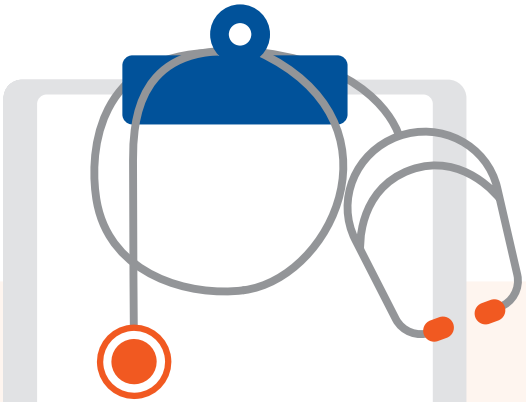
Apathy is common even at the moderate stage. The person becomes confused, disorientated and unable to make their way around the house. The person may also become incontinent and lose all intelligible speech.

Finally, in the **severe stage**, those affected will not be able to care for themselves and will need round-the-clock help with all aspects of daily life.

When to See a Doctor

It is important to seek medical attention as early as possible, as medications may achieve a better effect when started at an early stage of the disease.

Seek consultation with your doctor for a referral to the nearest memory clinic at the earliest.



Signs that your loved one may be suffering from dementia

Forgetfulness such as being repetitive or behaviour changes

Caregiver experiences burnout or inability to cope

Endangers themself and others

Presence of behavioural symptoms such as aggression, hallucinations, delusion, mood changes, sleep problems and suspicion which may be difficult for family members to cope with

Refuses to take medication or takes the wrong dose / at the wrong time / repeat dosing due to poor memory

Makes major mistakes with the usual tasks which they used to perform well at work or at home

Diagnosis & Treatment

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Diagnosing Dementia

There is no single test to determine if someone has dementia. The diagnosis process includes an interview and various assessments, such as mental cognitive tests, a brain scan and lab tests.

1 Interview

Both the patient and caregiver will be interviewed by a specialist to understand the situation faced.

2 Assessments

Various tests may be conducted in order for the specialist to make a diagnosis. The specialist will also need to do a physical examination as part of assessment.

Mental cognitive tests (not all tests may be done)	
Abbreviated mental test (AMT)	AMT is a 10-point test for a rapid assessment of an elderly person for the possibility of dementia. A score of <7-8/10 suggests cognitive impairment at the time of testing. AMT scores are also affected by education level.
Clinical dementia rating scale (CDR)	CDR is a 5-point scale used to characterise six domains of cognitive and functional performance applicable to Alzheimer's disease and related dementias. 0 = No dementia 1 = Mild cognitive impairment 2 = Moderate cognitive impairment 3 = Severe cognitive impairment

Mental cognitive tests (not all tests may be done)	
Mini-mental state examination (MMSE)	MMSE is a 30-point questionnaire that is used extensively in both clinical and research settings to assess cognitive impairment based on education-adjusted cut-off scores.
Montreal cognitive assessment (MoCA)	MoCA is a widely-used 30-question test to detect cognitive impairment.

Brain scans	
Computed tomography (CT) and magnetic resonance imaging (MRI) scans	A CT or MRI scan may be ordered to look for a treatable cause of dementia, volume loss or a tumour at certain parts of the brain from previous strokes.
Positron emission tomography (PET) scan	A PET scan can confirm the presence of amyloid and tau pathology. PET scans are currently not widely available.

Lab tests	
Blood test	Blood samples are tested for vitamin deficiencies, thyroid disorders and markers of infection/ inflammation. An overnight fast is generally not required.
Cerebrospinal fluid (CSF) testing	CSF is drawn from the spine to test for markers of Alzheimer's disease. As this procedure will take a few hours, patients are advised to be accompanied by a caregiver who can provide support. CSF testing is currently not widely available.

Treatment Options and Medications for Dementia

Treatments

There is currently **no cure for dementia**.

However, **certain causes of cognitive impairment may be reversible with treatment**. These include problems with the thyroid, calcium, low folate, vitamin B12 and an old syphilis infection.

There are also unusual causes of cognitive disorders like autoimmune diseases, paraneoplastic syndromes (cancer-related), infections, HIV, etc., which require further work-up and treatment.

There are also rare inheritable causes of dementia like Huntington's disease, for which there is no treatment.

Treatment is guided by the cause of dementia, stage of illness and symptoms.

Some cases may be reversible with early detection and treatment. However, in many cases such as Alzheimer's disease, dementia is irreversible and there is currently no cure. Treatment is available to alleviate symptoms, mitigate decline and maximise the quality of life for persons with dementia.

Medications

There are two classes of drugs which are approved for the treatment of Alzheimer's disease:

- **Acetylcholinesterase inhibitors** (e.g., donepezil, rivastigmine and galantamine)
- **N-methyl-D-aspartate (NMDA) antagonists** (memantine)

These drugs are not a cure for Alzheimer's disease, but they can help:

- Slow down disease progression
- Reduce caregiver burden
- Maintain function
- Reduce the emergence of behavioural symptoms

Not all types of dementia are responsive to these drugs. Your doctor would be able to provide appropriate advice for the prescription of these drugs.

In addition to these two classes of drugs, your doctor may also prescribe medications for the **management of behavioural symptoms**.

These medications may include:

- Antipsychotics (e.g., risperidone, olanzapine, quetiapine)
- Mood stabilisers (e.g., sodium valproate, carbamazepine)
- Antidepressants
- Sedatives (e.g., lorazepam, zolpiclone)

Most of these medications are prescribed for a limited period of time, and your doctor may reduce the dose or even stop prescribing them when the behavioural symptoms are better.

Dementia vs. Delirium

What is delirium?

Delirium is an acute confusion state that is common among the elderly, compared to young people, especially among elderly with dementia. The onset of delirium is usually triggered by a new medical or surgical problem. It may also be due to medication side effects.

Differences between delirium and dementia

Delirium is common among older adults and persons with dementia. Unlike dementia, delirium is usually reversible if the underlying cause(s) is treated.

Delirium is sometimes mistaken for dementia or depression because the symptoms are similar, so it is important for caregivers to notify medical or nursing staff of any sudden change in the patient's mental state.

Delirium is different from depression and dementia. Delirium takes a while to resolve, and once resolved should not return unless the patient is unwell. This does not happen with dementia and depression. However, delirium does not always fully resolve, as frequently the patient's cognition does not fully return to normal.

Symptoms of delirium

A person with delirium will often have the following symptoms:

- Poor concentration and attention is easily shifted.
- Changes in sleep patterns.
- Occasionally, persons with delirium may see things which are not there.

- Mood disorder, gets lost, poor memory, difficulties with understanding spoken words and may exhibit behavioural symptoms unlike their usual self.

- Emotional lability with frequent mood swings. For example, they may not be able to understand that others are trying to help them and instead get upset and angry with their loved ones or the hospital staff. They may start to think that everyone is against them or trying to harm them.

Delirium has been described as the experience of being in the middle of a very strange dream or nightmare, but while being awake.

Causes of delirium

Delirium can be caused by:

Physical illness (resulting in hospitalisation)

- Infection (such as pneumonia or urinary tract infection)
- Constipation
- Dehydration / malnutrition
- Severe pain
- Heavy alcohol consumption or alcohol withdrawal
- Post-surgery

Medications

- Withdrawal from medications such as sleeping pills
- Painkillers – certain types of painkillers may not be suitable for the elderly with dementia. It is advisable for their relatives to remind the doctors that their loved one has dementia.
- Drug interactions / sensitivity
- Antihistamines like chlorpheniramine (Piriton) and hydroxyzine, or painkillers like Anarex

Treatment for Delirium

There is no specific treatment for delirium. The main approach is to find the underlying medical or surgical reason or medication causing delirium and manage that.

Help and Support in the Community

Community services are necessary to alleviate the burden of care and caregiver stress.

Dementia day care provides a stimulating and enjoyable environment to encourage practical and social skills.

Respite care provides short stays for persons with dementia when caregivers need a break from caregiving.

The community services listed here are just a few of the many available. Please ask your doctor or medical social worker for a referral, should you require any of these services.

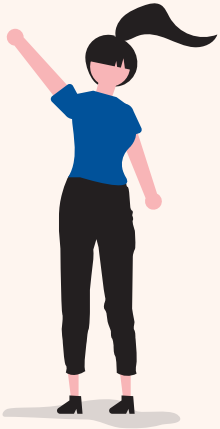
1 DEMENTIA DAY CARE CENTRES

- **New Horizon Centre**
  www.dementia.org.sg/nhc
  Tel: 6377 0700
- **Yong En Dementia Day Care**
  www.yong-en.org.sg
  Tel: 6225 1002
- **Peacehaven Bedok Day Centre**
  www.salvationarmy.org.sg/wwd-peacehaven-bedok-arena
  Tel: 6243 2527
- **SASCO Senior Citizens' Home**
  www.sasco.org.sg/our-services
  Tel: 6273 5183
- **Sunlove Dementia Day Care Centre**
  www.sunlove.org.sg/dementia-day-care
  Tel: 6387 3548
- **Sunshine Welfare Action Mission (SWAMI)**
  www.swami.org.sg
  Tel: 6257 6117
- **Thong Teck Home for Senior Citizens**
  www.thongteckhome.org
  Tel: 6846 0069

2

DEMENTIA RESPITE CARE

- **Apex Harmony Lodge**
  www.apexharmony.org.sg
  Tel: 6585 2265
- **Lions Home for the Elders**
  www.lionshome.org.sg
  Tel: 6252 9900 / 6244 0667
- **Peacehaven Nursing Home for the Aged**
  www.salvationarmy.org.sg/wwd-peacehaven-nursing-home
  Tel: 6546 5678
- **Orange Valley Nursing Home**
  www.orangevalley.sg
  Tel: 6499 4699 / 6266 3053



3

SPECIALISED SERVICES AND SUPPORT

- **Agency for Integrated Care (AIC)**
  www.aic.sg
  Tel: 1800 650 6060
- **Dementia Singapore**
  www.dementia.org.sg
  Tel: 6377 0700
- **AWWA Caregiver Service**
  www.awwa.org.sg
  Tel: 6511 5200
- **Care Corner Family Service Centre (Toa Payoh)**
  www.carecorner.org.sg/family-service-centre
  Tel: 6356 1622
- **O'Joy Care Services**
  www.ojoy.org
  Tel: 6749 0190
- **SAGE Counselling Centre**
  www.sagecc.org.sg
  Tel: 1800 555 5555
- **Touch Caregivers Support**
  www.touch.org.sg/about-touch/our-services/touch-caregivers-support-homepage
  Tel: 6804 6565

Managing Behavioural & Psychological Symptoms

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Behavioural and psychological symptoms of dementia (BPSD) are neuropsychiatric symptoms and behaviours displayed by persons with dementia.

These symptoms constitute a huge aspect of dementia syndrome irrespective of its subtype, and they demonstrate a strong correlation with the degree of functional and cognitive impairment.

In the following pages, we will cover some of the common symptoms displayed by persons with dementia with tips to better manage them.

Repetitive Behaviour

Repetitive behaviour is a set of behaviours characterised by **repetition, sleep problems, agitation, aggression and sometimes screaming and shouting**.

Persons with dementia may often repeat a word, statement or question, or perform an activity repeatedly. This includes the tendency to 'shadow' their caregivers even when their caregivers go to the bathroom.

While these repetitive behaviours are usually harmless for persons with dementia, it can annoy and increase stress on caregivers.

POSSIBLE REASONS FOR REPETITIVE BEHAVIOUR

1. The person with dementia is probably unware and has no recollection of having already said or done something.

2. The feeling of boredom, anxiety, stress or pain may cause restlessness, pacing and agitation.

3. The inability to express other needs such as hunger, thirst, feeling tired or having to go to the bathroom.

4. A need to be meaningfully occupied and to feel that there is a purpose and structure to their lives (e.g., a housewife who may feel restless in the early evening because she used to cook dinner at that hour – although she may not remember what she needs to do, the feeling of restlessness may cause agitation).

Tips on managing repetitive behaviour

It is important for the caregiver to remain calm, avoid getting angry and have the patience of a saint. It may be very difficult to do so, but bear in mind that the person with dementia is not out to annoy intentionally. The behaviour is a result of dementia.

Do not remind the persons with dementia that they had previously asked the question or had just performed the task, as they cannot remember.

1
Distract and engage your loved one with simple hands-on activities such as sorting laundry or vegetables, or provide a 'rummage box' with objects familiar to them, like an old button, old pictures, pieces of jewellery, watch, wallet, etc.

2
Acknowledge their feelings and reassure them that they are safe and loved.

3
Find out if there are unmet needs or discomfort such as thirst, hunger, feeling tired, toilet needs, etc.

4
Schedule exercises or activities to expend their energy, but not to the point of exhaustion.

5
Examine your home environment and try to reduce or eliminate noise levels, visual clutter or anything that could possibly trigger the behaviour.

6
If they are shouting for someone from the past, encourage them to talk about the person.

7
If shouting occurs at night, a night light in the room may be reassuring.

Remember:
If the behaviour is not causing any harm, you may choose to ignore it. However, do only ignore the behaviour, and not the person with dementia.

Apathy

Apathy is **a state of being indifferent** to happenings in one's surroundings and the well-being of family, friends or even oneself.

There is little emotional response throughout much of the day, and the person with dementia may spend the majority of their time in bed or being inactive.

Persons with dementia may exhibit apathetic behaviour at any time during their course of illness. This may increase the burden of family and caregivers as concern, love and care shown towards their loved one are not reciprocated.

POSSIBLE REASONS FOR APATHETIC BEHAVIOUR

1. Progression of dementia resulting in changes in brain matter
2. The loss of ability to retain memory and perform complex tasks, such as making a snack when hungry or planning a day to occupy time
3. Depression

Tips on managing apathetic behaviour

1 Medical check-up

- When the person with dementia starts to experience apathetic behaviour, arrange for a medical check-up to rule out the possibility of depression or other medical problems, and seek necessary treatment if required.

2 Do not use force

- Try not to do something against your loved one's will as it may upset the both of you.
- Interest them in activities that they had previously enjoyed and are still capable of performing.
- Invoke interest by injecting purpose into activities.
- Ask them for 'help' in completing tasks such as dusting, watering plants, washing rice, preparing ingredients, pairing up socks, folding clothes and sorting out beans.
- Participate in the activities together with your loved one to keep them motivated.

3 Be selective with activities

- If they refuse to participate, try activities that do not require participation. For example, listening to music, looking at old photos or reading to them.

4 Day care centre

- Consider enrolling them at a day care centre as they may be more willing to participate in group activities that allow interaction with their peers.

5 Praise or reward

- Give frequent and appropriate praises or rewards to instil a sense of well-being and raise their self-esteem. The end result of the activity is not important. What is more important is that they had fun and enjoyed the activities.

Sundown Syndrome

Sundown syndrome is a condition that describes persons with dementia **becoming more confused, restless or insecure in the late afternoon which may continue until the night**. They may be more demanding, agitated, restless, upset, suspicious or disoriented, and may even hallucinate.

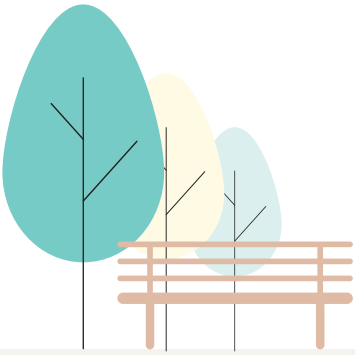
POSSIBLE REASONS FOR SUNDOWN SYNDROME

1. End-of-the-day fatigue can lead to an inability to cope with stress.

2. Reduced lighting and increased shadows can create confusion and hallucinations as common objects may look different under poor lighting. This is possible especially if the person with dementia has poor vision.

3. Their circadian cycle (the body's natural sleep and wake pattern) can be deranged as a result of dementia – i.e., the person cannot distinguish day from night.

4. A lack of structured activities in the late afternoon can lead to restlessness later in the day.



Tips on managing sundown syndrome

1
Provide exposure to sunlight (e.g., engage in outdoor activities from 7 am to 9 am) as this helps to set the circadian cycle of the person with dementia.

2
Monitor and restrict the intake of caffeinated food and beverages to an earlier time of the day, such as in the morning or late morning.

3
Maintain a regular meal and bedtime schedule as much as possible.

4
Schedule exercises or activities to expend their energy during the day, but not to the point of exhaustion.

5
Discourage naps in the late afternoon. However, if napping is unavoidable, keep it to a maximum of 30 minutes.

6
Avoid appointments, bathing, travelling or any other stressful activities in the late afternoon or evening.

7
Create a calm and soothing atmosphere before the symptoms of sundown syndrome begin to appear.

8
Engage them in a simple and quiet activity. Activities that are familiar to them from their earlier days may be helpful.

9
Close the curtains and provide adequate lighting to lessen shadows when it begins to get dark.

10
Refrain from restraining the person with dementia if possible.

11
Keep a record of the timing when sundown syndrome usually occurs. Take note of its frequency and duration as well, to show doctors/ nurses so they can advise accordingly or adjust medications.

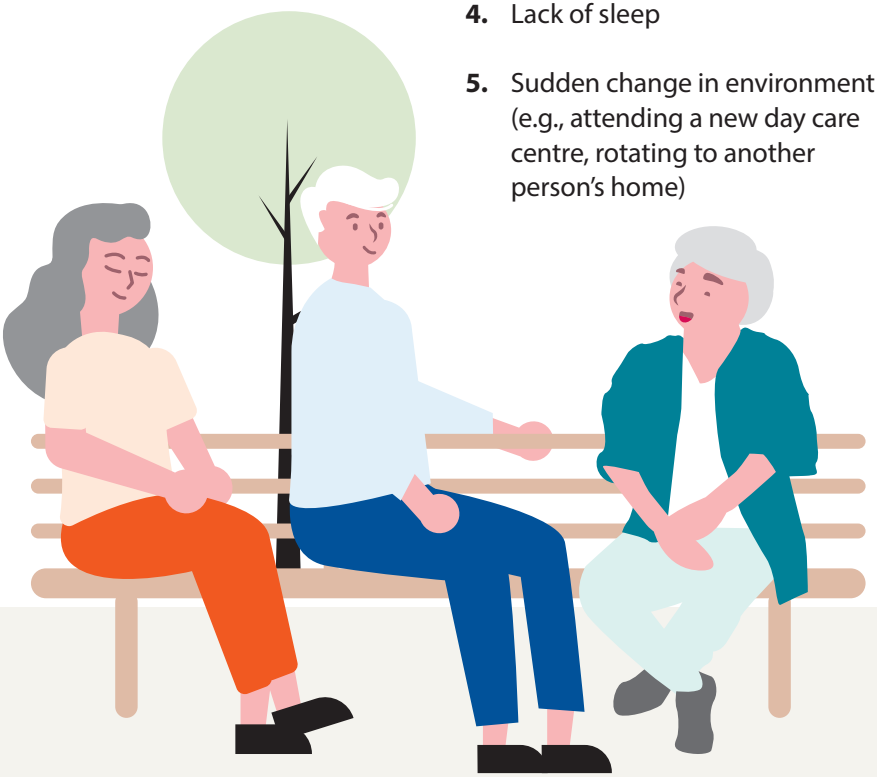
Hallucinations

Hallucinations are experiences **where a person smells, tastes, feels, hears or senses something that does not exist**. This may be a result of the changes in the brain caused by dementia.

'Visual mistakes' such as illusions and misperceptions are not hallucinations, although they are sometimes mistaken as such. Visual mistakes can result from poor vision and any form of damage in the visual system including the brain.

POSSIBLE REASONS FOR HALLUCINATIONS

1. Disease progression of dementia
2. Medical conditions such as stroke, infection, pain, fever and dehydration due to medications or medical conditions
3. Clarify if the hallucinations are new and not caused by medical conditions or medications
4. Lack of sleep
5. Sudden change in environment (e.g., attending a new day care centre, rotating to another person's home)



Tips on managing hallucinations

1
When the person with dementia newly experiences hallucinations, arrange for a medical check-up to rule out the presence of other physical or psychiatric problems as well as to check for side effects of medications.

2
Acknowledge that they may be frightened by the hallucinations, and do not argue with them as what they experience is very real to them.

3
Explain the real situation calmly. If your loved one does not accept it, repeat it when they are calmer and rested.

4
Ensure adequate lighting to lessen shadows when it is dark.

5
Distracting them with activities such as music, exercise or even conversations with friends may help.

6
Some hallucinations can be ignored if they are harmless and do not cause the person to become agitated.

7
If the hallucination episodes are distressing to your loved one and their caregivers, discuss the issue with the primary physician.

8
Take accurate notes or observations about:

- What was seen or sensed
- When it occurs (the time of day) and after what event (e.g., nap, meal, exercise)
- Where it occurs (details of exact location)
- How long the episode lasts, and whether it is intermittent or a regular occurrence
- Words that your loved one uses to describe what they think they saw, heard, sensed, tasted or smelled
- Current and NEW medications (including self-prescribed) and dosage
- Recent bereavements

This information may facilitate the primary physician in deciding whether treatment for hallucinations is necessary.

Agitation and Aggression

Agitation is a state of heightened emotional response to provocation. **In the context of dementia, a person with dementia may become agitated without provocation**. Agitation is often associated with anxiety, anger and restlessness which may show as pacing, worry, etc.

Aggression is a further level of agitation in which the behaviours can be expressed through verbal abuse, threats, damaging property, physical violence towards another person or overreacting to a minor setback or criticism.

Tips on managing agitated and aggressive behaviours

Dealing with aggressive behaviour is not easy. **It is always useful to identify what triggers the aggression and find effective ways to manage it.**

It is important to realise that the behavioural symptoms can be a form of miscommunication depending on how the person with dementia behaves. If we can establish what they are trying to communicate, it may prevent them from feeling frustrated and acting aggressively.

1 Look out for signs

- Identify signs or behaviour indicating agitation or aggression.
- Distract them early with appropriate activities before an outburst.

2 Ensure a safe environment

- Keep away any dangerous objects that can possibly cause harm (e.g., scissors, knife).

3 Show tenderness, love and care

- Approach your loved one slowly and calmly; reassure them and acknowledge their feelings.
- Ensure that their needs are met (e.g., hunger, thirst, sufficient sleep)

POSSIBLE REASONS FOR AGITATION AND AGGRESSION

1. Disease progression of dementia leading to loss of emotional control or control over behaviour
2. Physical discomfort such as pain, fever, illness or constipation
3. Fatigue due to sleep deprivation
4. Defensive behaviour when independence and freedom are threatened
5. Frustration due to inability to cope with daily tasks
6. Fear of surroundings/people as the person with dementia can no longer recognise them
7. Adverse reaction to medications
8. Frustration as they are unable to communicate their needs (e.g., pain) clearly to the caregivers, and hence their needs are not fully attended to

- Try to adhere to their daily routines, environment and caregivers.

4 Avoid fighting fire with fire

- Stay calm and avoid an argument. A heated response from you may worsen the situation.
- If the person with dementia gets agitated or aggressive when you are caring for them:
  - Explain your actions in short, simple sentences – "I am going to help you remove your shirt" or "We are here to help you".
  - Ask yourself if what you are doing for the person really needs to be done at that moment.
  - Give them some time and space and return in a while to gently try again.
- If the person with dementia gets physically abusive:
  - Distance yourself from the person (at least one arm's length) to prevent yourself from getting physically injured.
  - Do not try to restrain or restrict the outburst of anger unless they are causing harm to themselves or others.
  - Call for help if needed.

Wandering Behaviour

Wandering is a common behaviour observed amongst persons with dementia that can put them at risk while also attributing great stress to their caregivers.

Persons with dementia who wander risk getting lost when they wander off. Getting lost can be dangerous for them as they may run into accidents or injuries.

Wandering also increases fall risk. Persons with dementia are generally at a higher risk of falling due to the damage in the brain caused by dementia.

POSSIBLE REASONS FOR WANDERING BEHAVIOUR

1. The inability to recall where they were going or why.
2. Disorientation in the environment – the person with dementia may get lost in their own home.
3. Disorientation with the past and present – when they become confused and search for someone or something related to their past.
4. Disease progression of dementia – they lose the ability to concentrate and wandering keeps them occupied.
5. Physical discomfort such as heat, toilet needs and uncomfortable clothes.
6. Disorientation due to sleep issues.
7. The inability to adjust to a change of environment.

Tips on managing wandering behaviour

Depending on the personality of the person with dementia and how well they are able to cope, their reasons for wandering and the safety of their surrounding environment, you can consider the following management strategies.

Persons with dementia are also at fall risk as dementia can affect their gait. It is best for them to have some supervision if their gait is unsteady.

1 Identify

- Identify their wandering behaviour by keeping records or a diary (e.g., does the behaviour show up at certain times of the day or in response to certain

situations which can be carefully controlled?).

- Allow them to carry identification such as an identity bracelet or card with their name, address and/or contact numbers of family members. This can be helpful when they are found by others or the police.

2 Remove

- Reduce access to objects that may prompt or encourage them to wander (e.g., handbags, house keys).
- Remove any obstacles to allow them to wander about safely such as coffee table, loose wires, toys, etc. Ensure supervision is available and that they have their walking aids nearby at all times.
- Other common strategies include hiding the door knobs or door handles. Sometimes the door can be painted the same colour as the wall, so it is 'invisible', or a curtain can be put over the door so it does not look like the door.

3 Distract

- Engage or distract them with a simple and quiet activity from their earlier days that is familiar to them.
- Orientate them over the course of the day. Orientation to the time, date, place and people helps to reduce anxiety.

WHEN A PERSON WITH DEMENTIA GOES MISSING, YOU SHOULD:

- Remain calm.
- Do a thorough search of the house and familiar places.
- Try to recall what they were wearing.
- Walk or drive around the vicinity and to other places that they visit regularly. Have someone stay at home in case they return home, or to answer any phone calls.
- Contact the police if immediate searches yield no result. Tell them that the person has dementia and highlight any concerns you may have for their safety.

WHEN THEY RETURN HOME:

- Notify the police immediately.
- Do not scold or show any anxiety as this may confuse or frighten them.
- Provide reassurance and get them back into their regular routines as quickly as possible.

Disinhibited Behaviours

Disinhibited behaviours are actions which **may appear offensive, inconsiderate and disrespectful**.

They occur when people act and express themselves in a socially inappropriate manner, such as being over-friendly to strangers, making inappropriate sexual advances at caregivers or strangers, undressing in public, or making inappropriate or rude comments about others in pubic.

People displaying such disinhibited behaviours may be perceived as causing deliberate embarrassment or harassment to others.

Disinhibited behaviours in persons with dementia can contribute to caregiver burden of their families and caregivers. These changes in behaviour may be particularly challenging for others, as well as for the person with dementia, who might find it difficult to cope and react accordingly.

POSSIBLE REASONS FOR DISINHIBITED BEHAVIOURS

1. **Disease progression** of dementia, especially when they forget their social skills or lose their ability to judge. Certain types of dementia which affect the front parts of the brain may cause these disinhibited behaviours.

2. **Medical conditions** (e.g., infection or pain) that may cause sudden confusion.

3. **Disorientation to places** (e.g., mistaking a public venue for their own room).

4. **Misidentification** (e.g., mistaking a caregiver for someone else).

5. **Disorientation to time** (e.g., being confused about the time of the day and believing that it is time for their bath or bed at the wrong time).

6. **Discomfort** (e.g., their clothes may be too tight but they are unable to express themselves).

Tips on managing disinhibited behaviours

1
Try not to overreact even though the behaviour may be embarrassing. Remember that these behaviours are not intentional and they stem from the condition that they are suffering from – dementia.

2
Look for the reason behind their behaviour (e.g., their clothes may be making them feel too hot or their diaper may be wet).

3
Check with the doctor whether it is a physical illness, the side effects of medication or discomfort that is causing such behaviour.

4
Explain the condition of your loved one to others.

5
Provide privacy and time for their needs discreetly.

6
Adjust their wardrobe according to their needs. Consider buying pants without zippers so that it is easier to dress.

7
If your loved one engages in inappropriate sexual behaviour, gently remind them that it is improper and lead them to a place where it can be carried out in private.

8
Try to distract them by keeping them occupied with activities.

9
Frequently orientate them to the time, people and place, as well as keep them informed of any upcoming activities.

Caregiver Tips

Information contributed by:

SingHealth DukeNUS ACADEMIC MEDICAL CENTRE

Memory & Cognitive Disorder Centre

Singapore General Hospital SingHealth
www.sgh.com.sg

Changi General Hospital SingHealth
www.cgh.com.sg

Sengkang General Hospital SingHealth
www.skh.com.sg

National Neuroscience Institute SingHealth
www.nni.com.sg

SingHealth Community Hospitals
Bright Vision • Outram • Sengkang
www.singhealth.com.sg/sch

Polyclinics SingHealth
polyclinic.singhealth.com.sg

Communicating with Persons with Dementia

Being able to communicate effectively with your loved one with dementia can make caregiving less stressful.

Good communication skills may also help in preventing misunderstandings and reducing resistance or anger episodes from your loved one.

Difficulties with language are common for the person with dementia:

- They may have difficulties understanding what is said to them.
- They may not be able to find the right words and thus substitute with an incorrect word, or may not be able to find any words at all.
- There may come a time when they can hardly communicate accurately or successfully through language.

HealthBuddy

Scan the QR code for more resources for caregivers on the Health Buddy app!

- Caregiver well-being checklist
- More caregiver tips
- Support groups
- Community resources

TIPS ON IMPROVING YOUR COMMUNICATION

1. Watch your non-verbal cues

- Non-verbal communication is particularly important when a person with dementia is losing their language skills.
- Watch for signs of discomfort or distress such as frowning, anxiety, agitation or restlessness.
- Body language, facial expression, and tone and pitch of voice play a more important role in conveying your message than the words used.
- Gently touching or holding the person's hand may provide a sense of tenderness, calm and reassurance.

TIPS ON IMPROVING YOUR COMMUNICATION

2. Get the person's attention and minimise distractions 	• Approach your loved one within full view to avoid scaring them. • Ensure they are able to hear, see or feel you. Consider hearing or visual aids if your loved one has vision or hearing problems. • Address them by name and identify yourself by name and/or relationship. • Minimise distractions. Turn off the radio or television, or move to a quieter place.
3. Convey clear messages 	• Use simple words and short sentences. • Repeat your message or question, or rephrase it in a different way if your loved one cannot understand you. • Avoid short forms and use terms and words that they are familiar with. • Use visual cues (e.g., while assisting them with getting dressed, show them the clothes they can choose from).
4. Ask simple questions 	• Ask only one question at a time. • Avoid questions that rely on short-term memory (e.g., what they had for lunch). • Ask close-ended questions so that they only need to answer 'yes' or 'no'. • If you are asking them to make a choice, narrow it down to only two options. For example, instead of asking "What do you want to drink?", ask "Do you want coffee or tea?". It would be best to show your loved one the choices to choose from.

5. Listen with your ears, eyes and heart 	• Be patient when waiting for your loved one's reply. • If they are struggling for an answer, you can help by suggesting words. • Watch for non-verbal cues and body language, and respond accordingly.
6. Respond with reassurance 	• Try not to tell your loved one that they are wrong or incompetent to do certain tasks. • Respond with verbal and physical expressions of reassurance to allow them to feel loved and safe (e.g., touching, hugging). • Offer frequent praises and encouragement when they complete a task, regardless of mistakes or how well they have done.
7. Talk about the good old days 	• Reminiscing about the past is often a soothing and affirming activity. Allow your loved one to talk about their past. • You may use old photos or objects to start the conversation.
8. Use humour and laughter 	• Engage with humour whenever possible, but not at the person's expense. Persons with dementia tend to retain their social skills and are usually happy to laugh along with you. Even when language abilities fail, the five senses and sense of humour remain intact. • You can also use music (hearing), colours/objects (sight), spices/food/drink (smell), animals/blankets/pillows (touch), food which is familiar and enjoyed by your loved one and sweet treats/snacks (taste) to evoke happy memories.

Helping Your Loved One Eat Better

There are many reasons why persons with dementia, particularly the elderly, do not eat well. Getting them to eat their meals consistently can get increasingly challenging as the disease progresses.

Persons with dementia may have difficulties with swallowing or an inability to recognise food. They may also forget or refuse to eat, or become easily distracted or agitated during mealtimes.

Physiological changes associated with ageing, such as decreased sensations of thirst and hunger, and reduced senses of taste and smell may also contribute to the problem.

Dry mouth due to ageing or medications also reduces the ability to appreciate sweet, salty or sour flavours of the food offered.

As a result, persons with dementia often end up eating very little and also taking a very long time to finish their meals, causing lots of stress and worry to their caregivers.

Undernutrition is a serious matter because aside from weight loss, the person also loses muscle bulk and strength.

Furthermore, the elderly often do not have the surplus storage of energy in the form of glycogen or fat that younger people do.

When the elderly are ill or hospitalised, their appetite is often poor and their metabolic rate goes up as their bodies fight infections or heal surgical wounds. As a result, they end up burning their muscles as fuel.

Once they lose weight, muscle mass is lost and their muscle strength may never be regained, leaving them with physical disabilities and overall poorer health.

Undernutrition can increase frailty, risk of falls, fractures, infections and mortality.

Hence, having a balanced, nutritious diet is vital for staying healthy, especially during hospital stay and generally to maintain a healthy body weight.

SCREENING FOR MALNUTRITION

Persons with dementia are at **risk of malnutrition**.

Therefore, **nutrition screening is important for early identification** of individuals who may be at risk. This allows for early intervention to provide adequate nutrition support, thus preventing further nutritional or functional decline.

Undernutrition is one of the causes of weight loss. Thus, it is advisable to monitor weight on a regular basis and highlight any significant weight loss to the doctor.

You may use the table below to monitor their body weight at regular intervals, such as once a month.

Weight Monitoring

Date	Weight

NUTRITIONAL CHALLENGES IN PERSONS WITH DEMENTIA

Challenges	Strategies
1. Chewing and swallowing difficulties 	• Ensure that dentures are well-fitted. Use dental adhesives or make new dentures if the current ones are ill-fitting. • Check for any swollen or bleeding gums, or dental caries that could be causing pain. • Modify food texture. Seek advice from a speech therapist on the recommended food and fluid consistency.
2. Difficulties in grocery shopping and food preparation 	• Have a family member or domestic helper aid in purchasing and/or preparing food. • Consider meal delivery services (e.g., tingkat, Meals on Wheels) • Have nutritious drinks or snacks available for them in between meals, if they do not finish their meals.
3. Increased frequency of eating (leading to excessive/ undesirable weight gain) 	• Split one meal into two portions. Offer one portion first and the second portion later when requested. • Keep high-calorie snacks out of sight and reach. • Give snacks in controlled portions. • Provide healthier snack options (e.g., fruit platter or vegetable sticks like carrot/celery sticks). • Offer water or diet drinks in place of sugary beverages. Alternatively, use artificial sweeteners instead of sugar to flavour their drinks. As some people will not drink water, these alternatives will keep them from getting dehydrated. • Distract them with other activities.

Challenges	Strategies
4. Forgetting to eat or drink 	• Set a daily routine with scheduled meal and snack times. • Provide verbal reminders to eat or drink. • Sit down and eat with them – your actions are a demonstration and reminder for them. • Schedule fluid intake regularly to encourage adequate fluids in a day. Use a water bottle or flask to monitor intake. *Note: Ice cream, jelly, pudding, Milo and milk are also considered fluids and contribute towards hydration.*
5. Difficulties in self-feeding and using utensils 	• Have someone supervise and assist with feeding. • Encourage independent feeding with 'finger food' – food that can be easily picked up and eaten with hands, such as sandwiches, bread, buns and sliced fruit. • Provide gentle reminders and demonstrations on the use of utensils. • Demonstrate eating motions and give step-by-step verbal cues. • Try using a straw or a cup with a spout to help with drinking.

NUTRITIONAL CHALLENGES IN PERSONS WITH DEMENTIA

Challenges	Strategies
6. Refusal to eat or poor appetite 	• Offer small portions at mealtimes with frequent nourishing snacks throughout the day. • Fortify meals with additional calories and protein as advised by dietitians. • Offer nourishing fluids such as oral nutritional supplements (ONS) and water throughout the day for hydration. • Offer sweet snacks (e.g., pudding, custard, ice cream, mousse, cakes) as persons with dementia usually have a liking for sweet food. Consult a dietitian or medical expert if the person with dementia has poorly-controlled diabetes. • Serve ONS to complement meals. Consult a dietitian for an appropriate choice of ONS if required. • Be flexible with food preferences and experiment with new foods, while offering foods that they like and are familiar with. Do keep in mind that they may suddenly reject these foods or develop new preferences. • Add extra seasonings and try stronger tasting foods, as food may taste bland due to the reduced ability to taste and smell. • Offer flavoured beverages (e.g., coffee, tea, Milo, barley, bandung, milk, juices) as these may be better accepted than plain water, especially if fluids need to be thickened. • Observe their eating patterns and habits. Observation is important as communication or language problems may affect their ability to communicate their wants.

Challenges	Strategies
7. Confusion, agitation or getting easily distracted 	• Provide a calm or quiet and familiar setting for meals. • Help them put on glasses, dentures and their hearing aid, if required, at meal times. • Play comforting and familiar music in the background as it can have a calming effect. • Identify and remove sources of distraction (e.g., television). • Allocate plenty of time for meals. Each meal can take up to one hour. • Provide reassurance and comfort through words and/or physical touch. Encourage them to eat and feed themselves. • Serve one or two food options at a time, as too many options can be overwhelming and contribute to confusion. • Serve food on a plate of a contrasting colour to the food and table, for easier identification of the food. • Avoid patterned plates and tablecloths as they can be distracting and confusing. • Do not force-feed. Re-attempt feeding when the patient is less agitated to minimise tension.
8. Spitting out food or holding food in mouth 	• Provide verbal reminders to chew. • Gently move the chin in a chewing motion and massage the cheeks. • Try softer foods like fish, tofu, eggs, mashed potato and soft cakes. • Try blended or pureed foods.

AVOID DIETARY RESTRICTIONS FOR PERSONS WITH DEMENTIA

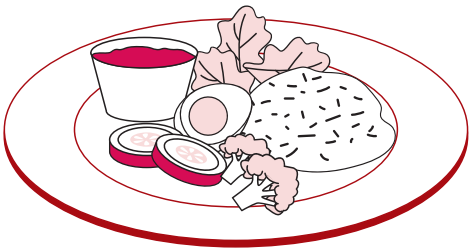
While a healthy and balanced diet is important, **the priority is to encourage the person to eat adequately to prevent undernourishment and weight loss**, especially in the advanced stage of dementia.

Dietary restrictions are to be lifted (in consultation with a doctor or dietitian) if chronic diseases such as diabetes, hyperlipidaemia and hypertension are well controlled. This can improve the variety and palatability of food, which in turn encourages greater intake.

MEAL FORTIFICATIONS

Meals can be fortified with appropriate amounts of **high-calorie and high-protein foods** to increase nutrient density and to reduce the risk of undesirable weight/muscle loss.

Refer to the table on the next page for ways to increase the nutrient density of their meals.



WAYS TO INCREASE NUTRIENT DENSITY OF MEALS	
Add	**Foods**
1. Cooking oil 	• Use to stir-fry rice/noodles, meat and vegetables. • Add sesame oil or cooking oil to porridge or congee.
2. Margarine or butter 	• Spread thickly on toast, biscuits, crackers and pancakes. • Use to stir-fry rice/noodles, meat and vegetables.
3. Dairy products 	• Add full cream milk or full-fat cheese to mashed potatoes, scrambled eggs, omelettes, pancakes, cereals, cream soups or milkshakes. • Have cheese with crackers and put extra slices on toast/sandwiches. • Serve fruits with ice cream or yoghurt for dessert. • Serve coffee, tea or malt drinks with full cream milk. • Have cheese, ice cream, yoghurt or pudding as a dessert or snack. • Have full cream milk instead of other low-calorie drinks. Use full cream milk with tea, coffee or Milo instead of skim milk or condensed milk.
4. Jam, sugar, syrup or honey 	• Pour over pancakes, desserts, bread, oatmeal or crackers. • Spread jam generously over bread on both sides, with butter if preferred.

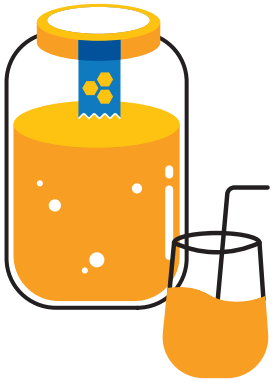
ORAL NUTRITIONAL SUPPLEMENTS

Oral nutritional supplements (ONS) provide both **macronutrients** and **micronutrients**. They are recommended for individuals with poor oral intake and those who are losing weight to meet their energy and nutrient requirements.

They are available in a wide range of flavours and various nutrient compositions, and are disease-specific. The use of ONS should always be tailored to an individual based on nutrient needs and medical conditions. Consult a dietitian on the appropriate choice of ONS, if required.

How to improve the acceptance of ONS

- ONS can be served chilled or warm according to preference.
- Do not boil ONS. Gently warm them by placing them in a bowl of hot water if necessary. A microwave can be used – select the low setting and always check its temperature before serving.
- Water or ice cubes can be added to ONS to dilute the sweetness.
- Prioritise ONS over tea, coffee or water which provides little energy and protein.
- Add ONS into food or beverages to improve their acceptance (e.g., in oats, coffee, tea or Milo). Use ONS as well for dessert such as puddings, bubur cha cha and soups.



Note: *Most ONS can be purchased at major retail pharmacies or hospital pharmacies. They have to be refrigerated once opened and should be discarded within 24 hours if not consumed.*

ARTIFICIAL NUTRITION AND HYDRATION

In the advanced stages of dementia, the person may consume very little food and drink, or completely refuse to eat or drink.

Artificial modes of feeding such as enteral feeding (tube feeding) allow for the provision of nutrients when oral intake is inadequate.

However, this can be very uncomfortable and distressing. The decision for or against tube feeding should be made on an individual basis after consultation with a doctor, taking into consideration the person's and the family's wishes, the goals of care and the clinical benefits.

Discuss with a doctor on what is appropriate for your loved one.

Making the Home Dementia-Friendly

Persons with dementia often cannot remember where they are and sometimes see the environment as threatening. New environments with new faces and voices can easily confuse them, while overstimulation can make them angry or anxious.

The following tips will help promote a sense of security and ensure safety at home for persons with dementia:

1. Home safety devices	• Install safety latches or locks on cabinets to prevent mishandling of dangerous items. • Install electrical safety switches, gas leak detectors or smoke alarms if necessary. • Ensure that the main door is always locked. Install surveillance cameras at the entrance of the house if necessary.
2. Prevention of accidents at home	• Look out for flammable/sharp objects at home; keep them away from the person and educate them on the safe use of these objects. • Label daily use objects and orientate the person to their locations, to allow them to adapt to everyday tasks and maintain independence. • Remove all unnecessary furniture as they may obstruct the person's movement around the house, in particular for those with walking aids. • Avoid carpets and floor mats if possible, to prevent tripping. • If there are young children at home, make sure the toys are neatly kept away. Toys may become a fall hazard. • Ensure electrical cords are secured and cannot be tripped over.

3. Removal of harmful items 	• Keep all medication supplies in a safe place to prevent overdosing. • Avoid placing confusing items near each other (e.g., shaving cream and toothpaste). • Lock away poisonous items such as cleaning detergents and insecticides to prevent misuse.
4. Making the kitchen safe 	• If the person is home alone most of the time, explore with the gas company or electrician ways to make the stove and other electrical appliances inoperable. • Supervise cooking if the person is keen to cook. • Label spices and food around the kitchen to prevent confusion. • Keep knives away from reach.
5. Making the bathroom safe 	• Ensure dry floors at all times and that anti-slip mats are placed in toilets to prevent falls. • A chair/stool in the shower area may be useful because it is safer to shower while seated so that they do not lose their balance while they wash their lower body. Similarly, the chair/stool may be useful while they get dressed. • Install grab bars around the house, and gates for stairs at home to prevent falls. • Ensure good lighting is installed. • Keep unnecessary items away. • Ensure the temperature gauge on the water heater is turned to the lowest to prevent scalding. Orientate the person from time to time on how to use the thermostat. • Advise them not to lock the door so that they remain accessible in case of emergencies.
6. Making the bedroom safe 	• Ensure a clear path to the bathroom or provide a bedside commode/urinal. • Avoid high platform beds especially for persons at high risk of falls. • Install night lights as persons with dementia may be fearful when waking up to complete darkness.

The Last Journey

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Care for Late-Stage Dementia

As dementia progresses, the person's body may continue to be physically healthy while his/her thinking and memory deteriorates.

Caregivers may want to plan ahead for care and treatment decisions. End-of-life decisions for persons with dementia can be a challenge for caregivers and loved ones. Such decisions should respect the values and wishes of the person while considering their comfort and well-being.

The following signs suggest that a person may be entering the final stage of dementia.

Difficulty in swallowing

Fever episodes with coughing or choking at mealtimes

Unable to move around on their own

Unable to verbalise and express themselves

Needing help with most activities of daily living

Role of Palliative Care in Dementia

The World Health Organization (WHO) 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." *(WHO, 2002)*

Palliative care is a specialised field of medical care for people living with many diseases which are not curable, such as dementia.

The goal of palliative care is to provide the best possible quality of life so that the person with dementia can spend their last days in comfort and dignity.

It focuses on supporting persons with dementia and family caregivers in the care of pain and symptom relief.

Advance Care Planning

Advance Care Planning (ACP) is the process of forward-planning for future healthcare options in the event that the person with dementia is no longer able to make his/her own decisions.

It involves nominating a substitute decision-maker who will make decisions about personal care on behalf of the person with dementia. The ACP takes into consideration the person's wishes, goals, personal values and beliefs.

Benefits of Advance Care Planning

It enables one to **identify a nominated healthcare spokesperson** (NHS) to communicate one's wishes and values to the healthcare team when they become unable to speak for themselves.

It can **guide primary care physicians in making treatment decisions** based on expressed values, beliefs and personal goals of care.

It can **reduce the burden and distress on family**.

Caring for Persons with Dementia at the End of Life

During the late stages, the caregiver's role becomes more challenging with a focus on **preserving quality of life and dignity.**

Here are some tips to effectively manage common challenges faced at this stage of the dementia journey.

Communication

Communication is difficult for a person with advanced dementia due to their reduced ability to interact with their surroundings. Non-verbal ways of relating through touch and one's loving presence becomes important.

Tips for effective communication:

- Engage the person through **gestures** such as a gentle tone of voice, non-threatening body language, facial expressions and touch.
- Use **physical contact** such as holding hands or a hug for affirmation and assurance.
- Maintain **eye contact.**
- The use of **pictures** may be helpful.
- Take time to **observe non-verbal signals** suggestive of distress.
- Continue to **engage and maintain the connection** with the person.

Dysphagia

Dysphagia is the medical term for **swallowing difficulty**.

It is not uncommon for people in the later stages of dementia to have difficulties with eating and drinking. Dysphagia causes problems with swallowing of food or fluids, leading to episodes of coughing or choking during mealtimes.

A possible consequence of dysphagia is aspiration (food or fluids going down the windpipe instead of food pipe), which leads to coughing, choking or a chest infection.

Some important advice includes:

- Feed the person only when they are alert and sitting in an upright position.
- Maintain them in an upright position 20 minutes after a meal.
- Look out for signs of a wet or gurgly voice during or after swallowing.
- Do not rush them. Allow ample time to chew and swallow before giving another spoonful.
- Feed a small amount each time.

Functional decline

Generally, a person in the advanced stage of the disease will experience weight loss and loss of muscle strength. A reduction in metabolic rate and physical activity with prolonged immobility and bed rest can result in **joint contractures**.

In this situation, a caregiver or physical therapist can **assist the person with joint exercise** if they find it hard or is unable to make any effort. Passive range of motion can prevent joint stiffness and prevent pressure ulcers or bedsores.

Urinary incontinence

Incontinence is the **involuntary leakage of urine**.

Persons with dementia may be more prone to this problem for the following reasons:

- Inability to react quickly to the sensation of needing to use the toilet
- Failing to get to the toilet in time
- Unable to communicate the toilet need
- Failing to find, recognise or use the toilet
- Unable to, or forgetting how to, perform the activities of using the toilet
- Not letting others help with going to the toilet

Other exacerbating factors include a urinary tract infection, an enlarged prostate gland, drinking too much caffeinated beverages, certain medications, impaired mobility and constipation.

The following advice can be helpful:

- **Bring the person to the toilet at regular intervals** (timed toileting), and pay careful attention to their usual toileting habits.
- If the person is using diapers, **ensure regular diaper changes** to keep the area dry and clean.
- **Use a skin protective/barrier cream** to minimise skin irritation from soiled diapers.

Constipation

People with severe cognitive problems may become less concerned or aware of their bowel habits.

As dementia progresses, there is increased damage to the brain and

confusion increases, and the person may start to ignore the sensation of stool in the rectum, leading to constipation.

Other reasons for constipation may include reduced food, fibre and fluid intake.

The following advice is useful:

- Ensure **adequate hydration and intake of high-fibre foods** such as wholegrain bread, wholegrain breakfast cereals, fruits and vegetables.
- If the person is not keen to drink plain fluids, introducing **soft jellies, ice cream and soups** may help. Encourage fluid intake in the day time, but restrict fluid intake in the evenings so that the person with dementia and their caregivers can sleep at night.
- **Use laxatives** if necessary.
- **Increase physical activity** as this helps to increase bowel activity. For example, seated exercises, walking a short distance or standing up from a chair may help.

Skin

In the late stage of the disease, the person may become immobile. The inability to move around and lying in the same position for prolonged periods can cause **skin breakdown (pressure sores)**.

The following can be done to keep the skin and body healthy:

- **Change the person's position** at least every two hours to relieve pressure and improve blood circulation.
- Help the person with **range of motion exercises** by carefully moving the arms and legs for about 30 minutes, two to three times a day.
- Provide a **pressure-relieving mattress**.
- **Use gentle motions and avoid friction** when cleaning for the person. Clean with mild soap and blot dry. Check daily for rashes, sores or skin breakdown.

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