

Dementia Caregiver Guidance Brochure

01 | Introduction to the manual





This handbook consists of four sessions focusing on the thoughts, feelings and behaviours of carers with dementia, and the stress response of being a carer. This series of courses is aimed at primary caregivers of people with dementia in the community. We know how hard, stressful, and sometimes overwhelming long-term care can be. Therefore, our courses will help you monitor your emotions, improve your caring skills, and increase your caring confidence. The challenge we all face is how to maximize the quality of life as a caregiver in the face of worsening dementia.

Course targets

We will teach you a variety of techniques to help you change your thoughts, feelings and behaviours so you can better cope with the care process in different ways, while also learning how to manage your stress as a caregiver and frustration. Research shows that non-pharmacological interventions are very successful in helping people adjust cognition and behavior, but mastering all the relevant skills requires study and practice. Over the next four sessions, you'll see that these skills are not just for taking better care of your family, but for improving the quality of life for the caregivers themselves.

Topic follow-up

You will be required to actively participate in 4 sessions, with some time between sessions to review classroom knowledge. Please feel free to share these exercises and materials with other family members or friends. We encourage you to take notes in the handbook to help you study the course material and review it as you go.

In addition, we keep track of your learning to check your learning, help you apply course materials to your family, and help you integrate these skills into your daily life.

Thank you for giving us this opportunity to serve you, and we welcome any feedback so we can improve the curriculum to better meet the needs of you and your family. Remember the researcher's phone for further personalized information.



Course Outline

course	time theme	1/1 hour home visit per week, 4 times in total.
Lesson 1	pressure <ul style="list-style-type: none"> Mood monitoring 	Section 1 The impact of disease on the elderly Section 2 Stress in the care process Section 3 Stress Relief - Relaxation Training, Informational Breathing Exercises: Emotional Scale
Lesson 2	happy event <ul style="list-style-type: none"> Activity planning 	Section 1 The Importance of Tracking Your Feelings SECTION 2 RECORD YOUR EXCLUSIVE PLEASURE ACTIVITIES Section 3 CHOOSE PLEASURE ACTIVITIES FOR YOU AND YOUR LIVES EXERCISE: happy activity log
phone tracking		Reinforce or modify pleasant events based on feedback
Lesson 3	manage problem behaviors and communication skills <ul style="list-style-type: none"> activity modification 	Section 1 Understanding Problem Behavior Section 2 "Triggering Events - Reactions - Cope with "chain lock" Session 3 Communication Skills Exercise: Behavior Record Sheet
Lesson 4	Future planning and care Confidence boost <ul style="list-style-type: none"> Revision of activities 	Section 1 discusses reserved medical directives Section 2 Balancing Self-Care and Caring for Others Section 3 Identifying Resources and Applying Strategies Exercise: future planning table

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Dementia Caregiver Guidance Brochure

02 | Lesson 1

Stress: Mood Monitoring





Section 1 The impact of disease on the elderly

Section 2 Stress in the care process

Section 3 Stress Relief - Relaxation Training, Information Breathing

Exercises: Emotional Score Sheet

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Section 1 The impact of disease on the elderly

About Dementia

We know you already know a lot about dementia. However, we want to make sure that everyone involved has the same view on the topic. For example, the term "dementia" is used to describe symptoms that occur when the brain is affected by specific diseases and conditions. These include cognitive disorders associated with Alzheimer's disease (AD) and vascular disease.

Dementia is progressive, which means symptoms get progressively worse. The rate at which dementia develops depends on the individual. Everyone is unique and experiences dementia in their own way. As a result, it can be difficult to determine what will happen to your loved one next. However, in all forms of dementia, nerve cells in the brain responsible for memory, learning, speech, emotion and movement fail. This can lead to confusion, poor judgment, forgetfulness, and changes in behavior and personality.

Although this is a very serious disease,
And there is no clear cure.

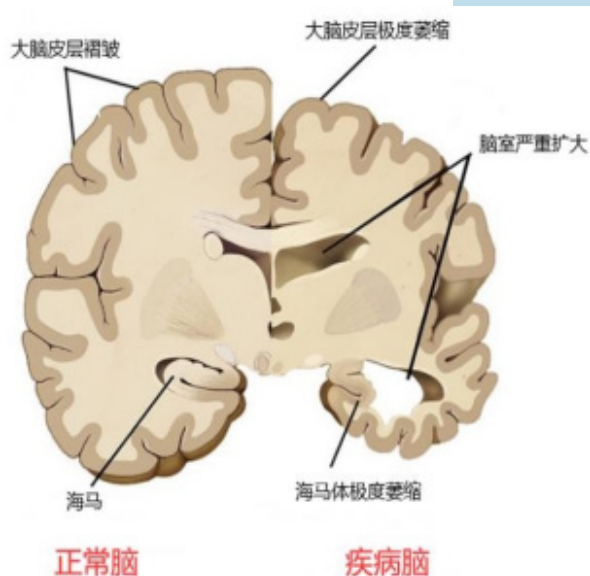
Research is being done all over the world,

Find the cause of dementia. us

I hope that one day there will be a cure

treatments can improve the health of patients

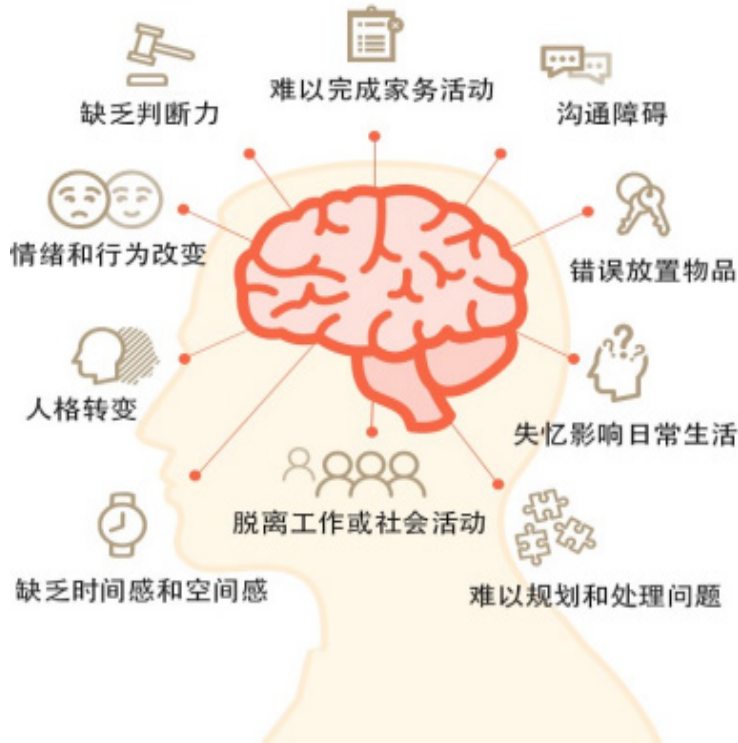
Kang.





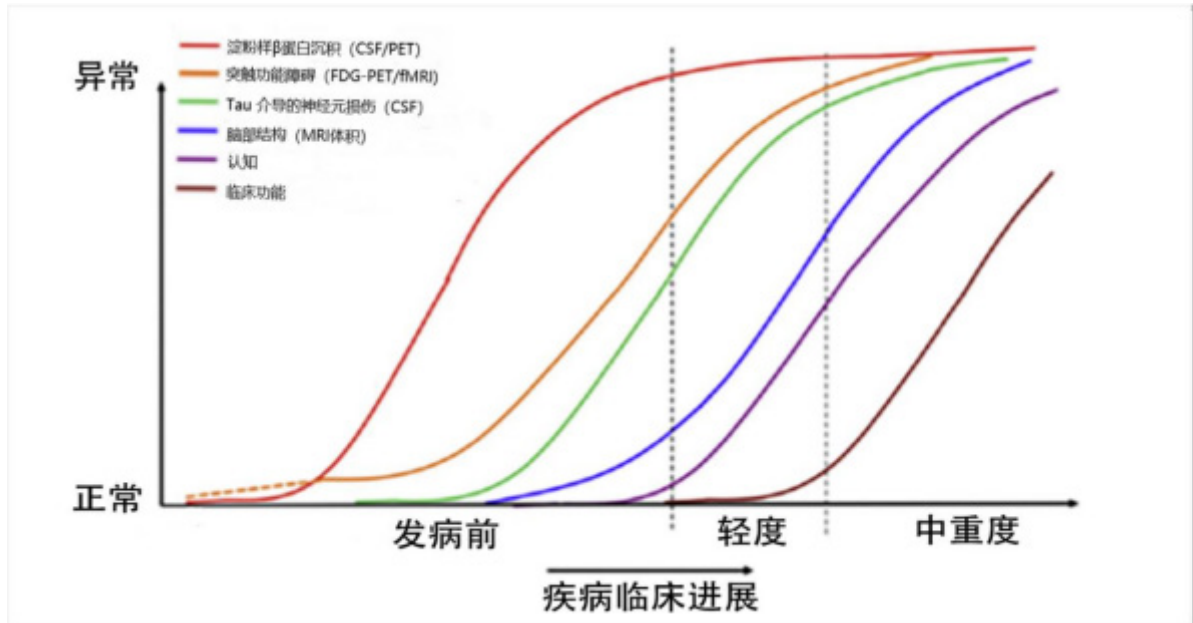
认知症 10项重要警讯

了解认知症的症状，尽早发现疾病，可以为患者和家庭成员带来积极影响。



病人会有什么症状?





"Alzheimer's disease" (AD) is a continuous process of synaptic and neurodegeneration.

diagnosis:

Cerebrospinal fluid examination is recommended as a routine examination for patients with dementia, and structural imaging CT or MRI is a routine examination for the diagnosis and differential diagnosis of dementia. Dementia patients with a clear family history of dementia should undergo genetic testing to aid in the diagnosis.

- * CT (Computed Tomography): Electronic Computed Tomography
- * MRI (Magnetic resonance imaging): Magnetic Resonance Imaging

Detection:

Auto comparison:

with one's own past knowledge and daily living ability
Is there a drop.

Differences between individuals:

with age and education level
matched normal population
Compared.

NIA-AA诊断指南推荐的生物标志物



01	02	03
AD的分子生物标志物	“下游”神经退变指标(损伤生物标志物)	致病基因突变 (PSEN1, PSEN2, APP)
<ul style="list-style-type: none"> ✓ 低水平的CSF Aβ42 ✓ CSF tau蛋白和磷酸tau蛋白水平升高 ✓ 淀粉样蛋白成像(PET示踪剂, 11C PIB, 18F Florbetapir, 其他) ✓ Tau蛋白示踪剂也在研究阶段 ✓ 血液生物标志物尚不成熟 	<ul style="list-style-type: none"> ✓ FDG-PET显示颞顶代谢 ✓ MRI显示全脑和/或局部萎缩 ✓ fMRI显示连接功能中断 	<ul style="list-style-type: none"> ✓ APOE4尚不足以作为特异的诊断标记物

Mckhann G, et al. Alzheimer's & Dementia. 2011;7:263-269

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cholinergic hypothesis

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阿尔兹海默氏症病人脑中乙酰胆碱缺乏

❖ 胆碱缺乏

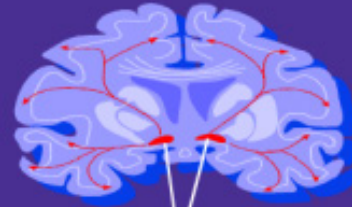
胆碱神经元逐渐死亡



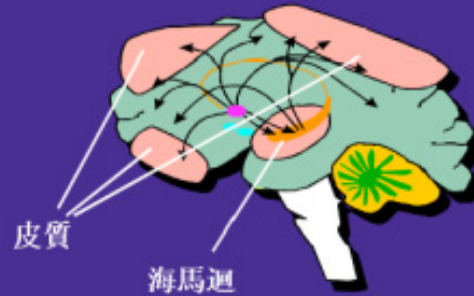
可用的乙酰胆碱逐渐减少



影响病人认知行为和日常功能



梅納德氏基底核 (nucleus basalis of Meynert)

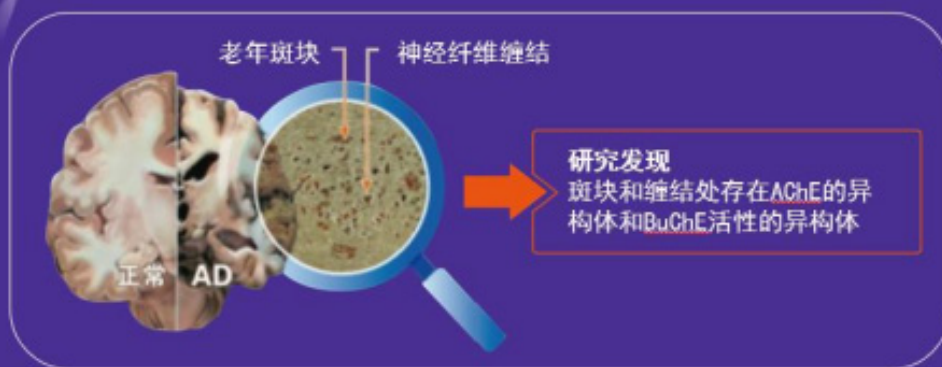


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海馬迴

Bartus et al., 1982; Cummings and Back, 1998, Perry et al., 1978

AChE和BuChE的异常变化在AD疾病进展中起重要作用



AD患者大脑的重要改变：脑普遍萎缩，以与高有序认识能力相关区域如海马及相应皮质部位尤为明显，脑室扩大，脑沟变宽

AChE: 乙酰胆碱酯酶 BuChE: 丁酰胆碱酯酶

Geula C, Mesulam M-M. *Alzhi Dis Assoc Disord.* 1995;9(suppl):23-28.
Saez-Valero J, Barquete M-S, Marcos A and Small D. *Neurobiol Aging.* 2000;21(suppl 1):S272. Abstract 1246.



drug

There is currently no cure for the disease, but at least four drugs have been shown to slow disease progression.

● Aricept (Donepezil)

It is currently the most prescribed drug by doctors and is usually used to improve the following

Several symptoms: ① hallucinations, believing in the existence of some unreal things; ② apathy, loss of interest in daily activities; ③ wandering disorder, wandering back and forth, usually at night.



● Asneng®(rivastigmine)

For Alzheimer's patients in the early and middle stages, it can slow the onset of the disease development, helping moderate patients to maintain a longer-lasting bond with their family,

Stay engaged in activities they enjoy.



指南共同推荐

——艾斯能® 轻中度AD治疗一线药物



2011中国痴呆与认知障碍诊治指南¹
胆碱酯酶抑制剂（如卡巴拉汀）是现今治疗轻、中度AD一线治疗药物



2011英国NICE指南²
卡巴拉汀、多奈哌齐、加兰他敏这三个胆碱酯酶抑制剂被推荐为阿尔兹海默病治疗的首选药物



2008美国内科医师协会指南³
众多研究证实，胆碱酯酶抑制剂（如卡巴拉汀）能有效改善患者症状，改善认知功能



2012欧洲神经科学协会联盟指南⁴
卡巴拉汀具有I类证据支持，被批准用于治疗痴呆

1 曹建平等. 中华医学杂志. 2011;91(14): 940-945.
2 National Institute for Health and Clinical Excellence. Donepezil, galantamine, rivastigmine (review) and prescribing for the treatment of Alzheimer's disease (amended). Includes a review of NICE technology appraisal guidance 19. September 2009.
3 Doody RS, Stevens JC, Beck C, et al. Neurology. 2001;57(2):1154-1166.
4 Serbi S, et al. European Journal of Neurology. 2012;15(11):1153-1173.

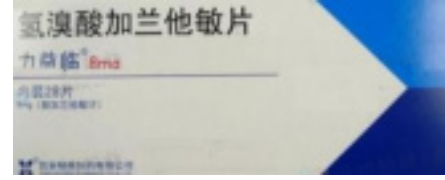
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● Galantamine

This drug is also prescribed to patients in the early and middle stages, which can delay the progression of the disease, and can improve or prevent cognitive functions such as memory, orientation, and language subsides so that it can continue daily activities such as dressing, eating, and bathing and other activities.



● memantine

This prescription is the first and only treatment drug used in patients with advanced Alzheimer's disease. Alone or in combination with Aricept, it can slow memory loss.

痴呆与认知障碍诊治指南 AD治疗 – 美金刚

2011版指南	2015版指南
<ul style="list-style-type: none"> 明确诊断为中-重度AD患者可以选用美金刚或美金刚与多奈哌齐、卡巴拉汀联合治疗 (A级) 	<ul style="list-style-type: none"> 明确诊断为中-重度AD患者可以选用美金刚或美金刚与多奈哌齐、卡巴拉汀联合治疗。对出现明显精神行为症状的重度AD患者，尤其推荐胆碱酯酶抑制剂 (ChEIs) 与美金刚联合使用 (A级推荐) 必须与患者或知情人充分地讨论治疗益处及其可能出现的不良反应 (专家共识)

* The above drug pictures are for reference only, please follow the doctor's advice when using the drug.



Can Alzheimer's disease be cured?

痴呆与认知障碍诊治指南

AD治疗 - 胆碱酯酶抑制剂

- 明确诊断为AD患者可以选用胆碱酯酶抑制剂治疗 (A级推荐)
- 胆碱酯酶抑制剂存在剂量效应关系, 中重度AD患者可选用高剂量的胆碱酯酶抑制剂作为治疗药物, 但应遵循低起始剂量逐渐滴定的给药原则, 并注意药物可能出现的不良反应 (专家共识)

MCI治疗: 指南推荐意见

对症治疗

- 促智药、麦角生物碱类、钙离子拮抗剂、银杏叶提取物、胆碱酯酶抑制剂等

推荐

- 临床应积极寻找MCI的病因, 以期对可治的病因进行针对性治疗。(专家共识)
- 根据现有循证医学证据, 治疗MCI的药物疗效有待进一步证实。(A级推荐)

诊治指南: 新概念

主观认知障碍

- 长期随访研究提示SCI发展为AD的风险高于非SCI人群。(专家共识)
- 对SCI人群应给予充分重视, 密切跟踪随访。(专家共识)

AD前阶段

- 推荐进行AD痴呆前阶段的诊断, 特别是MCI的诊断 (专家共识)
- 推荐针对临床前AD开展早期诊断研究和早期干预研究 (专家共识)
- AD痴呆前阶段的饮食推荐主要摄入鱼类、水果蔬菜、富含多不饱和脂肪酸的植物油, 适度饮用红酒而较少食用猪肉等红肉 (A级推荐)
- 推荐在AD痴呆前阶段将饮食调整、体力锻炼和认知训练相结合来延缓认知功能下降 (A级推荐)

2015痴呆与认知障碍诊治指南-神经心理量表使用

疾病	筛查功能	诊断功能
痴呆	MMSE、mini-Cog、MIS、AD8、ECOG	CERAD成套神经心理测验、Fuld物品记忆测验、积木测验、言语流畅性测验、数字广度测验、痴呆严重程度分级量表(CDR)、智能筛查测验(CASI)、Addenbrooke's 认知检查修订版(ACE-R)和剑桥老年认知量表(CAMDEX)
MCI	MoCA、简明记忆与执行测验(BMET)、快速MCI筛查量表(QMCI)	基本测验组合: 记忆功能采用听觉词语学习测验、语言功能采用言语流畅性测验、注意力功能采用数字广度测验、空间功能采用复杂图片模仿测验、执行功能采用连线测验等

medicine:

· Cholinesterase inhibitors can be used in patients with a clear diagnosis of AD (mild to severe)(A-level recommendation)

There is a dose-response relationship with cholinesterase inhibitors, and high-dose cholinesterase inhibitors can be used as treatment drugs in patients with moderate to severe AD(Expert Consensus)

· For patients with moderate-to-severe AD who are clearly diagnosed, memantine or the combination of memantine with donepezil and rivastigmine can be used. For severe AD patients with obvious mental and behavioral symptoms, cholinesterase inhibitors (ChEIs) and memantine are especially recommended. joint use(A-level recommendation)

Cholinester inhibitors and memantine may be used in DLB, PDD, VaD, no evidence in FTD(A-level recommendation)

As your loved one's condition progresses, you'll notice changes in his or her behavior. For caregivers, these changes are often a major source of frustration, stress, anger, sadness or other disturbing emotions.

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Section 2 Stress in the care process

You may have expectations of your loved ones, yet they often fail to live up to your expectations. sometimes you may

Confused as to why a loved one handles some tasks well and not others (or

or do something inconsistent). You sometimes think that their actions are deliberately irritating yourself.

Example: "I don't know what's going to happen."

"I think she did it to upset me."

"She can do it if she wants to...she does it sometimes."

Caregivers often experience stress, depression, sadness, and worry about caring for a loved one with memory problems.

The main reasons for these responses are the carer's thoughts and attitudes, relationships with significant others, attitudes and ideas of significant others, and lack of knowledge and skills.

1. Thoughts and attitudes

Another source of frustration, irritation, stress, guilt, or sadness can be our thoughts and attitudes toward caring for the environment. For example, a caregiver may think life should be fair, but feel annoyed that the caregiver has to give up her own retirement plans to be with a loved one with dementia. Caregivers may become frustrated with other family members who criticize them, leaving themselves alone with most of the caregiving responsibilities. Alternatively, caregivers may have unrealistic expectations about how much care they can provide; if they need help, they may think they have failed, or sometimes have negative feelings about their loved ones and their behavioural problems. reaction.

Example: "I can't handle it."

"I have no one to help me."

"It's no use, my father will never get better."



2. Past relationships

Caregivers' past relationships with care recipients may also influence their responses to care. Those who have had a long-term positive relationship with a loved one may be saddened by their loved one's inability to recall many of the good times they once shared, or grieving while struggling with a loved one's aggressive behavior. By contrast, caregivers with chronically negative relationships with loved ones may feel dissatisfied with having to give care, or want to resolve past conflicts. However, these caregivers are likely to be frustrated because their loved ones are no longer able to meet their needs. Therefore, it is important to respect the caregiver's past relationship experience.

Example: "No matter what I do, my mom doesn't like it. I don't want to take care of this person, but I must take care of her. "

"Even my daughter pointed out how bad she was to me. I knew that if things got better, I would Now in a nursing home. "

3. Other people's reactions or situations

Sometimes we can't control how other people influence our reactions. Especially when we're prevented from doing what we think is important, or when our safety feels threatened.

Example: "I was so stressed today that I couldn't get the daycare information I needed."

"My wife soiled the sofa."

"More than one person needs my attention at the same time."

4. Skills

Frustration, worry, guilt, sadness and stress can persist if caregivers lack the skills to reduce negative reactions. For example, if we don't know how to communicate effectively, we may express ourselves angrily, or suppress ourselves passively, neither of which helps!

Example: "I just kept biting my tongue until my chest hurt!"

"There was nothing I could do, I was stuck and couldn't change his behavior."



Behavioral activation therapy can help caregivers break out of a vicious cycle of stress, frustration, depression, or other disturbing emotions by activating new behaviors and improving communication. First, we'll teach you the importance of relaxation and learn a technique to help you manage stress.

Section 3 Stress relief - relaxation training, information breathing

Why is it important to learn to relax?

It's hard to keep our mind clear when we're feeling down or helpless. At this time, we

The chances of being able to handle the situation well are slim. It is very difficult, both for ourselves and for the patient. When we're under stress, we'll be able to handle things better if we've learned relaxation techniques.

way to relax

People relax in different ways, and you probably already know some relaxation methods, such as:

- lie down and rest for a while
- Watch your favorite TV show
- read newspaper
- ...

How do you usually relax?

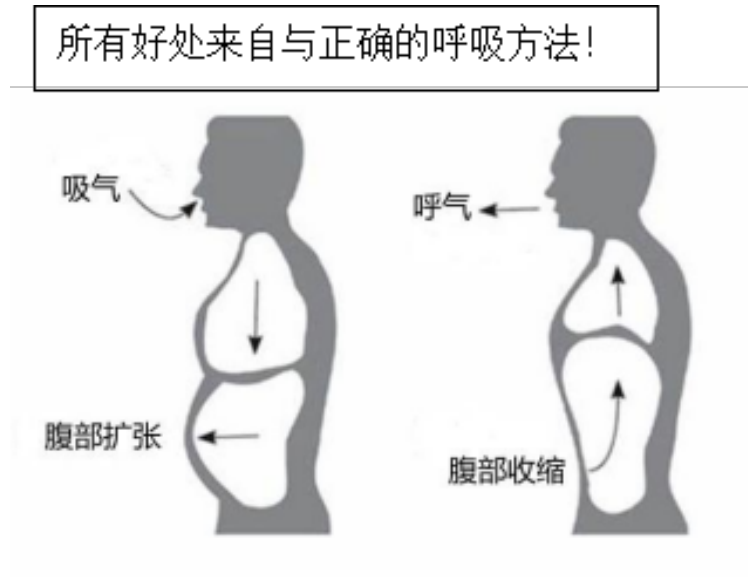
You can continue to use these relaxation methods, but in many different stressful situations, especially when you need immediate relaxation, you may not have enough time for the above activities. In this course, we will teach you a special relaxation technique that you can use anytime, anywhere. This method is called Information Breathing, which has been used by humans for thousands of years for relaxation. ! Doctors have found that this relaxation method can reduce stress and lower your blood pressure.

It's not the same as taking a short nap or taking a short break, and the methods we teach you can be used anytime, anywhere, standing or sitting. The point is to calm you down quickly so you can clear your mind.



Information Breathing

One of the fastest ways to change your feelings. This breathing pattern can calm you down, however, the wrong way to breathe can actually make you more nervous.



practice part

Sit or lean back in a chair soothingly, move other objects away, put your hands on your lap, close your eyes, and begin to notice your own breathing, slow it down.

When you take in a breath, count to five seconds silently. When you start to breathe in (belly out), count from one, slowly count to two...three...four...five...when you count to five, you should have reached the most relaxed in the same state, take a full breath, and then slowly exhale the breath (belly inward) and count one...two...three...four...five in the same way. So by the count of five your breath should be completely out, then relax and take a few normal breaths in the usual way.

Next, breathe in again and count to five, and as you breathe out, repeat the words "safe," "relax," or any other word you feel soothing.

" Cozy, comfortable, comfortable, comfortable, happy, freehand, sparse, satisfying, fun, hearty, comfortable,

Happy, comfortable, comfortable..."

Repeat the above breathing movements at your own pace!

The time is about 5-15 minutes



Practice of Continuous Information Breathing

This relaxation method is new to most people and requires more practice. It can only be developed into a skill with regular practice.

Practice at least twice a day,

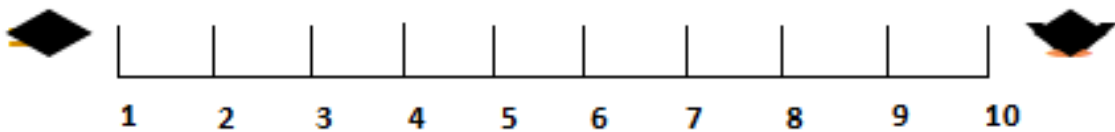
At least four minutes at a time!

Don't expect to feel relieved or calm right away, as with everything, learning a new thing takes time and practice. First of all, please use your time to practice when you are not under stress. Regular practice is more important than immediate pressure reduction. Once you develop this particular skill, you will automatically remember to use it whenever you need it.

Exercise: Mood Rating Scale

Exercise 1

1. Using the scale below, how would you rate your level of frustration, anger, worry, or stress as you consider yourself and your caregiving roles, responsibilities, and the needs and behavior of your loved ones? Please circle the corresponding score on this "Mood Thermometer".



数字 1 代表你情感的最低状态 数字 10 代表你情感的最佳状态

2. How does it feel to give you a stress score?

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Exercise 2

Think about a recent experience that was frustrating and stressful for you.

1. How do you feel when you think about this experience?

2. How do you know when you are frustrated, annoyed or stressed? What are the signs?

3. What healthy strategies do you use to reduce these reactions?

4. What unhealthy strategies do you use to manage these reactions? (Obviously, these are all things to avoid!)



Dementia Caregiver Guidance Brochure

03 | Lesson 2

Pleasant Activities: Schedule of Activities





- Section 1 The Importance of Tracking Your Feelings
- SECTION 2 RECORD YOUR EXCLUSIVE PLEASURE ACTIVITIES
- SECTION 3 CHOOSE YOUR PLEASURE ACTIVITIES WITH YOUR LOVE
- EXERCISE: PLEASURE ACTIVITIES RECORD FORM

Section 1 The Importance of Tracking Your Feelings

In order to take advantage of these newly learned skills, self-examination is important. The purpose of the exam is to ask yourself, "How do I feel now" or "How do I feel today". Let's practice how to monitor our mood.

step one: Start with a blank mood monitor. Examples are below.

Step 2: At the end of each day, you will write down the numbers on the mood watch. This number is the performance

How did you feel that day. You will rate your mood on a scale from 1 to 10.



数字 1 代表你情感的最低状态 数字 10 代表你情感的最佳状态

Step 3: Complete the mood monitoring form and simply write down 2 reasons: Why are you in the mood today so? Try to be as precise and detailed as possible.

As you fill in this number at the end of each day, think back to how you generally feel about your day today. Most people experience ups and downs throughout the day, so try to pick a general feeling that you can relate to throughout the day.



mood monitor

Use a 10-point "mood thermometer" to rate your daily mood.

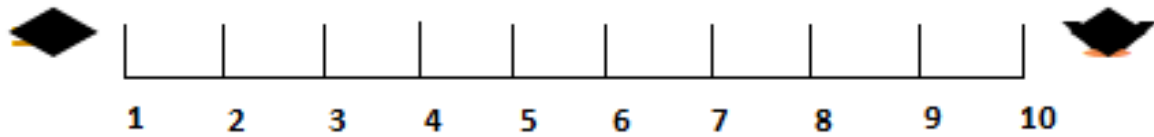
If you feel good, circle a high number.

If you feel "fair", score 5 points.

If you feel down, in a bad mood, sad or upset, please circle a lower number.

Next to your daily mood rating, briefly state the main reason and explain how you feel about that mood.

Be as specific and concise as possible.



date	Mood Score	Reasons for Mood Scores

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chapter 2

Record your own exclusive and enjoyable activities

Let's think of some enjoyable activities together that you can do regularly. Start with some simple activities.

Below are some activities that you may find enjoyable.

- singing or listening to music
- **walk**
- Eating out with friends or family
- See a movie
- Picnic in the park
- a friend is visiting
- look at the moon and stars
- with your children or grandchildren
- watch your favorite tv shows
- square dance
- go shopping or buy something for yourself or someone special
- listen to the radio
- sports
- cook your favorite food
- Watch small video on mobile phone
- drive for a drive
- see or smell flowers
- gardening
- **nap**
- **read**
- do handicrafts

Which of these activities do you believe you can do on a daily basis? If you have them, write them down on your personal enjoyment activity sheet. If there are some activities that are not in this list, please add them to the table. Remember to pick something that is easy to do in your daily life. Try to list 10 items, the more the better. (see exercise section)

The goal is to be able to do four pleasant activities a day, and it is only when you consciously want to do it and do it on your own initiative! Research shows that if you do it regularly and consistently, your mood will improve.



Exercise 1: Pleasure Activity Record Sheet

My Happy Events Record Sheet (2021)

Please list 10 happy events that you consciously want to do and do it on your own initiative. one day

Among them, there will be a "do" in the event column✓", and added up to several pleasant events in one day.

Goal: To be able to do a pleasant event in a day.

date joy event	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Total for the day							

Most people can't imagine ten regular things to do. Please think of ten pleasant activities as much as possible. During the day, put a "" in the activity column.✓", and did a few pleasant activities in one day.

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Section 3

Choose an enjoyable activity for you and your loved ones

We identify enjoyable activities as things you can do on your own, without the presence of your loved ones. But because you're a caregiver, you can't always be alone, you've got a lot to do, but we think it's just as important that you enjoy life with your loved ones. So together, we'll create a list of enjoyable activities that you and your loved ones can share.

List of activities you can do with your loved ones

● listen to music (or play a simple instrument)

- go to the riverside
- Listening to or reading stories, newspaper articles, poems, etc.
- go out to eat together
- cooking and preparing snacks
- Write letters, cards, etc.
- View albums and photos
- Go to the movies
- Go to a senior college or other entertainment venue
- exercise
- watch sports
- See the clouds or explore nature
- see, smell, or admire flowers and plants
- look at the moon and stars
- listen to the radio
- meditation
- sitting in the park
- Dance

- shopping for yourself or others

● Relax and take a walk anywhere!

- Read travel brochures or magazines

● with animals or pets

- observe birds or animals

● do handicrafts

- Organize drawers or closets

● watch mobile video

- go for a drive

- Recall and discuss happy memories

- have more friends

- Have a coffee or tea in a cozy place

- Rub each other's neck and shoulders

- with children/with grandchildren

- read literature

- Memories of time with friends

- Organize old photos



Exercise 2: Pleasure Activity Record Sheet

Our Pleasure Activity Sheet

In the table below, think of 10 enjoyable activities you enjoy. Arrange events in order, favorite event move at the top. Remember, the most enjoyable things may not be the most ideal things, but you can often

The most enjoyable thing to do.

- 1, _____
- 2, _____
3. _____
4. _____
5. _____
6. _____
7. _____
- 8, _____
- 9, _____
10. _____

Important things to remember when choosing and planning activities with loved ones

Simplify Activities: Start Small and Simple

Do not force your loved one to participate: Encourage or reward him/her often do other activities do short activities

Ask your friends and family for help if you can

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Dementia Caregiver Guidance Brochure

04 | Lesson 3

Managing Problem Behaviors and Communication Skills:

activity modification





Section 1 Understanding Problem Behavior

Section 2 "Trigger Event-Reaction-Response" Chain Section 3

Communication Skills

Exercise: Behavior Record Sheet

Section 1 Understanding Problem Behavior

- Behaviors are specific, observable things that a person does.
- Behaviors can increase (eg, sleep, eat) or decrease (eg, wander, over and over again) ask the same question).
- Behavior should be described in such a way that it is measurable or recordable.
- A good behavior description: You can record when, where, who, and what happened to the behavior.
- Because we can measure them (talking, walking, yelling), how often and how long they occur Sustained time or just sitting still, all of which can be called behaviors. We cannot directly
- measure thinking, feeling, concentration, and other "mental processes" that are not is behavior.

Disturbing behaviors caused by dementia:

- refuse your assistance with bathing, dressing or other activities;
- missing or misplaced things or things;
- do things that embarrass you;
- looking anxious or worried;
- threaten to harm oneself;
- Verbally provocative to others;
- Expressing hopelessness or sadness about the future ("I never did anything right"...);
- Ask the same question multiple times;
- start something, but can't finish it;
- waking you or other family members at night;
- participation is a potential danger to self or others;
- threaten to harm others;
- weeping and weeping;

Of course, perhaps your loved one has other behaviors that make your specific care situation more difficult.

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behavior definition

We need to figure out why your loved one is having behavior problems. As we face these difficult and challenging behaviors, it is important to remember that all behaviors have a purpose. This seems odd. Yet even behaviors that seem odd to us may "make sense" for people with dementia. For people with memory problems, the behavior may occur for several reasons.

Tips:

It may seem odd, but behaviors, including difficult ones, are often purposeful. While setting goals can be challenging, it can be very useful to help increase, decrease, or maintain behavior.

For example, some people with memory problems have difficulty finding the right words to express themselves. They may not remember the word "pain" and instead yell when trying to get out of bed because of back pain. If we want to stop yelling, we must first understand why yelling happens. Behaviors can have many purposes, and these purposes can change over time and from person to person. These behavioral changes are often key signals of increased stress in caregivers.

For people with memory problems, there are at least 4 main reasons for their difficult and challenging behaviors:

1. Get attention
2. Increase sensory stimulation
3. Approaching objects
4. Avoid or avoid unpleasant things

As we have seen, most carers face many worrying, burdensome, frustrating or disturbing behaviours during the caring journey. Now that we know what behavior is, we'll teach you some ways to help you determine the purpose of your loved one's behavior.



environmental factor

Triggers can be any of the following:

- an event or activity, such as noise (loud TV) or a request made to a person (such as taking a shower) a general
- condition that affects a person in the long term (eg, time of day, season, and/or physical illness) cues in the
- environment, such as car keys or the presence of others.

When identifying the triggers for a particular behavior, keep the following questions in mind:

1. What time of day did the behavior take place?

2. Is the environment quiet or noisy?

3. Is the environment dark or bright?

4. Is your loved one alone or is someone present? If anyone was present, who was it?

5. Did a specific event occur, such as bathing, taking medication, or providing other direct care?

6. Does your loved one want something like food or drink?

7. Are your loved ones seeking attention?

your reaction to your loved ones

Your reactions to the actions of your loved ones include:

- what are you doing
- your feelings. (Remember to use relaxation techniques if stressed out) Your
- loved one's behavior.

As you think about how you or a loved one will react after the behavior, keep the following questions in mind:

1. Is the environment quiet or loud?

2. Have you stopped activities (eg, bathing, taking medication, or providing other care)?

3. Did your loved one get what he/she wanted (such as food or drink)?

4. Are your loved ones being noticed?

5. Are your frustrations and stress increasing or decreasing? (Check the effect of the course)



Section 2 "Trigger Event-Reaction-Response" Chain

deal with problem behaviors

The first step in identifying the purpose of the behavior is to notice what happens before and after the behavior. Something usually happens before and after the behavior.

What happens before an action is called a "triggering event", and what happens after the action is called a "reaction".

trigger event

In order to understand the purpose of the behavior, it is important to focus on what happened before the behavior.

A "triggering event" can refer to any of the following:

- An event or activity, such as a loud noise or a request made to a person (e.g. bathing) General
- things that affect a person in the long term (e.g. specific time of day, season, illness) Reminders
- of surroundings and things (e.g. keys, photos) , clothes, another person)

"Trigger event-reaction-response" chain

A person with memory problems has difficulty learning new things. For example, it is difficult for him/her to distinguish between right and wrong behavior. The only thing you can control is the trigger event and your own reaction.

When we can't change the triggering event, changing your response and coping patterns will keep your emotions stable.

Exercise: Change "Trigger Event" and "Reaction"

Now let's discuss three ways to change your response:

- Change "Trigger Event"
- change our "reactions"
- Change the "trigger event" and our "reaction"



Case 1

Troubled behavior: Asking the same question repeatedly

After breakfast, Dehua asked his wife Shufen: What are you doing? Shufen: I'm cleaning up. Five

minutes later, Dehua asked Shufen again: What are you doing? Shufen: I'm doing the dishes. Five

minutes later, Dehua asked Shufen again: What are you doing?

Shufen became annoyed and said: I told you just now that I was washing the dishes. Stop asking the same question all

the time!

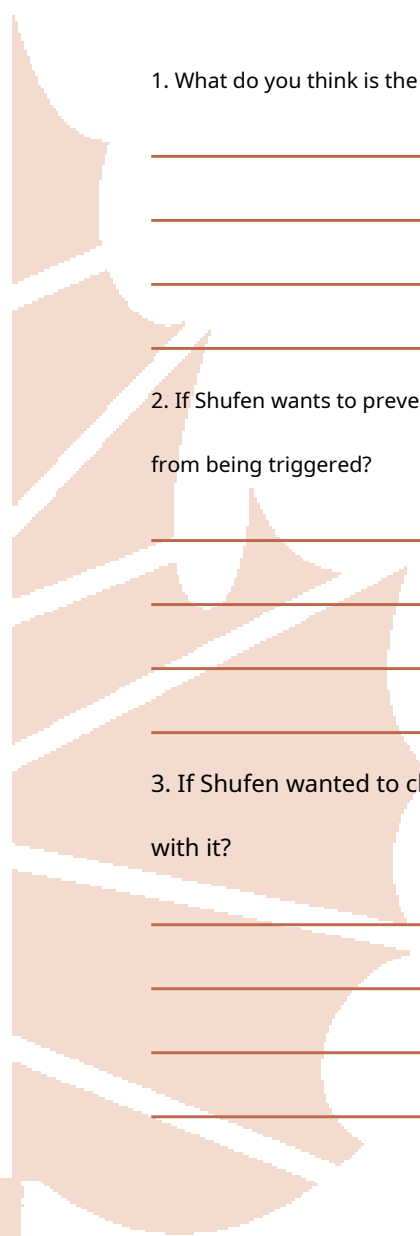
think:

1. What do you think is the purpose of Dehua's actions?

2. If Shufen wants to prevent this behavior from happening, what coping strategies can Shufen take to prevent Dehua's behavior from being triggered?

3. If Shufen wanted to change her reaction to prevent her mood swings, how would you advise Shufen to deal with it?

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Section 3

communication skills

When a loved one doesn't understand what you're saying, or when a loved one can't find the words to express their thoughts, it can be frustrating and embarrassing for everyone involved. We'll discuss some of the key issues you face in communicating with your loved ones.

What is the state of the environment?

People with memory problems can have trouble filtering out things.

For example, if the TV is on and you are about to talk to your loved ones. He/she will not be able to pay attention to two noise sources at the same time. For people with memory problems, having two sources of information at the same time is overwhelming and overwhelming. The ideal communication environment with your loved one is quiet and free of distractions (eg, no television, music, or other conversations).

Did you startle your loved ones?

Memory problems can lead to confusion and disorientation. Approach your loved one from the front of your loved one. People are easily startled when you approach suddenly or from behind. It can also be helpful to remind your loved ones frequently what happened. For example, when it's bath time, approach your loved one gently and gently tell him/her every step.

How much information have you provided?

People with memory problems may not be able to remember many words at once. Try to speak slowly and give them more time to answer. Try reciting 10 in your mind before asking your loved ones questions.

Avoid communicating in the following ways:

- Don't argue with your relatives
- Don't tell him/her what not to do. Instead of saying, "You can't go out," try saying, "No
Let's sit down and read the newspaper together."



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Ideal Steps for Confident Communication

Confident communication is another useful skill for caregivers to communicate with professionals, family members and friends.

Please Note: This Rational Step is not designed to communicate with your loved ones as

It is often overcomplicated for people with memory problems.

5 Ideal Steps to Confident Communication

(1) identify (2) describe (3) express (4) assert and (5) listen

(1) Identification

Identify a situation where you can use assertive communication. For caregivers, this is usually about: asking someone for help with caring tasks, household chores, or even observing the person being cared for while you are resting. Discuss the needs of the care recipient with a health care or other professional. Talk to family and friends about other issues that are important to you.

(2) Description

Describe your situation. Speak clearly your thoughts and feelings.

(3) Expression

Express what you need to know or what you want your audience to do for you. If you can offer something in return, express it.

(4) Assertion

Assert why you need this request and how it helps.

(5) listen

Listen to whether the other party can meet the requirements. If so, say thank you and explain how or when you will do things for them. If he or she cannot meet the requirements, ask if a different time or requirement is available, and then start negotiating.

Tips:

Perfection is not the goal, learning and practicing skills is the goal.



Preparing for your doctor's visit

We will also provide a medication list to facilitate communication between you and your doctor.

看医生的就诊前准备事项：医疗项目

请保留一份患者的用药处方，每一次就诊时将它带去给医生，你也可以将实际的药罐带去给医生参考。

药品名称	用药目的？药物说明？（药的外表形状像什么）	开药医师	用药量	用药指示
例如： 阿司匹林	心脏病药（大小如手表电池；白色；中间有一条线）	张医生	10mg (毫克)	每天用 10 毫克的阿司匹林 2 次

在您购买药物之前，或是从另外一位医师拿的药，亦或是购得非处方药之前，请先咨询您现在的主治医师的意见。

看医生的就诊前准备事项：医疗项目

请保留一份患者的用药处方，每一次就诊时将它带去给医生，你也可以将实际的药罐带去给医生参考。

药品名称	用药目的？药物说明？（药的外表形状像什么）	开药医师	用药量	用药指示
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在您购买药物之前，或是从另外一位医师拿的药，亦或是购得非处方药之前，请先咨询您现在的主治医师的意见。



Exercise: Behavior Record Sheet

Method: Please use this record sheet to fill in the behavior of the "care receiver" that annoys you, i.e.

The triggers for your mood swings, your reactions, and your coping strategies.

"Trigger event-reaction-response" chain

date

time

① Identify the triggering events that make your mood swings.

② Then think: Why did the triggering event affect your mood?

③ Then think about how you all reacted and responded to this triggering event?

④ Think of a coping strategy that can change the trigger event or your own response, and implement it.

⑤ What changes have you observed since you implemented this coping strategy? Please note the change to the fifth space.

* We encourage you to practice a few times on your own to help you see what's not working and what's working.

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Dementia Caregiver Guidance Brochure

05 | Lesson 4

Future Planning and Care Confidence Enhancement:

Revision of the activity





Section 1 discusses reserved medical directives

Section 2 Balancing Self-Care and Caring for Others

Section 3 Identifying Resources and Using Strategies

Exercise: Future Planning Sheet

Section 1 Discuss Comfort Care

What is Comfort Care?

Comfort Care helps meet the emotional and spiritual needs of critically ill patients, as well as manage pain and treat physical problems. (such as shortness of breath, constipation, nausea, or skin problems). The goal of comfort care is to improve the quality of life of individuals and families during times of illness, death and grief. If quality of life is your goal, comfort care can help you and your loved ones. You can plan for comfort care early in a serious illness, rather than waiting until the end. As part of your healthcare plan, you may also need to learn about medical techniques such as CPR, artificial nutrition, and dialysis. Because comfort care doesn't mean "no treatment."

Dementia causes a slow and permanent loss of cognitive abilities, such as speaking, making decisions, and thinking. In advanced dementia, the patient is completely dependent on others. They are unable to speak, walk or move, and have no control over bowel and bladder function; they have poor appetite, difficulty swallowing and eating, and do not know their loved ones. Despite advances in medicine, the goals of medicine: to cure disease, restore health and relieve symptoms, do not always happen. Patients can survive for months or years with life-extending machines and medical measures, but never recover. While comfort care may not prolong life, it will provide the greatest improvement in quality of life, an option you may wish to discuss with your doctor.



question

What can comfort care provide in a critically ill situation?

Do I need life support technology to prolong life in case of serious illness? Who should I talk to about my views on these situations?

What are the benefits and problems of aggressive medical treatment for people with serious illness?

How do I know when comfort care is better than aggressive medical treatment?

pain management

People with dementia are often overlooked by medical research on pain management, but it has been shown that they frequently experience pain that is often overlooked and not addressed.

- In the final stages of dementia memory loss, their families will experience
- distress. Pain should be treated as carefully as disease.
- In many cases, severe pain and physical distress may be relieved by medical procedures (narcotic and non-narcotic), surgery, and non-medical methods such as relaxation therapy, massage, and nursing care.
- People with dementia sometimes cannot tell you that they are in pain.

How to ensure good "pain management"?

- Ask your doctor how he/she will manage your loved one's pain. When you and your loved ones do pain management,
- consider the pros and cons. Some people would rather endure more pain (eg it means staying more awake).
- Pain should be taken seriously.



chapter 2 Balancing self care with caring for others

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In the care, physical and mental illness, family tension, etc. are frequent problems. even from

If you need some personal time for yourself, or asking someone to take care of the elderly temporarily, you may also feel guilty.

Realistically assess your own caring abilities and ask for help when you need it, so you can feel better

It is possible to control and take care of it.

In addition to recognizing the resources an individual has and mobilizing support from other caregivers, correctly foreseeing the future

What needs to be done to care for the elderly and take targeted actions can increase the sense of control and prevent the loss of control caused by the increasing number of caregiving tasks.

Ten Tips for Family Caregivers

- Choose to take control of your life and don't let a loved one's injury always take center stage. Remember
- to be kind to yourself. Love yourself, respect yourself, and value yourself. What you do is not easy, and it is worth having some good times just for yourself.
- Watch for signs of depression and seek professional help when you need it. Accept when
- someone offers to help, and tell them exactly what can be done. Enrich yourself and take
- control of your loved ones. knowledge is power.
- Taking care is not the same as digging in. Be open to techniques and ideas for improving family self-care skills. Trust your intuition. Gets you in the right direction most of the time.
- Mourning what you lost and building new dreams.
- Stand up for your rights as caregivers and citizens.
- Seek support from other carers. Knowing that you are not alone can bring enormous power. These tips illustrate the importance of fueling yourself and having ongoing positive self-talk.

Catherine McGinnis-Dietrick, translated by Sui Yujie (2008) Social Work for the Aged: Assessment and Intervention in Physiological, Psychological and Social Aspects (Second Edition) / Social Work Practice Translation Series. Beijing: Renmin University of China Press .

Self-care isn't just about taking time for activities or taking a break from someone you care for. It can help you build



Create a new mindset, plan long-term personal care responsibilities, be open to help from others, and have a positive assessment of your own performance as a caregiver.

Section 3 Identify resources and apply strategies

Your loved one's future plans face many questions. These issues can be difficult to discuss, but it is important that you plan ahead, identify resources and apply the right strategies. You can negotiate with your loved one, but remember that the decision rests with the person being cared for.

You may think that discussing the Advance Care Plan is a burden to family members, but they are likely to thank you for it, because most people have to guess and bear a lot of pressure to make these important decisions during these difficult times. While we can't cover all the issues you may face when planning for the future, we will discuss some of the most common issues raised by carers, including: Families and other important people tend to delay making important decisions until a crisis occurs. But, as you can imagine, making decisions under pressure is not advisable. By contrast, having discussions before a crisis hits may help your loved one's decision-making.

We know that families already spend a lot of money on these issues. However, no matter where you are in the process, our goal is to help you be more confident and informed when making these difficult care decisions.

Introduction to Care Options

home health care

A range of services can be provided for your loved one while living at home.

Possible services include:

- * Personal care: bathing, grooming, dressing, cooking
- * Healthcare: medication administration, injections

Home health workers are available through companies that specialize in this type of care. Often caregivers provide most of this care themselves, relying on professionals for more advanced care if necessary.



Adult Day Care Program

Provides daily activities designed for people with dementia.

These programs focus on keeping a person physically and mentally active and can be very helpful in improving quality of life. Carers are also allowed time to rest, take care of their own personal needs or maintain a job. Transportation to and from the patient's home is sometimes available.

Caregiver Respite Care

Allow the carer to take a break to care for his or her own personal needs.

You can get caregiver respite care at home or in specially designed facilities such as adult day care centers.

Depending on the project, it can last from a few hours to a few days.

institutional care

People with dementia are asked to move to a different living environment to meet care needs.

General Aged Services: Provides a range of services including meals, activities, security and assistance with bathing, dressing and household chores.

Dementia care beds: Some institutions have dementia care beds, and conduct special assessments on dementia care for patients staying in dementia care beds, formulate exclusive care plans, and staff relevant practitioners for dementia care. Partnerships with neurologists or psychiatrists in healthcare settings.

palliative care or hospice

is a comprehensive approach to the treatment of end-stage disease. It focuses on meeting physical, mental and spiritual needs.

The goal is to safeguard the quality of life of the elderly at the end of life by reducing pain and suffering while helping patients maximize their function.

Respect for the patient's culture, beliefs and values is an important part of palliative care.

Palliative or hospice care can be provided at home.

Finally, we encourage you to share your care information options with family and friends so they can understand them too.



Exercise: Future Planning Sheet

You have a variety of options for caring for your loved one during their illness, each with their own advantages and limitations. We'll draw some of the care options on the "Continuum of Care Diagram" presented, then discuss each option in detail. But first, we would like to ask about any services your loved one is currently receiving. Please answer the following questions:

1. What informal services does your loved one receive (eg, services provided by family, friend care options)?
2. What formal services does your loved one receive (eg, family doctor, community meal delivery, adult day care)?
3. What is your experience with these care modalities? What are their strengths? What are the limitations?

- care options
- home health care
- Adult day care
- institutional care
- Comfort Care
- Hospice

- Legal Issues
- advance medical directive
- Do Not Resuscitate (DNR) Order
- Hospice Decisions
- life support measures
- pain management

Strengths and Limitations of Nursing Experience

Service type	Advantage	limited
home health care		
community care (Example: food delivery)		
Adult day care		
respite service		
Comfort Care		
Hospice		

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06 | Summary





Summarize

Why is this course important?

For people with dementia and caregivers, behavioral problems can be stressful for both parties. Inappropriate stress coping can trigger mental health problems in caregivers that require timely prevention and intervention.

How will this course help me?

Accompany you in the care process, give you more strength when you are helpless, relieve your stress, and make you feel happy.

What will I learn?

1. Things to keep in mind when dealing with behavioral changes

- * It is common for behavioral problems to be stressful for both the patient and yourself.
- * Try to make the patient feel more comfortable.
- * Find ways to prevent or reduce behavioral problems, such as using memory aids.
- * Try to distract the patient and not argue.
- * **When one method doesn't work, try another.**
- * Recognize that there can be good and bad days.
- * Consult a doctor to determine any questions related to medication or disease.
- * Determine if the environment or your communication methods may be causing some specific behavioral problems.
- * Remind yourself that behavioral problems are part of the disease, but other possible causes should be identified before accepting the disease as a cause.

2. Practical tips for not blaming yourself, sharing your feelings with others, and making time for yourself



Here are some tips for related courses. If you haven't already received tutoring, you can do it after class.

- * Keeping a happy mood can reduce the burden of care. Learning information breathing helps you to use relaxation techniques anytime, anywhere, and to clarify your problem-solving ideas. If you want to understand your emotional state, watch Lesson 1 and monitor your emotions using the Mood Rating Scale.
- * It is important to make time for yourself. Do something you value in life, like being with other people or enjoying your favorite hobby. If you want to learn more about the planning of enjoyable activities, see Lesson 2, Section 2, and make time for your own enjoyable activities.
- * Don't blame yourself or the person with dementia for your problems. If you want to learn how to control your emotions, see Lesson 3, Section 2, to understand the chains before and after behavior, and use the behavior log to help you think.
- * Planning for the future can reduce panic. Comfort care can help you balance self-care with caring for others. If you want to know what resources are available, see Lesson 4, Section 3, and use the Behavior Planning Sheet to help you make decisions.



you have completed the course study,

Congratulations!