



Dementia Awareness Kit



A series of initiatives were announced in the Policy Agenda 2017 to strengthen care and support services for people living with dementia and their families at the community level. In September 2018, the Social Welfare Department (SWD) launched the "Dementia Friendly Community Campaign", a 3-year public education programme which aims at raising public awareness and understanding of dementia, with a view to building a dementia friendly community for people living with dementia and their families. The campaign includes various community-level activities under 11 District Social Welfare Offices of SWD.



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What is Dementia?

Dementia is a collective name for many progressive brain syndromes. Drastic degeneration and death of brain cells arising from diseases lead to an abnormal decline in cognitive functions. Consequently, dementia will affect one's memory, time and spatial orientation, thinking, understanding, judgment and language abilities, as well as behaviours, mood and physical mobility.

Current situation

In Hong Kong, according to various studies, about 100 000 people are estimated to be living with dementia and this number is expected to increase due to an ageing population.



Types, Causes & Impact

There are many types of dementia arising from different causes and their symptoms and impact vary.

	Alzheimer's disease	Vascular dementia	
How common	Most common form (50-75% of all cases)	Second most common form (20-30% of all cases)	
Cause Unknown; however, researchers have found that presence of abnormal amyloid		Accumulated brain damage caused by multiple strokes or vascular diseases	
	plaque and neurofibrillary tangles in Alzheimer's brain tissues lead to rapid degradation and death of brain cells		
Process	Progressive	"Stepwise" deterioration in cognitive abilities may occur with recurrent strokes	
Symptoms	Deterioration in brain functions, including memory (especially short-term memory), judgment, decision-making and executive abilities, and possible impact on self-care ability, behaviours and emotions	Depending on which parts of the brain are affected; may overlap with those of Alzheimer's disease	

Dementia with Lewy bodies Less common	Fronto-temporal dementia Less common
Abnormal development of Lewy bodies inside the brain that lead to cell death	Shrinkage of the frontal and temporal lobes, causing progressive brain degradation
Unstable,changeable and unpredictable	Onset in one's forties to sixties usually; unstable, changeable and unpredictable
Parkinson's-like symptoms, including tremor, muscle rigidity, unsteady walking and vulnerability to falls; some may act out their dreams while some have visual hallucinations	Declines in personality, behaviours (usually disinhibition) and speech occur earlier and more significantly than memory loss

Symptoms and Stages

Dementia, a degenerative disease, can be roughly divided into three phases: early, middle and late stages, each with different symptoms. As the impact of dementia varies between individuals, the following table is for reference only:

	?	? • ?	? • ?
	Early stage	Middle stage	Late stage
Memory	Decline of short-term memory	Confusion between distant memories and reality	Memory loss; may not be able to recognise familiar people and recall significant things
Communication	Difficult to express and understand more abstract terms	Repeating words and using inappropriate ones	Loss of speech or regression to babbling
Self- care ability	Capable of self-care with reminders from others	Assistance from others required	Full-time personal care required, including feeding and toileting
Orientation of date, time and place	Able to understand but hard to master due to poor memory	Prone to confusion with date, time and place; May get lost in familiar places	Losing track of date, time and place
Emotions and behav- iours	Abnormal emotional behaviours, becoming suspicious, e.g. accusing others of stealing	Prone to mood swings; may experience obvious personality changes or behavioural problems, including wandering or disruption of rest/activity and day/night patterns	Changes in temperament and behaviours, e.g. becoming passive, withdrawn and reclusive
Physical/ muscular conditions	As usual	Possible decline	May become wheelchair or bed-bound



Uncle Chan (Age 70):

"I am old and my memory is getting worse. I must be suffering from dementia..."





Isn't memory loss a normal part of ageing?

Our memory degrades over time. However, this may also be one of the early symptoms of dementia. By confusing normal ageing with dementia, some people may fail to receive diagnosis and appropriate treatment (including drug and non-drug approaches) in time.

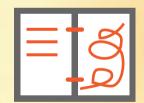
Nevertheless, it is not necessarily dementia if your beloved elder has worsening memory problems. Other diseases, such as cerebral edema, brain tumor, depression, etc., may also affect cognitive functions. When problems arise, seek professional medical assessment and diagnosis promptly! In any case, it is essential to **be ALERT!** Please pay more attention if you find yourselves or loved ones develop the following symptoms:

Loss of short-term memory

One may have difficulties recalling recent events or do or say the same thing repeatedly, and struggle to remember things even after being reminded as if they never happened.



Difficulties handling familiar work



Especially with more complicated tasks.

Difficulties making judgment

One may fail to perceive daily matters or make timely and correct judgment, such as dressing appropriately for weather or the occasion, coping with or seeking help in case of getting lost or escaping from a fire scene, etc.





Shoving things randomly

One may put things in inappropriate places, such as fruits in the wardrobe, or believe their items are stolen as they may have forgotten where they are.

Confusion with time and directions



One may fail to figure out the date and time, get lost in familiar places, have no idea where they are or forget how they get to a certain place or back home.

Difficulties solving problems and calculating

One may, for example, fail to understand simple transactions in a bank passbook or often have troubles counting change.



Difficulties with language expression or comprehension

One may find it difficult to express and understand more abstract words, communicate by using simple expressions and sometimes struggle to find the right word for something.



Loss of initiative

One may become passive or even lose interest in what they used to like.



Abnormal changes in emotions and behaviours

One may encounter mood swings with a decline in emotional control, and become more anxious and short-tempered.



Changes in personality

One may become insecure, suspicious and indifferent.



What to do if you find your loved ones have the above symptoms?



Anyone who has the above symptoms should seek assistance as soon as possible. Medical treatment is delayed for those who mistake these symptoms as normal ageing, while some may refuse to see a doctor as they think that dementia cannot be cured yet, have negative thoughts or are in denial about the condition. However, early diagnosis can indeed help people living with dementia receive the most appropriate treatment.

Some community service organisations provide assessments on cognitive functions and daily living abilities for suspected cases, and conduct preliminary analysis according to the results and thus suggest further follow-up options. Details of these organisations can be found on the SWD website (http://www.swd.gov.hk/dementiacampaign).

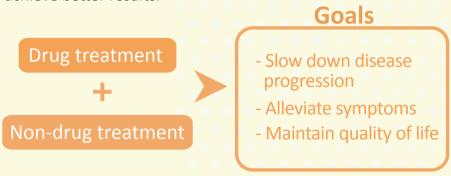
Moreover, people who are worried or suspect that they have dementia may directly visit a doctor, who will usually conduct a clinical assessment, and make enquiries on individual and familial medical history, and how the symptoms affect their daily living. CT Scan, MRI or PET will also be conducted if needed to aid diagnosis.



Those diagnosed with dementia should access proper treatment and support in order to prepare for the future and plan ahead.

Despite various ongoing researches on drugs and vaccines, most cases of dementia cannot be cured as yet. Nevertheless, there are many treatments that can defer disease progression. Proper treatment and care may enable someone with dementia to live well with the condition. Care and support should be "person-centred", with the needs and preferences of the person being the primary concerns.

Both drug and non-drug treatments should be employed to achieve better results.



The behaviour and emotions of people living with dementia may also be affected by their illness, the environment and other factors. Besides appropriate treatment, companion, care, support and understanding from family members, friends and neighbours are crucial as well.

Drug treatments

At present, drugs such as Donepezil, Rivastigmine, Galantamine and Memantine are commonly used in treating dementia in Hong Kong. These drugs mainly help slow down disease progression, maintain existing functioning to defer decline and at the same time alleviate behavioural and emotional problems.

A wide range of other drugs, including those treating depression, anxiety, sleeping disorder or antipsychotics, may be prescribed for a person living with dementia at different stages in order to ease distressing symptoms.





Non-drug treatments

Non-drug treatments help defer cognitive decline and maintain the physical, mental and social wellbeing of a person living with dementia.

Suitable activities and training include:

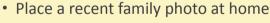


Selection and design of non-drug treatments should be determined by relevant parties after clinical assessment on the conditions and needs of a person living with dementia. Nevertheless, family members or caregivers can flexibly integrate the following elements into the daily life of the person concerned:

Reality Orientation

People living with dementia are trained to master the concept of time, people, place and environment, in order to alleviate their anxiety and consolidate their existing community living abilities. For example:

- · Establish a regular daily routine
- Refer more to information relevant or important to them in daily conversation, such as mentioning today's weather every morning
- Put relevant items, food and decorations at home before festive occasions







Reminiscence Therapy

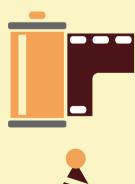
People living with dementia are guided to recollect and share their stories, and encouraged to develop positive attitudes towards their past experience, in order to help maintain their long-term memory, stimulate their cognitive functions and improve their mood.

Examples:

- Retain some items they frequently used and cherished in the past
- Select decorations and furniture similar to the ones they used before
- Accompany or assist them in organising photo albums in accordance with the time sequence, and revisit the past with them
- Choose some familiar places for family gatherings, such as dining in traditional Chinese restaurants or shopping at vintage furniture stores









Multisensory Therapy

Exposing people living with dementia to different stimuli in daily life will help improve their mood and alleviate their hyperactive behaviour. It can also sustain their abilities to receive, analyse and respond to stimulation so as to stay connected with the environment. For example:

Take them to a walk in the park, where the sounds of different animals, insects or kids playing can be heard. They may also touch and smell various plants, and feel the cool breeze or the warmth of the sun.









Cognitive stimulation activities

Activities that match with their abilities and interests are arranged in order to train their memory, attention, spatial recognition and calculation, which can slow down the decline in cognitive functions. For example:

- Ask them to purchase goods within a designated amount, or to assist in calculating the total price of the purchased goods when shopping in supermarkets
- Invite them to handle simple household chores, such as hanging the laundry (sorting clothes/pairing socks)





Living arrangement

Family members or caregivers need to arrange appropriate daily care and adjust the home setting for people living with dementia to stay in their familiar communities and maintain their quality of life.

Daily care

The self-care abilities of people living with dementia will continuously decline. Their family members or caregivers should pay close attention to any changes in their conditions and arrange appropriate daily care. During the course, please take note of the following:

- Help establish a regular daily routine and arrange adequate day-time activities that complement with their habits and preferences
- Caring modes and communication approaches of different caregivers should be consistent

Help sustain their capabilities and avoid taking over completely. For example:

If they just temporarily forget a step

Give simple verbal reminders only



If they are totally at a loss about the next step

Give verbal reminders and offer step-by-step guidance



If they fail to complete the step on their own

Assist them at a certain step



Caregivers should complete the task on their behalf if they still cannot finish the remaining tasks. This must be the last resort as the ultimate goal of daily care is to encourage participation from people living with dementia and thereby maintain their independence

Take over the task

With the decline of cognitive abilities, people living with dementia will not be able to handle more complex tasks. Family members or caregivers can prepare or provide some assistive tools to streamline the procedures. For example:

- Electronic payment methods are available for people living with dementia who can still shop independently to avoid troubles with money change
- If the person living with dementia forgets the correct sequence of dressing, line up the clothes in order

Home setting

An ideal home setting should suit the habits, preferences and needs of the people living with dementia. It should also alleviate their emotional problems, strengthen their orientation, offer moderate stimulation and enhance their self-care abilities. Family members or caregivers may take note of the following when adjusting the home setting:

1. To alleviate their emotional problems, you should:

- provide an environment familiar to them; keep the original setting as far as possible and avoid large-scale renovations or replacement of furniture
- · keep the lighting bright and even

2. To strengthen their orientation, you should:

- arrange rooms with windows to reinforce their sense of day and night
- place a calendar with enlarged fonts or a clock with AM/PM display
- install safety handrail or toilet seat in contrasting colours with the walls for easy identification
- avoid choosing floor plates with different colour shades or patterns that may be mistaken as uneven ground



3. To provide moderate stimulation, you should:

- stick paintings on the walls or paint them in mild colours
- open the windows as much as possible to bring in natural light for differentiating the change of weather
- avoid installing large panes of glass or mirrors that may cause confusion in judgments on the environment
- arrange low-maintenance plants or aromas for sensory stimulation

4. To improve the self-care ability of people living with dementia, you should:

- place items in a fixed position at an appropriate height (ideally at 90-130cm), or in an open cupboard for easy location of articles in need
- not affix too many labels on items to avoid causing confusion
- use induction cooker or electric water heater to reduce the risk of flame cooking



Communication skills

For people living with dementia, their skills of language expression and comprehension may continuously decline. You may refer to the following suggestions when communicating with them:

1. Arrange a suitable environment

 Avoid environmental disturbance, such as noise or inadequate lighting

2. Make good use of body language

- Stay close and make eye contact to get their attention
- Smile and nod to express encouragement and recognition
- · Avoid showing impatience

3. Talk in the right tone and speed

- · Keep a steady tone
- Slow down the pace of speaking

4. Use simple wording

- · Use plain words for easy understanding
- Mention the specific names of people, places and articles instead of using pronouns
- Avoid using abstract words, such as replacing "hungry" with "eating"
- Speak concisely, conveying one message only in each sentence

5. Pay attention to the questioning skills

- · Raise only one simple question at a time
- Provide multiple choices of answers as the first step; use "yes/no questions" to guide their expression of ideas if the first step does not work

6. Observe reactions

- Pay close attention to their facial expresions, tones and gestures
- Listen carefully and learn to experience their emotions and feelings

7. Assist them in finding the right word

- Provide one to two words for choice when they have troubles with speech
- Try to guess their meaning or assist them to paraphrase

8. Avoid conflicts

• Try to change topics in case of disagreement to avoid conflicts

9. Take their self-esteem into consideration

Do not treat them as children such as using reduplication

10. Be flexible

 Find the most suitable communication method through repeated attempts and improvement

Common problems and solutions

"Poor memory" is the major symptom of dementia. However, family members and caregivers of people living with dementia are more likely to be at a loss about their behavioural and psychological problems. We have to understand that they are not doing these things on purpose. Rather, their abilities of judgment, control and comprehension of the surrounding environment are impaired by dementia, which renders them misunderstood or incapable of doing what they intend to do, leading to deviant behaviour.

Behavioural and emotional problems

When abnormal behaviours or negative emotions (such as repeated, disruptive or aggressive behaviours, hoarding, anxiety, indifference, depression, delusions and hallucinations, etc.) are observed and they are causing disruptions to a person living with dementia themselves or others, family members and caregivers should act promptly. Early identification of the causes will help family members and caregivers figure out the most appropriate ways to prevent and handle those issues.

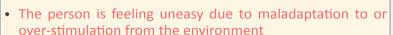
Common causes include:



 The person is stressed out for being unable to cope with the existing task or workload



• The person is frustrated with the difficulties in verbal expression and understanding



• The person is suffering from other diseases



Family members and caregivers may refer to the following suggestions:

- Reduce environment-induced stress or stimulation
 - Simplify decorations to create a quiet and cozy environment
 - Avoid drastic changes to the living environment (such as moving home)
 - Pay attention to the reasons behind such behaviours and avoid these conditions in future
- When people living with dementia become emotional, try to soothe them first and divert their attention by letting them do what they like or talking about what interests them
- Consult a doctor if depression, delusions, hallucinations or violent behaviour are identified. The doctor will consider prescribing medication to relieve the symptoms. Meanwhile, family members and caregivers should pay heed to and record the condition after receiving medication (e.g. any behavioural and emotional changes or side effects). The updated situation should be reported to the doctor during the follow-up consultation to facilitate adjustment in treatment methods and dosage accordingly

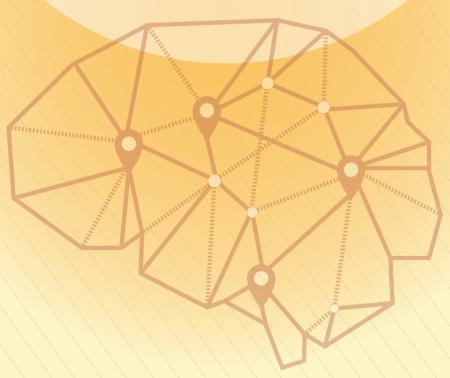


Wandering

Wandering is common for people living with dementia. While it is harmless under an appropriate and safe environment, they can easily get lost or even come across accidents if they go out alone.

To prevent them from getting lost, family members and caregivers should understand the reasons behind and take precautions accordingly in order to reduce their desire to go out on their own. For example:

- Accompany them to go out regularly or allow them to move around in a safe venue
- Arrange familiar and manageable activities to preclude feelings of idleness



How to prevent and handle missing incidents:

- Utilise environmental design and assistive tools to reduce the risk of missing incidents
 - Use assistive tools such as doorbells with sensors and anti-loss alarms
- Make sure the person living with dementia wears accessories or watches imprinted with the contact number of their family member. This allows the police or passersby to contact the family member in case of missing incidents
- Do not panic if the person living with dementia goes missing. Provide sufficient details to the police, such as height, physique, characteristics, clothing worn at the time of missing, etc. A recent colour photo should also be provided
- When the person living with dementia has been recovered, remember to offer comfort and bring them back to a familiar environment as soon as possible. Avoid expressing anxiety or scolding them because they may already feel confused and frightened

Sleeping problems

Many people living with dementia suffer from changes in sleeping habits. Some may get night and day mixed up or have their rest time shortened due to reduced activity. Caregivers can try to find out the causes of the sleeping problems and seek solutions accordingly.

Common causes:

Physical or psychological factors



- The brain's decline may affect a person's biological clock and in turn disrupt their sleep patterns
- Emotional problems, such as depression and anxiety, cause a person living with dementia difficulty staying or falling asleep
- Plagued by illness or physical discomfort
- Affected by side effects of drugs

Environmental factors

• Temperatures that are too high or too low may make them feel unwell



- Excessive or insufficient illumination may lead to confusion, unease or fear
- Changes in the environment, like moving home, can induce anxiety

Other factors

- Prolonged sleep during daytime
- Excessive energy level due to inadequate daytime activities
- Excessive intake of caffeine or alcohol

Solutions

Physical or psychological factors

- Consult a doctor to assess whether the sleeping problems are caused by drugs or illness
- Let the person living with dementia take sleeping pills when needed as prescribed by a doctor and pay attention to side effects

Environmental factors

- · Maintain optimal indoor temperature and lighting
- · Minimise changes in the environment

Other factors

- Maintain a regular sleep schedule with suitable aytime activities for the person living with dementia
- Reduce intake of caffeine or alcohol after dusk
- Dress the person in a different set of clothes in nighttime as a reminder to rest

Financial and medical care arrangements

People living with dementia and their families should plan ahead for future financial or medical arrangements. This can relieve family members of not only the anxiety or disputes that may arise, but also the psychological stress of having to make decisions on behalf of the person living with dementia in a life-and-death situation.

Family members should encourage and assist the person living with dementia to make financial and medical care arrangements as wished before a total loss of cognitive abilities. At present, various legal channels, such as enduring powers of attorney (EPA), advance directive and will, are available for these arrangements to be made in advance.

EPA 🙇

A legal instrument which allows its donor (i.e. the person who wishes to give the power of attorney to someone). while they are still mentally competent, to appoint attorney(s) to take care of the donor's financial matters under specific areas in the event that they subsequently become mentally incapacitated; an EPA has to be signed in the simultaneous presence of a registered medical practitioner and a solicitor

Advance directive

A legal statement, in which a person indicates when mentally competent the instructions as to the refusal of treatment or invasive medical procedures at a future time when they are no longer competent; the sample form of advance directive can only be used to refuse life-sustaining treatment in advance under the 3 circumstances as follows: 1. terminal illness; 2. an irreversible coma; or 3. a persistent vegetative state.

Will 🔗

A legal document which allows one when they still have the capacity to make a will to plan for the disposal of their estate upon passing away so as to alleviate possible dissension and conflicts between family members.

Please refer to the following websites for details:

Enduring power of attorney

Community Legal Information Centre http://www.clic.org.hk/en/topics/enduring_Powers_of_Attorney/

Advance directive

Senior Community Legal Information Centre http://www.s100.hk/en/topics/Health-and-care/Advance-directives/What-is-an-Advance-Directive/#content

Will

Senior Community Legal Information Centre

31 http://www.s100.hk/en/topics/Farewell-to-life/Probate/How-your-assets-are-going-to-be-distributed/



Self-care of caregivers

People living with dementia require long-term care from family members and caregivers, who initially may be in denial of the situation and feel doubtful and overwhelmed. Apart from long-term physical and psychological depletion, problems including worry about missing incidents, and unwillingness to receive care or non-cooperation on the part of the person living with dementia also put extra pressure on family members and caregivers. Faced with progressive memory decline and personality changes of the person under their care, they may feel saddened, lost and helpless, or blame themselves for not doing enough. Some caregivers may feel baffled or exhausted when dealing with certain behavioural problems. Therefore, they should keep in continuous communication with other family members, and seek assistance and support from doctors and relevant service agencies when necessary.

When assuming a carer's role, family members and caregivers should not overlook their own needs as being overly dedicated can lead to excessive stress on their mental and physical health.

Hence, apart from taking care of the person living with dementia, caregivers also need to watch out for their own physical, mental, social and spiritual wellbeing. It is important to enjoy private time and maintain a regular social life. If necessary, assistance may be sought from relatives, friends, elderly support service agencies and relevant professionals.



Many organisations and service units in the community provide dementia-friendly information, advice and support services. For details, please visit the SWD website on "Dementia Friendly Community Campaign".



Website: http://www.swd.gov.hk/dementiacampaign



Keep a healthy mind

Last but not least, despite the diversity of causes for different types of dementia, all of us, regardless of age, can reduce the risk of developing dementia by following the advice below.



Prevention of cerebrovascular diseases

 Prevention and monitoring of hypertension, diabetes, heart disease and stroke



Maintain a healthy lifestyle

- Opt for low-sugar, low-salt, low-fat, high-vitamin and high-protein food and keep a balanced diet
- Exercise regularly
- · Avoid smoking and excessive drinking



Maintain an active social life and develop personal hobbies

- Expand social network, meet more people, and share with family and friends
- Develop healthy hobbies and interests that bring stimuli to the brain



Take action before it is too late

- Undergo regular body check and cognitive assessment
- Seek help as early as possible



Keep a positive mind

· Be cheerful, appreciative and grateful



Exercise your brain and be willing to take up new challenges

- Keep your mind active; learning new skills can help train your mind
- Develop Six Arts® multi-cognitive domains (i.e. interpersonal and social, musical, visual-spatial, kinesthetic, linguistic and logic-mathematical elements)



Protect your body and reduce the chance of brain injury





http://www.swd.gov.hk/dementiacampaign

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