

Acknowledgement

The completion of this booklet could not have been possible without the assistance of Malaysian Society of Geriatric Medicine and their group of experts.

Their contributions are sincerely appreciated and gratefully acknowledged, particularly to the following:

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Understanding Alzheimer's Disease



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Understanding Alzheimer's Disease (AD)

1. What is Alzheimer's Disease (AD)?

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Alzheimer's Disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and eventually the ability to carry out the simplest tasks. Alzheimer's Disease is the most common cause of dementia among older adults. Dementia is the loss of cognitive functioning - thinking, remembering, and reasoning - and behavioral abilities to such an extent that it interferes with a person's daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living.



2. Myths about Alzheimer's Disease(AD).

Myth No. 1: Alzheimer's Disease happens only to older people.

Most people with Alzheimer's Disease are 65 years and above. But it can happen to younger people. About 5% of people with the disease get symptoms in their 40s or 50s. It is called early-onset Alzheimer's Disease.

Myth No. 2: Alzheimer's Disease symptoms are a normal part of aging.

Some memory loss is normal part of aging. But Alzheimer's Disease symptoms like forgetfulness that interferes with a person's daily life and disorientation are not. For example, it's normal to forget where your keys are sometimes, but forgetting how to drive to a familiar place, or losing track of months or days points to a more serious problem. Unlike the mild memory loss that can happen with aging, Alzheimer's Disease gradually worsens, and takes away someone's ability to think, eat, talk, and more.

Myth No. 3: Alzheimer's Disease doesn't lead to death.

Even though Alzheimer's Disease does not cause death directly, individuals with advanced Alzheimer's disease may die from its complications. They can forget to drink or eat, or they might have trouble swallowing, which can lead to a severe malnutrition or deadly intercurrent infections e.g. pneumonia.

Myth No. 4: Medications can cure Alzheimer's Disease.

The Food and Drug Administration (FDA) has approved several medications that may help slow the progression of Alzheimer's Disease - but these are not considered cures. These medications might help with thinking, memory, language skills, and some behavioral problems. But they don't work for everyone.

Myth No. 5: "I don't need to worry about Alzheimer's Disease because no one in my family has it."

In addition to genetics, many other factors play a role in determining a person's risk for developing Alzheimer's Disease. Whether we carry an Alzheimer's Disease gene or not, our risk for developing the disease doubles every five years after age 65 and it reaches nearly 50 percent after age 85. This disease is very common as we age, so everyone is at risk.

3. What is(are) the cause(s) of Alzheimer's Disease(AD)?

Scientists believe that for most people, Alzheimer's Disease is caused by a combination of genetic, lifestyle and environmental factors that affect the brain over time. The importance of any one of these factors in increasing or decreasing the risk of development Alzheimer's Disease may differ from person to person. Less than 5 percent of the time, early-onset Alzheimer's Disease is caused by specific gene change that pass down from parent to child, and symptoms first appear between a person's 30s and mid-60s. More commonly, a host of factors beyond genetics may play a greater role in the development and course of Alzheimer's Disease. For example, vascular conditions such as heart disease, stroke and high blood pressure, and metabolic conditions such as diabetes and obesity are found to have relationship with cognitive decline.

Although the causes of Alzheimer's Disease aren't yet fully understood, its effect on the brain is clear. Alzheimer's Disease damages and kills brain cells. As more and more brain cells die, Alzheimer's Disease leads to significant brain shrinkage. As a result, people with Alzheimer's Disease have loss of connection around the brain cells, and signal transmission is not effective.

4. What are the symptoms of Alzheimer's Disease(AD)?

The symptoms of Alzheimer's Disease are generally mild to start with, but they get worse over time and start to interfere with daily life. For most people, the earliest symptoms are increasing forgetfulness or memory lapses.

Memory loss due to Alzheimer's Disease persists and worsens, increasingly interferes with a person's daily function at work and at home as the condition progresses.

The person may:

- lose items (for example, keys, glasses) around the house, often put them in illogical places
- struggle to find the right word in a conversation or forget the names of family members and everyday objects
- forget conversations, appointments or events, and not remember them later
- get lost in a familiar place or on a familiar journey
- repeat statements and questions over and over, not realizing that they've asked the question before

SYMPTOMS

SYMPTOMS

5. What are behavioral & psychiatric symptoms of Alzheimer's Disease (BPSD)?

Thinking and reasoning:

Alzheimer's Disease causes difficulty concentrating and thinking, especially about abstract concepts like numbers. Multitasking is especially difficult, and it may be challenging to manage finances, balance checkbooks and pay bills on time.

Making judgement and decision:

Responding effectively to everyday problems, such as food burning on the stove or unexpected driving situations, becomes increasingly challenging.

Planning and performing familiar tasks:

Once-routine activities that require sequential steps, such as planning and cooking a meal or playing a favorite game, become a struggle as the disease progresses. Eventually, people with advanced Alzheimer's Disease may forget how to perform basic tasks such as dressing and bathing.

New problems with words in speaking or writing:

People with Alzheimer's Disease may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue or they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a "watch" a "hand-clock").

Changes in personality and behaviors:

People with Alzheimer's Disease may experience change in their mood and personalities. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset at home, at work, with friends or in places where they are out of their comfort zone.

The term "behavioral and psychiatric symptoms" refers to a large group of symptoms that occur in many — but not all — individuals with Alzheimer's Disease. In early stages of the disease, people may experience irritability, anxiety, apathy or depression.

In later stages, other symptoms may occur, including:

- Sleep disturbances
- Physical or verbal outbursts
- Emotional distress
- Restlessness, pacing, shredding paper or tissues and yelling
- Loss of inhibitions
- Delusions (firmly held belief in things that are not real)
- Hallucinations (seeing, hearing or feeling things that are not there)

The chief cause of behavioral and psychiatric symptoms is the progressive deterioration of brain cells. However, medication, family's attitudes, environmental influences and some medical conditions can also cause symptoms or make them worse.

6. What treatments are available for Alzheimer's Disease(AD)?

The following situations and environmental conditions can also trigger behavioral symptoms:

- **Moving to a new residence or nursing home**
- **Changes in the environment or caregiver arrangements**
- **Misperceived threats**

Correctly identifying what triggered the behavior can help in selecting the best intervention. Often, the trigger is some sort of change in the person's environment, such as change in caregiver or in living arrangements; travel; admission to a hospital; presence of houseguests; or being asked to bathe or change clothing.



Alzheimer's Disease has no cure for the time being and treatment is aimed at slowing the disease progression and to control the behavioral and psychological issues that come with it. In general, the drugs used to treat AD fall into two main categories:

- **Acetylcholinesterase inhibitors**
- **NMDA receptor antagonists**

Acetylcholinesterase inhibitors (AChEI)

There are currently three main AD drugs in the AChEI class, which have shown to be useful in mild to severe AD. The AChEIs are prescribed to patients for the relief of some early symptoms.

NMDA receptor antagonists

Memantine is the only drug in this class and approved treatment for moderate to severe stages of AD. Treatment with memantine has been shown to improve various symptoms of AD related to thought, function and behavior, even in the advanced stages of AD.

All of these drugs are taken orally as tablets or patch. It is important that someone else checks that the medication is being taken regularly and according to the doctor's instructions to ensure efficacy and to avoid unwanted side-effects or overdose. Frequently, the person will be started on a low dose of medication and will be increased gradually by the doctor until the optimum dosage is reached.

Response to the drugs varies from one person to another. As the disease progresses, medications might cease to work. It is important to have an on-going discussion with the doctor as your loved one walks through the stages of AD. A doctor will monitor the individual's reaction once they have taken the drug for a few months. If there is no evidence that the drug is helping, the doctor may then recommend that the medication be stopped.

Treating associated behavioral and psychological symptoms.

As well as treating AD itself, other drugs may be prescribed for dealing with specific symptoms of the disease. For example, anxiety and depression can both be managed by medication, and this can lead to an improvement in the patient's quality of life.

Other non-medical therapies

Substances such as Ginkgo biloba and Vitamin E are the most frequently mentioned natural preparations. Some people may find that such remedies provide benefit. However, it is essential that before taking any substances, all options are discussed with a medical doctor.

Other methods can also be used to help with the symptoms of AD. For example, the person's environment can be made more agreeable (more bright and cheerful, less cluttered or easier to move around) in order to lessen feelings of depression, anxiety or disorientation. Methods of relaxation such as massage may also be beneficial, and something as simple as showing affection can also help to ease stressful times.

7. Coping tips through the disease progression.

In the very early stages of the disease, it is possible for the person with AD to maintain a fairly independent life. However, it will become increasingly necessary for another individual to oversee certain details such as medication, money matters and daily chores. As the AD symptoms become more obvious, the person will need more and more assistance, eventually leading to full-time care.

Here are some tips on how to cope as the disease progresses:

General tips

a) Communication

Avoid conflicts, confrontation and arguments. Maintain calm and humorous environment. Use simple and short sentences in a soft and clear voice. Use distraction if person keeps repetitive questions.

b) Home environment

Make sure home safety such as sufficient lighting, remove loose mats, power cords that can cause fall, remove sharp/fragile objects, place rail in the bathroom, comfortable furniture with no sharp edges, avoid highly polished floors and keep an enclosed and secure garden area.

c) Financial plan and Advanced Care Plan

Making arrangements for the future, before independence is lost. For example, usual processes such as making a 'will' can be accompanied by signing a 'power of attorney' that gives a named individual the authority to take over decision making and/or financial matters, once the person is unable to take care of these aspects themselves. Talk to your loved one's doctor or nurse regarding Advanced Care Plan. Discussing or officially stating preferences for their future health care ensures that the person with AD makes their opinion known, and takes some of the decision-making burden away from the carer.

Activities of daily living

It is important to keep a daily routine as consistent as possible and to encourage independence. Keeping a predictable daily routine will allay anxiety of your loved one.

Always bear in mind about safety during activities. For example; using non-slip bath mats during bathing and removing sharp utensils during cooking/gardening. Hazards of driving should be discussed gently with your loved one should it come to you that it is no longer a safe option

Behavior

If sleep disturbance happens, try to have more daytime exercise and discourage sleep during daytime. However, a short nap might be needed to avoid sun-downing from over exhaustion. Look out for symptoms of depression and discuss with your doctor. Sleeping pills might have more harm than benefit in this situation.

Do not argue if your loved one displays suspiciousness (e.g. theft, losing things), delusions and hallucinations. Keep duplicates of important items such as keys. Distract the person with providing comfort and draw attention to something real in the room or talk about his favourite subjects.

Inappropriate sexual behavior should be discouraged and try to distract the person while performing personal care such as bathing. If the person removes clothing, offer him a room for privacy. Do not confront or overreact.

Provide identification bracelet/ GPS device such as a watch if the person wanders. Provide meaningful activities and ensure the safety of the area.

Agitation, violence, aggression usually has a cause. Look for potential triggers such as pain, fatigue, noise, medication side effects, confrontation or being given too many complex tasks. Avoid testing his memory persistently and schedule adequate rest in between tasks/exercise. Check with your doctor and look for source of pain including constipation or infection. Keep calm and do not project fear or violence.



Global Deterioration Scale

Stages	Signs	Usual Care Setting
Pre-dementia	Subjectively and objectively normal	Independent
	Subjective complaint of mild memory loss. Normal on testing. No impairment in daily activities.	Independent
	Mild cognitive impairment (MCI) - Functionally normal but co-workers can see declining work performance. Deficit in objective testing. Denial might appear.	Independent
Dementia	Early dementia – Clear-cut deficit on clinical interview. Difficulty managing complex tasks; finance, travelling.	Might live independently – perhaps with some assistance from family members/care-givers.
	Moderate dementia – Unable to survive without some assistance. Unable to recall major relevant aspect of current lives example; home address, telephone number, names of grandchildren. Basic activities still independent but might need help choosing appropriate clothing.	At home with live-in family members. In senior residence home with support. In facility care if have issues with behavior or co-existing physical disabilities.
	Moderately severe dementia- Occasionally forgets name of spouse. Largely unaware of recent events. Will require assistance with basic ADLs. May be incontinent of urine. BPSD common: agitation, delusion, hallucination, repetitive behavior.	Most often in Complex Care
	Severe dementia- Loss ability to talk. Incontinent. Needs assistance with feeding. Lose ability to walk. Might be bed/chair-bound.	Complex Care

8. Stages of Alzheimer’s Disease(AD) and the usual care setting.

The amount of care required by a person with AD increases as the disease progresses. In the same way, the type of care also alters. Initially, the person may need assistance with remembering names, dates, words, directions, and where things have been placed. Following on from this, they may require help with some daily activities such as cooking, cleaning and shopping, and at later stages with dressing and washing. It then becomes necessary, for reasons of safety, for the person to be accompanied at most times - limiting the effects of disorientation, confusion and the frequently observed wandering behavior.

Once the severe stages of AD are reached, the physical side of the illness becomes apparent and help is required with walking, toileting and the person may become confined to bed or a wheelchair. While earlier symptoms may prove emotionally tiring for carers, these later difficulties also require considerable physical effort.

There are certain practical ways to help ease the care of a person with AD. This includes ways to help deal with memory issues by e.g., labeling photographs and rooms, practical issues by e.g., laying out clothes, and behaviors by e.g., learning simple communication.

Throughout the illness, the most important factor needed by a person with AD is a loving and stable environment. Perhaps surprisingly, it is this type of care that may prove to be most draining for those acting as carers. Having to deal with the symptoms that AD can bring can be distressing and mentally exhausting for the caring team.

Due to increasing demands, it is often necessary for one or more professional carers to visit the person's home to help with daily needs, as well as providing the main carer with some essential time off. Even with outside help, the situation often becomes increasingly difficult to cope with in the family home and it may then be necessary for the person with AD to be looked after in a residential home, where they can receive around-the-clock care.

Doctors, nurses and care workers can help to identify the type of help that is available or required for each individual situation, and may also be able to provide contact information for such services.



9. Caregiver stress is real: Can I cope with caring by myself?

Caring for a person with AD can be demanding and exhausting job for both emotionally and physically. An individual can become mentally tired through constant caring, and the active demands such as helping with bathnig, walking and dressing require much physical effort.

What are the signs that you are under stress?

Depression	Feeling sad and unable to cope with your daily living
Anger	Frustrated and upset that this is happening. Angry toward your loved one when you cannot control the circumstances.
Anxiety	Worried about what future might bring or if you are capable to care if the disease is advancing.
Irritability	Over reacting/being negative to issues that arises no matter how small it is.
Exhaustion	Feeling tired even after sleep/break.
Sleeplessness	Trouble falling asleep even if you feel very tired.
Health Problem	Neglecting your own health.
Lack of concentration	Too much attention to your loved one that you could not perform familiar tasks.
Social Withdrawal	Stop doing leisure activities with friends.
Denial	If possible, you do not want visitors to come to your house due to your loved one's behavior.

What can you do if you have any of these signs?

Gain more knowledge

Ask your doctors/nurses/psychologists on carer stress management. Attend caregiver workshops for more understanding - networking with other professionals and also caregivers can relieve your stress and they can share valuable tips with you.

Realign your expectations with family.

Have a back-up from family members to care for your loved one whenever you need time for yourself.

Accept changes and turn the negative events into positive energy.

Acknowledge that you are doing your best.

It is normal to feel guilty because you can't do more but individual needs change as dementia progress.

Plan for the future

Alternative caregiving plan in the event you can't provide care. Legal and estate planning should be discussed

Make time and take care of yourself

30 mins everyday for yourself. Take a break whenever you can. Daycare (ADFM) respite care at nursing home (receive care in a safe environment)

Reflection, relaxation techniques and meditation

Keep a daily journal (behavior changes and triggers. Remember that preventing the behavior is easier than treating them). Count your blessing (focus on what your loved one is still capable of doing), celebrate what is possible. Be in his shoes.

Due to these strains, it is extremely difficult for a person with AD to be cared for by just one individual. Individuals who are carers should try to recognize their limits and feel able to ask for as much help as they need. There is no need to be embarrassed or feel guilty about asking for extra support – the needs of the carer are just as important as those of the person with AD. Family and friends may offer help, and as long as all those involved are happy with the arrangement then this can be a good way of sharing responsibility. Alternatively, regular home visits from professional carers, or time spent in a day centre or nursing home may prove to be the most appropriate choices for the person with AD.

Throughout the course of AD, the responsible carer can go through a lot of emotions, such as; anger, loneliness, embarrassment, or even grief and it is not wise to try to manage this alone. Seeking advice, sharing problems and making time for personal needs should all be priorities for the carer. Family and friends can be a great source of comfort, but there are alternatives such as AD support and self-help groups, which are specially designed to help the carers of those with AD.



10. Memory Clinics

Wilayah Persekutuan

Hospital Kuala Lumpur (HKL)	03 2615 5555 (Ext 1784)
Pusat Perubatan Universiti Kebangsaan (HUKM)	03 9145 5555
Pusat Perubatan Universiti Malaya (UMMC)	03 7949 4422

Selangor

Hospital Banting	03 3187 1333
Hospital Tengku Ampuan Rahimah(Klang)	03 3375 7000
Hospital Selayang	03 6126 3333
Hospital Sungai Buloh	03 6145 4333

Kedah

Hospital Sultanah Bahiyah (Alor Star)	04 740 6233
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Pulau Pinang

Hospital Seberang Jaya (Permatang Pauh)	04 382 7333
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Perak

Hospital Taiping	05 820 4400
Hospital Raja Permaisuri Bainun (Ipoh)	05 208 5000

Negeri Sembilan

Hospital Tuanku Ja'afar in Seremban	06 768 4000
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Pahang

Hospital Temerloh	09 295 5333
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Kelantan

Hospital Raja Perempuan Zainab II (Kota Bharu)	09 745 2000
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Johor

Hospital Sultan Ismail (Johor Bahru)	07 356 5000
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Sarawak

Hospital Umum Sarawak (Kuching)	082 276 666
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Sabah

Queen Elizabeth 1 Hospital (Kota Kinabalu)	08 857 1555
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Melaka

Hospital Melaka	06 2892 344
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AD Support Groups

ADFM National Dementia Helpline: (603) 7931 5850

ADFM AD Support Group (Federal Territory/Putrajaya/Selangor)

Contact Person: Jenny
Tel: 03 7931 5850 / 016 608 2513 (Jenny)
Email: jenny@adfm.org.my / jennyho8@gmail.com

Johor Bahru Alzheimer's Disease Support Association (JOBADA)

Contact: Jobada Office
Tel: 07 222 2016
Email: jobadajohor@gmail.com

Dementia Society Perak Ipoh AD Support Group

Contact Person: April Loh
Tel: 05 241 1691 / 019 571 2738
Email: tdsperak@gmail.com

PENANG AD Support Group

Contact Person: Yep Beng Hong/Tan Yeow Joo
Tel: 04 656 4537 / 017 457 7868
Email: adfmpgsg@gmail.com

Kelantan Dementia Family Support Group

Contact Person: Dr Nurul Nadia binti Ismail
Tel: 09 767 3525/3526
Email: kelantandementia.sg@gmail.com

Sabah Alzheimer' Disease Association (Sabah AZ) 78

Contact Person: Kent Chau
Tel: 088 231 030 / 088 270 730
Email: kjchau88@hotmail.com

Melaka AD Support Group

Contact: Patrick / Jenny Tan or Alice Tay
Tel: 012 6018125 / Alice at 06 284 7886 / 016 902 0757
Email: pat_hktan@yahoo.com / alicetayagape@gmail.com