

iSupport For Dementia

Training and support manual
for carers of people with dementia





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iSupport for dementia. Training and support manual for carers of people with dementia

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PREFACE

Dementia is a major cause of impairment that affects a person's memory, thinking and behaviour, and interferes with one's ability to perform daily activities. It affects people worldwide, in particular older people. Globally, families provide the majority of care to people with dementia. The impact of dementia is significant to the individual who lives with dementia, their families, societies and countries, both in financial terms and human costs.

The *Global action plan on the public health response to dementia 2017-2025* represents an important step forward in achieving physical, mental and social wellbeing for people with dementia, their carers and families. It is an opportunity for individuals, communities and countries to realize the vision of a world in which dementia is prevented and people with dementia and their carers receive the care and support they need to fulfil their potential with dignity, respect, autonomy and equality.

Being a carer for someone with dementia may affect one's physical and mental health, well-being, and social relationships. Long-term care systems must account for the significant emotional, financial and social impact of caregiving on families and relatives, while addressing the needs of people with dementia. This includes providing carers with access to education, skills training, respite and social support through affordable, evidence-based resources.

To address this need, the World Health Organization (WHO) has developed iSupport, an online skills training and support programme for carers of people with dementia. This iSupport manual allows carers who do not have access to the internet, or who prefer a manual, to benefit from the tool. The iSupport online programme and manual are currently being field-tested. It is our hope that the programme will be adapted by, and implemented in, many countries around the world.

Dévara Kestel

Director, Department of Mental Health and Substance Abuse



USER GUIDE

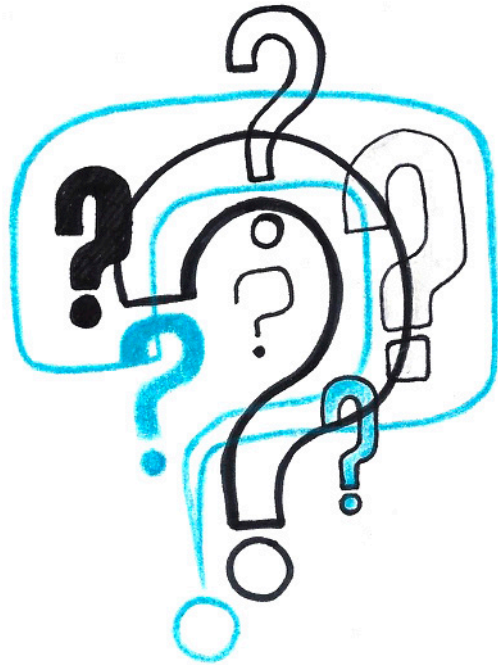
Worldwide, carers of people with dementia should have access to information and support tailored to their needs in order to effectively respond to, and manage, the physical, mental and social demands associated with caring for someone living with dementia. iSupport has been developed to provide accessible, evidence-based training and information, tailored to carers' needs. It aims to improve knowledge and caregiving skills, such as carers' ability to cope with dementia symptoms and care for themselves. iSupport seeks to enable people with dementia to live in the community while preventing or reducing carer stress. The lessons included in this manual were carefully designed to help carers tackle the important challenges that they may face when caring for someone living with dementia.



What is included in the iSupport manual?

The manual is organized into five modules (see Figure 1 page vi): (1) **introduction to dementia**; (2) **being a carer**; (3) **caring for me**; (4) **providing everyday care**; and (5) **dealing with behaviour changes** that might happen in people living with dementia.

Module 1 provides an introduction to what dementia is, including what happens to people with dementia and what to do if you think that your family member or friend has dementia. **Module 2** focuses on improving communication, shared decision-making and involving others in caring for the person living with dementia. **Module 3** aims to reduce carer stress by making time for pleasant activities and thinking differently. **Module 4** focuses on eating and drinking, including creating more pleasant mealtimes and preventing health problems, using the toilet and continence care, and personal care.



Finally, **Module 5** provides an introduction to common changes in behaviour for people with dementia that might be distressing and upsetting for both the person with dementia and you as the carer. These symptoms include memory loss, aggression, depression and anxiety, difficulty sleeping, delusions and hallucinations, repetitive behaviour, walking and getting lost as well as poor or decreased judgement.

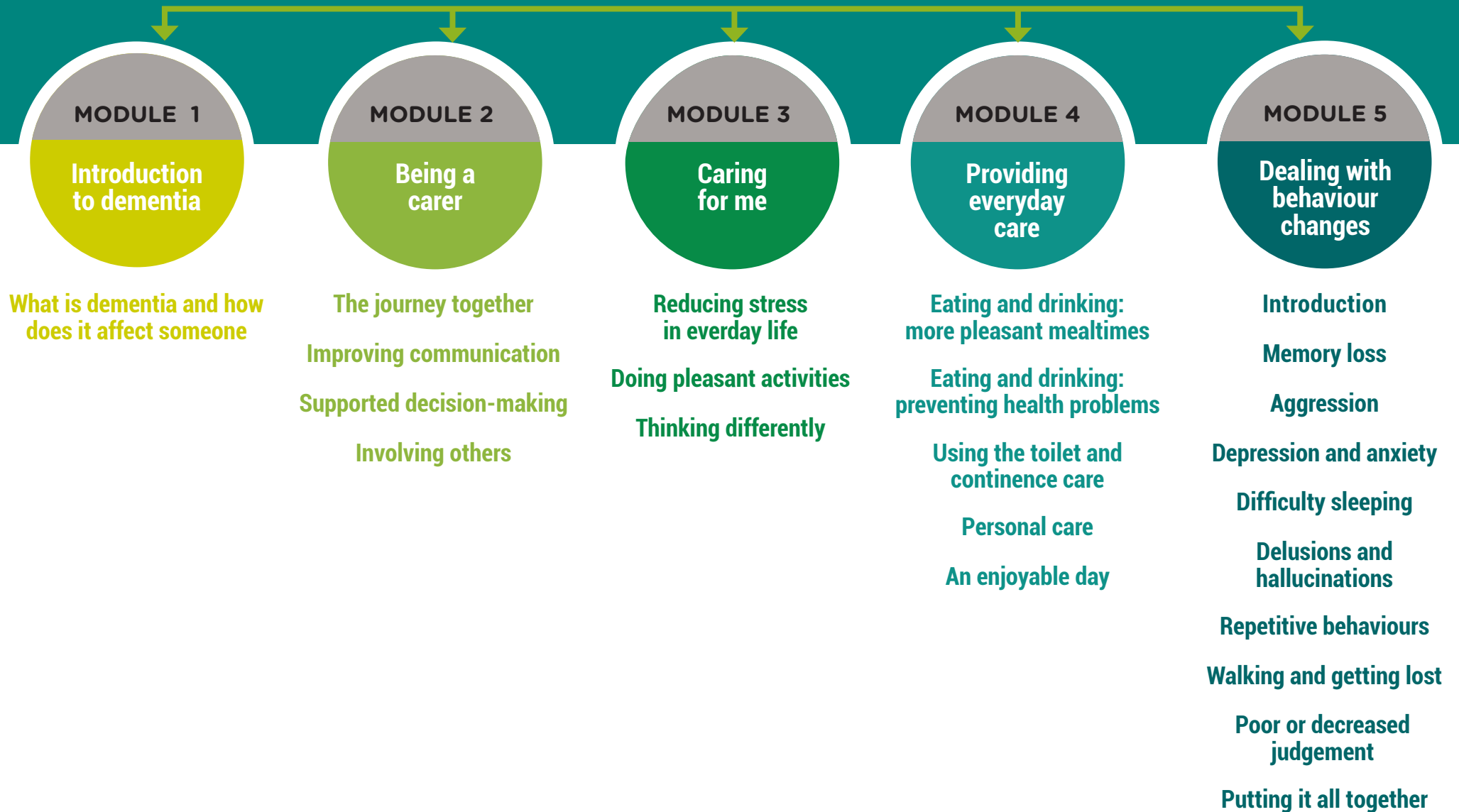
Who is the target audience?

This iSupport manual is primarily for carers of people with dementia, including family members and relatives, friends, and other carers. However, iSupport may also be of interest to others, for example:

- nongovernmental organizations (NGOs) providing skills training, support and/or information to carers of people with dementia;
- health and social care workers providing care and information to carers of people with dementia; and
- private sector representatives involved in the development of health technologies for dementia, dementia health care service delivery or health care insurance.

Figure 1

iSUPPORT



How was iSupport developed?

iSupport is grounded in WHO's Mental Health Gap Action Programme (mhGAP) guidelines for carers of people with dementia. mhGAP aims to scale health and social care services for mental, neurological and substance use disorders for all countries, with a focus on low- and middle-income countries (LMICs). iSupport was developed based on evidence related to the feasibility and effectiveness of carer training and support interventions, both in person and online. Finally, the programme was developed in collaboration with international experts in the field of caregiving for people with dementia and internet-based interventions, and reflects the voices of carers of people with dementia. For more information on the development of iSupport see Pot et al (2019)¹.

How to use this iSupport manual?

iSupport has been developed as a self-help tool for carers of people living with dementia. Each module is divided into individual lessons (see Figure 1). All lessons are structured in the same way. At the beginning, there is an overview of why the lesson is important, how the lesson will help you as a carer and what you will learn. Each lesson then consists of a mixture of brief reading to provide new information, descriptive examples, multiple choice questions and activities to practice what you have learned. You may choose to work through the entire manual from beginning to end or select the lessons that are most relevant to your everyday life. You can also come back to individual lessons.



¹ Pot AM, Gallagher-Thompson D, Xiao LD, Willemse BM, Rosier I, Mehta KM, Zandi D, Dua T. iSupport: a WHO global online intervention for informal carers of people with dementia. World Psychiatry. 2019.

Below is a guide to the individual exercises and activities that you will encounter throughout the manual. These exercises and activities allow for you to check your understanding and reflect on your learning in practical ways.

Tip/Reminder/Keep in Mind



Tips help you reflect on your learning or give practical reminders of how to apply what you have learned to your everyday life.

Check your understanding



Here you will be asked a question about what you have learned. Answers are at the end of every lesson.

Example: What color is the sky?

- Green
- Blue
- Red
- Orange

Activity



Here you will be asked to reflect upon how caregiving for a person with dementia is affecting your life or the life of the person with dementia.

Example. How are you feeling right now? *Please select all that apply.*

- Sad
- Happy
- Angry
- Confused

Relaxation activity



These exercises will help you feel calm and reduce stress. We include one relaxation activity at the end of each lesson.

There is also an entire lesson on relaxation activities included in Module 3.

Other uses of iSupport

Although iSupport is primarily a self-help tool, we encourage a broader use. For example, iSupport might be supplemented by guidance from volunteers or health care workers to create more impact. The iSupport manual can also serve as a tool to structure educational or support group meetings for carers of people with dementia, or it may simply be used as a resource tool for participants of self-help groups. Finally, health care workers might find iSupport useful in assisting and supporting carers.

Please note that both the iSupport online training programme and this manual are subject to ongoing rigorous field-testing and evaluation. More research is needed to evaluate the effectiveness of local adaptations and implementations.

How to adapt iSupport?

The iSupport manual represents a template that can be adapted to national or local contexts and needs. An adaptation and implementation guide is available to assist countries/communities in this process.

WHO owns the copyright on iSupport. If you are interested in adapting and implementing iSupport, please contact WHO at whodementia@who.int to request a copyright license. This applies to both the iSupport manual and the online programme, accessible at www.iSupportForDementia.org.

MODULE

1

INTRODUCTION TO DEMENTIA

Introduction to dementia

Why is this lesson important?

Dementia is a disease that can be overwhelming for the person with dementia, but also for you as a carer. There are many myths about dementia and learning more will help explain some common misunderstandings.

How will this lesson help me?

This lesson helps you to understand the basics of what dementia is and how it affects someone. This information is essential when you are a carer.

What will I learn?

1. What is dementia?
2. What causes dementia?
3. What happens to people with dementia as the disease progresses?
4. What to do if you think that the person you care for has dementia?
5. How to reach out for help?
6. What is the focus of this manual?

1. What is dementia?

Dementia occurs as a result of a disease process that increasingly damages the brain over time. Dementia affects all groups of society and is not linked to social class, gender, ethnic group, or geographic location. Dementia is not a part of normal ageing. Although dementia is more common among older people, younger people can also be affected.

2. What causes dementia?

Dementia is caused by a number of diseases which destroy nerve cells and damage the brain, as outlined below.

Alzheimer's disease

Alzheimer's disease is the most common cause of dementia. It destroys brain cells and nerves, disrupting the transmitters that carry messages in the brain, particularly those responsible for storing memories.

Vascular dementia

Vascular dementia occurs where blood vessels are damaged, the supply of oxygen to the brain fails and as a result, brain cells die. The symptoms of vascular dementia can occur either suddenly, following a stroke, or over time, through a series of small strokes. Vascular dementia accounts for 20%-30% of all cases of dementia.

Dementia with Lewy bodies

Dementia with Lewy bodies is similar to Alzheimer's disease in that it is caused by deteriorating and dying nerve cells in the brain. It takes its name from abnormal deposits of protein - Lewy bodies - in the nerve cells of the brain. It may account for around 10% of all cases of dementia. Approximately, half the people with Lewy body disease also develop signs and symptoms of Parkinson's disease.

Fronto-temporal dementia

In fronto-temporal dementia - including Pick's disease - damage is usually concentrated in the front part of the brain. In the beginning, personality and behaviour are more affected than memory.

Rarer causes of dementia

There are many other rarer causes of dementia, such as alcohol-related dementia and dementia due to HIV/AIDS.



3. What happens to people with dementia as the disease progresses?

Every person is unique and dementia affects people differently. No two people will develop the same difficulties in exactly the same way. It is not just the brain damage that determines how dementia affects someone, but also other factors including an individual's personality, life course, general health and functioning, and living environment.

1. Check your understanding



What happens to people with dementia?

People with dementia often forget things or have trouble with their memory. *Select the correct answer.*

- TRUE
- FALSE

Dementia has stages

Dementia symptoms can range from minor memory loss to severe difficulties in memory and thinking that make it impossible to manage daily activities without help. It can be helpful to view dementia as a series of stages to understand the illness. However, it is important to realize that this only provides a rough guide to the progress of dementia. Not all people with dementia will have all symptoms and some of the symptoms may only appear at one stage of the disease.

In the early stage of the disease, people with dementia may have memory problems, become disoriented with respect to time, lost in familiar places and show difficulties making decisions.

As dementia progresses to the middle stage, people with dementia may become very forgetful and in need of help with daily activities such as shopping, dressing, and washing.

In the late stage, people with dementia may not recognize relatives or friends anymore may display changes in behaviour that can be upsetting and distressing to the person with dementia and those around them.



1. Activity



Here are some common things that may happen to people with dementia.

Do you think that your family member/friend/the person that you care for experiences any of the following?
Please select all that apply.

Does the person you care for...	Examples
Have trouble remembering things that happened minutes before? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Forgetting recent events</i> ● <i>Repeating questions</i>
Find it difficult to perform daily activities? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Money management</i> ● <i>Shopping</i> ● <i>Preparing dinner</i>
Struggle to identify time or place? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Forgetting the date and time of appointments</i>
Communicate differently than they did before? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Difficulty expressing oneself</i> ● <i>Difficulty finding the right words</i>
Misplace things? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Not finding common objects, such as keys</i> ● <i>Suspecting things are stolen</i>
Withdraw socially? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Showing decline in social activity</i> ● <i>Lacking urge to do something</i>
Show changes in feelings or personality? <input type="checkbox"/> Yes <input type="checkbox"/> No	<ul style="list-style-type: none"> ● <i>Having a lot of ups and downs</i> ● <i>Becoming more anxious than before</i>

4. What to do if you think that the person you care for has dementia?

If you think that a family member or friend may have dementia, a good first step is to make sure that they see a medical doctor. The doctor will examine their body and brain functioning.

One important point to rule out is whether the person's memory problems are caused by other treatable conditions such as depression, urinary tract infection, medication side effects, lack of vitamins or a brain tumor.

It is important to identify whether the person's memory problems are really part of dementia or are part of something else. Only a medical doctor can do this, not this manual.

2. Check your understanding

What to do if you think that the person you care for has dementia?

What is the first step if you think that a family member or friend has dementia?

Please put a check mark (✓) in front of the answers that you think are correct and a cross (×) in front of those that are wrong.

First steps

- Call a friend or relative.
- Use iSupport alone for help.
- Call a medical doctor's office and make an appointment.
- The person has been to a medical doctor already and has been diagnosed with dementia.

5. How to reach out for help?

It is important to realize that you, alone, are not going to be able to provide all the care that the person living with dementia needs, especially not as things get more complex over time. So, we encourage you to reach out to family members, friends, and professional organizations or services for help.

In many countries there are several resources that are very helpful. Some are free while others are not. Please contact your local Alzheimer's Association for information, support and care that is available in your area and could benefit the person you care for as well as yourself.

6. What is the focus of this manual?

The focus is on you, a carer of someone with dementia.

Dementia can be overwhelming. For this reason, iSupport provides you with support to cope with caregiving on a day-to-day basis. It is really important that you not only take care of the person living with dementia but also take care of yourself. iSupport will show you how. It will also show you some common scenarios that might happen with people with dementia so that you are aware and can practice how to respond to such situations.

Keep in Mind



- Dementia affects a person's brain.
- Dementia is common, especially in older people.
- Dementia is a disease, not a part of ageing.
- As a first step it is important to see a medical doctor, if possible.
- It is important for you to take care of yourself, not only the person you care for.
- iSupport can support you as a carer.



You finished this lesson, well done!

ANSWERS - INTRODUCTION TO DEMENTIA

1. Check your understanding

What happens to people with dementia?

People with dementia often forget things or have trouble with their memory.

- ✓ True: This is the correct answer.
- ✗ False: This is the incorrect answer.

The right answer is that people with dementia often forget things or have trouble with their memory.



2. Check your understanding

What to do if you think that the person you care for has dementia?

What is the first step if you think that the person you care for has dementia?

- ✗ **Call a friend or relative**
While friends and family can offer support, this cannot replace a medical exam given by a certified medical doctor.
- ✗ **Use iSupport alone for help**
While this manual provides information and support, it cannot replace a medical exam given by a certified medical doctor.
- ✓ **Call a medical doctor's office and make an appointment**
This is the best first step if you have not done so already.
- ✓ **The person has been to a medical doctor already and has been diagnosed with dementia**
You have already completed the first important step.

MODULE

2

BEING A CARER

Lesson 1. The journey together

Lesson 2. Improving communication

Lesson 3. Supported decision-making

Lesson 4. Involving others

Lesson 1. The journey together

Why is this lesson important?

Dealing with dementia is a journey you will take together, because it changes the daily life of both the person living with dementia and the carer.

How will this lesson help me?

This lesson teaches you skills for your journey together: to stay connected, involve others, take care of yourself, and plan for the future.

What will I learn?

1. How may your roles change over time?
2. How to stay connected with the person you care for?
3. How to plan pleasant activities and relaxation?
4. How to involve others?
5. How to plan well for the future?

1. How may your roles change over time?

You may feel as if your role is changing. In the early stages of dementia, you may still be able to enjoy many different activities together.

As dementia progresses, the person will have more difficulty with everyday tasks. This will require a carer to do more to help with everyday life, such as giving medications and taking the person with dementia to appointments.

In the middle and later stages of dementia, a carer might need to do even more for the person with dementia. This may include personal care, such as bathing, going to the toilet and dressing.

Some tasks may be challenging for carers and cause stress.

Let's look at an example

Olivia has dementia and lives with her husband Jacob. During the past few months, Olivia's memory loss seems to be more frequent. The last few times Olivia went shopping, she could not remember what to buy. She came home with the wrong things, which was frustrating.

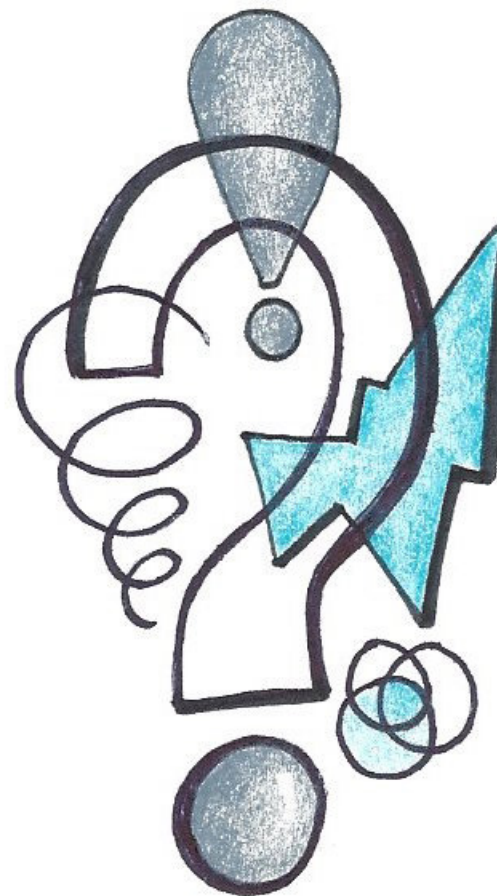
1. Check your understanding



Frustration about memory loss.

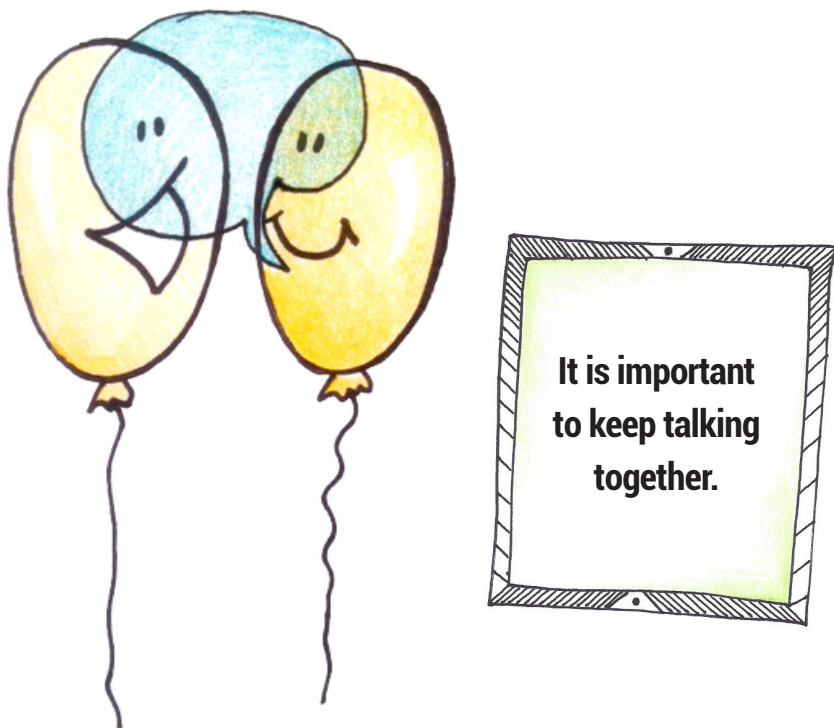
How should Jacob approach Olivia about what happened?
Check all the responses you feel are appropriate.

- Leave Olivia alone and see what happens.
- Ask Olivia to 'work harder' to remember things.
- Do not let Olivia shop anymore.
- Ask Olivia how she feels about her memory loss.
- Do not blame Olivia, but make a shopping list together with her each time prior to shopping.



2. How to stay connected with the person with dementia?

It is important to keep talking together. The sooner you start talking about dementia and its effects on you and the person you care for, the better. Dementia will make doing this more difficult as time goes by. Talk about the changes happening now and what might happen in the future. Stay connected with each other and discuss the changes that may occur over time.



Tip



Here are some small tips to help you communicate better with someone living with dementia:

- use simple sentences;
- try to stay in control of your feelings;
- create time for yourself and for each other.

For more tips on how to improve communication with the person living with dementia, including in the later stages of the disease, read **Lesson 2. Improving communication in this module.**

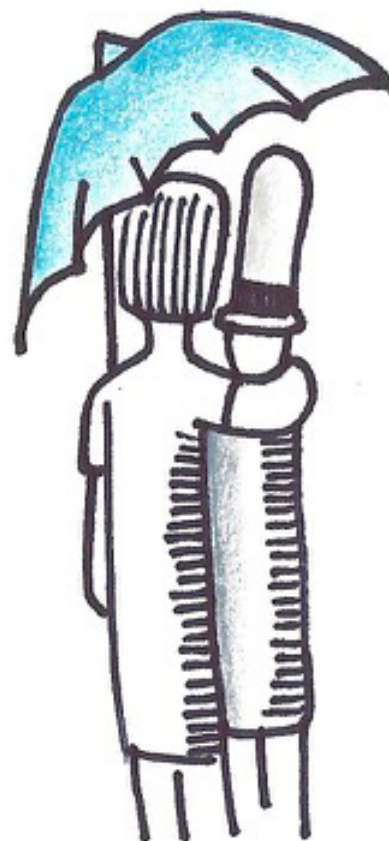
3. How to plan pleasant activities and relaxation?

Providing care may become increasingly time consuming as the disease progresses. Sometimes carers do not take enough time for themselves. It is really important to try and take care of yourself as best as you can, as some carers may break down from the stress. Part of the journey together should include planning pleasant activities and relaxation for yourself.

For more tips on how to relax, read **Lesson 1. Reducing stress in everyday life in Module 3.**

For more tips on how to stay in control of your feelings read **Lesson 3. Thinking differently in Module 3.**

For more tips on how to plan pleasant activities for yourself, read **Lesson 2. Making time for pleasant activities in Module 3.**



4. How to involve others?

Caregiving can sometimes challenge friendships and relationships. It is common for people providing care to feel that no one understands what they are going through. Talking about your thoughts and feelings with others might help make you feel better.

Caring for someone with dementia does not have to be a lonely experience. Let friends and family members know when you could use a break. Caring for a loved one with dementia is sometimes too big a job for one person.

2. Check your understanding



Feeling stressed due to conflicting duties.

Molly's mother-in-law, Jess, has dementia. Molly has a big deadline at work and needs to leave at 7:30 the next morning. The paid in-home helper is not able to arrive until 9:00 in the morning. This leaves Jess alone for over an hour. Molly wonders whether it would be okay to leave Jess alone and feels stressed because she is not sure what to do.

How could Molly deal with the situation?

Check all of the responses that you feel are appropriate.

- Leave Jess alone and see what happens.
- Ask a neighbour to come visit Jess until the paid in-home helper arrives.
- Ask Jess to 'take care of herself'.
- Ask her husband to go into work late so he can be with Jess until the paid in-home helper arrives.
- Ask the paid in-home helper to come in early.

5. How to plan well for the future?

Preparing for the future is a topic that will need to be discussed. You will need to make decisions with the person you care for about preferences for who might provide care, planning for the costs of future care needs, and preferences in case of more advanced care needs and end of life decisions.

Many people providing care, like you, worry about the future. The earlier you plan for the future, the better and easier it will be for you. Planning early will also ensure that the person you care for will be better able to say what their wishes are. Where possible, discuss topics that concern you.

1. Activity



Here are some common questions that carers have. You may want to discuss these with the person you care for.

Write down the responses to the questions.

What are the person's preferences when they are no longer able to bathe themselves? For example, would they prefer a male or female to help bathe them? How do they feel about having a close family member bathe them or would they prefer a qualified professional who is unrelated?

What does the person you care for want to do themselves for as long as possible?

1. Activity

If more assistance is needed at home, what kind of help would the person you care for prefer now and/or in the future?

What are their wishes at the end of life?

If you find it helpful, please write down the questions that you might want to discuss in the space below.

Intimate relationships may change

As you progress through the journey together, partners may experience some changes in their intimate relationship.

At first, sexual relationships between partners may still be possible. As the disease progresses, sexual relationships and physical intimacy may become more difficult.

Let's revisit the scenario with Olivia and Jacob

Olivia is in the early stages of dementia and lives with her husband Jacob. Olivia and Jacob have a healthy, mutually satisfying physical relationship, but Jacob is worried about the day when these relations may stop.

2. Activity

What are some ways that Jacob and Olivia can maintain their intimacy as Olivia's dementia progresses?

Think about it before reading on.

Here are some tips for partners on how to maintain intimacy, even when sexual relations may no longer be possible with the person living with dementia.

Tip



Ways to stay connected

- Use touch, hold hands or do a gentle massage to communicate warmth, connection, safety and love.
- Use music – it is truly a universal language. Play music that the person you care for likes and that makes them feel good.
- Try to maintain your sense of humour. This will help reduce frustration and tension.
- Talk with them about what they like and need – it's an important conversation to have more than once, as things change over time.

Taking care of yourself

One of the most important things to remember as roles change is that you, as someone providing care for a person with dementia, need to care for yourself too. Throughout this manual we will teach you ways to do this.

Reminder



- It is okay to take a break.
- It is okay to ask for help.
- It is okay to feel frustrated sometimes.
- It is okay to feel lonely sometimes if you feel that the person you care for is no longer able to meaningfully communicate with you.

Let's review what you have learned

- As your role changes, it is important to stay connected during your journey together.
- Make sure that you plan pleasant activities and relaxation so that your role does not become overwhelming.
- Ask for help because providing care to someone with dementia can be tiring.
- Make sure that you plan well for the future.
- There are many different ways to maintain intimacy and stay connected.

For more tips on how to relax,
read **Lesson 1. Reducing stress in
everyday life** in **Module 3**.



You finished this lesson, well done!

1. Check your understanding



Frustration about memory loss.

How should Jacob approach Olivia about what happened?

✓ **Ask Olivia how she feels about her memory loss**

This is a good response because Jacob is addressing the issue by discussing its impact on Olivia and staying 'connected'. Jacob could also share his own worries about his memory loss.

✓ **Do not blame Olivia, but make a shopping list together with her each time prior to shopping.**

This is a very good response, because this will help Olivia to continue shopping and maintain her independence as long as possible.

✗ **Leave Olivia alone and see what happens**

This is not a helpful response, because Olivia and Jacob both feel frustrated. To stay connected it is important to talk about their frustration and worries about the future.

✗ **Ask Olivia to 'work harder' to remember things**

This is not a good response, because memory loss is part of living with dementia, it is unlikely to change.

✗ **Do not let Olivia shop anymore.**

This is not a good response because doing the shopping is important to Olivia. Shopping may give Olivia purpose in life and a feeling of dignity.

2. Check your understanding

Feeling stressed due to conflicting duties.

How could Molly deal with the situation?

- ✓ Ask a neighbour to come visit Jess until the paid in-home helper arrives.

This is helpful because it ensures Jess' safety. Molly can do her work and also gets a short break from caregiving.

- ✓ Ask her husband to go into work late so that he can be with Jess until the paid in-home helper arrives.

This is a good response. It shows that Molly is trying to involve her family members for support and gives her the break that she needs.

- ✓ Ask the paid-in home helper to come in early.

This is a good response but it may not be possible because of the short notice.

- ✗ Leave Jess alone and see what happens.

This is not a good response, because it potentially puts Jess in danger and Molly will not be able to perform well at work with the added stress of leaving Jess.

- ✗ Ask Jess to 'take care of herself'.

This is not a good response because her dependence on others is part of living with dementia and unlikely to change.

Lesson 2. Improving communication

Why is this lesson important?

Dementia can often make communication difficult.

How will this lesson help me?

This lesson helps you to talk in a simple and direct way and show your compassion in everyday situations.

What will I learn?

1. How to improve communication?
2. How to check the person's ability to hear and see?
3. How to get attention in a respectful way?
4. How to keep it simple?
5. How to take the person seriously?
6. How to pay attention to reactions?
7. How to give compliments?
8. How to show compassion?

1. How to improve communication?

In this lesson you will learn about tools and tips for good communication. Dementia can often make communication difficult. This can have an impact on your relationship with the person you care for. It can even make them or you frustrated, sad or angry.

When you communicate with the person you care for, for example by talking to them or giving them a hug, make sure that they understand what you mean by your action and that you understand them too.

Show compassion by listening, take the person you care for seriously, treat them with respect and dignity, show interest, or give them a smile or a hug. This is very important for every human being, including people with dementia.

In this lesson we help you to show compassion. Some important basic skills for communication will be explained.

1. Check your understanding



Imagine that you are living with dementia.

Imagine for a moment that you are living with dementia.

What would you like other people to do?

Please select all that apply.

- Listen to how you feel.
- Talk behind your back.
- Give you a smile.
- Say that they do not care.
- Tell you that they love you.
- Treat you like a child.
- Approach you with respect and dignity.

2. How to check the person's ability to hear and see?

For all communication - talking, touching or gestures – the basics, like the ability to see and hear, are important. Unfortunately, dementia may impair someone's ability to hear and see. Therefore, it is important that you check whether the person's hearing and sight could be improved by making changes in their environment or arranging for any relevant medical check-ups.

1. Activity



Exercise to improve sight

The ability to see is important for communication. *Check the items below to help improve sight.*

Tips

Is there enough light?

Yes
 No

In general, people with dementia need more light to see clearly. Increase light levels and use daylight where possible. It will help the person living with dementia to see well. You may also think of leaving lights on at night so the person can find the bathroom.

Is there enough contrast in colours?

Yes
 No

Dementia can make it hard to see contrasts. For example, if there is a white plate on a white table, people with dementia may have difficulty seeing the plate. A coloured plate or tablecloth may help.

Is the person living with dementia wearing their glasses?

Yes
 No

Does the person living with dementia lose or misplace their glasses frequently? Encourage them to always put the glasses in the same spot to reduce frustration over having to look for them. Sometimes a neck cord is also helpful in that case.

Are the glasses still okay?

Yes
 No

If the person living with dementia wears glasses, check whether they are clean and still comfortable to wear. Are the glasses comfortable around the ears and nose?

Do you need to consult a doctor?

Yes
 No

If the person living with dementia does not have glasses, but cannot see well anymore, consult a doctor. If the person living with dementia wears glasses, check to see if the prescription is still accurate, or consult a doctor.

2. Activity

Exercise to help improve hearing

The ability to see is important for communication. *Check the items below to help improve hearing.*

Tips

Is there too much noise?

Yes
 No

Minimizing background noise will help to improve hearing. Perhaps take the person living with dementia to a quieter location with fewer distractions. Turn off the television or radio when trying to communicate with them.

If the person living with dementia has a hearing aid, is he/she wearing it?

Yes
 No

The person living with dementia may forget to wear the hearing aid or require help or assistance with putting it in properly.

Is the hearing aid still okay?

Yes
 No

If the person living with dementia is wearing a hearing aid, check whether it is clean, fits snugly in the ear canal, is still comfortable to wear and the batteries are charged.

Do you need to consult a doctor?

Yes
 No

If the person living with dementia wears a hearing aid, check if the prescription is still accurate, or whether you need to consult a doctor. If the person living with dementia does not have a hearing aid, but cannot hear well anymore, you should also consult a doctor.

3. How to get attention in a respectful way?

The person living with dementia is a person with feelings, no matter how serious the disease is or how advanced communication problems are. Therefore, an important first step is to make contact with the person you care for by catching their attention.

Remember



- Gaining attention is a first important step for good communication.
- There are different ways to gain the attention of a person living with dementia in a respectful manner.

2. Check your understanding



Get attention in a respectful way.

Below are some suggestions regarding how to capture the attention of a person living with dementia.

Please put a check mark (✓) in front of the answers that you think are correct and a cross (×) in front of those that are wrong.

- Raise your voice or shout.
- Speak clearly and slowly, at a volume that is comfortable for the person, face to face and at eye level.
- Tap a hand, arm or front of the shoulder.
- Stop and hold the person to make him or her listen.
- Approach the person from the back and touch their shoulder.
- Call the person living with dementia by a name that they recognize.

4. How to keep it simple?

Often the language we use to get a message across is too complicated. Keeping it simple will help the person you care for understand you better.

3. Check your understanding

Keep it simple.

Jonathan takes care of his father who has dementia. Jonathan notices that his father does not understand him.

Can you tell why?

Check the items in the list below that you think could impair communication between Jonathan and his father.

- The radio is on.
- Jonathan is making a phone call.
- Jonathan asks multiple questions at the same time.

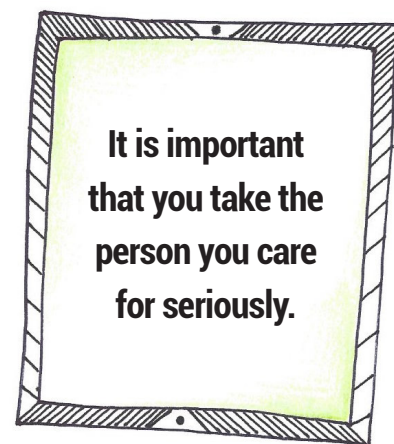
Keep in Mind

- Ask or tell the person living with dementia one thing at a time.
- Use simple language and keep sentences short. Avoid long and complicated sentences, focus on one subject at a time.
- When needed, change from open-ended to closed-ended questions that can be answered with YES or NO.
- Make sure there are no distracting background noises such as a television or radio.

5. How to take the person seriously?

At some point, you may not understand what the person you care for means. The language they use may even seem strange or funny.

However, it is important that you take them seriously. The person you care for is trying to tell you something, even though their communication skills may be impaired due to the dementia.



Let's look at an example

John is visiting his father who has dementia. When his father wants to describe his morning to John, he cannot find the right words. John says to his wife in front of his father: "I have no clue what he means!" His wife answers: "Yes, I don't know either. He is just like a child!"

4. Check your understanding

Take the person seriously.

Which of the following statements do you think is correct?

Check all the responses that you feel are appropriate.

- John should not talk about his father when he is in same the room. John could have said: "It is difficult to understand what you mean." In addition, he could have asked some questions that his father could have answered with 'YES' or 'NO'. For example: "Have you gone outside this morning?"
- John and his wife could be more patient.
- John and his wife could ask John's father if it is okay when they try to guess what he wants to say.
- It is important that John and his wife talk about the difficulty to understand John's father in front of him.
- His wife is right: a person living with dementia is just like a child.

Remember

- It is important to take the person that you are caring for seriously and treat them with respect and dignity.
- Do not talk about them in their presence.
- Be patient and give them time to find the right words.
- When the person you care for is difficult to understand, it may help to ask closed-ended questions that can be answered with YES or NO to understand what they mean.

6. How to pay attention to reactions?

You can tell a lot from the way someone speaks and looks. For example, if someone is smiling, you can assume that this person is in a good mood. Keeping this in mind will help you communicate with the person you care for.

5. Check your understanding



Pay attention to reactions.

Take a look at the cartoons below. Do you understand these feelings?

Select the right answer for each cartoon.



Happy
Angry
Sad
Scared



Happy
Angry
Sad
Scared



Happy
Angry
Sad
Scared



Happy
Angry
Sad
Scared

Keep in Mind



- Facial expressions and body language tell us how a person is feeling. Other examples of body language include fidgeting, having arms crossed or pacing. These can give us messages about how the person may be feeling. For example whether the person may be nervous, upset or anxious.
- Take notice of the responses and body language of the person you care for.

7. How to give compliments?

Complimenting the person you care for is important. In general, it is much more effective to say what someone is doing well, than to say what they are doing wrong.

A compliment can range from commenting that someone has done something well to saying that they look nice. You can give compliments in different ways and in different situations.

Keep in Mind



- The person you care for will feel good if you say something positive.
- Compliments can be given in many different ways.
- Saying something negative will make a person feel bad.

6. Check your understanding



Give compliments.

Here is a list of statements. These statements include several compliments. However, there are also some statements that are not compliments.

Please put a check mark (✓) in front of the statements that are compliments and a cross (×) in front of those that are not.

Statements

- You look beautiful.
- You are good at ...
- What are you doing?! Stop it!
- You are very helpful. Thank you.
- You are making a mess.
- You should be ashamed of forgetting everything.
- I love having you around.
- You are driving me crazy.
- You have a great smile.

3. Activity



Think about all the things that you like about the person you care for. *Now try to write down something you would say to give them a compliment.*

8. How to show compassion?

It is important that you show compassion, even if a person living with dementia is repeating the same questions over and over again, or understanding each other becomes increasingly difficult.

You need to remember that dementia is a disease that can make communication difficult. For example, a person living with dementia may have forgotten what they just said. You need to use extra effort and be patient with the person you care for.

Let's look at an example

William often visits his sister, Elena, who lives with dementia. Elena's husband passed away six months ago. When William is visiting, Elena often asks where her husband is. William finds this difficult. He knows Elena is missing her husband and may have forgotten that he died. William tries to distract her by asking questions about other things, such as: "How was your day?" Elena persists in asking where her husband is.

7. Check your understanding



How to show compassion (1).

Did William respond well?

Please select the correct answer below.

- YES
 NO

Today William tries a different approach

William says to Elena: "It must be difficult for you that he died". He gives Elena a hug. William shows Elena some pictures of her husband that he brought from home and talks to her about her husband.

William showed that he understands that Elena is missing her husband and tries to support her.

8. Check your understanding



How to show compassion (2).

Did William respond well?

Please select the correct answer below.

- YES
 NO

Let's review what you have learned

You have practiced the following communication skills:

- check ability to hear and see;
- get attention in a respectful way;
- keep it simple;
- take the person seriously;
- pay attention to reactions;
- give compliments;
- show compassion.

Keep in mind that people with dementia also have the right to grieve the loss of a loved one in a safe and supportive setting.

The example of William and his sister, Elena, shows that:

- You can show compassion in different ways.
- It is important to take a person living with dementia seriously and to pay attention to the questions they have.
- Showing compassion helps to improve your relationship with the person you care for.



You finished this lesson, well done!

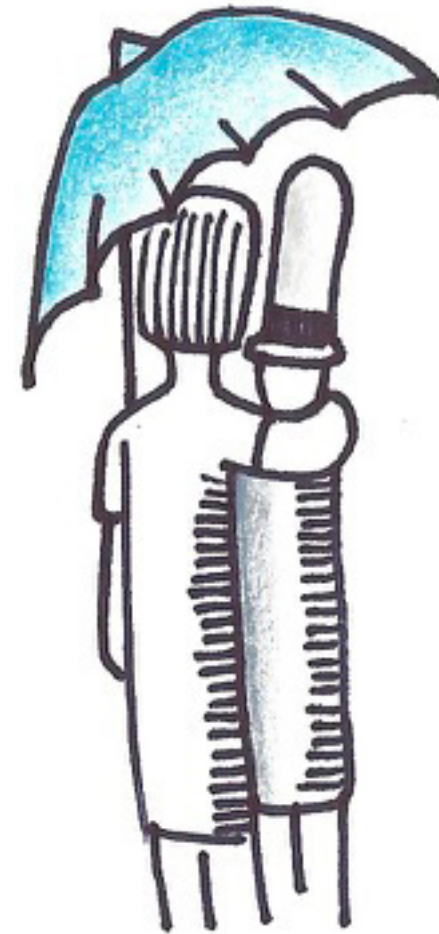
1. Check your understanding



Imagine that you are living with dementia.

What would you like other people to do?

- ✓ Listen to how you feel
- ✗ Talk behind your back
- ✓ Smile at you
- ✗ Say that they do not care
- ✓ Tell you that they love you
- ✗ Treat you like a child
- ✓ Approach you with respect and dignity



2. Check your understanding



Get attention in a respectful way.

Below are some suggested ways to get the attention of a person living with dementia.

What are the right and wrong answers?

- ✗ Raise your voice or shout.

Raising your voice is **not a respectful way** to gain attention. It may even make the person living with dementia feel sad, frustrated or angry.

- ✓ Speak clearly, slowly, at a volume that is comfortable for the person, face to face and at eye level.

This is an appropriate way to make contact. It shows that you are seeking contact in a respectful manner.

- ✓ Tap a hand, arm or front of the shoulder. **This is a good way** to attract the attention of a person living with dementia.

- ✗ Stop and hold the person to make them listen.

This is not a respectful way to get attention. It may even make the person living with dementia feel distressed or angry.

- ✗ Approach from the back and touch the person's shoulder.

This may startle someone who is not expecting you or perhaps did not hear you coming.

- ✓ Call the person living with dementia by a name that he or she recognizes.

This is a good way to attract the attention of a person living with dementia. You might use their first name or a nickname that was used in the past.

3. Check your understanding

Keep it simple.

Jonathan takes care of his father who has dementia. Jonathan notices that his father does not understand him.

Can you tell why?

- ✓ The radio is on.

Very good! A radio can be very distracting. It makes it difficult to follow what someone else is saying, especially for people with dementia who can have difficulty concentrating.

- ✓ Jonathan is making a phone call.

Very good! Making a phone call does not show interest and will confuse his father. It's important for people with dementia to try and stay focused on one task. It will be difficult to get back on the same subject after making a phone call.

- ✓ Jonathan asks multiple questions at the same time.

Correct! Asking too many questions at the same time makes it difficult for his father to understand.

4. Check your understanding

Pay attention to reactions.

Which of the following statements do you think is correct?

- ✓ John should not talk about his father when his father is in same the room. He could have said, "It is difficult to understand what you mean." In addition, he could have asked some questions that his father could have answered with 'YES' or 'NO'. For example: "have you gone outside this morning?"

Correct! John takes his father seriously when trying to understand what he wants to say. Do not talk about the person you care for while they are in the same room.

- ✓ John and his wife could be more patient.

Correct! It takes people with dementia longer to find the right words and they need time and patience to be understood.

5. Check your understanding



Pay attention to reactions.

Take a look at the cartoons below. Do you understand this feeling?
Select the right answer below.



- ✓ Happy
- Angry
- Sad
- Scared



- ✓ Happy
- Angry
- Sad
- Scared



- ✓ Happy
- Angry
- Sad
- Scared



- ✓ Happy
- Angry
- Sad
- Scared

6. Check your understanding



Give compliments.

- ✓ You look beautiful.
- ✓ You are good at ...
- ✗ What are you doing?! Stop it!
- ✗ You are very helpful. Thank you.
- ✗ You are making a mess.
- ✗ You should be ashamed of forgetting everything.
- ✓ I love having you around.
- ✗ You are driving me crazy.
- ✓ You have a great smile.

7. Check your understanding



How to show compassion (1).

Did William respond well in the first example?

✗ No

Will wants to distract his sister's attention because he knows she is missing her husband and will be sad to be reminded that he died. Although Will has the best intentions, ignoring her questions is not the right way to respond especially because his sister persists in asking.

8. Check your understanding

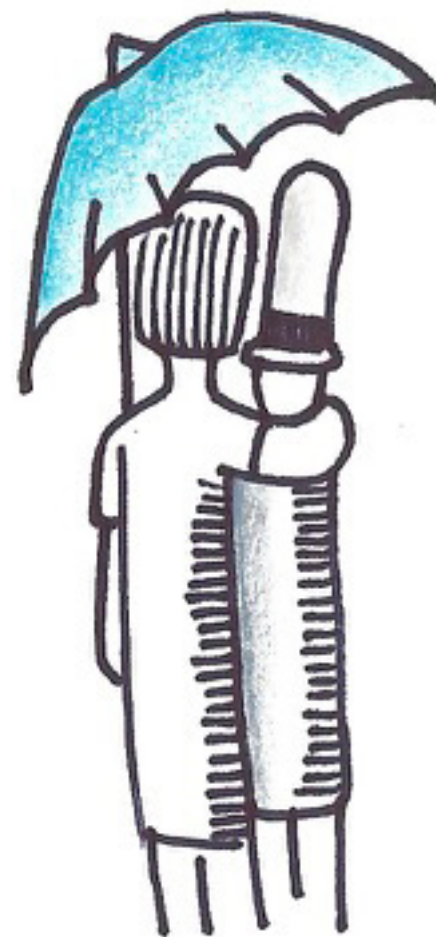


How to show compassion (2).

Did William respond well in the second example?

✓ Yes

It is important to try different responses to identify the one which will cause the less distress. Initially William tried to distract his sister with no success. Today, by showing his sister pictures of her husband, they had a good conversation about him.



Lesson 3. Supported decision-making

Why is this lesson important?

Making decisions can become more difficult for a person living with dementia over time.

How will this lesson help me?

By practicing how to support a person living with dementia to make their own decisions for as long as possible or to assist in making decisions in the person's best interest.

What will I learn?

1. Why is support in decision-making needed?
2. How to make decisions in someone's best interest?
3. How to support someone with dementia to make everyday decisions?
4. How to support someone with dementia to make everyday decisions as the dementia progresses?
5. How to support someone with dementia in making complex decisions?

1. Why is support in decision-making needed?

Supporting someone with dementia to make their own decisions is very important. Like everyone else, people living with dementia have the right to participate in all decisions that affect their lives and wellbeing. However, making decisions may become difficult due to the progression of dementia. Sometimes this results in relatives taking over decision-making, instead of supporting people with dementia to make their own decisions.

In this lesson, you will learn how you can support the person you care for when they need to make a decision.

2. How to make decisions in someone's best interest?

Everybody needs to make decisions, whether they are big or small. Because the person you care for has dementia, your support is needed to help them clarify what they want. Decisions in line with the interests, needs and wishes of the person you care for will make them more independent.

Decision-making can be difficult

Why do you think decision-making can be difficult for a person living with dementia? *Have a look at the reasons below to find out more.*

- **Memory loss**
Having memory loss will cause someone with dementia to sometimes forget the information that is needed to make a decision.
- **Problems with thinking or difficulties identifying and describing what someone with dementia thinks**
When a person living with dementia has problems thinking or describing what they are thinking, it might be more difficult for them to make a decision and share it with you.
- **Problems with making complex decisions**
Complex decisions, such as deciding whether or not to go outside alone, can be more challenging, therefore support is important.

1. Activity



Think about your own situation

- Making decisions will become more difficult as the dementia progresses.
- Your support for the person you care for to make their own decisions is needed.
- Enabling them to make their own decisions might not be easy because of their dementia.

Do you support the person you care for to make decisions? You may want to write down the ways that you support their decision-making:

3. How to support someone with dementia to make everyday decisions?

It is important to encourage the person you care for to do whatever they are still able to do. Supporting them in making decisions will help them to be more independent. Supporting them in making decisions might also improve their self-esteem.

Let's look at an example

Manuel has Alzheimer's disease and is married to Maria. Manuel always used to lay out his clothes for the next day in the evening. Now he has dementia, he forgets to do so and sometimes wears the same clothes everyday.

1. Check your understanding

Support for making everyday decisions.

What do you think is the best way to make sure that Manuel wears clean clothes, without taking over his decisions at the same time?

- Before Maria and Manuel go to bed, Maria asks Manuel what he wants to wear the next day. She then asks Manuel to lay them out.
- Maria chooses clothes for Manuel and she asks him to lay them out.
- Maria chooses clothes for Manuel in the morning and gives them directly to Manuel to wear.

Keep in Mind

- It is important to encourage the person that you care for they continue doing whatever they are still able to do.
- Supporting the person you care for in making decisions will help them be more independent.
- Support the person you care for in making decisions may add to their self-esteem.

4. How to support someone with dementia to make everyday decisions as the dementia progresses?

Let's look at an example

After some time, Manuel feels stressed when choosing his clothes for the next day with Maria. He starts to worry about everything else he needs to do the next day and becomes anxious. This makes it difficult for Maria to support Manuel in making his decision.

2. Check your understanding



Support for making decisions as the dementia progresses.

What should Maria do? *Please check all the responses that you feel are appropriate.*

- Instead of supporting Manuel to choose his clothes the evening before, she asks him in the morning, at the beginning of the day.
- Maria lays out Manuel's clothes in the evening.
- When Maria asks Manuel what he wants to wear she can give him only a few choices and, for example, ask him whether he wants to wear his blue or black trousers.

Remember



- Supporting someone with dementia in making their own choices is possible, even as dementia progresses.
- It may help to simplify decisions by limiting the number of choices or discuss the situation at a better time when the person is in a better mood or less worried.

5. How to support someone with dementia to make complex decisions?

There comes a time in the course of dementia when someone may not be able to make complex decisions anymore, such as decisions concerning medical treatment.

Let's look at an example

Mary has vascular dementia and is taken care of by her daughter Chrissy. The doctor advises Mary to start using medication for her blood pressure. Mary says that she does not want to take pills because she does not understand why she needs them.

3. Check your understanding



Support for making complex decisions (1).

What should the doctor and Chrissy do?

Multiple answers are correct.

- Mary says what she wants, so she does not need support in making the decision whether or not to start with the medication.
- The doctor says that she should take the medication because it is good for her health.
- The doctor explains that taking the medication is good for her health, because it will slow down further damage in her brain because of her dementia.
- Her daughter says: "Mom, you know that you are forgetting things and that you have difficulties to find the right words when you want to say something. By taking the medication these problems may slow down a bit."

Let's look at another example

Jack who has dementia lives with his wife, Ella. Jack's condition deteriorates. Ella decides to make an appointment with the doctor without Jack to discuss his medical condition and to make a decision regarding his medication. Ella discusses the issue with Jack's sister as well, who asks her what she thinks Jack would have decided before he was diagnosed with dementia. Ella talks to the doctor and tries to imagine what Jack would have decided if given all the information.

4. Check your understanding



Support for making complex decisions (2).

What do you think are reasons that Jack can no longer make the decision himself? *Please check all the responses that you feel are appropriate.*

- Jack is unable to understand the information that is relevant to making the decision.
- Jack does not agree with the doctor.
- Jack is unable to communicate his decision (by talking, using body language or any other means).
- Jack is unable to use or weigh the information as part of the decision-making process.

The capacity to make a decision may be affected by the following considerations:

- **The type of decision being made.**
Someone with dementia might still be able to choose what kind of clothes to wear, but perhaps not whether to take medicines.
- **Change over time.**
Imagine that Jack had a severe infection that made him very confused. After this infection is cured, he might be able again to decide whether or not to take the medication.
- **Can be difficult to assess.**
Sometimes it is not clear, in which case there is no other alternative other than to help the person living with dementia make a decision that is in their best interest.

Remember



- Someone with dementia can be involved in making complex decisions, such as medical decisions, with the right support.
- Support for making complex decisions should focus on providing correct information to help the person you care for understand what the consequences of the decision are.

Remember



You can make decisions in the best interest of a person living with dementia by taking the following aspects into account.

- Their past and present wishes and feelings (and, in particular, any relevant statement written when they did not have dementia).
- Beliefs and values that may have influenced the person's decision when he or she did not have dementia.
- The views of anyone named by the person you care for as someone to be consulted to help with making decisions.
- Be aware that the best interest of the person you care for is not always the same as your own best interest or that of other family members. In the end, it is the best interest of the person you care for that counts, since the decision concerns them.
- Take into account that someone's past wishes can be different from their present ones.

Preparing for decisions

To prepare for decisions that you might have to make for the person living with dementia it is important to:

- Gather the information you need to make informed choices for the person as early in the course of the disease as possible.
- Talk about decisions with your family, friends, doctor and any others close to you to help with decisions that are important to you both.
- Prepare instructions that accurately reflect the wishes of the person living with dementia, in accordance with your country's law (advance directives), and inform each other and your doctor about your preferences and decisions concerning medical treatment.

2. Activity



Think of the following choices when you prepare instructions that accurately reflect the wishes of the person you care for.

- Where does the person you care for prefer to live if it is no longer possible to stay at home?

- What aspects of home/community/facility care are important to the person you care for?

- Who does the person you care for want in charge of their finances when they are no longer capable of doing it?

- How does the person you care for want to be treated at the end of their life?

- Are there medical treatments that the person you care for wants to receive or refuse?

- What does the person you care for want when eating is no longer possible? Would they want to get a feeding tube?

- Does the person you care for have any particular fears or concerns about medical treatments?



You finished this lesson, well done!

1. Check your understanding



Support for making everyday decisions.

What do you think is the best way to make sure that Manuel wears clean clothes, without taking over his decisions at the same time?

✓ Before Maria and Manuel go to bed, Maria asks Manuel what he wants to wear the next day. She then asks Manuel to lay them out.

This is the right answer! This way Manuel is encouraged to do the things he is still able to do.

✓ Maria chooses clothes for Manuel and she asks Manuel to lay them out.

This answer is okay. It is good that Manuel is encouraged to lay out his clothes himself; however, it would have been better if Maria supported Manuel in making his own decision about what to wear.

✗ Maria chooses clothes for Manuel in the morning and gives them directly to Manuel to wear.

This is not a good option. Maria is taking control away from Manuel. It would be better if she supported him in making his own decision and encouraged him to do the things which he is still able to do, such as laying out the clothes.

2. Check your understanding



Support for making decisions as the dementia progresses.

What should Maria do?

- ✓ Instead of supporting Manuel in choosing what he wants to wear in the evening for the next day, she asks him in the morning at the beginning of the day.

Correct! Maria still supports Manuel in deciding what he wants to wear, but he will not start to worry the evening before.

- ✗ Maria lays out Manuel's clothes in the evening.

This is not a good option. Maria is deciding for Manuel, while he still might be able to make his own decisions.

- ✗ When Maria asks Manuel what he wants to wear in the evening she can give him only a few choices and, for example, ask him whether he wants to wear his blue or black trousers.

In some cases this might be a good option. Even though Maria decides which trousers Manuel should wear the next day, Manuel can still make the final decision himself.

However, in this case it might not be the best thing to do, because it might not solve the problem that Manuel will worry about the next day.

3. Check your understanding



Support for making complex decisions (1).

What should the doctor and Chrissy do?

Multiple answers are correct.

- ✘ Mary says what she wants, so she does not need support in making the decision whether or not to start the medication.

This is not correct. Since Mary has dementia, we are not sure whether or not she understands why she needs the medication and what the consequences of taking or not taking the medication might be.

- ✘ The doctor says that she should take the medication because it is good for her health.

Incorrect. Although it is true that the medication will be good for her health, the doctor is telling Mary what to do, which is not so good.

- ✔ The doctor explains that taking the medication is good for her health because it will slow down damage to her brain resulting from her dementia.

This is right! Her doctor's explanation allows Mary to understand the importance of taking the medication and will enable her to make an informed decision.

- ✔ Her daughter says: "Mom, you know that you are forgetting things and that you have difficulties to find the right words when you want to say something. By taking the medication these problems may slow down a bit."

Correct! Using different words to explain the possible reasons for taking the medication might help Mary understand why taking the medication would be beneficial for her.

4. Check your understanding

*Support for making complex decisions (2).*

What do you think are the reasons that Jack can no longer make the decision himself?

Multiple answers are correct.

- ✓ Jack is unable to understand the information relevant for the decision.
- ✗ Jack does not agree with the doctor.
- ✓ Jack is unable to communicate his decision (by talking, using body language or any other means).
- ✓ Jack is unable to use or weigh the information as part of the decision-making process.

Lesson 4. Involving others

Why is this lesson important?

Sharing caregiving responsibilities with other people will help you to continue providing care in the long term.

How will this lesson help me?

By practicing the skill 'asking for help'.

What will I learn?

1. The importance of involving family and friends.
2. Types of help and support that you might need.
3. Effectively asking for help from others.

1. The importance of involving family and friends

It might be difficult to involve others caring for the person living with dementia. You could think that others will not be able to provide care as well as you can, that they do not have time or might say 'no' when asked for help.

As time progresses, the person you care for will need more and more help with daily activities. Therefore, it is important to involve others so that the tasks can be shared. It can also be helpful to have someone to talk to who understands your situation and feelings.

Do not wait too long, since help early on will allow you to continue providing care to your family member or acquaintance in the long term.

2. Types of help and support that you might need

First let's look at an example to find out whether Li, David and Fatima are receiving help, and if so, what kind of help.

- **Li** takes care of her mother who has dementia. She receives no help from others. She spends a lot of time taking care of her mother and feels overwhelmed. She would like to get some help from others.
- **David** takes care of his wife who has dementia. David has involved his two sisters in the care. The sisters regularly take his wife out for shopping or help clean the house.
- **Fatima** takes care of her husband who has dementia. Fatima receives help from her family, friends and neighbours. Some helpers assist with shopping or cleaning the home, others take her husband for a walk or just listen to the difficulties she has with his memory loss.

The types of help and support that Fatima receives are presented below.

Practical help

- Family: once a month my sister helps with cleaning the house.
- Friends: once a week my friend Hiba comes over to help with shopping and cooking.

Help with pleasant activities

- Family: several family members take my husband out for a walk on a regular basis.

Emotional support

- Friends: Mohammed is always there to listen when I need it.

Providing information

- Acquaintances/neighbours: my neighbours help to find information on dementia.

1. Activity



What kind of help do you receive?


Please write down the types of help that you receive in the spaces below. If the help you receive is not listed below, use the 'Other help' box at the end to fill in your answer.

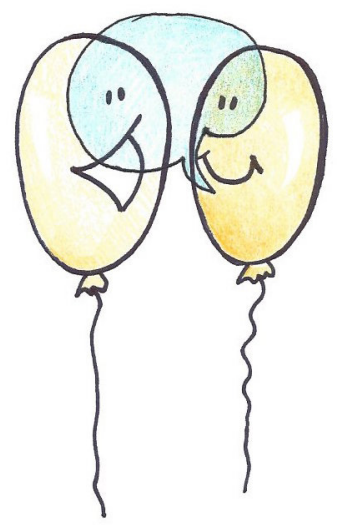
Do your family, friends, neighbours or others provide:


Practical help?

Emotional help?

Help with pleasant activities?

1. Activity	
Information?	
<hr/> <hr/> <hr/>	
Other help?	
<hr/> <hr/> <hr/>	



Tip 

Keep in mind that sharing care tasks is common. It may allow you to do something pleasant for yourself, run an errand without having to bring the person you care for, or just enjoy a well-deserved break.

2. Activity



Your own support network

Take a look at your own network as stated in the previous pages, what do you see? *Please select the response that applies to the help that you receive.*

I receive help in one category.

It is very good that you are already involving others. You might want to receive help in other ways too. Think about people who might be able to help you.

I receive help in more than one category.

It is very good that you are already involving others in caring for your family member or acquaintance. If needed, you can ask for help from other people as well. Perhaps the examples helped you identify people you had not considered before.

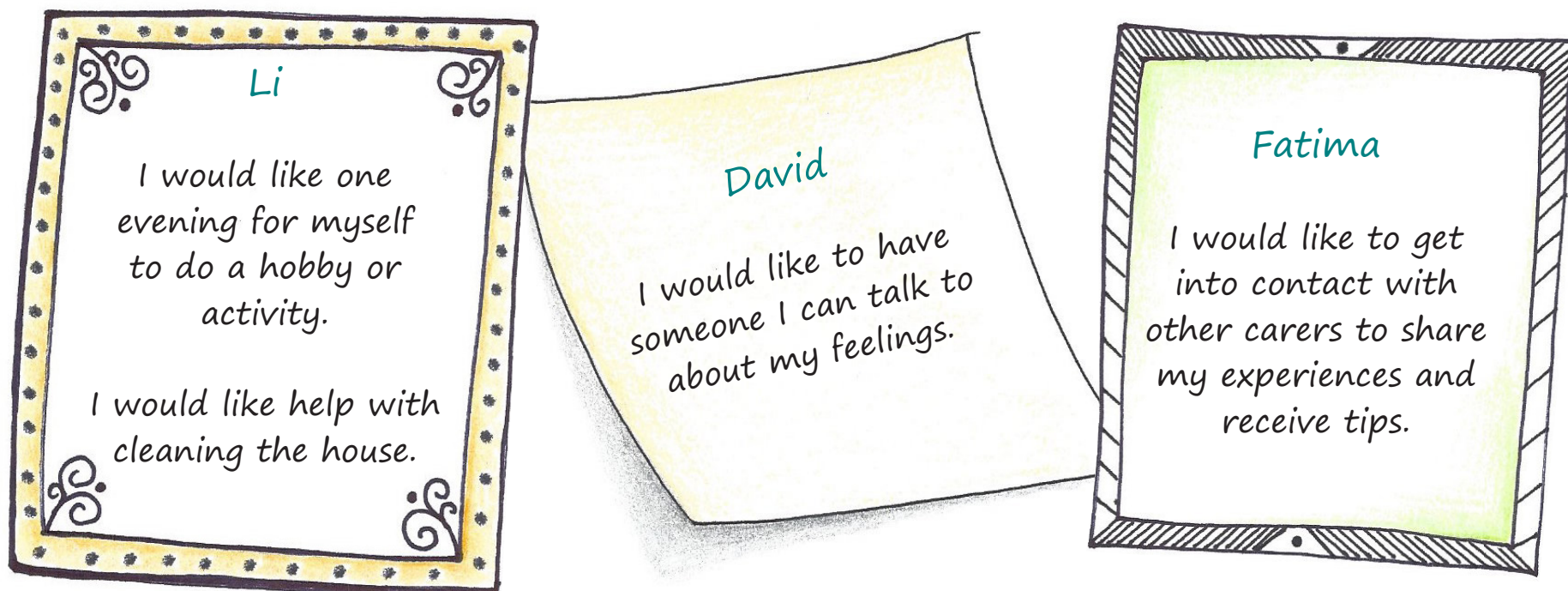
I do not receive help.

Keep in mind that providing care can be difficult. Think about ways to involve others in sharing the tasks. Remember that you do not know whether people will want to help unless you ask. It can be difficult to find help if you don't have family nearby or live in a rural or isolated area, or if your family refuses to help. Think about alternatives such as your faith community, contacting your doctor for advice, or your national / local dementia association.

What would you like to get more help with?

Before you ask someone for help, it is important to know what it is you would like to ask. It can help to make a wish list of your needs.

Let's first have a look at Li, David and Fatima. You can see their wish lists below.



What is on your wish list?

Make your own wish list for the help or support that you would like to receive.

Wishes could be for example:

- I would like help with bathing the person I care for.
- I would like advice on how to deal with the person I care for.
- I would like adjustments to be made in my home to accommodate the care needs of the person I care for.

List those wishes that you think are achievable. If you know beforehand that you might not be able to achieve a certain wish, it might be better to list a different wish that is more attainable.

For instance, Li would prefer to hire someone to clean the house every week. However, Li cannot afford this and realizes that her wish is not realistic.

She could hire someone to clean the house once every two weeks or ask someone who she does not need to pay, such as a friend or relative. She can ask the person to clean the whole house, or to help with specific tasks that are difficult for her, such as cleaning the floors.

3. Activity

Make a list of wishes that seem achievable

Wish 1 _____

Wish 2 _____

Wish 3 _____

Who can I turn to?

Now it is time to think about who could help. Some people have no problem asking for help, other people are not used to it but do not mind giving it a try. There are also people who find it very difficult to ask for help. The next section will teach you skills to ask for help effectively. Keep in mind your support wish list.

3. Effectively asking for help from others

If you would like to ask others for help it is important to do so in an effective way. This means that you should be able to talk to others about your thoughts, feelings and experiences. It also means that you stand up for yourself.

Things that will help you to effectively ask for help:

- Think about what you want or need and what your feelings are about the current situation.
- Describe your problem in one or two sentences.
- Describe your thoughts and feelings clearly, so that the other person can understand your point of view.
- Be honest and direct.
- Keep the feelings of the other person in mind.
- Give detailed information about what kind of help you need.
- Be flexible: maybe you won't get exactly what you asked for, but you will get something that will be helpful.
- Break it down into smaller parts – it's usually easier for people to say yes to a little request than to a big one.
- If you reach a point where you do not know what to do anymore: take a break – go back to the discussion at a future time. For example: agree to think about it and talk again tomorrow afternoon.
- If appropriate, offer to do the task together first.
- Don't give up. It may take many attempts before things change.
- Asking for help will not always lead to the result you want, but it is important that you feel able to ask for it.

Let's have a look at Li again

She knows who to turn to for help and decides to ask her sister. Li would like to have an evening to herself once a week. She tries to ask for help in three different ways.

1. Check your understanding



Asking for help effectively.

Which of the following examples represents an effective way to ask for help?

Please check the one response that you think is correct.

- Li tells her sister that she wants to take care of their mother, but that she just needs a short break from caregiving during the week. She says: "I would like to discuss how you could help in a way that is possible for you."
- Li decides to attend a weekly one-hour class in the evening to have a break from providing care. However, she does not discuss with her sister the importance of having a break during the week. When she asks her sister to take care of their mother for an hour, her sister said: "Sorry, I have no time." Li cancels her class.
- Li approaches her sister by saying, "I'm sick and tired of you not doing anything! You never have time to help me care for our mother!"

4. Activity



Your own plan to involve others

Make your own plan to involve others in caring for your family member or acquaintance with dementia. Now think of your wishes and who you can turn to for help. Imagine yourself in a situation in which you will ask for help. *Please answer the following questions in the boxes below.*

Who would you like to ask for help?

What would you do if the person does NOT want to help?

What would you like to say?

What would you do if the person does want to help?



You finished this lesson, well done!

ANSWERS - BEING A CARER

Lesson 4. Involving others

1. Check your understanding

*Asking for help effectively.***Which of the examples is an effective way to ask for help?**

✓ Example 1

Passive. This is not an effective way of asking for help. Her sister may not be aware that Li is feeling overwhelmed. Li is not being honest about her feelings and is trying to avoid a conflict with her sister. She does not stand up for herself. It is a passive way of asking for help.

✗ Example 2.

Aggressive. This is not an effective way of asking for help. Li becomes angry. However, her sister may not be aware that Li is feeling overwhelmed, because she did not clearly mention this. She does not approach her sister in a respectful way. It is an aggressive way of asking for help.

✓ Example 3

Effective. This is an effective way of asking for help. Li stands up for herself, says what she is thinking and is honest about her need for a regular break. She also keeps the interests of her sister in mind.

MODULE

3

CARING FOR ME

- Lesson 1. Reducing stress in everyday life
- Lesson 2. Making time for pleasant activities
- Lesson 3. Thinking differently

Lesson 1. Reducing stress in everyday life

Why is this lesson important?

It is important to take care of yourself while caring for another person. This lesson will help you to keep providing care.

How will this lesson help me?

This lesson helps to reduce stress and renew your energy with exercises that do not take much time.

What will I learn?

1. The importance of relaxing.
2. Different ways to relax:
 - basic breathing;
 - mindful breathing;
 - neck movements;
 - number counting;
 - imagery;
 - total stretching;
 - muscle relaxation.
3. Relaxing at any time and any place.



1. The importance of relaxing

Let's look at an example

Diana: no time, no energy

Diana takes care of her husband Dan who has dementia. She feels increasingly tense.

A friend advises her to try to relax and not ask too much of herself. Diana tells her friend that she does not have the time or energy to relax. Her friend explains that there are ways to relax that do not take much time, and that relaxing might give Diana renewed energy that could help her get tasks done more easily.

Diana succeeds in relaxing

Diana decides to follow her friend's advice and tries the breathing exercise her friend showed her.

When Diana sees her friend again she says: "Thank you for the good advice. Although I still have a lot to do, I feel less tense." Diana decides to do the breathing exercise every time she is feeling tense.

Reminder



Relaxation:

- makes you feel less tense;
- might give you renewed energy;
- may make it easier to get tasks done; and
- does not have to take much time.

2. Different ways to relax

There are different ways you can relax. Try and see which one(s) suit you best.

Before you try an exercise ask yourself: "How tense am I feeling"? After the exercise, ask yourself again. This might help you understand whether this type of relaxation helps you feel less tense.

In this lesson you will find seven relaxation exercises. The first three exercises will take only a few minutes (i.e. 5 minutes max.). The other exercises will take a little longer (i.e. 10-15 minutes max.).

Use the scale below of 1-10 and tick what number describes how tense you are feeling now, 1 is very small amount of tension and 10 is very high amount of tension.



1. Relaxation activity - Basic breathing

Focusing on your breathing is relaxing. By doing a breathing exercise you could reduce tension.

This exercise will take: less than 5 minutes.

Caution: if you experience difficulty breathing, this exercise might not be the best option for you.

This is how you do it:

- When sitting down, sit up straight in your chair with your back against the back of your chair.
- When standing, stand up straight.
- Put both of your feet flat on the surface.
- Focus on your breathing.
- Keep breathing like you are used to.
- Try to feel how you breathe. Put your hand on your stomach to feel how you inhale and exhale.
- Exhale from your mouth and pull in your stomach as much as possible.
- Follow your breathing in this manner a couple of breaths and then stop the exercise.

2. Relaxation activity - Mindful breathing



This exercise will help you feel calm and reduces stress. You will breathe with your stomach according to a rhythm.

This exercise will take: 5 minutes.

This is how you do it:

- Sit straight in a chair and make sure your face and shoulders are relaxed.
- Bring your hands to your stomach and breathe into it.
- Breathe in for 4 counts and out for 8 counts, at a comfortable pace.
- Your stomach should expand with each inhale and contract with each exhale.
- Return to your normal breathing and spend one minute just observing yourself breathing and noticing how you feel.
- Practice listening to your own thoughts without negative judgement.
- If your mind wanders, refocus on breathing and meditation.

3. Relaxation activity - Neck movements



With this exercise you will feel less tension in your neck. It will also increase the blood flow to your brain.

This exercise will take: 5 minutes.

This is how you do it:

- Make sure to move slowly and with attention.
- Bend your neck forward and backward.
- Inhale while you lift your head up and back. Exhale while you drop your chin to your chest.
- Rotate your chin from side to side.
- Inhale when your chin is in the centre. Exhale when you look to the side.
- Drop your ear towards your shoulder.
- Inhale when you are in the centre. Exhale when you drop your ear to your shoulder.
- Repeat 5 times.

4. Relaxation activity - Number counting



You can relax by focusing on your breathing and counting back from 20 to 1.

This exercise will take: 5 minutes.

This is how you do it:

- Sit or lie down comfortably in a quiet place.
- Breathe slowly.
- With each breath, take at least 3 seconds to breathe in and 6 seconds to breathe out.
- Focus on your breathing and your lower stomach when you breathe until you feel calm and peaceful inside your heart and mind.
- Say the word 'relax' whenever you breathe out.
- Tell yourself that you will start counting down from 20 to 1.
- Tell yourself that you will double your level of relaxation for each and every count, and will be totally relaxed when you reach 1.
- Start counting down from 20 to 1 slowly. Say the word 'relax' whenever you count (that is, take a deep breath, say '20', breathe out slowly and say 'relax', take a deep breath, count '19', breathe out slowly and say 'relax', and so on).
- Now repeat this exercise but with your eyes closed.

5. Relaxation activity - Imagery



You can relax by imagining you are in a place or surrounded by people and things you like.

This exercise will take: 5 minutes.

Before completing this exercise, take a look at the helpful guidelines below.

- Only imagine places, people and things you like.
- Imagine what you can hear, feel, smell, and/or taste if you were in that place.
- Try to think of very specific details of the place, thing or person. For example, how does the surface of the thing feel and how does it smell?

Now try to relax while imagining that you are in a place or with the people or things that you like.

This is how you do it:

- Sit or lie down comfortably in a quiet place.
- Breathe slowly.
- With every breath, take at least three seconds to breathe in and at least six seconds to breathe out.
- Focus on your breathing and your lower stomach when you breathe until you feel peaceful inside.
- Imagine you are in a place or surrounded by things or people you like.
- Now do this exercise again but close your eyes.

6. Relaxation activity - Muscle relaxation



This exercise is particularly helpful when your muscles feel tense. This exercise will help you relax by tensing and relaxing your muscles.

This exercise will take: 10-15 minutes

Caution: if you have any injuries or any other physical limitations, this may not be the best exercise for you. Try one of the other exercises.

Below are some general instructions for you to keep in mind.

- When you are ready to begin, tighten the muscle group described. Make sure that you can feel the tension, but no pain. Keep the muscle tensed for approximately 5 seconds.
- Relax the muscles and keep it relaxed for approximately 10 seconds. It may be helpful to say 'relax' as you relax the muscle.
- When you have finished the muscle relaxation, remain seated for a few moments allowing yourself to become alert.

This is how you do it:

- **Right hand and forearm:** make a fist with your right hand. Hold for 5 seconds and then relax for 10 seconds. Don't forget to breathe. It might be helpful to inhale while tensing your muscles and exhale while relaxing your muscles. Do the same for your left hand and forearm.
- **Right upper arm:** bring your right forearm up to your shoulder to 'make a muscle'. Hold for 5 seconds and then relax for 10 seconds. Do the same for your left upper arm.
- **Forehead:** raise your eyebrows as high as they will go, as though you were surprised by something. Hold for 5 seconds and then relax for 10 seconds.
- **Eyes and cheeks:** squeeze your eyes closed. Hold for 5 seconds and then relax for 10 seconds.
- **Mouth and jaw:** open your mouth as wide as you can, as if you are yawning. Hold for 5 seconds and then relax for 10 seconds.

Please continue the exercise on the following page.

6. Relaxation activity - Muscle relaxation (continued)



- **Neck:** be careful as you tense these muscles. Face forward and then pull your head back slowly, as though you are looking up to the ceiling. Hold for 5 seconds and then relax for 10 seconds.
- **Shoulders:** tense the muscles in your shoulders as you bring them up towards your ears. Hold for 5 seconds and then relax for 10 seconds.
- **Hips and buttocks:** squeeze the muscles in your buttocks. Hold for 5 seconds and then relax for 10 seconds.
- **Right upper leg:** tighten your right thigh. Hold for 5 seconds and then relax for 10 seconds. Repeat for your left upper leg.
- **Right lower leg:** do this slowly and carefully to avoid cramps. Pull your toes towards you to stretch the calf muscle. Hold for 5 seconds and then relax for 10 seconds. Repeat for your left lower leg.
- **Right foot:** curl your toes downwards. Hold for 5 seconds and then relax for 10 seconds. Repeat for your left foot.

7. Relaxation activity - Total stretching



Stretching your muscles can help to decrease tension. Stretching exercises are very convenient since you can do them anywhere and anytime.

This exercise will take: 10 minutes.

This is how you do it:

- Stand up, or do this exercise in your chair.
- Take a deep breath, all the way down to the bottom of your stomach, and slowly let it out.
- As you exhale, feel the tension drain from your body.
- Take one more breath and hold it for a moment... and let it out slowly.
- With each breath you are becoming more and more relaxed.
- Now, gently reach your arms out to the sides as though you were trying to touch the walls.
- Relax your shoulders and stretch yourself a little.
- Gently reach your arms out in front of you.
- Feel the muscles in your back and shoulders loosen up.
- Stretch out in front a little further.
- And now reach up as high as you can.
- Push up your arms towards the sky, as if you were trying to reach the sun.
- Again, reach your arms out to the sides as though you were trying to touch the walls, as though you were trying to push them outwards.
- Reach out in front of you.
- Feel your muscles in your back and shoulders become looser and less tense.
- Reach towards the sky one more time.
- Reach as high as you can.
- Try to touch the sun.
- Lower your arms to your sides.

Please continue the exercise on the following page.

7. Relaxation activity - Muscle relaxation (continued)



- Now, roll your shoulders back.
- Feel the tension drain from your body.
- Roll your shoulders back again. One more time roll your shoulders.
- Now roll them forward. Forward again. One more time forward.
- Now shrug your shoulders, lifting them up and then pushing them down. Shrug your shoulders again. Shrug them one more time.
- Now another deep and refreshing breath and exhale all of the tension in your body.
- Take one more breath...and exhale letting go of any remaining tension.



3. Relaxing at any time and any place

You can take some time to relax at any time of the day and in any place.

Let's look at an example

Diana: relaxing while waiting in line

Diana often feels tense when there is a long line in the store, as she is aware she still has many other things to do. She decides to do the breathing exercise while waiting in line. Afterwards, she feels less tense.

You can also plan a specific time to relax, for example every day after lunch. You can choose what suits you best. If necessary, you can use a reminder to make sure that you do not forget to take some time to relax.

Keep in Mind



- You can take some time to relax anywhere and at any time of the day.
- Set a goal: try to do a relaxation exercise at least once a day.
- You can plan a specific time to relax every day (if necessary, use a reminder).
- You will benefit from having renewed energy and a better mood after doing the relaxation exercises.
- Even a brief exercise can make a difference!
- You will also be able to reduce feelings of tension and continue caring for your family member or acquaintance over the long term.

Was this helpful for you?

If not, there might be different reasons why relaxation was not helpful to you:

- Perhaps you could not focus on relaxing.
- Try again at another time!
- Maybe you like an exercise, but you need some more practice to really benefit from it. Try to do this exercise regularly.
- The exercise you chose may not have suited you. Try a different exercise!
- The exercise you chose was too short.
- Try this exercise again or do another one!

If the exercises are still not helping you after these tips, try to do an activity you enjoy. Have a look at **Lesson 2. Making time for pleasant activities** in this module to find out which activities you may enjoy.



You finished this lesson, well done!

Lesson 2. Making time for pleasant activities

Why is this lesson important?

It is important to take care of yourself while caring for another person. This lesson will help you to keep providing care.

How will this lesson help me?

This lesson will help you to take time for yourself and do pleasant activities to relax.

What will I learn?

1. The importance of pleasant activities.
2. Barriers to doing pleasant activities.
3. Making pleasant activities achievable.
4. Doing pleasant activities together.

1. The importance of pleasant activities

Pleasant activities are important because caregiving can last a long time and doing pleasant activities can help you to relax and continue providing care. Pleasant activities can be small things such as going for a walk or talking to a friend. This may not always be easy, because providing care can be time-consuming and someone might have to take over the care for your family member or acquaintance while you are not there.

Let's see how Amy, Jose, and Umit experience caregiving and the importance of planning pleasant activities.

Amy

Amy takes care of her mother who is living with dementia. She dedicates most of her time to caregiving and rarely takes time for herself. She does not engage in any pleasant activities. Amy notices that recently she is more tired than usual and feels that she is not able to care for her mother as she did before.

Jose

Jose takes care of his brother who is living with dementia. Jose does not get a lot of sleep and rarely has time for afternoon naps. He recently started asking his sister to come by and help with caregiving so he can take a nap and read a magazine each afternoon.

Umit

Umit takes care of his wife who is living with dementia. Recently, he has hired a professional carer who stops by three times a week to help him care for her. When the professional carer is there, Umit reads the newspaper or goes for a walk.



Keep in Mind

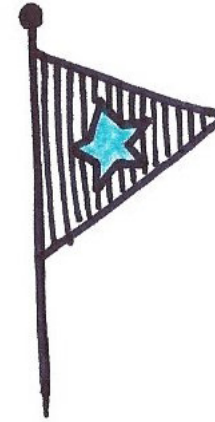


- If you are not able to make time for yourself, you can get very tired which may make you less able to continue providing care.
- You can ask family and friends to help care for the person living with dementia so that you can take some time for yourself.
- If it is affordable, you could hire a professional carer to help you care for your family member or friend so you can take some time for yourself.

Which pleasant activities would you like to do?

Once you have some time for yourself, it can be hard to think of the things you would like to do. There are many possibilities and even in a short amount of time, you can still do an activity that you like.

In this exercise you will make a list of pleasant activities that you would like to do.



1. Activity



Please check at least two activities that you would like to do more often. If your favourite activity is not listed below, use the 'other' box to write your own activity.

- | | |
|--|--------------------------------------|
| <input type="checkbox"/> Do a crossword puzzle | <input type="checkbox"/> Take a nap |
| <input type="checkbox"/> Watch TV | <input type="checkbox"/> Go shopping |
| <input type="checkbox"/> Visit friends or family | <input type="checkbox"/> Take a walk |
| <input type="checkbox"/> Cook | <input type="checkbox"/> Exercise |
| <input type="checkbox"/> Listen to music | <input type="checkbox"/> Other: |
| <input type="checkbox"/> Do crafts | |
| <input type="checkbox"/> Read | |

2. Barriers to doing pleasant activities

Let's go back to Amy's example

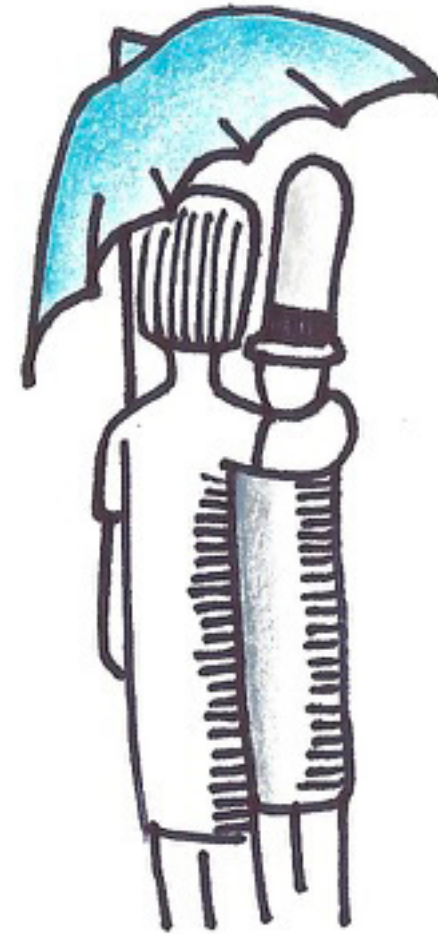
Amy dedicates most of her time to caring for her mother who has dementia. She does not receive any help and is tired all the time. She is struggling to care for her mother and has stopped doing the things she likes because she feels that she does not have enough time.

Eventually, Amy is so tired that she decides to ask her friend for help. She is now able to make some time for herself and engage in pleasant activities. Amy feels more energized afterwards. She also feels that she is better able to handle the care for her mother as a result.

Other reasons you may feel unable to do pleasant activities

Not having time was the reason that Amy did not feel as though she could do any pleasant activities.

However, there are several other reasons.



2. Activity

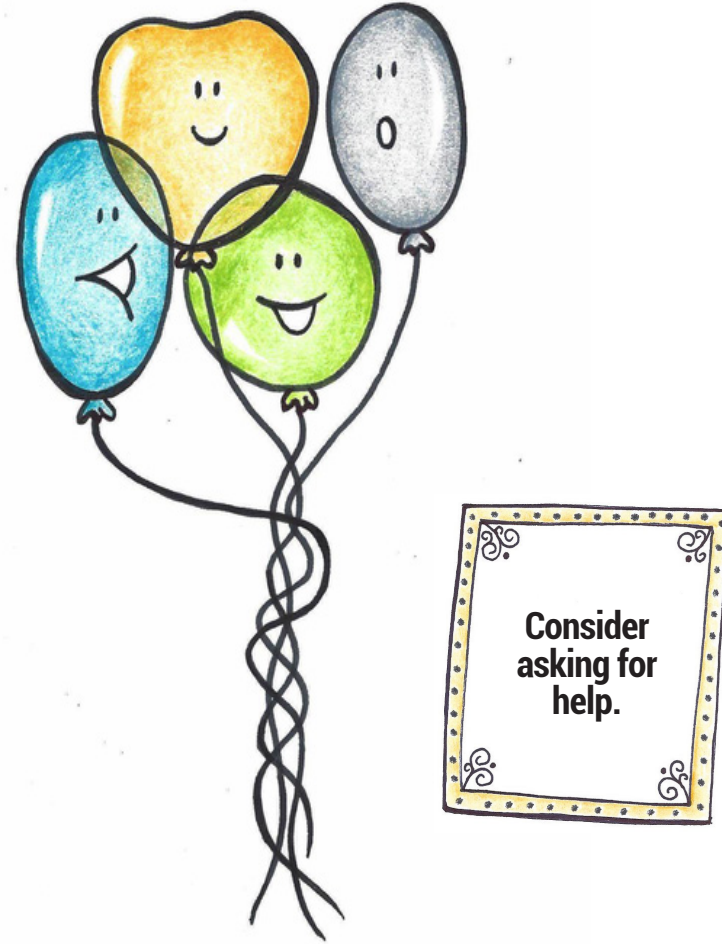


Do you recognize any of the following? *Please select any that may apply to you.*

- No time.** You might feel that you are too busy and not able to find any spare time. It is really important that you try to make some time during the day or in the evening to do something you enjoy. If you have little time, there are some pleasant activities that do not take up a lot of time and which you can fit in around your day.
- No energy.** You might have less energy because caregiving can be tiring. Although it is hard to imagine, it is likely that you will feel more energized after doing something you like.
- No money.** You might think that you have to spend lots of money to do something pleasant. Pleasant activities do not have to be costly. You can keep the activities as simple as you want them to be. For example, things like meeting a friend for a cup of tea or going for a walk by yourself do not cost money.
- Not in the mood.** You might not feel like doing pleasant activities. Although it is hard to imagine, it is likely that your mood will be better after doing something you like. On the other hand, not doing pleasant activities will likely worsen your mood.
- Physical limitations.** You might think that if you have physical limitations, you are not able to do a pleasant activity. If you have physical limitations, think of activities that you can do despite your limitations. There are many possibilities, such as reading, playing a game or talking to a friend.
- Guilt.** You might feel guilty because you will feel that you are running away from the person you care for. You need time to do things you like, relax and recharge so that you can provide adequate care for them. Being a good carer means taking care of yourself as well.

Suggestions for doing pleasant activities

- Consider asking someone to help you with some of your day-to-day tasks.
- Consider the impact of not doing certain tasks at that moment. For example, what is the impact of not cleaning the house every day? You may realize that you can be more flexible and have more time as a result.
- Try to do one activity at a time and finish the things you have started as much as possible. If you leave something unfinished, it may make you feel dissatisfied. You may not be able to focus entirely on your next activity. You could feel more energized if you complete an activity before taking on another.
- Think about ways to better manage your time. Consider using an agenda or calendar.
- Talk to someone about how you might be able to better manage your time. Seeking another opinion or suggestions may be helpful.



3. Making pleasant activities achievable

Now rate how achievable it would be for you to do the pleasant activities that you chose earlier in this lesson (see the exercise on page 16).

Read every activity and consider whether the activity is:

1. unachievable;
2. unlikely to be achievable;
3. somewhat achievable;
4. achievable;
5. very achievable.

3. Activity



Please check at least two activities that you would like to do more often. If your favourite activity is not listed below, use the 'other' box to write your own activity.

	Unachievable	Unlikely to be achievable	Somewhat achievable	Achievable	Very achievable
<input type="checkbox"/> Do a crossword puzzle					
<input type="checkbox"/> Watch TV					
<input type="checkbox"/> Visit friends or family					
<input type="checkbox"/> Cook					
<input type="checkbox"/> Listen to music					
<input type="checkbox"/> Do crafts					
<input type="checkbox"/> Read					
<input type="checkbox"/> Take a nap					
<input type="checkbox"/> Go shopping					
<input type="checkbox"/> Take a walk					
<input type="checkbox"/> Exercise					
<input type="checkbox"/> Other:					

Which of your activities can you do today?

It is a good idea to start with your pleasant activities as soon as possible and incorporate them into your routine.

Which of your activities can you do today? If it is inconvenient to start an activity today, think about the pleasant activities you could do tomorrow.

Remember



Start with small goals and add more pleasant activities after you feel successful with your first try. Rethink the activities that you would like to do to help make them more achievable.

- Pleasant activities should be achievable.
- There are different reasons why you can feel that pleasant activities are not achievable.
- There are ways to undertake pleasant activities despite these reasons.

4. Doing pleasant activities together

It can be very rewarding to do pleasant activities with the person that you care for. However, it might be difficult at first to think of pleasant activities that are suitable for both of you.

In this exercise we will make a list of the pleasant activities that you can do with the person you care for. First, take a look at Jose's experience from the previous exercise.

Jose

Jose takes care of his brother who is living with dementia. In addition to taking a nap while his sister takes care of his brother, Jose takes his brother out for walks around the neighbourhood. His brother enjoys the walks and Jose is also able to get some exercise and fresh air.

What would you like to do more often?

Take a look at the list on the next page for examples that you can do with the person that you care for.

Activity



Please select at least one activity that you would like to do together more often.

If an activity is not listed below, use the 'other' box at the bottom of the list to add the activity that you would like to do.

- | | |
|---|---|
| <input type="checkbox"/> Listen to music | <input type="checkbox"/> Watch birds or animals |
| <input type="checkbox"/> Play a musical instrument | <input type="checkbox"/> Do handiwork or crafts |
| <input type="checkbox"/> Take a relaxing walk | <input type="checkbox"/> Look at photos |
| <input type="checkbox"/> Listen to or read stories, newspaper articles, poems, etc. | <input type="checkbox"/> Watch the clouds or explore nature |
| <input type="checkbox"/> Go out to eat together | <input type="checkbox"/> Recall and discuss happy memories |
| <input type="checkbox"/> Cook and prepare snacks | <input type="checkbox"/> Have friends over to visit |
| | <input type="checkbox"/> Other: |

Keep in mind that despite the challenges, pleasant activities are good for you and are necessary to ensure that you are able to keep providing care to your family member or acquaintance.



You finished this lesson, well done!

Lesson 3. Thinking differently

Why is this lesson important?

Your thoughts determine how you feel. Unhelpful thoughts can make us feel bad.

How will this lesson help me?

This lesson will help you think differently and change your unhelpful thoughts into helpful ones.

What will I learn?

1. Thoughts determine how we feel. You cannot change what happens, but you can change your response.
2. Learn to think differently by changing unhelpful thoughts into helpful ones.
3. Thinking differently makes you feel better.

1. Thoughts determine how we feel

There are different ways to deal with stressful events. One way is to think differently. Let's look at an example.

It is not an event that makes you feel angry, sad, happy or guilty, it is how you think about it.

An event can be anything. Here are a few examples:

- The person you care for becomes angry when you ask him/her something.
- Your family member who promised to help you does not turn up or cancels on you.
- The person you care for cannot find something.
- Your family member is blaming you for not providing the right care.

Many people think that their feelings are a direct consequence of an event. However, it is the way that you think about the event that determines how you feel.

Lost keys

Jo is married to Max who is living with dementia. She is about to leave the house to visit a friend. Max says, "I can't find my keys! You cannot leave me without keys!" Jo thinks to herself: "I cannot leave him alone anymore." She starts to feel miserable.

1. Check your understanding



Feelings and thoughts.

What do you think Jo should do?

Please check all the responses that you feel are appropriate.

- Tell Max that she cannot help him search now and leave.
- Search for the keys until she finds them.
- Tell Max that he should be more careful not to lose his keys in the future.
- Think to herself, "Max has dementia and is sometimes worried when he loses things. I can take some time to help and then go." Then call her friend and explain that she will come later.

Keep in mind



- There are many different ways of dealing with events.
- Negative thoughts can make us feel bad.
- By thinking differently, you might feel better and be able to better deal with events.



Jo's unhelpful and helpful thoughts

Jo thinks to herself when Max cannot find his keys: "I cannot leave Max alone anymore." This makes her feel miserable.

This means that Jo is thinking in an unhelpful way. Unhelpful thoughts can make it harder to respond in useful ways to situations like this.

Instead, Jo could think: "Max has dementia and is sometimes worried when he loses things. I can take some time to help and then go." This different way of thinking will probably make Jo feel better and help her stay calm and compassionate.

Helpful thoughts can make it easier to respond in useful ways to situations like these.

Keep in mind



- It is not the event itself that makes you feel angry, sad, happy or miserable.
- Helpful or unhelpful thoughts can determine how you respond to a situation.
- By changing your thoughts, you could help change the way you feel.

Unhelpful thoughts make you feel bad

Aryan has been caring for her family member who is living with dementia for several years now. She has many thoughts. Some make her feel worse, some make her feel better.

2. Check your understanding

Thoughts that can make you feel better.

Can you indicate which of Aryan's thoughts may help make her feel better?

Aryan might think...

- Making time for myself helps me to provide better care.
- I am a bad carer if my family member is not always happy.
- Maybe the person living with dementia will become better.
- No one understands how hard it is to care.
- No one can provide the care the way I do.
- Asking others for help can help me to share the duties of care.
- Dementia is a disease, it is not my or anyone else's fault.

Keep in mind

- Unhelpful thoughts can make you feel bad.
- Helpful thoughts are important to feel better and will assist you in dealing with situations in a more useful way.
- To feel better, it is important to identify unhelpful thoughts.

2. Learn to think differently by changing unhelpful thoughts into helpful ones

Xavier meets his friend Gabriel

Xavier takes care of his father, who is living with dementia. While he is shopping, he meets his friend Gabriel, who asks, "How are you? Do you need any help caring for your father?"

Xavier thinks to himself, "if Gabriel thinks I need help, he must think that I am a bad carer".

What if Xavier instead thinks to himself, "if Gabriel thinks I need help, he must care about me and my father and wants to make sure we are doing well"?

3. Check your understanding



How thoughts influence our feelings.

How do you think Xavier is feeling?

Please check all the responses that you feel are appropriate.

- Angry
- Guilty
- Happy
- Lonely
- Sad
- Supported
- Upset

4. Check your understanding



Match feelings to a helpful thought.

How does Xavier feel now?

Please check all the responses that you feel are appropriate.

- Angry
- Guilty
- Happy
- Lonely
- Sad
- Supported
- Upset

Keep in mind



Sometimes you cannot change the things that happen (events), but you can change your response (thoughts).

1. Activity



Which unhelpful thoughts do you have?

In an earlier example you indicated which thoughts are helpful and which may be unhelpful. Below you will find a list of unhelpful thoughts.

Please check the unhelpful thoughts that you have or provide additional examples.

- I have to do everything alone.
- The person I care for does not care about me anymore.
- When the person I care for is not happy, it means that I am a bad carer.
- Maybe the person I care for will get better.
- I must always be available for the person I care for.
- I should not consider my own needs if I want to be a good carer.
- No one understands how hard it is to care.
- No one can provide care the way I do.
- He/she being diagnosed with dementia has complicated my life.
- I have no time for others as a carer.
- I feel sorry for the person I care for.
- Other people are better off than the person I care for and I.
- Other:

2. Activity



Which helpful thoughts do you have?

In an earlier example you indicated which thoughts are helpful and which may be unhelpful. Below you will find a list of helpful thoughts.

Please check the helpful thoughts that you have or provide additional examples.

- It is okay to take time to relax as it will help me to provide a good standard of care.
- Sharing my feelings with others helps to take the pressure off.
- Asking for help from others can help me to share the burden of care.
- Making time for myself helps me to provide better care.
- Dementia is a disease; it is not my or anyone else's fault.
- I do not have to give others their way all the time.
- Other:

Keep in mind



Changing your unhelpful thoughts to helpful ones can make you feel better.



3. Thinking differently makes you feel better

You cannot change the things that happen, but you can change your response. In other words, you cannot change events but you can change your thoughts.

Example 1: Wei

Wei takes care of his wife Xu, who is living with dementia. He writes the following:



Name:	Wei
What was the event that made you feel upset or miserable?	<i>Yesterday my wife Xu and I visited some friends. We had tea together. Xu dropped her cup on the floor. When they started to clean the floor, Xu did not help, but she stood in the way. She did not apologise for her behaviour, but laughed.</i>
What were your unhelpful thoughts?	<i>Our friends are upset with my wife and won't invite us to their house again.</i>
What would be more helpful to think?	<i>My wife has dementia and is unable to think and act in the same way that she used to. Our friends won't blame my wife as I have explained to them that she has dementia and that her thinking has declined.</i>
How could the helpful thoughts make you feel?	<i>Instead of feeling worried and ashamed, I would have felt happy about the day we spent with our friends.</i>

Example 2: Helen

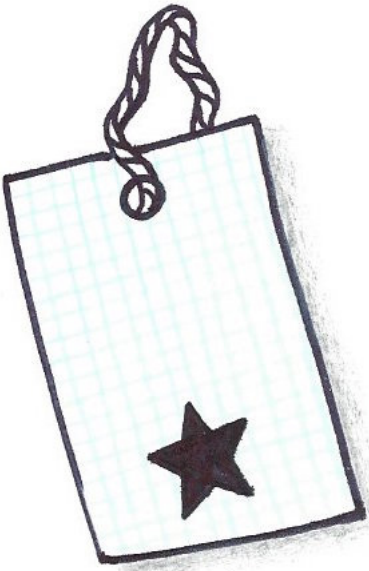
Helen takes care of her brother Matty, who is living with dementia. She writes the following:



Name:	<i>Helen</i>
What was the event that made you feel upset or miserable?	<i>A week ago, our sister came to visit us. At the end of the day, I said to Matty, "it was a great day, don't you think?" Then he said that he was not sure, because he could not remember exactly what we had been doing. He said that he was tired and wanted to sleep.</i>
What were your unhelpful thoughts?	<i>Nothing we do is worthwhile because Matty forgets everything. Everything is ruined because of his dementia.</i>
What would be more helpful to think?	<i>Even though he cannot remember what we did, I know that he had a great day too, and that is what counts. He smiled a lot today and kept saying how nice it was that our sister came.</i>
How could the helpful thoughts make you feel?	<i>Instead of feeling sad and miserable, I would have felt happy about the day we spent with our sister.</i>

Now it's your turn. In the next exercise you will work to change your unhelpful thoughts into helpful ones.

Try to think of a recent event that made you feel upset and answer the questions below. You can refer back to the examples on the previous page for some help.



Name:	
What was the event that made you feel upset or miserable?	
What were your unhelpful thoughts?	
What would be more helpful to think?	
How could the helpful thoughts make you feel?	

Practice makes perfect. Do you want to try one more time? Please answer the questions below for a different event.



Name:	
What was the event that made you feel upset or miserable?	
What were your unhelpful thoughts?	
What would be more helpful to think?	
How could the helpful thoughts make you feel?	

Let's review what you have learned in this lesson

- You cannot change what happens, but you can change your response.
- You can learn to think differently by changing your unhelpful thoughts into helpful ones.
- Thinking differently makes you feel better.

Keep in mind



There are events in which feeling upset, miserable, sad or angry is inevitable. Examples include: if the person you care for needs to go to the hospital or if you lose a dear friend or family member. To change your thoughts in such events would not do justice to your feelings.



You finished this lesson, well done!

1. Check your understanding

*Feelings and thoughts.***What do you think Jo should do?**

- ✗ Tell Max she cannot help him search now and leave.

This is bad advice. Max has dementia and is feeling worried. He could be very upset if Jo leaves the house right now.

- ✗ Search for the keys until she finds them.

This could be helpful. Max might feel safer if he has the keys. However, this may mean Jo misses meeting her friend and is left feeling miserable.

- ✗ Tell Max that he should be more careful not to lose his keys in the future.

This is not such good advice. Max has dementia, he cannot help misplacing things.

- ✓ Think to herself, "Max has dementia and is sometimes worried when he loses things. I can take some time to help and then go." Then call her friend and explain that she will come later.

This is good advice. It is not the fact that Max has lost the keys that is making Jo miserable, but her concern that she always needs to help Max and cannot leave him alone anymore. After Jo has called her friend, she can help Max search for the keys, which will make him feel safer. Then she can go to see her friend.

2. Check your understanding



Thoughts that can make you feel better.

Which of Aryan's thoughts may help make her feel better?

- ✓ Making time for myself helps me to provide better care.

This is a helpful thought. No one should feel guilty when taking time for themselves. It might help the carer to continue providing care in the long term.
- ✗ I am a bad carer if my family member is not always happy.

This thought will **make Aryan feel unhappy** and sad. The mood of the person living with dementia does not depend solely on the carer. For example, mood can also be related to dementia, depression, functional ability or personality.
- ✗ Maybe the person living with dementia will get better.

This thought may **make Aryan feel disappointed** as people with dementia continue to decline. There are many diseases that cause dementia. Unfortunately, there is no cure for any of these diseases yet.
- ✗ No one understands how hard it is to care.

This thought may **make Aryan feel upset**, isolated and lonely. There might be people who do not understand how hard it is to care. However, talking to other people may help them better understand what dementia is and help you to take some pressure off.
- ✗ No one can provide the care the way I do.

This thought could **make Aryan feel lonely**, isolated and under a lot of pressure. Although others may provide care in a different way, that does not mean that it is always of a lower standard. It is important to involve others in caring for a person living with dementia, to avoid getting overwhelmed.
- ✓ Asking others for help can help me to share care duties.

This is a helpful thought that may make Aryan feel more in control. Involving other people in caregiving has lots of potential benefits. For instance, the carer will be able to take breaks more regularly and provide care for a longer time.

3. Check your understanding

How thoughts influence our feelings.

Xavier thought, "if Gabriel thinks that I need help, he must think I am a bad carer."

How do you think Xavier is feeling?

This is an unhelpful thought that may make Xavier feel:

- ✓ upset
- ✓ lonely
- ✓ sad
- ✓ angry
- ✓ guilty

4. Check your understanding

Matching feelings to a helpful thought.

Xavier thought, "if Gabriel thinks I need help, he must care about my father and want to make sure that we are doing well".

How does Xavier feel now?

This is a helpful thought that may make Xavier feel happy or supported.

MODULE

4

PROVIDING EVERYDAY CARE

- Lesson 1.** Eating and drinking - more pleasant mealtimes
- Lesson 2.** Eating and drinking - preventing health problems
- Lesson 3.** Toileting and continence care
- Lesson 4.** Personal care
- Lesson 5.** An enjoyable day

Lesson 1. Eating and drinking - more pleasant mealtimes

Why is this lesson important?

Dementia can affect eating and drinking in various ways depending on the stage of dementia and other health conditions.

How will this lesson help me?

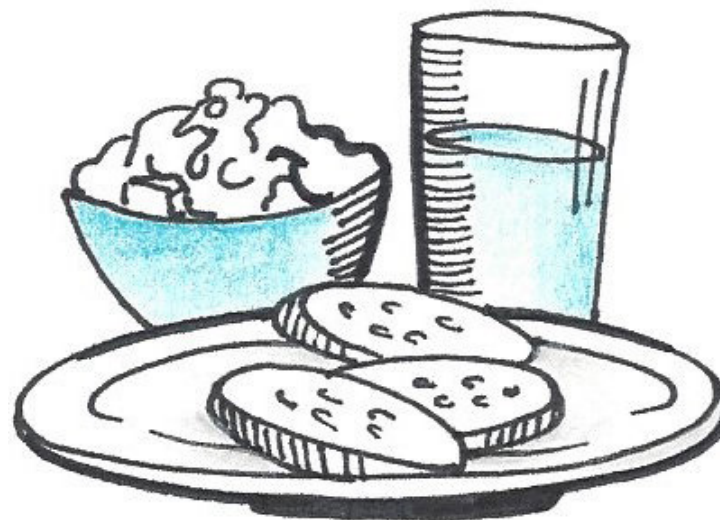
By learning how to help create more pleasant mealtimes and prevent dehydration.

What will I learn?

1. Making mealtimes more pleasant.
2. Promoting a good mealtime atmosphere.
3. Health conditions that affect eating and drinking.
4. Preventing dehydration.

1. Making mealtimes more pleasant

Engaging people with dementia in simple tasks around mealtime helps to make the most of people's skills, promote feelings of self-worth, and enjoy the mealtime.



Let's look at an example

Siya was a housewife and cooked every day for her family for many years. Recently, she lost her husband and now lives with one of her sons. Adi, her daughter-in-law, provides all the cooking in the new household. Siya has been very sad in her new home and says she's not hungry when she is offered food. She does not join the family for dinner.

1. Check your understanding



Making mealtimes more pleasant.

How would you advise Siya's family to deal with this situation? *Please select the answer that you think is correct from the list.*

- Bring Siya's dinner to her room.
- Demand that Siya joins them for dinner.
- Let Siya help with meal preparation and cleaning activities.



Now, try to think about involving the person that you care for around mealtimes.

1. Activity

Mealtime activities

Please select all activities from the list below that you think the person you care for can still engage in and would enjoy.

Mealtime activities	Example
Shopping together	<input type="checkbox"/> Let the person living with dementia choose what food and drinks they like to buy for breakfast, lunch and dinner.
Meal preparation	<input type="checkbox"/> Let the person living with dementia help chopping, stirring, or cooking.
Preparation of the table	<input type="checkbox"/> Let the person living with dementia lay the table for breakfast, lunch and dinner.
Cleaning the table	<input type="checkbox"/> Let the person living with dementia remove everything from the dining table and wipe the table.
Washing or drying dishes	<input type="checkbox"/> Let the person living with dementia put dishes in the sink or wash and dry the dishes.

If you think that the person you care for can still engage in and would enjoy any of the listed activities, perhaps you could ask or assist them in trying these activities the next time you have a meal.

2. Promoting a good mealtime atmosphere

Mealtime is a good opportunity for carers to show their care and support for the person living with dementia. An enjoyable mealtime atmosphere may help encourage them to eat and drink. Let's look at an example again.

Spilling food

Shang has Alzheimer's disease and lives with his oldest son since his wife passed away a year ago. The family now has four generations who eat together at the table. Shang sees the mealtime as the best time of the day. Recently, Shang's hands have started to tremble and he often spills or drops food on the table and the floor.

2. Check your understanding




Promoting a good mealtime atmosphere.

How would you advise Shang's son to deal with this situation? *Please check the responses that you feel are appropriate.*

- Buy adaptive eating and drinking aids from the shop for Shang.
- Set up a separate table for his father to eat in his own bedroom, because spilling and dropping food may make the family irritated.
- Organize a family meeting to ask all family members to think of more positive and constructive ways to respond to the situation at mealtimes.

Health conditions

Common health conditions can affect eating and drinking. The activity below teaches you how to improve these conditions, if they are present.

2. Activity 		
Health condition	Changes that you may have observed	Recommended actions you may try
Poor appetite	<ul style="list-style-type: none"> <input type="checkbox"/> Does not want to eat the meal <input type="checkbox"/> Eats only small amounts of food <input type="checkbox"/> Takes a long time to eat a small amount of food 	<ul style="list-style-type: none"> ● Make food appealing: use different textures, flavours, smells, tastes, sounds and colours that the person enjoys ● Eat with the family, rather than alone ● Play soft music that they like during mealtime ● Increase physical activities that they can do during the day
Toothache	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Has a facial expression indicating pain 	<ul style="list-style-type: none"> ● Ask whether the person is in pain ● Ask them to point out the area of pain ● Check whether there are loose teeth, mouth ulcers, etc. ● Seek help from a doctor or dentist
Poorly fitting artificial dentures	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Has a facial expression indicating pain <input type="checkbox"/> Refuses to wear dentures <input type="checkbox"/> Throws dentures on the floor 	<ul style="list-style-type: none"> ● See above for toothache ● Check that the dentures are in good condition and fit properly

2. Activity



Health condition	Changes that you may have observed	Recommended actions you may try
Body pain	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat and drink <input type="checkbox"/> Is restless <input type="checkbox"/> Unusual body postures <input type="checkbox"/> Has a facial expression of pain 	<ul style="list-style-type: none"> ● Ask whether the person is in pain ● Ask them to point out the area of pain ● Seek help from a doctor
Does not have bowel movement for more than 7 days	<ul style="list-style-type: none"> <input type="checkbox"/> Hard and dry faeces <input type="checkbox"/> Difficulty passing faeces/straining <input type="checkbox"/> Having a feeling of incomplete bowel movements <input type="checkbox"/> Becomes anxious or agitated <input type="checkbox"/> Hard stomach <input type="checkbox"/> Nausea and vomiting 	<ul style="list-style-type: none"> ● Seek help from a doctor ● Upon resolution of the problem: <ul style="list-style-type: none"> ○ Increase fibre in diet ○ Increase drinking of fluids ○ Increase physical activity
Diarrhoea	<ul style="list-style-type: none"> <input type="checkbox"/> Liquid faeces <input type="checkbox"/> Increased number of bowel movements <input type="checkbox"/> Incontinency and difficulty controlling bowel movements 	<ul style="list-style-type: none"> ● Seek help from a doctor
Side effects from medications	<ul style="list-style-type: none"> <input type="checkbox"/> Nausea, vomiting, liquid faeces or constipation <input type="checkbox"/> Does not want to have a meal <input type="checkbox"/> Eats only small amounts of food 	<ul style="list-style-type: none"> ● Seek help from a doctor

2. Activity 		
Health condition	Changes that you may have observed	Recommended actions you may try
Memory loss; forgets to eat or drink	<ul style="list-style-type: none"> <input type="checkbox"/> Asks when the next meal is even if it already happened <input type="checkbox"/> The person says that they are hungry even if they already ate 	<ul style="list-style-type: none"> ● Remind the person to eat and drink regularly ● Model eating and drinking (i.e. eat and drink with the person) ● Provide snacks between meal times
Depression	<ul style="list-style-type: none"> <input type="checkbox"/> Refuses to eat or says they are not hungry <input type="checkbox"/> Eats small amounts of food <input type="checkbox"/> Has no interest in food 	<ul style="list-style-type: none"> ● Seek help from a doctor
Weight loss	<ul style="list-style-type: none"> <input type="checkbox"/> Forgets to eat <input type="checkbox"/> Eats smaller amounts of food <input type="checkbox"/> Eats regular amounts of food but still loses weight 	<ul style="list-style-type: none"> ● Increase the amount of food ● Provide foods that they will like ● Increase flavourful foods as the person's taste might be impaired ● Seek advice from a doctor
Weight gain	<ul style="list-style-type: none"> <input type="checkbox"/> Eats all the food that is served <input type="checkbox"/> Eats more snacks than before because they forget that they already ate <input type="checkbox"/> Is obsessed with food 	<ul style="list-style-type: none"> ● Model eating and drinking ● (i.e. eat and drink with the person) ● Serve smaller portions ● Remove the plate when the person indicates that they are full ● Provide low calorie snacks

4. Preventing dehydration

People living with dementia have a higher risk of being dehydrated.

There can be several reasons for this:

- inability to explain their needs;
- decreased thirst sensation;
- not offered enough to drink; and,
- swallowing problems in the late stage of dementia.

The person you care for needs to be encouraged to drink 8-10 glasses (1500-2000 millilitres) of fluid (water, iced lollies, soup and juice, not including tea or coffee every day.

Severe dehydration

Ben has Alzheimer's disease, but he is able to eat and drink without assistance from his wife, Mary. Ben likes to walk a lot. One hot afternoon, Mary also notices that Ben seems very tired, walks very slowly and then collapses on the floor. Ben is sent to the local hospital's Emergency Department and is diagnosed with dehydration. After treatment in the hospital, Ben has recovered and is able to go home again.

3. Check your understanding



Severe dehydration.

How would you advise Mary to deal with the situation after Ben is discharged home? *Please select all the responses that you feel are appropriate.*

- Mary needs to let Ben make the decision about when to drink.
- Mary needs to ensure that Ben drinks 8-10 glasses of water during the day.
- Mary records the time and the amount of fluid Ben actually consumes.

3. Activity

Timetable for eating and drinking

The timetable below is for you to remind the person living with dementia to eat and drink. Give them the opportunity to choose what to drink.

Time of day	Type of fluid (e.g. water)	Amount of fluid (e.g. 3 glasses)
Morning - Noon		
Noon - Dinnertime		
Dinnertime - Bedtime		

WARNING!



If the person you care for is not allowed fluids due to a heart condition, you need to follow the doctor's order regarding how much to drink.

Let's review what you have learned

- The person you care for needs to be encouraged and supported to eat and drink.
- You can engage the person you care for in a variety of mealtime activities to create a pleasant mealtime for them, which helps to improve self-worth and a feeling of achievement.
- Eating and drinking can be facilitated by modifying food, utensils and the environment.
- You can maintain good eating and drinking for the person you care for by improving their health condition. Seeking assistance from health professionals might be necessary.
- To help prevent dehydration, it is important to prompt the person living with dementia to drink.
- Record and monitor the amount of fluid they consume.



You finished this lesson, well done!

1. Check your understanding

*Making mealtimes more pleasant.***How could Siya's family deal with the situation?**

- ✗ Bring Siya dinner in her room.

This is not helpful because it might further isolate Siya from her family. Siya may not feel welcome in the new home. She has lost her husband, her own home and now also her previous roles as cook and housekeeper.

- ✗ Demand that Siya joins them for dinner.

This is not such a good response because it may make Siya angry or cause her to further withdraw.

- ✓ Siya's family should let her help with the meal preparation and cleaning activities.

This is a good response because her family knows Siya still enjoys cooking and should therefore support her to continue engaging in the activities that she likes and is still able to do.

2. Check your understanding



Promoting a good mealtime atmosphere.

How could Shang's son deal with the situation?

- ✓ Buy adaptive eating and drinking aids from the shop for Shang.

This is a good response because Shang's son recognises that his father is no longer able to manage eating and drinking using the usual utensils. By providing other utensils he is trying to solve this problem.

- ✗ Set up a separate table for his father to eat in his own bedroom, because spilling and dropping food may make the family irritated.

This is not helpful because separation will make Shang feel sad or angry, which might prevent him from eating and drinking properly.

- ✓ Organise a family meeting to ask all family members to think of more positive and constructive ways to respond to the situation at mealtimes.

This is a good response because Shang's son is trying to provide a positive mealtime atmosphere for everyone.

3. Check your understanding



Severe dehydration.

How could Mary deal with this situation after Ben is discharged home?

- ✗ Mary needs to let Ben make the decision about when to drink.

This answer is not so good even though she is respecting Ben's autonomy. Since people with dementia have decreased thirst sensation, it could be dangerous to leave it up to them whether to drink or not without reminding them. If not reminded, Ben may get dehydrated again and collapse.

- ✓ Mary needs to ensure that Ben drinks 8-10 glasses of water during the day.

This is a good response. Mary notices that Ben may forget to drink, so she is trying to help her husband drink enough water every day.

- ✓ Mary records the time and the amount of fluid Ben actually consumes.

This is a good response. It can be helpful to establish a routine and record the number of glasses Ben drinks from breakfast time to dinner time. Drinking after dinner time may potentially increase night time visits to the bathroom.

Lesson 2. Eating, drinking and preventing health problems

Why is this lesson important?

Dementia can affect eating and drinking in various ways depending on the stage of dementia and other health conditions.

How will this lesson help me?

By learning how to improve eating and drinking, prevent weight loss and promote drinking and eating safely.

What will I learn?

1. Improve eating and prevent weight loss.
2. Help the person you care for to eat safely and prevent aspiration pneumonia.

1. Improve eating and prevent weight loss

In the late stages of dementia, a person living with dementia may experience difficulty chewing and swallowing. Reduced abilities to smell, taste and see may also happen due to ageing and dementia. These can have a negative impact on the person's health. Depression and changes in eating patterns may also impair eating and digestion.

Let's look at an example

Chiu has been living with dementia for 9 years and is cared for by her daughter, Ling. Recently, Ling notices that her mother sleeps during the day and is very difficult to wake and assist with her meals during the normal mealtimes. Ling believes that her mother is not hungry and does not want to disturb her sleep. A recent check-up showed that Chiu has lost 2.5 kg since the last check-up 5 weeks ago (5% of her body weight).

1. Check your understanding



How to improve eating and prevent weight loss.

What would you advise Ling to do to improve Chiu's eating? *Please select all the responses that you feel are appropriate.*

- Be flexible to have meals when her mother is awake.
- In a diary, keep a record of what and how often her mother eats.
- Ensure Chiu has access to foods she enjoys eating.

2. Help the person you care for to eat safely and prevent aspiration pneumonia

People with dementia may experience the problems listed below.

- People with dementia may not be able to judge what can or cannot be eaten. They may eat inedible materials that are within reach when feeling hungry. Make sure to keep inedible materials and chemicals in safe places.
- If the person is in the late stages of dementia, they may experience swallowing difficulties that can cause a lung infection called aspiration pneumonia. Aspiration pneumonia occurs when food is swallowed in the wrong way and goes into the person's lungs instead of their stomach. This can then cause an infection. Eating, drinking and feeding methods may need to be modified to prevent this life-threatening problem.

Inedible materials

Oliver has been living with dementia for 10 years and is cared for by his wife, Ella. Ella starts to observe her husband closely during the day. Recently, Ella notices that the soaps she put in the kitchen and bathroom have disappeared. She also notices that her husband is eating the flowers that she puts on the dining table. She sees Oliver go to the kitchen and mistakenly pick up a soy sauce bottle and even a bottle of dishwashing detergent to drink.

2. Check your understanding



Inedible materials.

What do you think Ella should do? *Please select all the responses that you feel are appropriate.*

- Recognize that she needs to lock household chemicals, such as dishwashing soap, in a cabinet.
- Leave some inedible household materials in the places Oliver is able to reach, because she thinks Oliver should be taught that those cannot be eaten.

Helping a person to eat safely

Lu has been living with dementia for 10 years and is bedridden. Her husband, Wei, helps her to eat safely. Recently, he found Lu has difficulty swallowing soft foods that he makes for her. He also notices that she coughs when she drinks something. She seems to have a high temperature and is admitted to the hospital.

Lu is diagnosed with aspiration pneumonia. After a month of treatment in the hospital, Lu has recovered and is discharged home. The doctor orders a healthy, soft diet and thickened drinks for Lu to consume at home to prevent future aspiration pneumonia.

3. Check your understanding

Helping a person to eat safely.

What do you think Wei should do? *Please select all the responses that you feel are appropriate.*

- Learn how to make healthy, soft foods and thickened drinks for Lu.
- Not pay attention to how Lu is sitting when they are helping her eat.

Tip

A healthy soft diet can be made by hand without using an electric blender. Thickened fluids can be made by adding corn flour to water or other fluids while heating and stirring it, until it thickens.

Note: commercial stir-in thickeners are available in the supermarket in many countries.

Let's review what you have learned

- You can modify eating patterns for the person you care for to improve nutrition.
- You can help the person living with dementia to eat and drink safely by keeping inedible materials and household chemicals in a safe place.
- You can help prevent aspiration pneumonia by modifying the foods and drinks that they eat and positioning the person you care for in an upright position when helping them eat.



You finished this lesson, well done!

1. Check your understanding



How to improve eating and prevent weight loss.

What would you advise Ling to do to improve Chiu's eating?

- ✓ Be flexible to have meals when her mother is awake.

This is a good response. People in late stages of dementia need rest, so flexibility in planning meals will be very helpful when they are sleeping during normal mealtimes.

- ✓ Keep a record of what and how often her mother eats in a diary.

This is a good response. Recording what people with dementia eat is important. This way, carers will better understand when and what kind of food is needed for sufficient food intake.

- ✓ Ensure Chiu has access to foods that she enjoys eating.

This is a good response. What foods did she enjoy eating before her diagnosis of dementia? What foods does she seem to enjoy now?

2. Check your understanding

Inedible materials.

What do you think Ella should do?

- ✓ Recognize that she needs to lock household chemicals, such as dishwashing soap, in a cabinet.

This is a good response. Keeping these dangerous things away will help protect the person living with dementia.

- ✗ Leave some inedible household materials in the places Oliver is able to reach because she thinks that Oliver should be taught that those cannot be eaten.

This is not a good response. People in late stages of dementia can have a changed judgement of what they can or cannot eat. Keeping these dangerous things away from them is very important.

3. Check your understanding

Helping a person to eat safely.

How can Wei help Lu?

- ✓ Learn how to make healthy, soft food and thickened drinks for Lu.

This is a good response. Providing healthy, soft food and thickened drinks will make it easier for people in the late stage of dementia to continue to eat and drink on their own and maintain a healthy weight.

- ✗ Not pay attention to how Lu is sitting when they are helping her eat.

This is not a good response. They should sit Lu in an upright position which will help her eat and drink better and prevent aspiration pneumonia.

Lesson 3. Toileting and continence care

Why is this lesson important?

Poor toileting and incontinence may lead to infections and other health problems, low self-esteem and withdrawal from social activities for a person living with dementia.

How will this lesson help me?

This lesson will help you think about the health concerns, and assist the person you care for with using the toilet and continence.

What will I learn?

1. Possible solutions for problems such as urinating on the floor or losing bladder control.
2. Using incontinence aids and equipment.

1. Possible solutions for problems such as urinating on the floor or losing bladder control

Urinating on the floor

Dementia can affect a person's ability to find their way to the bathroom and identify the toilet and/or toilet seat.

You should not blame the person living with dementia for this behaviour, nor punish them as this type of response will cause them and yourself stress. Modifying your house may help them use the bathroom.

Let's look at an example

Zhen is taking care of her husband, Fu, since he developed vascular dementia several years ago. Fu is able to go to the toilet himself without assistance, but recently, Zhen finds Fu urinating on the floor outside the toilet.

1. Check your understanding

Prevent urinating on the floor.

What do you think is the right response for Zhen?

Please select the correct answer.

- Make some simple changes to the environment and clothing, such as putting an image of a toilet on the bathroom door, using a contrasting colour for the toilet seat or changing Fu's trousers to a pair of pants that does not need a belt.
- Tell her husband, Fu, that he is making trouble and punish him by not taking him for his daily walk in their neighbourhood.

Tip

Below are some tips in case the person you care for experiences difficulties using the toilet.

- Put an image of a toilet on the toilet door to help them find it.
- Provide directions to the toilet if they are unable to find it.
- Provide adequate nightlights in the hallway between the bedroom and the toilet.
- Use contrasting colours for the toilet seat.
- Change the person's trousers to some that are easier to remove.
- Provide step-by-step instructions to the person if they forget how to use the toilet.

What other factors may contribute to urinating on the floor or losing bladder control?

Contributing factors	Recommended solutions
A long distance to go to the toilet in the house	<ul style="list-style-type: none"> ● Direct the person you care for to the toilet ● Provide a bedside commode at night ● Use nightlights in the bedroom and the house
Public toilet that is at a distance from the house	<ul style="list-style-type: none"> ● Provide a commode for them to use in the house
Not being able to find the toilet	<ul style="list-style-type: none"> ● Put a picture of a toilet on the toilet door
Not enough colour contrast of the toilet seat	<ul style="list-style-type: none"> ● Replace the toilet seat with a different colour to increase the contrast
Not enough lighting in the hallway	<ul style="list-style-type: none"> ● Provide adequate lighting in the hallway
Not enough lighting in the toilet	<ul style="list-style-type: none"> ● Provide adequate lighting in the toilet

Contributing factors	Recommended solutions
Narrow toilet doors that do not allow the walker or wheelchair to pass	<ul style="list-style-type: none">● Modify the door opening to allow a walker or wheelchair to pass
Visual impairment	<ul style="list-style-type: none">● Direct the person you care for to the toilet during the day● Provide a bedside commode at night
Unable to undo trousers	<ul style="list-style-type: none">● Change trousers to ones that are easily undone and removed● Assist the person you care for to pull on and do up trousers
Forgetting what to do in the toilet	<ul style="list-style-type: none">● Remind the person you care for of the activities they need to do● Provide step-by-step instructions for them to use the toilet

Urinating in public places

Dementia affects the person's ability to explain their needs, for example needing to go to the bathroom. Additionally, dementia can affect a person's judgement of what is normal or not in public.

You could help prevent these accidents (incontinence) by maintaining a regular, daily schedule to assist the person you care for to go to the toilet. Identifying how often they used the toilet before they had dementia might be helpful. You can also identify whether the person you care for needs to go to the bathroom by the way they behave, e.g. if they become agitated, stressed, anxious or restless.

Let's look at an example

Joshua is taking care of his mother Esther, who received a diagnosis of dementia 5 years ago. Joshua usually takes his mother shopping in the neighbourhood as she enjoys meeting people.

Recently, Joshua notices that his mother has lost bladder control during the day.

2. Check your understanding

Dealing with losing bladder control.

What do you think is the right response for Joshua?

Please select the correct answer.

- Since this is an embarrassing situation for Joshua, he should stop taking his mother shopping.
- Joshua should try to make sure that his mother uses the toilet before leaving to go shopping.

To improve bladder or bowel control, it may help to fill out a toilet diary.

Toilet use diary			Date:
Time	Number of trips to the toilet	Number of times lost control of bladder or bowel	What possible causes did you observe?
06:00-09:00			
09:00-12:00			
12:00-15:00			
15:00-18:00			
18:00-21:00			
21:00-00:00			
0:00-03:00			
03:00-06:00			

2. Using incontinence aids and equipment

In the late stages of dementia, the person living with dementia may not be able to control their bladder and bowel movements. Before using any incontinence aids and equipment, you should ask a health professional to help identify the cause(s) of incontinence, as these may be treatable and therefore reversible.

Tip



There are numerous disposable and/or washable incontinence aids, pads and equipment. When selecting products, you should consider their cost, effectiveness, comfort and convenience.

For bedridden males, using urinals to collect urine may help. Some of these urinals are designed to prevent the backward leaking of urine.

Let's look at an example

Gloria is in a late stage of Alzheimer's disease and is living with her son's family. Her daughter-in-law, Marina, is taking care of her. Since Gloria cannot control her bladder or bowel movement, the doctor suggests that Marina try incontinence pads for Gloria.

In the beginning, Marina encounters a number of problems:

- Gloria constantly takes the pad off and throws it on the floor.
- Gloria still has wet pants even when using incontinence pads.
- Gloria has skin problems in her genital area.

3. Check your understanding



Use of personal hygiene products.

What do you think is the right response for Gloria?

Please select the correct answer.

- Marina should force Gloria to wear the pad.
- Marina should remind her mother-in-law to use the bathroom at scheduled times if she is not doing so herself.

Tip



Below are some tips for incontinence care.

Problems	Possible causes	Recommended solutions
Constantly taking the pad off and throwing it on the floor	<ul style="list-style-type: none">● Feeling uncomfortable with the pad● The pad size is wrong● The pad is wet and needs to be changed	<ul style="list-style-type: none">● Check whether the pad size is correct● Change the wet pad on time● Consult the doctor regarding the person's behaviour
Still having wet pants even while using the incontinence pads	<ul style="list-style-type: none">● The pad size is incorrect● The schedule for using the toilet has not been maintained	<ul style="list-style-type: none">● Use the right size and type of pad● Maintain scheduled trips to the toilet to minimize the use of pads
Having sore or irritated skin in the genital area	<ul style="list-style-type: none">● Incontinence pads can cause skin breakdown● Unsuitable pad size and delaying changes of soiled pads in a timely manner can cause skin infection	<ul style="list-style-type: none">● Select suitable pad size and type● Change the soiled pad on time and maintain hygiene around genital area● Apply protective creams or lotions that maintain healthy skin
Having fever, being in pain, strong smelling urine	<ul style="list-style-type: none">● Urinary tract infections are triggered by a number of factors, including incontinence and poor genital care	<ul style="list-style-type: none">● See the doctor● Maintain an intake of 6-8 glasses of water or juice per day except if the person is under fluid or dietary restriction● Maintain good genital care

Let's review what you have learned

- Do not blame the person after any accidents, such as urinating on the floor.
- Modify the environment to reduce the chance of bladder and bowel accidents (for example, put a picture of a toilet on the bathroom door).
- Take the person living with dementia to the toilet regularly to reduce accidents.
- The frequency of toilet visits will need to be established based on the toilet pattern that the person living with dementia had before the onset of dementia.
- If these changes do not help, incontinence aids and equipment may help.
- Be aware that the use of incontinence aids can irritate the skin if used incorrectly.
- Maintain good genital care to reduce the risk of a urinary tract infection.
- If the person living with dementia is not under fluid restriction, encourage them to drink 6-8 glasses of water or juice per day to help prevent urinary tract infections.

Tip



For more tips on how to stay in control of your feelings please refer back to **Lesson 3. Thinking differently** in **Module 3**.



You finished this lesson, well done!

ANSWERS - PROVIDING EVERYDAY CARE

Lesson 3. Toileting and continence care

1. Check your understanding

*Prevent urinating on the floor.***What do you think is the right response for Zhen?**

- ✓ Make some simple changes to the environment and clothing, such as putting an image of a toilet on the bathroom door, using a contrasting colour for the toilet seat or changing Fu's trousers to a pair of pants that doesn't need a belt.

This is the best answer. People with dementia may have difficulties finding and using the toilet, so these changes could help Fu.

- ✗ Tell her husband that he is making trouble and punish him by not taking him for his daily walk in their neighbourhood.

This is not a good answer. You should never threaten people with dementia in this way. Fu will feel ashamed and embarrassed and this response could cause him to become upset.

2. Check your understanding

Dealing with losing bladder control.

What do you think is the right response for Joshua?

- ✗ Since this is an embarrassing situation for Joshua, he should stop taking his mother shopping.

This is not the best response because his mother will miss out on a very important pleasant activity.

- ✓ Joshua should try to make sure that his mother uses the toilet before leaving to go shopping

This is a good response. It is a good way to help prevent Esther from losing bladder control.

3. Check your understanding

Use of personal hygiene products.

What do you think is the right response for Marina?

- ✗ Marina should force Gloria to have the pad on.

This is not the right answer! It's very important to check why a person living with dementia may feel uncomfortable with the pad. Is the size wrong? Is the pad wet and does it need to be changed?

- ✓ Marina should remind her mother-in-law to use the toilet at scheduled times if she is not doing so herself.

This is the best answer. Scheduled toilet visits may help minimise incontinence and the need for pads.

Lesson 4. Personal care

Why is this lesson important?

Dementia affects people's ability to maintain personal care, for example brushing teeth, showering/bathing and grooming. Therefore, assistance with maintaining good personal care is very important. Poor personal care may lead to infections and other health problems, low self-esteem and withdrawal from social activities for people with dementia.

How will this lesson help me?

This lesson will help you think about the health concerns of the person you care for and assist them with personal care.

What will I learn?

1. Modifying the environment to make personal care easier.
2. Tips for daily dressing, oral care and assisting in bathing.

1. Modifying the environment to make personal care easier

There are different reasons for not being able to perform personal care. One reason is that people with dementia may not find the things that they need for personal care.

For example, when you cannot find your toothbrush and toothpaste due to memory loss, it will be difficult to brush your teeth.

However, you can modify the environment to make it easier for them to find things that are needed for personal care.

Let's look at an example

Mariam has Alzheimer's disease, but she is able to care for herself without assistance from family members.

Recently, her husband, Mohammed, notices that she sits at the table for breakfast in a nightgown without having washed her face, brushed her hair, or doing her make-up as she usually does.

1. Check your understanding

Promoting personal hygiene.

What would you think is the right response for Mohammed? *Please select the correct answer.*

- Put personal care items in the order of use and label them with large print words and different colours for Mariam to read.
- Ask their daughter-in-law to take Mariam from the table to the bathing room and assist her with washing and changing clothes.

There may be several reasons why Mariam may not undertake personal care before breakfast anymore. One of them is that she may be depressed. For more information on depression please see **Lesson 4. Depression, anxiety or apathy** in **Module 5**.

Tip

Below are some tips that may help people with dementia find items or places, and to do personal care activities independently.

- To find the bathroom or toilet: put a picture or words on the bathroom door or direct the person to the bathroom.
- To find personal care materials: make items easy to see in the bathroom, label items with their name, use pictures or words on the bathroom wall to point out items, use contrasting colours.
- To help turn the tap on and off: use colour indicators to label the direction for turning the tap on and off, instruct the person to turn the tap on and turn off, assist if needed.

2. Tips for daily dressing, oral care and assisting in bathing

Difficulties choosing the right clothes or dressing appropriately

Dementia can affect the person's ability to choose clothes and dress appropriately.

You can assist the person you care for to choose clothes and to dress in a way that makes the most use of their remaining skills. You should not take over these tasks when the person living with dementia can still perform them.



Let's look at an example

Ted has Alzheimer's disease and is cared for by his wife Jane. Ted used to lay out his clothes for the next day in the evening.

Recently, Jane found that Ted forgets to do this and is inclined to wear the same clothes every day. Jane also observes that Ted leaves some buttons of his shirt undone, his belt unbuckled and forgets to lace up his shoes.

2. Check your understanding



Getting dressed.

What would you think is the right response for Jane? *Please select the correct answer.*

- Tell Ted that he needs to be less messy, choose clothes for Ted and dress him.
- Remind Ted to lay out his clothes in the evening and encourage him to wear pants that do not need a belt and shoes that do not need laces.

Difficulties brushing one's teeth

Dementia not only affects memory but also organization, coordination and concentration, which are required to perform mouth care. Poor mouth care is associated with poor appetite, bad breath, infections of the teeth or gums and other health problems.

The goal of assisting with mouth care is to help the person make the most use of their remaining skills.

Let's look at an example

Guoliang has Alzheimer's disease but is able to brush his teeth without assistance. Recently, Guoliang's wife, Lingling notices that her husband makes a big mess in the bathroom with water and toothpaste on the countertop and the floor. She also observes that her husband is unable to brush his teeth in the order that he usually does and can't insert his artificial dentures himself.

3. Check your understanding

Promoting mouth care.

What would you think is the right response for Lingling?

Please select the correct answer.

- Put Guoliang's dentures into his mouth without asking.
- Instruct her husband how to brush his teeth step-by-step and praise him when he is doing well.

1. Activity



Please select any mouth care steps that the person you care for needs help with from the list below.

- Putting toothpaste on the toothbrush
- Brushing teeth in an order that will clean teeth and gums
- Rinsing and cleaning mouth
- Using floss or toothpick to clean between teeth daily
- Applying balm to moisturize lips when needed
- Checking for signs of mouth infections or toothache when needed
- Removing, washing, cleaning, and storing artificial dentures if needed



Difficulties performing personal care and bathing

Dementia may also affect the person's ability to wash their hair and take a shower or a bath. A person living with dementia may view assistance with personal care as a threat to his or her privacy, safety and security, and may refuse or resist any help.

Let's look at an example

Feng has Alzheimer's disease and is cared for by his wife Yuan. Due to her age, Yuan is not strong enough to help bathe Feng anymore, so the family decides that the three sons-in-law could take turns to help with Feng's weekly bath.

The oldest son-in-law is very kind to Feng and reassures him that he will make him comfortable during the bath. He takes Feng to the bathroom and starts to undress him. Feng suddenly pushes him away, shouts at him and tells him to go away.

4. Check your understanding



Resisting help with bathing.

What would you think is the right response for Feng's family? *Please select the correct answer.*

- Since the family notices that Feng thought his son-in-law was a stranger, Yuan decides to be with Feng while her son-in-law bathes him.
- They should say to Feng that he should be grateful for the help he receives and if he continues to behave this way, he will be sent to a long-term care facility.

When assisting with personal care, ask the person living with dementia for their preferences whenever possible and respect their choice. Reassure them that they are safe and comfortable.

People with dementia may show resistance during personal care, or even become aggressive like Feng in this example. To read more about how to prevent or deal with aggression, please refer to **Lesson 3. Dealing with behaviour changes that might happen in people with dementia** in **Module 5**.

Tip



Below are some tips for assisting with bathing.

- Identify the times of day that the person you care for prefers to have a bath/shower.
- Switch from a shower/bath to a sponge bath. (Note: bath tubs are particularly difficult as they may lead to falls and it may be hard for the carer to lift the person living with dementia out of the tub.)
- If using the shower or bathtub, use a non-slip bath or shower mat to help prevent falls.
- Adaptive seating or equipment, such as grab bars and shower chairs, may help.
- For people with dementia who are afraid of water, try to reduce the water flow.

2. Activity



Select any personal care activities that the person living with dementia needs help with. Coach them through the individual steps involved in each activity.

- | | |
|--|---|
| <input type="checkbox"/> Selecting daytime clothing | <input type="checkbox"/> Undressing before shower/bath |
| <input type="checkbox"/> Putting non-slip mats on the floor | <input type="checkbox"/> Washing hair/body during shower/bath |
| <input type="checkbox"/> Taking pyjamas off/on | <input type="checkbox"/> Shaving |
| <input type="checkbox"/> Washing and drying hands | <input type="checkbox"/> Using towel to dry hair/body |
| <input type="checkbox"/> Washing and drying face | <input type="checkbox"/> Applying body lotion to moisturize skin |
| <input type="checkbox"/> Washing and drying feet | <input type="checkbox"/> Checking for signs of skin problems |
| <input type="checkbox"/> Washing and drying genital areas | <input type="checkbox"/> Dressing after shower/bath |
| <input type="checkbox"/> Drying body after washing | <input type="checkbox"/> Combing hair |
| <input type="checkbox"/> Changing night clothing into daytime clothing | <input type="checkbox"/> Using electrical hairdryer |
| <input type="checkbox"/> Preparing for a shower/bath | <input type="checkbox"/> Putting on make-up |
| <input type="checkbox"/> Turning the tap on, adjusting the water temperature and preparing for bathing | <input type="checkbox"/> Cutting fingernails and toenails when needed |

Let's review what you have learned

- Engage the person living with dementia in personal and mouth care as long as possible, using remaining skills.
- Modify the environment, for example by providing guidance, encouraging them to select different types of clothes or providing seating while performing personal care.
- Engage the person you care for in daily decision making, for example what clothes they would like to wear.
- Keep in mind that not have enough assistance with personal care may cause agitation or aggression.
- Be compassionate and try to understand why they resist being assisted with personal care.



You finished this lesson, well done!

1. Check your understanding

*Promoting personal hygiene.***What do you think is the right response for Mohammed?**

- ✓ Put personal care items in the order of use and label them with large print words and different colours for Mariam to read.

This is a good response. People with dementia may lose the ability to find items that are not obvious. Creating an 'easy to find' environment for them is very important.

- ✗ Ask their daughter-in-law to take Mariam from the table to the bathing room and assist her with washing and changing clothes.

This is not the right answer. Mohammed needs to first find out what the reason is for her not doing the personal care before breakfast anymore. Also, instead of assuming, Mohammed needs to ask his wife first if she wants help from their daughter-in-law. Not asking may upset her.

2. Check your understanding

Getting dressed.

What do you think is the right response for Jane?

- ✘ Tell Ted that he needs to be less messy, choose clothes for Ted and dress him.

This answer is not helpful. It is not Ted's fault that he is finding this task challenging. With some extra help, Ted may still be able to dress himself.

- ✔ Remind Ted to lay out his clothes in the evening and encourage him to wear pants that do not need a belt and shoes that do not need laces.

You are right! It will enable Ted to dress himself, which may also help improve his sense of self-worth.

3. Check your understanding

Promoting mouth care.

What do you think is the right response for Lingling?

- ✘ Put Guoliang's dentures in his mouth without asking.

This is not the right answer. Lingling is completely taking over care tasks and not even asking his permission. This response may upset Guoliang.

- ✔ Instruct Guoliang how to brush his teeth in a step-by-step manner and praise him when he is doing well.

This is the best answer. Guoliang maintains a level of independence in this way, which may also help to improve his sense of self-worth.

4. Check your understanding



Resisting help with bathing.

What do you think is the right response for Feng's family?

- ✓ Since the family notices that Feng thinks that his son-in-law is a stranger, Yuan decides to be with Feng while her son-in-law bathes him.

Good advice! A person living with dementia may no longer recognize people they used to know, so giving them plenty of transition time to get familiar with people is very important.

- ✗ They should say to Feng that he should be grateful for the help that he receives and if he continues to behave in this way, he will be sent to a long-term care facility.

This is bad advice. Never threaten people with dementia in this way. Saying things like this will not help the situation and will make Feng feel very distressed.

Lesson 5. An enjoyable day

Why is this lesson important?

It is important to maintain routines and activities that are familiar to a person living with dementia to help create an enjoyable day.

How will this lesson help me?

By learning how to adapt routines and activities as the abilities of the person living with dementia change.

What will I learn?

1. Establishing routines for the person with dementia during the day.
2. Adapting routines to the changing abilities of the person you care for.

1. Establishing routines for the person with dementia during the day

When someone is living with dementia, it is important to create an environment that supports them to do the things that they like to do.

This is also true for you.

It is important to try and maintain routines and activities that are familiar to the person living with dementia, and to adapt them as their abilities change.



What is a routine?

A routine is something that a person does every day or almost every day.

It is important to try and continue the routine of the person living with dementia for as long as possible. This is reassuring and can reduce stress at home. Be aware of the person's usual routine. If there has not been a routine, for example in the evening, then it is helpful to develop one and follow it regularly. This might include drinking a cup of tea, listening to soothing music, or saying prayers.

It is helpful to have routines for other times of the day as well, such as immediately after getting up from bed in the morning, when having the midday meal or planning what to do in the afternoon.

The simpler and easier these routines are to follow, the more likely they will reassure the person living with dementia and reduce stress at home.

Morning time: starting the day

It's helpful to have a set time for waking up and then several things to do in sequence to get the day started. Think of bathing, brushing one's teeth, getting dressed and then sitting down for breakfast. As dementia progresses, the person you care for will need help with each of these activities but one way to lower stress is to keep the basic routines as similar as possible.

During the day, it's also important to try and make time for activities that the person living with dementia enjoys, such as visiting a friend or another family member, going for a walk, reading, playing games, or listening to the radio. These activities will depend on the person's prior interests and current abilities.

In the early stages of dementia, your family member or friend may be able to do things that they like to do with minimal guidance. However, as the disease progresses, activities will need to be changed or modified so that they can still enjoy them. It's important to be flexible and creative in figuring out the routines and then adapting them as needed over time.

Let's look at an example

Martha has dementia and is used to drinking tea immediately after getting ready in the morning. Her daughter Penny really wants to encourage her mother to walk every day, as recommended by her doctor. Penny is not aware of her mother's usual routine, so when she tries to get Martha to go for a walk right after breakfast, Martha refuses.

1. Check your understanding



Morning routines.

What suggestions do you have for Penny?

Please select the correct answer from the responses below.

- If Penny suggests keeping to the routine by drinking tea first, it is likely that Martha will go for a walk afterwards.
- Penny should ask Martha what activities she is used to and in what order she would like to do them.
- Penny should force Martha to go for a walk because it was advised by the doctor.

Keep in Mind



It is important to keep routines (something the person living with dementia does every day or almost every day) for as long as possible. This may help to avoid confusion, agitation, restlessness and boredom.

It also helps to honour the person's dignity. Think for a moment about how you might feel if your routines were changed or planned by another person.

2. Adapting routines to the changing abilities of the person you care for

It is important to adapt routines as the abilities of the person living with dementia change.

Here are some common routines to establish during the day for a person living with dementia.

In the morning

Wake up at the same time every day

- **Adaptation:** help might be needed to wake up because the person with dementia may not be able to set the alarm correctly.

Have breakfast at a fixed time. In the earlier stages of dementia, your family member or friend might be able to make their own breakfast.

- **Adaptation:** the person with dementia may need someone to lay out ingredients. Later on, they may need more help with preparing and eating breakfast.

Performing grooming activities, such as brushing teeth, bathing/cleaning, getting dressed. In the early stages, the person you care for may be able to do all of these activities without help.

- **Adaptation:** items such as the toothbrush, toothpaste, etc. can be laid out in the bathroom in plain view to prompt the activity. In the later stages of dementia, it may be necessary for someone to do these activities for, or with, the person living with dementia.

Keep in Mind



- It is important to develop routines for morning activities and maintain them as long as possible.
- Make adjustments as needed when the abilities of the person living with dementia change.

For more tips, please refer back to **Lesson 4. Personal care in this module.**

During the day

It is helpful to plan activities that the person you care for enjoys doing, based on their prior interests and current abilities.

Let's look at an example

Martha loves baking and used to prepare special cakes and cookies for family gatherings. Now that she has dementia, she sometimes forgets the ingredients and the order in which to put them in.

At first, Martha uses a cookbook to help her continue baking but she finds this increasingly difficult. The cakes and cookies do not taste very good and have to be thrown away. Penny wants to help her mother keep up this activity.

2. Check your understanding



Maintaining prior activities and interests during the day.

What suggestions do you have for Penny?

Please select the correct answer from the responses below.

- Penny should put away the baking and cooking pans and tell her mother that it's just not possible to do this anymore.
- Penny should go shopping with her mother and buy easy to prepare cakes and cookies, "out of the box", with limited added work to enable Martha to continue to do some cooking and baking.
- As Martha's abilities change, Penny could plan some time during the afternoon to bake and cook with her mother.

What is sundowning?

Sometimes people with dementia become more agitated, aggressive or confused in the late afternoon or early evening. This is often referred to as 'sundowning'. It can be particularly distressing for carers. The exact cause of sundowning is not yet clear but a loss of routine might be one of the reasons. Try to give the person something meaningful to do at this time of day.

Let's look at an example

Martha likes to go to a community centre every day from 12:00 until 15:00. She has lunch there and meets friends to do activities together. At first Martha walks there by herself but as her memory loss becomes more severe, she cannot find her way to the centre anymore. Penny asks another family member to take Martha to the centre and bring her back home. This works well for a while but eventually the family member is unable to take Martha. Penny does not know what to do since she cannot be with Martha every afternoon.

3. Check your understanding



Maintaining activities and interests outside the house.

What suggestions do you have for Penny?

Please select the correct answer from the responses below.

- Penny could ask another family member to help Martha.
- Penny could ask other people outside the family to walk with Martha to the community centre, such as a neighbour.
- Penny could tell her mother to do a quiet activity in the afternoons such as watching television or listening to the radio.

Keep in Mind



It is important to respect the daily routines of the person you care for and maintain them for as long as possible.

When this is no longer possible, adapt the routine to the best of your ability so that the key activities that are important to the person with dementia are maintained for as long as possible.

At bedtime

At night, Martha is used to reading quietly for about 30 minutes before she goes to sleep. As her dementia progresses, she finds that she is no longer able to read. Sometimes she is just staring at her book. She increasingly finds reading confusing.

Penny wants to adapt this routine to fit Martha's current abilities.

4. Check your understanding



Adapting routines.

What suggestions do you have for Penny?

Please select the correct answer from the responses below.

- Penny could read to Martha for 15 minutes before she goes to sleep.
- Penny should take the books out of Martha's room.
- Penny should get some books that have more pictures than words or audiotapes for Martha.

Tip



- For the morning, afternoon and bedtime, establish and maintain routines for as long as possible, but be prepared to adapt these as the abilities of the person living with dementia change over time.
- Printing out a list of daily routines can help. Do one for each day and put it up in a prominent place.

1. Activity



Do you know any of the routines of the person with dementia that you care for?

Please write down any ideas that you have about routines for the person you care for and how they can be adapted.

A series of horizontal lines provided for writing down ideas.

Let's review what you have learned

- Establishing routines is important for people living with dementia.
- Try to keep routines similar to the ones your family member or friend had before developing dementia.
- Be prepared to adapt routines as necessary as the abilities of the person living with dementia change over time.



You finished this lesson, well done!

1. Check your understanding

*Morning routines.***What suggestions do you have for Penny?**

✓ If Penny suggests keeping to the routine by drinking tea first, it is likely that Martha will go for a walk afterwards.

Right! It will help Martha keep her routine.

✓ Penny should ask Martha what activities she is used to and in what order she would like to do them.

Indeed! Penny can learn Martha's routines. However, this may only work if Martha is in the early or middle stages of dementia. Later on, Martha might not be able to remember her routines.

✗ Penny should force Martha to go for a walk because it was advised by the doctor.

This response is not so good because it may make Martha feel agitated and upset.

2. Check your understanding



Maintaining activities and interests during the day.

What suggestions do you have for Penny?

- ✗ Penny should put away the baking and cooking pans and tell her mother that it's just not possible to do this anymore.

This is not very helpful. Penny has not tried to come up with an alternative to help her mother and it may make Martha feel upset.

- ✓ Penny should go shopping with her mother and buy easy to prepare cakes and cookies, "out of the box", with limited added work to enable Martha to continue to do some cooking and baking.

This is a good suggestion. It respects Martha's routine but adapts the activity to her current abilities.

- ✓ As Martha's abilities change, Penny could plan some time during the afternoon to bake and cook with her mother.

This is an excellent plan for the future! It allows Martha to continue her routine with support as needed.

3. Check your understanding



Maintaining activities and interests outside the house.

What suggestions do you have for Penny?

- ✓ Penny could ask another family member to help Martha.

This is a good idea. If others can come on a regular basis, this is the best solution for Martha as it maintains her routine and adapts to Martha's changing abilities.

- ✓ Penny could ask other people outside the family to walk with Martha to the community center such as a neighbour.

This is a good response. Family is not always available and sometimes other people don't know how they can help. This is a concrete way that Penny could ask for help.

- ✗ Penny could tell her mother to do a quiet activity in the afternoons like watching television or listening to the radio.

This is not likely to be a good solution at this time. It isolates Martha from other people and doesn't allow her to engage in the activities that she enjoys. It might be a better solution in the later stages of dementia, when Martha's abilities change.

4. Check your understanding



Adapting routines.

What suggestions do you have for Penny?

- ✓ Penny could read to Martha for 15 minutes before she goes to sleep.

This is a good idea. It helps Martha to continue enjoying reading but adapts the activity to her abilities.

- ✗ Penny should take the books out of Martha's room.

This is not a good response because it does not recognise how important reading is to Martha. Penny should recognise that her mother and her can still share this routine; it just needs to be adapted.

- ✓ Penny should get some books that have more pictures than words or audiotapes for Martha.

This is a helpful adaptation for people in the later stages of dementia who liked to read but find that they are not able to read books with a lot of words.

MODULE

5

DEALING WITH BEHAVIOUR CHANGES

Lesson 1. Introduction to behaviour changes

Lesson 2. Memory loss

Lesson 3. Aggression

Lesson 4. Depression, anxiety or apathy

Lesson 5. Difficulty sleeping

Lesson 6. Delusions and hallucinations

Lesson 7. Repetitive behaviour

Lesson 8. Walking and getting lost

Lesson 9. Changes in judgement

Lesson 10. Putting it all together

Lesson 1. Introduction to behaviour changes

Why is this lesson important?

Dementia changes the way that people behave, think or act. This can be distressing or upsetting not only for the person with dementia, but also for their families and carers, like you.

How will this lesson help me?

This lesson helps to improve your skills to prevent and cope with behaviour changes.

What will I learn?

1. Behaviour changes that may be particularly stressful.
2. Understanding the cycle of behaviour change.
3. Different approaches to respond to behaviour changes.

1. Behaviour changes that may be particularly stressful

Dementia changes the way people behave, think or act. This not only affects the person living with dementia, but can also be distressing and upsetting for carers, like you.

"Any behaviour that gets you or the person you care for upset is stressful."

In this introduction you will learn:

- How you can identify behaviours that are potentially upsetting, stressful or difficult for you and the person you care for.
- How you might handle behaviour changes.
- How you might change circumstances to reduce or prevent behaviour changes.

1. Activity



Does the person you care for ever experience any of the following behaviour changes?

Please select any that apply.

Behaviour changes	Example
<input type="checkbox"/> Memory loss	Forgetting or losing things, not being able to recall recent events or remember dates and days of the week.
<input type="checkbox"/> Aggression	Talking or acting in a threatening way, or doing things that make you feel frightened.
<input type="checkbox"/> Depression, anxiety or apathy	Feeling sad, worried, frightened, frustrated or angry, being unusually emotional, crying, agitated or restless, withdrawn, unhappy, apathetic or reacting slowly.
<input type="checkbox"/> Difficulty sleeping	Restless at night, waking you or other family members up.
<input type="checkbox"/> Delusions and hallucinations: seeing or hearing things that are not there	Misinterpreting the world, having fixed false beliefs, things a person sees or hears that are not there, or becomes suspicious of those around them.

1. Activity

Behaviour changes	Example
<ul style="list-style-type: none"> ■ Repetitive behaviour: doing things over and over 	Repeating a question or an action over and over.
<ul style="list-style-type: none"> ■ Wandering: walking around a lot 	Continuously walking around, leaving the house and getting lost.
<ul style="list-style-type: none"> ■ Changes in judgement 	Saying the wrong thing at the wrong time, acting inappropriately in a situation, not understanding own limitations.
<ul style="list-style-type: none"> ■ Not at this time 	None of these symptoms are present at this point in time.

Remember

Many things can cause behaviour changes that are upsetting to you or the person you care for. This can have a bad effect on your relationship with the person you care for. It can even make you feel sad, angry, confused, or anxious.

In some instances, you might even feel as though you can't cope with the situation.

In this lesson you will learn what you can do to reduce or prevent these situations.

2. Understanding the cycle of behaviour change

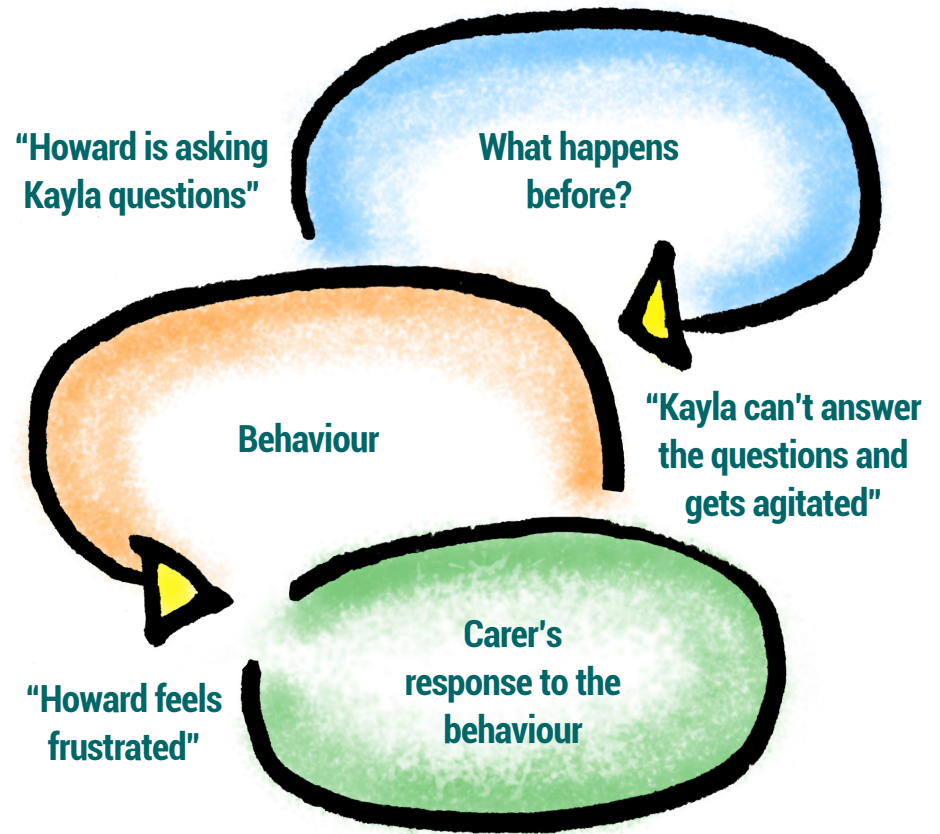
Understanding any behaviour change and what happens before and after the behaviour is very important. Sometimes you can reduce or even prevent certain behaviours. If you pay attention and understand what happens before or “triggers” the behaviour, this can help you to reduce or prevent the behaviour.

Let's look at the following example

Kayla has dementia like the person you care for. Her husband Howard is taking care of her, like you are caring for your family member or friend.

Howard often asks Kayla if she can remember who came to visit last week or what she had for dinner yesterday. Kayla cannot remember these things and gets agitated.

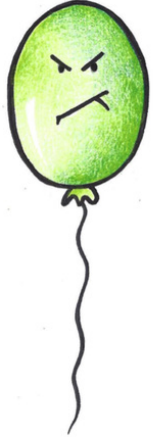
The diagram below shows what's happening.



What happens before the behaviour?

What do you think happens before Kayla gets agitated that you might be able to change? Below are some examples.

- 1. Howard asks questions that Kayla cannot answer.
- 2. The tone of voice that Howard uses to ask these questions makes Kayla feel nervous.



1. Check your understanding ?

Identifying what happens before the behaviour.

Now you try the next one. Please fill in your ideas on what comes before Kayla gets agitated in the box below. When you are done, check the answer section at the end of this lesson for more ideas.

Now let's look at Howard's response

So, what are we trying to do? We are trying to separate what comes **before** the behaviour and what the carer's response is **after** the behaviour.

How does Howard respond in this example?

Howard gets frustrated because his wife Kayla forgot who came to visit and what she had for dinner.

Howard can choose to change his response.

2. Check your understanding

Different ways of responding to behaviour change.

Here are some responses, some are good, others are not. Please check what you think could be good responses.

Howard could:

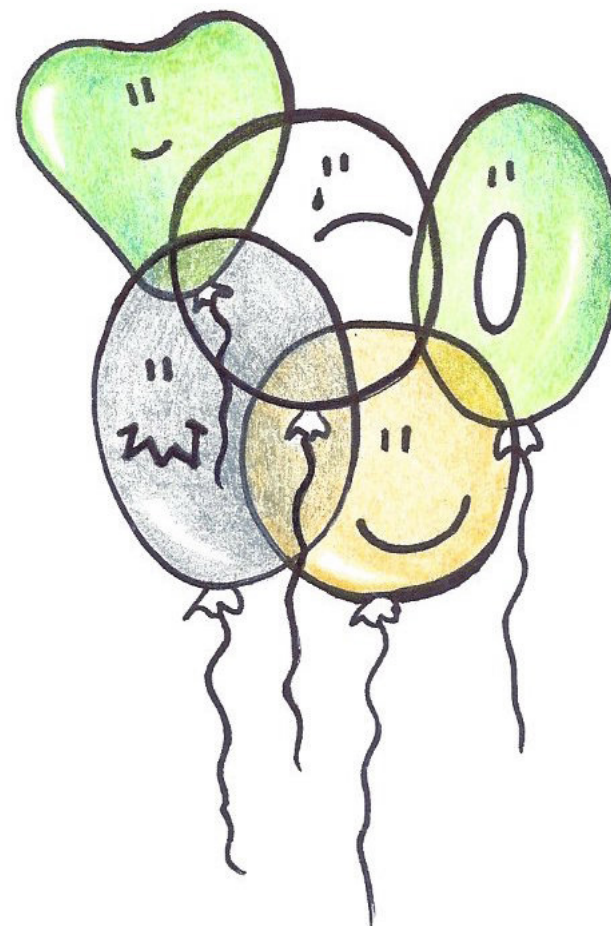
- Show that he is frustrated.
- Take a deep breath.
- Show his irritation by saying: "I already answered that, please stop bothering me".
- Remind himself that his wife has dementia and cannot help that she forgets things. She is not forgetting on purpose.
- Next time, remember that asking her such questions will only cause frustration, not only for him, but also for his wife.
- Work with Kayla to record significant family and social events in a family diary.

3. Different approaches work at different times.

What if Howard's approach doesn't work the first time? Different approaches work at different times, so Howard should not give up! Howard could try several approaches until he finds one that works.

Here are some examples of what Howard could do:

- He can ask other people's advice, for example his health care provider.
- He can also ask someone at the Alzheimer's Association (a community based organisation that provides support for people with dementia and their carers) in his country: <https://www.alz.co.uk/associations>.
- He can search for information on the internet.



2. Activity

Now think about your own situation

It is important to apply what you have just learned to your own situation with the person you care for. *Use the spaces below, like a diary.*

What is the behaviour that was the most distressing or upsetting to you in the past month?

What could you do to change what happened before the behaviour in order to reduce or prevent it?

How could you respond in that situation?

Let's review what you have learned

- People with dementia may experience behaviour changes that are distressing or upsetting to them or those around them.
- It is helpful to identify what happens before the stressful behaviour to understand what might cause it or make it worse.
- It is also helpful to identify how you usually respond, what you feel or what you do.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for.
- Try different responses and approaches, as the first one does not always work.
- Seek professional help if you cannot manage a situation.



You finished this lesson, well done!

1. Check your understanding

*Identifying what happens before the behaviour.*

- Kayla has dementia. Remembering who came to visit last week is difficult for her.
- Kayla has dementia and cannot remember what she had for dinner.



2. Check your understanding



Different ways of responding to behaviour change.

What are some of the ways that Howard could respond?

- ✗ Show that he is frustrated.

This is not the best response. Showing that he is frustrated is an inappropriate way to deal with the stressful behaviour, it may even make the person living with dementia irritable.

- ✓ Take a deep breath.

This is a good response. It shows that Howard is trying to control his frustration.

- ✗ Show his irritation by saying: "I already answered that, please stop bothering me".

This reaction is not so good, because Howard's irritability may upset Kayla even more.

- ✓ Remind himself that his wife has dementia and cannot help that she forgets things. She is not forgetting on purpose.

This is a good response, because Howard recognises that Kayla is living with dementia.

- ✓ Next time, remember that asking her such questions will only cause frustration, not only for him, but also for his wife.

This is a good response, because it may prevent this frustrating situation.

- ✓ Work with Kayla to record significant family and social events in a family diary.

This is a good response, because they can revisit the events from time to time if Kayla is missing family members and friends.

Lesson 2. Memory loss

Why is this lesson important?

Memory loss can be frustrating for the person living with dementia and the carer.

How will this lesson help me?

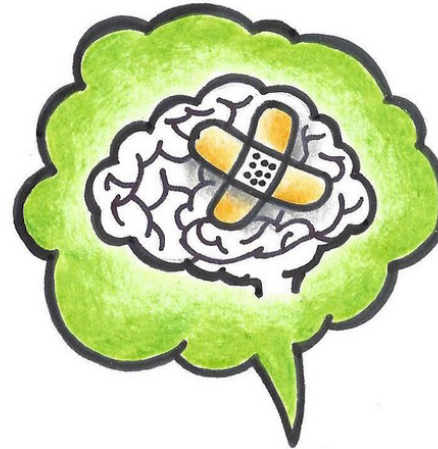
In this lesson you will practice several ways to respond to memory loss, and find out what may help you deal with the person's increasing forgetfulness.

What will I learn?

1. What is memory loss?
2. How to respond to memory loss?

1. What is memory loss?

People with dementia will increasingly lose their memory over time. In the beginning, they may forget recent events, where they put their keys, their wallet or a particular piece of paper. They find it harder to remember phone numbers, important dates and appointments. However, past memories, such as childhood memories, are often preserved for a longer period of time.



1. Activity

Does the person you care for sometimes forget things?
If so, what kinds of things do they forget? *Please write them down.*



2. How to respond to memory loss?

In this lesson you can practice several ways to respond to memory loss, and find out what may help you deal with it.

Let's have a look at an example

Anne is living with dementia. She has a daughter named Maya. They live very close to each other. When Maya goes to visit Anne's house, she notices that the fridge or cupboard is empty. Anne often forgets what she usually buys from the market.

The person you care for might also forget other things. The same goes for Anne.

1. Check your understanding



Forgetting to buy groceries.

How would you advise Maya to deal with her mother's memory loss?

Please check all the responses that you feel are appropriate from the list below.

- Ask a neighbour to go with Anne once a week to the market to buy groceries.
- Create a memory aid together with Anne, e.g. a list of groceries that Anne needs to buy, and put the list in a place where it can be seen, so that it is easy to access.
- Go out and buy groceries immediately.
- Ask: "Mom, what's wrong with you, there is no food in the house".
- Sit down with Anne and make a list of groceries. Go shopping together.

Let's look at another example

Maya and Anne are talking on the phone. Maya notices that Anne often forgets what she normally does during the day. Maya is impatient with Anne, and tells her mother, "this is getting worse".

2. Check your understanding



Forgetting daily activities.

What do you think Maya's response should be?

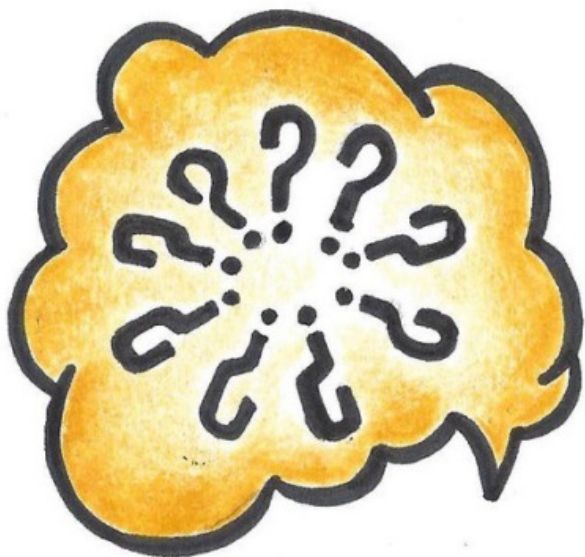
Please check all the responses that you feel are appropriate from the list below.

- Tell her mother what to do over the phone.
- Ask her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the market day.
- Move in with her mother.
- Go straight over and take charge of the situation, by ordering her mother around.
- Plan to visit Anne every weekend and write out to-do lists for every day of the week.
- Hire someone to stay with her mother all the time.
- Ask her mother while on the phone to get a pencil and paper. Talk through the plan for the day together.

Sometimes memory loss can be more serious, like in the next example.

Let's look at an example

Maya comes to visit and discovers that Anne is having trouble remembering which medications to take and at what time.



3. Check your understanding



Forgetting medication.

How do you think Maya should respond to this situation?

Please check all the responses that you feel are appropriate from the list below.

- Maya puts notes near the clock when her mother needs to take a pill.
- Maya says, "Mom, how could you forget your medications?", and "you know you really need them to stay healthy!"
- Maya goes through the medicine cabinet, sits down and cries about her mother's memory loss.
- Maya goes over the medications with her mom. She purchases a pill box, and puts the pills in the box at the right day and time and calls her mom every day to instruct her to take her medications.

2. Activity



Let's look at your own situation

It is important to apply what you have learned to your own situation. How could you respond to help the person you care for deal with their memory loss? *Write down some ideas.*

Let's review what you have learned

- Memory loss is very common for people with dementia.
- Memory loss can be stressful to deal with.
- In case of memory loss, try a memory aid like a note, pill-box, reminder/alarm, etc.
- If possible, involve the person you care for to find the best way to support them in case of memory problems.
- It is important to remember that the person living with dementia is not to blame, because he/she can't help that they forget.
- When one approach doesn't work, try another one.
- Realize there may be good and bad days.
- Remind yourself that memory loss is part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for in the case of memory loss.



You finished this lesson, well done!

ANSWERS - DEALING WITH BEHAVIOUR CHANGES

Lesson 2. Memory loss

1. Check your understanding

*Forgetting to buy groceries.***What would you advise Maya?**

- ✓ Ask a neighbour to go with Anne once a week to the market to buy groceries.

This might be helpful. Anne will have groceries and a nice visit with the neighbour.

- ✓ Create a memory aid together with Anne, e.g. a list of groceries that Anne needs to buy, and put it in a prominent place, so that the list is easy to access.

This is a good response. It addresses Anne's memory loss and may become a weekly shared pleasant activity.

- ✗ Go out and buy groceries immediately.

This answer is **not so good** because it is a panic reaction and a one-time solution. It does not solve the problem at hand.

- ✗ Ask: "Mom, what's wrong with you, there is no food in the house".

This answer is **not so good** because Anne cannot help that she forgets to buy food and may feel embarrassed that she has done something wrong. It does not improve the situation.

- ✓ Sit down with Anne and make a list of groceries. Go shopping together.

This answer may be a **good one** because Maya is addressing her mother's needs. However, she might first want to try another approach. For example, with a list of groceries that her mother may still be able to go shopping without help.

2. Check your understanding



Forgetting daily activities.

What do you think Maya's response should be?

- ✗ Tell her mother what to do over the phone.

This response is **not so good** because her mother may not understand or be able to follow a phone conversation.

- ✓ Ask her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the market day.

This response **may be a good one** because Maya can use this information to remind her mother.

- ✗ Move in with her mother.

This is **not the right response**. There are several other less drastic approaches that Maya has not yet tried.

- ✗ Go straight over and take charge of the situation, by ordering her mother around.

This response is **not so good** because it is a one-time solution and does not solve the problem at hand.

- ✓ Plan to visit Anne every weekend and write out to-do lists for every day of the week.

This is a **good response** because it may help her mother to remember.

- ✗ Hire someone to stay with mother all the time.

This is **not the right response**. There are several less drastic approaches that Maya has not tried yet.

- ✓ Ask her mother while on the phone to get a pencil and paper. Talk through the plan for the day together.

This is a good response because it may help her mother to remember. Maya could call her mother every morning at a certain time, and ask her to get a pencil and paper and to plan her day together.

3. Check your understanding



Forgetting medication.

How should Maya respond?

- ✓ Maya puts notes near the clock when her mother needs to take a pill.

This may be **good to do** because a memory aid could help Anne remember to take her pills.

- ✗ Maya says, "Mom, how could you forget your medications?", and "You know you really need them to stay healthy!"

This response is **not helpful** because Anne cannot help that she forgets to take her medications. Memory loss is part of her disease.

- ✓ Maya goes over the medications with her mom. She purchases a pill box, and puts the pills in the box at the right day and time and calls her mom every day to instruct her to take her medications.

This is a **good response** because this memory aid might help Anne to take medications at the right day and time. Some pill reminder boxes come with alarms that are pre-set to remind the person to independently take their medications.

- ✓ Maya goes through the medicine cabinet, sits down and cries about her mother's memory loss.

This is **not the way to deal** with her mother's memory loss. Getting upset will not solve her mother's problem of forgetting to take medications.

Lesson 3. Aggression

Why is this lesson important?

From time to time, people with dementia may become angry, aggressive or violent. This is often one of the most difficult things to cope with for carers.

How will this lesson help me?

This lesson helps to understand possible causes of aggression and improve your skills to prevent or deal with aggression.

What will I learn?

1. Why does aggression happen?
2. How to respond to aggressive behaviour?
3. How to deal with ongoing aggression?

1. Why does aggression happen?

From time to time, people with dementia may become angry, aggressive or violent.

Aggression can happen for a variety of reasons. It can be due to unmet needs, illness such as a urinary tract infection, medication combinations or side effects, or something that is happening around the person with dementia.

In addition, people with dementia may have difficulty understanding others, judging social situations, controlling their feelings or expressing themselves like they did before. They may also have personality or mental health changes that contribute to aggressive behaviours.

At times, aggression is displayed towards people known to the person living with dementia. At other times it can be with strangers. Aggression is often one of the most difficult things to cope with for carers.

1. Activity



Let's look at your situation

Check your answer, yes or no.

Does the person you care for ever **talk** to you or other people in an aggressive way?

- Yes
- No

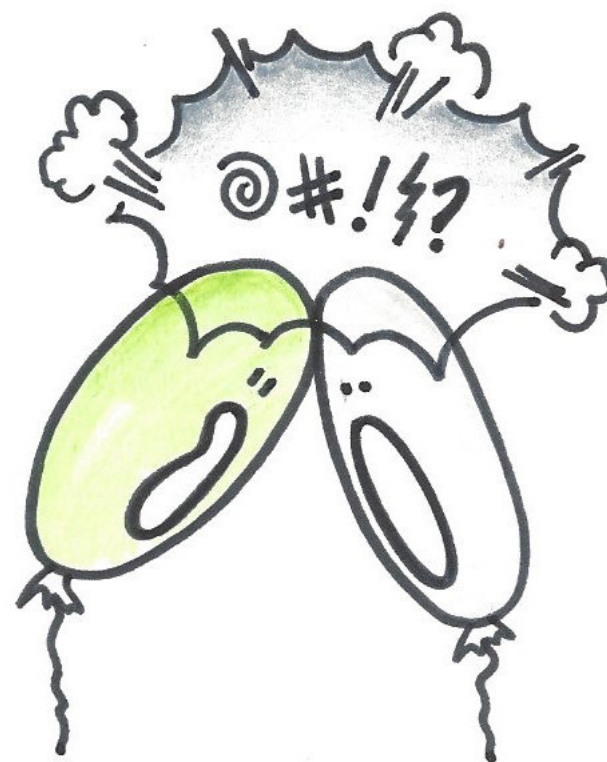
Does the person you care for ever **act** aggressively towards you or other people?

- Yes
- No

WARNING!



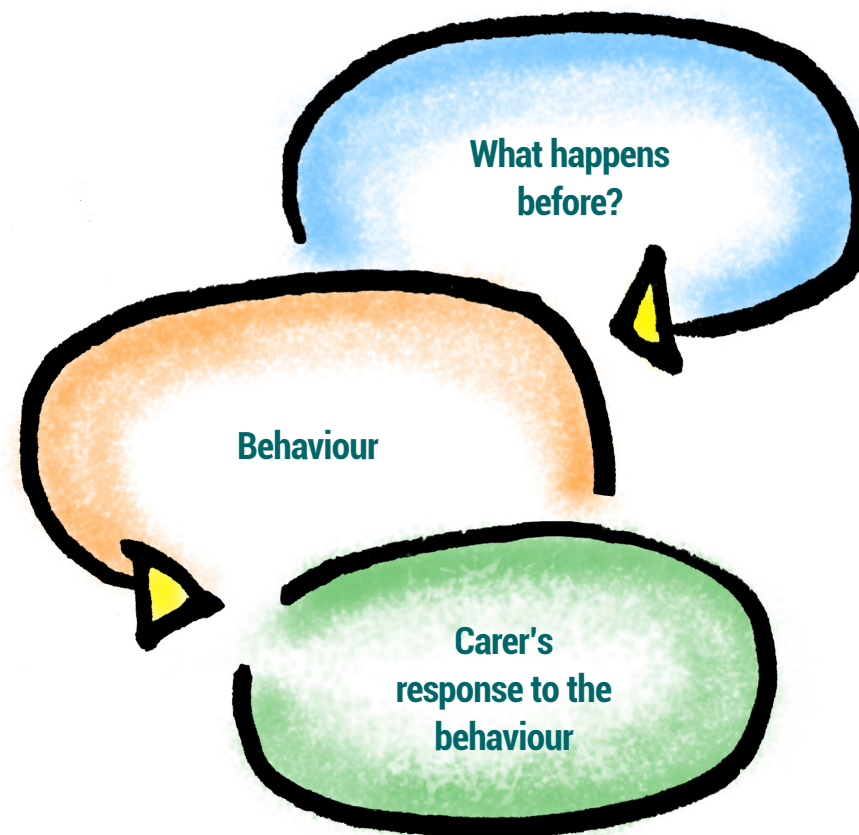
If the person is suddenly behaving aggressively, there may be an underlying cause (for example a urinary infection) that should be investigated by a doctor.



Do you remember the cycle of behaviour change?

Just like we mentioned in **Lesson 1. Introduction to behaviour changes**, it is important to break down the cycle of stressful responses into three parts in order to help you deal with them.

Here they are



Let's see how the cycle works with a different example.

Neil wants to assist his father-in-law, Amit, in taking a bath because Amit needs to see a doctor. Neil says: "it is time for your bath". Amit refuses. Neil has little time and tugs on his father-in-law's arm. He says: "you need to bathe because you're going to see the doctor." Amit pulls his arm back and

resists. He is much stronger than Neil. Neil tugs it again and says angrily: "you must take a bath because you are going to the doctor and need to be clean". Amit gets very angry, shouts and even tries to shove Neil, who becomes upset.

1. Check your understanding



Understanding aggressive behaviour.

Amit angrily refuses to take a bath

Can you break down the cycle of behaviour change in this example into its three parts? *Please fill in the boxes below.*

What comes before the behaviour?	What is the stressful behaviour?	What is Neil's response?

2. How to respond to aggressive behaviour?

There are many ways to respond to aggressive behaviour. Some are good, others are not. In the exercise below you can learn more.

2. Check your understanding



Responding to aggressive behaviour.

How could Neil react differently?

Please indicate what you think are good responses.

Neil could:

- Force his father-in-law to start bathing anyway.
- Maintain the dignity and privacy of his father-in-law. He could keep him in a robe or towel until he actually takes a bath.
- Play soothing music that Amit likes.
- Walk away and come back later.
- Explain logically why he should bathe.
- Put himself in Amit's shoes and try to understand why Amit might not want to take a bath.

3. Check your understanding (continued)



Responding to aggressive behaviour.

- Make sure that there is enough time so that it is not so stressful. Rather than trying to bathe Amit right before the doctor's appointment, when things are rushed, Neil might try to assist with bathing the day before.
- Before the next bath time, identify the best time of day for Amit to take a bath and find out whether he prefers a bath or a shower.
- When bathing Amit, keep a towel over his shoulders to help him maintain dignity and to keep him warm.
- Ask for someone else to help with Amit's bath time.
- Help Amit with a bed bath by using warm, wet towels with soap without taking Amit to the bath.
- Say in an irritated voice: "I have already answered that, please stop bothering me." "You must take a bath!"

3. How to deal with ongoing aggression?

Sometimes your first approach may not work. Don't get discouraged, different responses may work at different times.

4. Check your understanding



Ongoing aggressive behaviour.

What could Neil do if his approach does not work the first time?

Check all that apply.

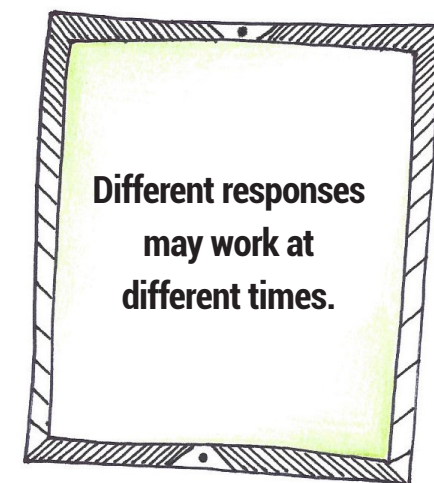
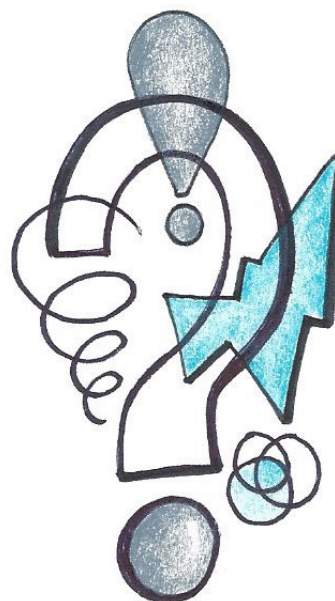
- Neil could try several approaches until he finds one that works.
- Neil could get suggestions from others.

Reminder



Take a deep breath and think about the most positive ways to respond that will be the least distressing to you and the person you care for.

Remind yourself that aggression can be a part of the dementia, or a reaction to the disease.



2. Activity

Let's look at your own situation

It is important to apply what you have just learned to your own situation.

Has the person that you care for ever been aggressive towards you? *If so, describe the last time that this happened in the spaces below.*

What happened before the person you care for became aggressive?

What could you do to change your response to this behaviour?

What could change in the environment to make it more calming?

Let's review what you have learned

- Aggression like shouting, shoving or pushing can happen to carers of people with dementia.
- Aggression can be very upsetting for the person living with dementia as well as the carer.
- Try to change the environment to make it more calming.
- Try to maintain the dignity of the person living with dementia; do not force them to engage in activities that they do not wish to do.
- If one approach does not work, try another one.
- Realize that there may be worse, but also better moments.
- Remind yourself that aggression can be a part of the dementia, or a reaction to the disease.
- If the person is suddenly behaving aggressively, there may be an underlying cause (for example a urinary infection) that should be investigated by a doctor.
- Take a deep breath and think about the most positive ways to respond that will be the least distressing to you and the person you care for.
- If the person you care for continues to show aggression, there are many resources available on the internet. For example, look at the website of the Alzheimer Association in your country (www.alz.co.uk/associations).



You finished this lesson, well done!

1. Check your understanding



Understanding aggressive behaviour.

Amit angrily refuses to take a bath

Can you break down the cycle of behaviour change in this example into its three parts? *Please fill in the boxes below.*

What comes before the behaviour?	What is the stressful behaviour?	What is Neil's response?
Neil tugs Amit's arm and says angrily: "you must take a bath because you are going to the doctor and need to be clean".	Amit gets very upset and shouts and even tries to shove Neil.	Neil becomes upset.

2. Check your understanding



Responding to aggressive behaviour.

How could Neil react differently?

Neil could:

- ✗ Force his father-in-law to start bathing anyway.

This is not helpful, because it does not change the situation and may only make it worse.

- ✓ Maintain the dignity and privacy of his father-in-law. He could keep him in a robe or towel until he actually takes a bath.

Correct. Maintaining dignity and privacy is always a good idea when caring for someone with dementia. By doing this Neil makes sure that the person living with dementia is comfortable.

- ✓ Play soothing music that Amit likes.

Yes. Though it may take extra time to arrange the music, this option may help sooth both Neil and Amit. This may create relaxation and less negative responses from both of them.

- ✓ Walk away and come back later.

This is a good response. It gives Neil time to calm down, take a deep breath and come up with a new strategy. It also gives Amit time to forget about the negative encounter and he may be in a better mood if approached differently later.

- ✗ Explain logically why he should bathe.

This answer is not so good. It does not take into account that Amit may not be able to understand because of his dementia.

2. Check your understanding (continued)



Responding to aggressive behaviour.

- ✓ Make sure that there is enough time so that it is not so stressful. Rather than trying to bathe Amit right before the doctor's appointment, when things are rushed, Neil might try to assist with bathing the day before.

Though taking more time may not always be feasible, **this option is good**. It may reduce tension for Neil and Amit.

- ✓ Before the next bath time, identify the best time of day for Amit to take a bath and find out whether he prefers a bath or shower.

This answer is good. Keeping people with dementia to their regular routines shows attention to their preferences.

- ✓ When bathing Amit, keep a towel over his shoulders to help him maintain dignity and to help keep him warm.

This answer is good. Amit could be embarrassed to be naked in front of his son-in-law or the temperature of the water or the room could be too cold. It's important to look for ways to make the situation more pleasant.

- ✓ Neil could ask for someone else to help with Amit's bath time.

This answer is good. Sometimes the person living with dementia is more comfortable with one family member helping them bathe than another. Sometimes even a stranger might find it easier as the person living with dementia might be less embarrassed than with a family member.

2. Check your understanding (continued)



Responding to aggressive behaviour.

- ✓ Neil could help Amit with a bed bath by using warm, wet towels with soap without taking Amit to the bath.

This answer is good. If the person living with dementia is afraid of the bath, or running water, this option will help relieve their distress and can sometimes be used instead of baths. There are also products such as dry shampoo and cleaning products used for young children that might help.

- ✗ Say in an irritated voice: "I have already answered that, please stop bothering me." "You must take a bath!"

This is not helpful, because it does not change the situation.

3. Check your understanding



Ongoing aggressive behaviour.

What could Neil do if his approach does not work the first time?

- ✓ Neil could try several approaches until he finds one that works.
- ✓ Neil could get suggestions from others.

There may be other approaches that you could try. This can be information from people that you know or that is available on the Internet. See for example: <http://www.alz.co.uk/>



Lesson 4. Depression, anxiety and apathy

Why is this lesson important?

Dementia may affect a person's mood and interest in daily activities, people and events.

How will this lesson help me?

This lesson helps you to understand the possible causes of depression and anxiety, while improving your skills to prevent or reduce mood problems.

What will I learn?

1. What are depression, anxiety and apathy?
2. How to respond when a person living with dementia is feeling depressed or anxious?
3. How to respond when a person living with dementia loses interest in daily activities?

1. What are depression, anxiety and apathy?

Depression, anxiety and apathy are common among people with dementia.

Dementia may affect a person's mood and interest in daily activities, people and events. This may be due to changes in the brain, but also to the emotional reaction of what is happening to them.

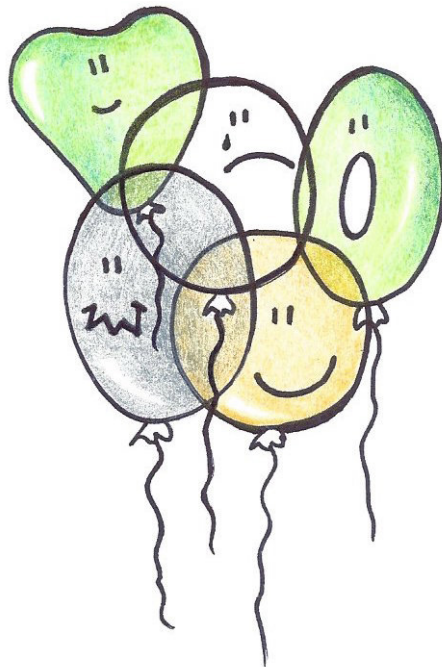
People with dementia may feel sad, worried, frightened, frustrated or angry, may cry and be unusually emotional, agitated or restless. They may also be withdrawn, unhappy and react slowly. These are all behaviours of depression and apathy.

Anxiety can lead to behaviours similar to depression. People with dementia can be worried about being left alone, who is handling their money, or where lost items have gone to and become anxious.

2. How to respond when a person living with dementia is feeling depressed or anxious?

Let's look at an example

Juan has dementia and lives with his sister, Isabel. On several occasions Isabel has found Juan sitting in his favourite chair looking very sad, hunched over, and sometimes crying. Isabel tries to cheer him up. Unfortunately, everything that she tries does not seem to work.



1. Check your understanding



Responding to a person with dementia who is feeling depressed.

How should Isabel handle this situation?

Below are some things that Isabel may do or say.

Please select all responses that you think might work.

- Walk over to Juan and say in a calm, reassuring tone, "I have some ideas about how you can feel better, let's talk."
- Say: "Juan, what's the matter with you? I'm tired of seeing you like this. Just get up and do something."
- Say: "men don't cry and get sad, we used to have so much fun together."
- Go over and touch Juan on the arm or shoulder. "I know that you feel bad, I do too. What we're going through is really hard."
- Sit with Juan and suggest that they do a pleasant activity together.
- Sigh and walk away, thinking that there is nothing that she can do.

Here is another example

Emma has dementia and lives with her family. Benjamin is her grandson. Because Benjamin's parents work and he is in school, he is the main carer in the afternoons. Benjamin is watching a TV show while his grandmother is sewing. The TV show has loud music and vulgar language. Suddenly, his grandmother jumps up and paces up and down the room, wringing her hands. She is muttering to herself "I need to go home", "I need to go home".



2. Check your understanding



Responding to a person with dementia who is feeling anxious.

How do you think that Benjamin should respond to this situation?

Below are some things that Benjamin may do or say. *Please select all the correct responses.*

- Think "Grandmother cannot help the way that she behaves."
- Say "Grandmother! Sit down, you're making it impossible for me to watch my show."
- Give his grandmother a smile and reassure her that she is safe.
- Ask his grandmother to help him with something.
- Turn up the volume to drown out the muttering and turn away from her.
- Look for his headphones and encourage his grandmother to go back to her sewing so that she is busy.

3. How to respond when a person living with dementia loses interest in daily activities?

Let's look at an example

George has dementia and lives with his wife Sofia. George used to be a shopkeeper and was very active in the community. Recently,

George has been sitting in a chair near a large window and staring blankly outside, this type of behaviour can also be known as apathy where the person with dementia has trouble becoming interested in doing something. Sofia has become very concerned, because this is not like him. He seems removed and distant from her. One day, she walks in and says "George, shall we go out for a walk?" He does not respond.

3. Check your understanding



Responding to a person with dementia who loses interest in daily activities.

How do you think Sofia should react? *Please check all the responses that you think are appropriate.*

- Sofia walks over to George and says "I'm sick and tired of this laziness, get up and let's go".
- Sofia goes over to George and strokes his hair. She says that she loves him and that she would like to do something together. George turns to her and smiles weakly.
- Sofia says: "you never do anything I want anymore, it is impossible to keep on living with you. I don't know what I'm going to do."
- Sofia says: "let's go for a walk together, I know how much you would enjoy getting out of the house for a little while."
- Sofia closes the door and doesn't try to engage with George anymore.
- Sofia thinks back to what George used to really like doing and thinks how she could help, for example by reading the newspaper to him, cooking his favourite dish or visiting a shop to let him straighten the shelves with the shopkeeper's permission.

1. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. *The spaces below are for you, like a diary.*

**Does the person living with dementia ever show changes in mood or interest, or any signs of depression or anxiety?
If so, what do these changes look like?**

What could you do to prevent this?

How could you respond in a different way?

Let's review what you have learned

- Signs of depression and anxiety are common in people with dementia.
- Changes in mood can be very upsetting to the person living with dementia and the carer.
- People with mood problems need extra love and support.
- It is important to identify ways to stop or reduce mood changes, by comforting and getting the person interested in things that they like to do.
- If one approach doesn't work, try another one.
- In case of mood changes, remind yourself that they may be part of the disease or a reaction to the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for in case they have mood problems or experience a loss of interest.
- If the symptoms persist for a longer period, the person you care for is in danger, or you feel otherwise unable to manage, please seek help from your health care professional.

Remember



It is important to recognize when things get serious. If the person you care for has serious and constant mood changes or you think that they are in danger of harming themselves, it is important to seek medical advice right away.



You finished this lesson, well done!

ANSWERS - DEALING WITH BEHAVIOUR CHANGES

Lesson 4. Depression, anxiety and apathy

1. Check your understanding

*Responding to a person with dementia who is feeling depressed.***Below are some things that Isabel may do or say.**

Please select all responses that you think might work.

- ✓ Walk over to Juan and say in a calm, reassuring tone, "I have some ideas for how you can feel better, let's talk."

This is a good response because Juan needs more support due to the changes in his mood.

- ✗ Say: "Juan, what's the matter with you? I'm tired of seeing you like this. Just get up and do something."

This response is **not helpful** because Juan cannot help that he is feeling sad.

- ✗ Say: "men don't cry and get sad, we used to have so much fun together."

This response is **not good** because it might embarrass Juan and may make him feel even more sad.

- ✓ Go over and touch Juan on the arm or shoulder. "I know that you feel bad, I do too. What we're going through is really hard."

This is a good response because people who are feeling sad need extra love, support and understanding.

- ✓ Sit with Juan and suggest that they do a pleasant activity together.

This is a **good response** because it may distract Juan and make him feel better.

- ✗ Sigh and walk away, thinking thinking that there is nothing that she can do.

This is **not helpful** because Isabel is further isolating Juan.

2. Check your understanding



Responding to a person with dementia who is feeling anxious.

Below are some things that Benjamin may do or say.

Please select all the correct responses.

- ✓ Think "Grandmother cannot help the way that she behaves."

This is a good response because it recognizes that Emma's reaction might be due to changes in her brain.

- ✗ Say "Grandmother! Sit down, you're making it impossible for me to watch my show."

This response is not good because a direct order like this may make Emma feel even more anxious.

- ✓ Give his grandmother a smile and reassure her that she is safe.

This is a good response because people who are feeling anxious need extra love and support.

- ✓ Ask his grandmother to help him with something.

This might help because it might distract Emma and change her reaction.

- ✗ Turn up the volume to drown out the muttering and turn away from her.

This is not a good response. It will only increase his grandmother's anxiety.

- ✓ Look for his headphones and encourage his grandmother to go back to her sewing so that she is busy.

This is a good response. Benjamin can still watch TV with headphones so it is not too loud for Emma, and Emma might be able to engage in her sewing again.

3. Check your understanding



Responding to a person with dementia who loses interest in daily activities.

How do you think Sofia should react? Please check all the responses that you think are appropriate.

- ✗ Sofia walks over to George and says "I'm sick and tired of this laziness, get up and let's go".

This response is not good because a direct order may make George more withdrawn. It doesn't show any understanding of his dementia.

- ✓ Sofia goes over to George and strokes his hair. She says that she loves him and that she would like to do something together. George turns to her and smiles weakly.

This is a good response because it recognizes that the problem is related to his dementia. She is not taking it personally and is expressing extra love and support.

- ✓ Sofia says: "you never do anything I want anymore, it is impossible to keep on living with you. I don't know what I'm going to do."

This is not a good response because it shows that she is giving up on George. He may become even more withdrawn from her.

- ✓ Sofia says: "let's go for a walk together, I know how much you would enjoy getting out of the house for a little while."

This is a good response because it is reassuring and may comfort George.

- ✗ Sofia closes the door and doesn't try to engage with George anymore.

This is not the right response because it may worsen George's loss of interest.

- ✓ Sofia thinks back to what George used to really like doing and thinks how she could help, for example by reading the newspaper to him, cooking his favourite dish or visiting a shop to let him straighten the shelves with the shopkeeper's permission.

This is a good response because it shows Sofia cares about George and wants to help him engage in an activity that he would enjoy.

Lesson 5. Difficulty sleeping

Why is this lesson important?

People with dementia may have difficulty sleeping which can impact the carer's sleep as well.

How will this lesson help me?

This lesson will provide examples and practice to promote good sleep.

What will I learn?

1. How to deal with sleeping problems in a person with dementia?
2. How to deal with a person with dementia who wakes up in the middle of the night?

1. How to deal with sleeping problems in a person with dementia?

Difficulty sleeping can be a problem for people with dementia and their families. People with dementia can have difficulty falling asleep, may wake up in the middle of the night, or wake up too early in the morning. Carers may have their sleep disrupted as a result, which can make it harder to provide care.

In this lesson, you will practice how to promote good sleep for the person living with dementia.

1. Activity



What is the main sleeping problems of the person that you care for? *Please select all that apply.*

- Difficulty falling asleep
- Waking up in the middle of the night
- Combination of the above
- Other (please specify):
- No problems at this point



Difficulty falling asleep

Rosie is an older woman with dementia. She lives with her family. She sleeps near her granddaughter, Grace. Usually, the family has dinner around 6pm. The family is used to doing some activities together afterwards. Rosie does not always like these activities so the family often wants her to go to bed as early as 8pm. Granddaughter Grace notices that Rosie has trouble falling asleep. Rosie continues to open and shut her dresser drawers noisily during the evening. When Grace goes to bed, the noise Rosie is making keeps Grace awake.

1. Check your understanding



Understanding sleeping difficulties.

Can you break down the cycle of behaviour change in this example into its three parts?

What comes before the behaviour?

What is the stressful behaviour?

What does this mean for Grace?

2. Check your understanding



Responding to sleeping difficulties.

Here are some examples of what Grace could do.

Please select all that you think may be appropriate to help Rosie fall asleep:

- Give her a pill to sleep.
- Try and ensure that Rosie does not drink coffee or too much fluid a few hours before going to bed.
- Make lunch the bigger meal of the day.
- Limit daytime naps to 15 to 30 minutes.
- Play soothing music before bedtime to help Rosie sleep.
- Create a bedtime routine, like lowering the lights, washing face and teeth, and changing into pajamas.
- Keep in mind that some people may require less sleep. Generally, 6 to 8 hours sleep from 20:00 means night waking between 2:00 to 4:00 in the morning.

So far, we have covered some basic steps to help the person with dementia fall asleep. What if the problems are a bit more complex?

2. How to deal with a person with dementia who wakes up in the middle of the night?

Let's look at another example

It is 3:00 in the morning, Vani wakes up and starts walking around the house. Her daughter-in-law, Geeta, is sleeping. Vani paces throughout the house and then goes to Geeta and wakes her up. Vani asks: "Where are we? I want to go home". Geeta is upset, because she has a long day at work tomorrow. Geeta says: "mother, you need to go back to bed, it is 3:00 in the morning." Vani says: "I am not sleepy." Geeta yells: "I can't take this anymore."

3. Check your understanding



Dealing with waking in the middle of the night (1).

What can Geeta do to keep Vani from wandering at 3:00 in the morning?

Please select all responses that you feel are appropriate.

- Try to understand what will help Vani sleep. Some people prefer to keep the room dark with no television or as little noise as possible while others prefer a night light, soft music or a television playing.
- Give Vani a favourite object to relax (e.g. blanket or stuffed animal).
- Schedule an appointment with the doctor to find out if there is a medical reason for her trouble sleeping (e.g. urinary tract infection, pain, medication causing hallucinations).
- Develop an activity schedule to keep Vani awake and busy during the day.
- Encourage physical exercise during the day (e.g. walking, stretching).
- Tell Vani that you won't take care of her anymore if you are continuously woken up at night.
- Ask if she has to go to the bathroom or is hungry or thirsty. If she says "yes", then just assist her to meet these needs.
- Physically take hold of her and put her back in bed.
- Ask for help from a family member, friend or a paid professional.

In the previous exercise, you identified several ways of dealing with waking in the middle of the night. Now let's look at your own situation and some additional responses.



Tip



Sleeping problems may be related to depression. If the person you care for has difficulty sleeping, you might want to read **Lesson 4 Depression, anxiety or apathy**. Please also seek advice from a doctor.

4. Check your understanding



Dealing with waking in the middle of the night (2).

Which of the responses below would you choose if the person you care for experiences sleeping problems?

Please select all responses that you feel are appropriate.

- Remind yourself to stay calm and focus on getting the person living with dementia to sleep. This way, you will use your energy to solve the sleeping problem, rather than reacting emotionally.
- Gently remind the person that it is dark outside and it is time to sleep. If needed try to relax the person, for example by playing soothing music.
- Read aloud to the person you care for. Choose something that you know has a calming effect, perhaps a poem or story. Sing a song or chant together. Another option is to pray or meditate for 15 minutes together.
- Comfort the person living with dementia. Give them a stuffed animal and hug or hold them until they fall asleep.

2. Activity



Let's look at your own situation

In an earlier Activity on page 46, you identified the main sleeping problem of the person you care for. It is important to apply what you have learned to your own situation. *The space below is for you, like a diary.*

What could you do to help tackle the sleeping problems?

What could you do to improve your reaction to sleeping problems?

Let's review what you have learned

- Difficulty sleeping is common in people with dementia.
- Sleeping problems can be very stressful to deal with.
- If the person you care for is having difficulty sleeping, try to make them more comfortable.
- Try to identify circumstances that may increase difficulty sleeping and change or address them.
- When one approach doesn't work, try another one.
- Realize that there will be good and bad days.
- Remind yourself that difficulty sleeping is part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing for you and the person you care for in case of sleeping problems.
- Ask for help. It is hard to provide good care on limited sleep.



You finished this lesson, well done!

1. Check your understanding

*Understanding sleeping difficulties.*

Can you break down the cycle of behaviour change in this example into its three parts?

What comes before the behaviour?	What is the stressful behaviour?	What does this mean for Grace?
Rosie is sent to bed as early as 20:00, so that the family can do activities together that Rosie does not like.	Rosie has trouble falling asleep and continues to open and shut her dresser drawers noisily during the evening.	This keeps Grace awake.

2. Check your understanding



Responding to sleeping difficulties.

Rosie has trouble falling asleep

- ✓ Go for a walk with Rosie and add more physical activity during the day.
This is a good idea! Physical exercise during the day may help sleep at night.
- ✗ Give her a pill to sleep.
This is not a good idea. It can make someone with dementia even more confused or agitated and sleeping pills may become addictive.
- ✓ Try to ensure that Rosie does not drink coffee or too much fluid a few hours before going to bed.
This is a good response. Coffee, tea, or too much liquid can keep people awake, and cause frequent urination.
- ✓ Make lunch the bigger meal of the day.
This is helpful. A light dinner makes it easier to sleep.

- ✓ Limit daytime naps to 15 to 30 minutes.
This might be a good idea. It addresses the need for sleep during the day, but it does not prevent Rosie from falling asleep later on.
- ✓ Play soothing music before bedtime to help Rosie sleep.
Good idea. Find relaxing activities before bed such as music, or reading to Rosie. Too much activity before bed can cause a person to be stimulated and stay awake.
- ✓ Create a bedtime routine, like lowering the lights, washing face and teeth, and changing into pajamas.
This is a good response because a routine will relax the person living with dementia.
- ✓ Keep in mind that some people may require less sleep. Generally, 6 to 8 hours sleep from 20:00 means night waking between 2:00 to 4:00 in the morning.
This is a good response. Select a normal sleeping time as much as possible.

3. Check your understanding



Dealing with waking in the middle of the night (1).

What can Geeta do to keep Vani from wandering at 3:00 in the morning?

- ✓ Try to understand what will help Vani sleep. Some people prefer to keep the room dark with no television or as little noise as possible while others prefer a night light, soft music or a television playing.

This answer is a good one. Each person is different and you may need to try several possible solutions before finding one that works.

- ✓ Give Vani a favourite object to relax (e.g. blanket or stuffed animal).

This response is a good one. It may help Vani feel relaxed and secure.

- ✓ Schedule an appointment with the doctor to find out if there is a medical reason for her trouble sleeping (e.g. urinary tract infection, pain, medication causing hallucinations).

While it is not necessary to seek medical attention every time that a person living with dementia can't sleep, **seek advice if it worries or upsets you or the person living with dementia.**

- ✓ Develop an activity schedule to keep Vani awake and busy during the day.

This is a good idea. It may improve sleep at night.

3. Check your understanding (continued)



Dealing with waking in the middle of the night (1).

- ✓ Encourage physical exercise during the day (e.g. walking, stretching).

This may be helpful to improve sleep at night.

- ✗ Tell Vani that you won't take care of her anymore if you are continuously woken up at night.

This is not a good response. Keep in mind that dementia is a disease and someone with dementia will be dependent on the care that others provide.

- ✓ Ask if Vani has to go to the bathroom or is hungry or thirsty. If she says "yes", then just assist her to meet these needs.

This is helpful. Such a break might help the person go back to sleep.

- ✗ Physically take hold of Vani and put her back in bed.

Never do this. Although it may be very difficult to deal with sleeping problems, respect the dignity of someone with dementia. Moreover, they may become agitated or angry. It definitely will not solve the sleeping problems.

- ✓ Ask for help from a family member, friend or a paid professional.

This might be helpful. Eventually, the lack of sleep can affect any family's ability to provide care. Someone else can assist by giving the family member a night or a weekend off.

4. Check your understanding



Dealing with waking in the middle of the night (2).

Which of the responses below would you choose if the person you care for experiences sleeping problems?

- ✓ Remind yourself to stay calm and focus on getting the person living with dementia to sleep. This way, you will use your energy to solve the sleeping problem, rather than reacting emotionally.

Correct!

- ✓ Gently remind the person that it is dark outside and it is time to sleep. If needed try to relax the person, for example by playing soothing music.

Great idea!

- ✓ Read aloud to the person you care for. Choose something that you know has a calming effect, perhaps a poem or story. Sing a song or chant together. Another option is to pray or meditate for 15 minutes together.

Good response!

- ✓ Comfort the person living with dementia. Give them a stuffed animal and hug or hold them until they fall asleep.

Great idea!

Lesson 6. Delusions and hallucinations

Why is this lesson important?

Unreal thoughts and seeing things that aren't there (delusions and hallucinations) can be very upsetting to the person living with dementia and the carer.

How will this lesson help me?

This lesson will help you identify ways to stop or reduce delusions and hallucinations and how you might change the way that you respond to them.

What will I learn?

1. Why do people with dementia have unreal thoughts and see or hear things that aren't there?
2. How to stop or reduce delusions and hallucinations?

1. Why do people with dementia have unreal thoughts and see or hear things that aren't there?

People with dementia may not understand the world around them because of changes in their brain. These misunderstandings are called delusions (unreal thoughts) and hallucinations (seeing or hearing things that are not there).

A delusion is a fixed false belief. For example, the person may hold the false belief of being under threat or harm from the carer. To the person living with dementia the error in thinking is very real, causes fear and may result in distressing self-protective behaviours.

If the person is experiencing a hallucination, they might see or hear things that are not there, for example, people talking in the room.

People with dementia with these ideas need a lot of understanding and support from the person taking care of them.

1. Activity



Has the person you care for ever had any unreal thoughts or seen or heard things that were not there?

You can describe them in the space below, like in a diary.

Remember



Unreal thoughts or seeing/hearing things that are not there are common problems for some people with dementia. In this lesson, you will learn how to deal with them.

2. How to stop or reduce delusions and hallucinations?

Let's look at the following example

Martin's wife Betty is living with dementia. One day, Martin and Betty are out for a walk. They see a woman in the distance. Betty starts calling loudly "Susan, Susan, I'm over here". Then she starts running towards a woman unknown to Martin; a young lady who is probably about 20 years old. Betty mistakenly believes that the young woman in the park is her sister who died in a car accident over 30 years ago. The young woman ignores her. Betty becomes very upset.

1. Check your understanding



Mistaking a person for someone else.

What would you recommend Martin do?

Please check all correct answers.

- Soothe her in a calm voice.
- Lead her away from the woman in the park.
- Directly tell the truth, harshly, to set the record straight.
- Argue with Betty that the young woman is not her sister.
- Say that the young woman in the park is someone who looks like her, but it is not her.
- Involve the woman in the park in any way.
- Try to 'convince' Betty of the truth. Say "Yes you are right, it is Susan".
- Say "When we get home, you can look at pictures of Susan and remember her".

Now let's look at another example

Mercedes' father Larry is living with dementia. One day, Larry is a bit restless. Suddenly, he starts to look very frightened while staring at a corner in the room. He calls out to his daughter and says, "Do you see them talking?" He screams, "What are you doing there?" Mercedes is so overwhelmed that she feels like running away. She thinks to herself "Dad's illness is much worse than I thought it was."

Tip



Check with the doctor regarding medication side effects that the person living with dementia is using. These may contribute to the problem.

2. Check your understanding



Seeing people that are not there.

What would you recommend Mercedes do?

Please check all correct answers.

- Soothe her father, by saying in a calm voice "You are safe, I am with you".
- Check if there is anything in the environment that could be causing Larry's hallucination, such as shadows in the room from the sunlight. Make changes as necessary.
- Lead him away from the room.
- Say that it is simply not true, that there are no other people in the room.

2. Activity



Let's look at your own situation

It is important to apply what you have learned to your own situation.

Unreal or unusual thoughts do not happen all the time. What would you do if the person you care for experiences them?

Try to describe different appropriate responses in the space below.

Which one would you try first?

Remember



Sometimes people with dementia have pleasant hallucinations, like seeing beautiful colours or children who are not there. If these visions are not causing the person distress then try to enjoy them together.

Let's review what you have learned

- Unreal thoughts or seeing/hearing things that are not there (delusions and hallucinations) are common in people with dementia.
- They can be very upsetting to the person living with dementia and the carer.
- Often, people with these visions and unreal thoughts need a lot of reassurance.
- It is important to identify ways to reduce them, not by arguing with the person you care for, but by comforting and distracting them.
- Check the environment to see if there is a cause for the delusion or hallucination.
- If one approach doesn't work, try another one.
- Remind yourself that unreal thoughts or visions are part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for if they are experiencing unreal thoughts or visions.



You finished this lesson, well done!

1. Check your understanding

*Mistaking a person for someone else.*

✓ Soothe her in a calm voice.

This is a good response because people with delusions and hallucinations may feel frightened and insecure.

✓ Lead her away from the woman in the park.

This is a good response because it will distract her from the young woman in the park.

✗ Directly tell the truth, harshly, to set the record straight.

This is not a good response as it may make Betty even more upset.

✗ Argue with Betty that the young woman is not her sister.

This is not a good response as it may make Betty even more upset.

✓ Say that the young woman in the park is someone who looks like her, but it is not her.

This is a good response because it maintains a positive social environment.

✗ Involve the woman in the park in any way.

This is not helpful because it may make the situation more complicated.

✗ Try to 'convince' Betty of the truth.

This is not a good response as Betty may not understand.

✗ Say "Yes you are right, it is Susan".

This is not correct because it is not the truth.

✓ Say "When we get home, you can look at pictures of Susan and remember her".

This is a good response because Martin addresses the importance of her sister, without arguing that the young woman Betty saw in the park was not her sister.

2. Check your understanding



Seeing people that are not there.

- ✓ Soothe him, by saying in a calm voice "You are safe, I am with you".

This is a good response because people with hallucinations are often feeling frightened and insecure.

- ✓ Check if there is anything in the environment that could be causing his hallucinations, such as shadows in the room from the sunlight. Make changes as necessary.

This is a good response because although a person's brain may be misinterpreting the environment there could still be a reasonable cause for confusion.

- ✓ Lead him away from the room.

This is a good response because changing the environment may distract her father and end the hallucination.

- ✗ Say that it is simply not true, that there are no other people in the room.

This is not a good response because arguing about what one sees or hears will not help a person experiencing delusions or hallucinations to calm down.

Lesson 7. Repetitive behaviour

Why is this lesson important?

If a person living with dementia repeats things over and over it can be stressful for themselves and the carer. We will refer to this as a 'repetitive behaviour'.

How will this lesson help me?

This lesson will help you understand why repetitive behaviours occur, and how to respond to, and reduce, them.

What will I learn?

1. What is repetitive behaviour?
2. How to comfort a person living with dementia in case of repetitive behaviours?

1. What is repetitive behaviour?

A person living with dementia may forget what they have said, heard or did from one moment to the next, leading to repeated questions and actions.

Usually doing things over and over is not harmful to the person living with dementia, if the carer knows how to deal with it. If not, the person living with dementia can become anxious, aggressive or depressed and the carer can become stressed. As a result, carers may respond inappropriately, for example by screaming, which often makes the person with dementia feel guilty.

1. Activity



Let's look at your own situation

Does the person you care for ever do or say things over and over again? What behaviour(s) do they repeat?
You can describe them in the space below, like a diary.

2. How to comfort a person living with dementia in case of repetitive behaviours?

Let's look at this example

John is taking care of his father Joe, because his mother, the main carer, is out of the house for a few hours. All seems fine, although John notices that his father is rather tense because John's mother is not there.

John and Joe eat lunch together. Sometime after finishing lunch, Joe asks "When is lunch?" and, "What are we having for lunch?" John does not think much of it at first. Then, again, a few minutes later, Joe asks "When is lunch?", "What are we having for lunch?", and "Where is your mother?" Joe repeats these questions again and again.

John is confused about why Joe is doing this and gets more and more worried about his father. John continues to answer the questions, but gets a bit upset and raises his voice. John responds, loudly and is annoyed, "I have already answered these questions, why do you keep asking?"

1. Check your understanding



Repeating questions.

What would you recommend to John? *Please select all correct responses.*

- Say "What's wrong with you? Can't you remember? We just had lunch!"
- Stay calm and reassure his father that his wife will be home soon.
- Engage his father in an activity.
- Write down the answers to his questions, for example where his wife is and when she is expected to return.
- Walk away.
- Accept the repetitive questions. If it isn't harmful, let it be. Find ways to adapt.
- Offer his father a snack or a drink.

2. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. *The spaces below are for you, like a diary.*

Now look back at the examples that you identified in the previous activity. Choose the repetitive behaviour that is the most stressful to the person that you care for, or to yourself, and list it below.

What could you do to help reduce this behaviour?

How could you change your response to this behaviour?

Let's review what you have learned

- Doing or saying things over and over again (repetitive behaviour) is common in people with dementia.
- Repetition can be very stressful to deal with.
- In case of repetition, try to focus on comforting the person you care for.
- Try to identify what comes before the repetitive behaviour and what may increase it. Then try to change it. Try to identify how you respond and change that also.
- Realize there may be worse, but also better moments.
- Remind yourself that repetitive behaviours are part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person living with dementia if they do or say things over and over again.



You finished this lesson, well done!

1. Check your understanding

*Repeating questions.*

- ✓ Say "What's wrong with you? Can't you remember? We just had lunch!"

This is not a good response because John is blaming his father for something that he can't help.

- ✓ Stay calm and reassure his father that his wife will be home soon.

This is a good response as repetition might worsen due to Joe's feelings of insecurity. He seems to feel insecure because his wife went out. By reassuring Joe that his wife will come back soon, the repetition may lessen or stop.

- ✓ Engage his father in an activity.

This can be a good response because it may distract his father and offer something else to see, hear or do.

- ✓ Write down the answers to his questions, for example where his wife is and when she is expected to return.

This might work well, may reassure Joe and stop him from asking again.

- ✗ Walk away.

This response is not so good because it will only upset his father more.

- ✓ Accept the repetitive questions. If it isn't harmful, let it be. Find ways to adapt.

This can be a good response. Perhaps if it is just repetitive questioning, by remaining calm the behaviour may decrease.

- ✓ Offer his father a snack or a drink.

This might be a good response. Perhaps Joe is still hungry or thirsty. It may help to calm him and meet his need.

Lesson 8. Walking and getting lost

Why is this lesson important?

Concerns about walking and getting lost can cause distress. Carers like you may worry whether the person will get lost.

How will this lesson help me?

This lesson will help you understand the reasons for walking and what to do to reduce the chances of the person living with dementia getting lost.

What will I learn?

1. Why is walking a concern?
2. Why a person with dementia might want to walk around?
3. How can I manage habits and reduce the chances that the person I care for gets lost?

1. Why is walking a concern?

People with dementia may have the habit of walking around the home or leaving the house and wanting to walk around the neighbourhood, this is also called wandering. This is very common. However, they may get lost. So, safety is a primary concern when people with dementia are out alone.

It is important to prevent wandering.

This lesson will teach you why people with dementia may have a desire to walk. You will also learn about the steps that you can take to help make this safer.

It is important to find ways to help prevent people with dementia from getting lost or ending up in an unsafe situation.

1. Activity

Does the person you care for sometimes walk around or walk away? *You can describe what happens in the space below, like in a diary.*

2. Why a person with dementia might want to walk around?

A person with dementia who wanders or walks away may be:

- Wanting to exercise.
- Continuing a lifelong habit of walking regularly.
- Relieving boredom due to not being sufficiently stimulated.
- Using up energy from sitting all day.
- Relieving pain and discomfort from joint pain or stiffness.
- Responding to stress or anxiety.
- Feeling lost or uncertain about their surroundings.
- Going out and forgetting where they were going.
- Searching for someone or something in the past or present.
- Seeking fulfilment and purpose such as the desire to go to work.
- Getting confused about the time.

3. How can I manage habits and reduce the chances that the person I care for gets lost?

There are certain things that may help manage a person's walking habits and prevent them from getting lost. For example, try to:

- Keep to the routines and activities of the person you care for. Identify the most likely times of the day that their walking may occur and plan activities such as a walk in the park together at that time.
- Reassure the person you care for if they feel lost, abandoned or disoriented, or want to leave to “go home” or “go to work”. For example, try saying: “we are staying here tonight. We are safe and I’ll be with you. We can go home in the morning after a good night’s rest.” Try to refrain from correcting the person living with dementia.
- Ensure that all basic needs are met. Has the person gone to the bathroom? Are they thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation, such as shopping malls, markets, grocery stores or other crowded places.
- Make sure that the person carries some form of identification.
- Make sure that your home is secure, that the person is safe in your home and cannot leave without you knowing. For example, camouflaging doors and door knobs may help, or using a bell or curtain that makes noise when someone uses the door.
- Keep an up-to-date photograph in case the person you care for gets lost and you must ask for help from others.
- After the person you care for is found, speak calmly, with acceptance and love, try to avoid blaming and showing anger.

Let's look at an example

Amit has dementia and is supported by his wife, Samia. Samia is cooking dinner when she hears Amit heading for the door. She knows that he likes to go for afternoon walks, but now is not a good time since she is cooking.

1. Check your understanding



Dealing with walking away.

What would you recommend to Samia?

Please select all correct responses.

- Yell to Amit from the kitchen, "please stop! I can't come with you now."
- Turn the cooker off and follow Amit.
- Forbid Amit to leave and pull him back into the house.
- Go to where Amit is standing by the door and calmly say: "let's eat dinner first and we'll go for a walk later."
- Lock the door so that Amit cannot leave.
- Let Amit leave and call a neighbour to keep an eye out for him.
- Ask another family member to go for a walk with him.
- Ask Amit to help with a task in the kitchen.
- Schedule more afternoon walks before dinner.



2. Activity

Let's look at your own situation

It is important to apply what you have learned to your own situation. *The spaces below are for you, like a diary.*

What are the possible reasons why the person you care for may have the desire to walk? *Please select all answers that apply.*

1.

- Wanting to exercise.
- Continuing a lifelong habit of walking regularly.
- Relieving boredom due to not being sufficiently stimulated.
- Using up energy from sitting all day.
- Relieving pain and discomfort from joint pain or stiffness.
- Responding to stress or anxiety.
- Feeling lost or uncertain about their surroundings.
- Going out and forgetting where they were going.
- Searching for someone or something in the past or present.
- Seeking fulfilment and purpose such as the desire to go to work.
- Getting confused about the time
- Other (please state): _____

2.

Based on the reasons that you selected, how might you react or respond the next time the person you care for wants to go outside or walk?

What could you do to help the person enjoy walking in a safe way?

Take a moment to summarize the points that you have learned in this lesson, which will help you going forward:

Let's review what you have learned

- Walking around or walking away is common.
- Walking can be healthy exercise, reduce boredom, and be a common habit or routine of the person.
- Walking away or walking alone might be a safety risk.
- Concerns about walking and getting lost can be very upsetting to the person living with dementia and the carer.
- It is important to identify possible reasons for walking around or walking away.
- How you respond to the desire to walk should be based on the possible reasons for it.
- If one approach doesn't work, try another one.
- Realize that there may be worse, but also better moments.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person living with dementia.

If you want to know more about how to plan an enjoyable day, please refer to the **Lesson 5. An enjoyable day** in **Module 4**.



You finished this lesson, well done!

1. Check your understanding

*Dealing with walking away.*

- ✗ Yell to Amit from the kitchen, "please stop! I can't come with you now."

This is not a good response because yelling at Amit from the kitchen may confuse and agitate him. It may also not stop him from going out on his own.

- ✓ Turn the cooker off and follow Amit.

This is a good response if there are no other alternatives.

- ✗ Forbid Amit to leave and pull him back into the house.

This is not a good response because Amit may get agitated and resist being pulled which could result in Amit or Samia being harmed.

- ✓ Go to where Amit is standing by the door and calmly say: "Let's eat dinner first and we'll go for a walk later."

This is a good response because Samia stays calm, does not yell, and honors Amit's wishes by telling him that they will go together after dinner.

- ✓ Lock the door so that Amit cannot leave.

This is a good response if no other options exist and Samia is in the house with Amit. For fire safety reasons, a person living with dementia who requires supervision should never be locked inside a house without another person there.

- ✓ Let Amit leave and call a neighbour to keep an eye out for him.

This is a good option if Samia has prearranged with the neighbours to keep an eye out for him. If Amit is in the very early stages of dementia, he may be okay while going out on his own to places that are familiar to him.

- ✓ Ask another family member to go for a walk with him.

This is a good option. Samia can finish cooking dinner and Amit can enjoy a nice walk before dinner.

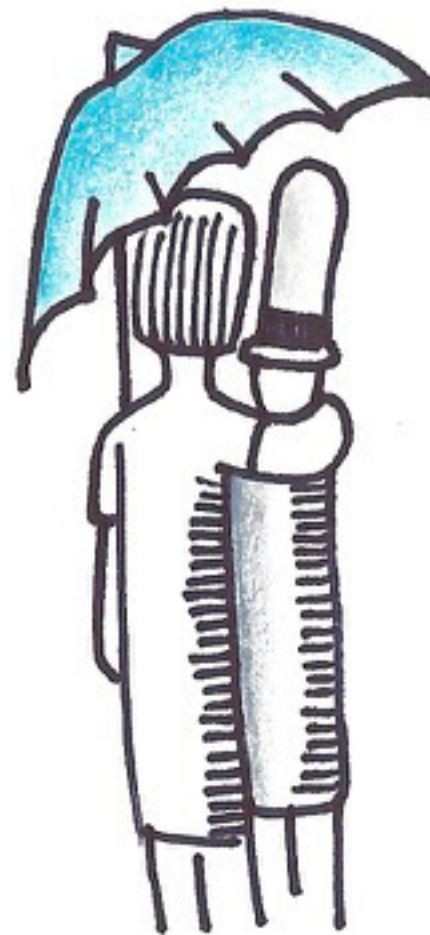
1. Check your understanding (continued)



Dealing with walking away.

- ✓ Ask Amit to help with a task in the kitchen.
This is a good response because it involves distracting Amit from going for a walk alone and gives him purpose and keeps him occupied.

- ✓ Schedule more afternoon walks before dinner.
This is a good response because planning ahead will prevent Samia from being interrupted when cooking dinner to assist Amit. It may also help Amit to release some energy and come home to relax before dinner.



Lesson 9. Changes in judgement

Why is this lesson important?

Changes in judgement can be upsetting to the person living with dementia and the carer.

How will this lesson help me?

This lesson will help you understand the reasons causing changes in judgement and teach you skills to manage this.

What will I learn?

1. What are changes in judgement?
2. How can you manage changes in judgement?
3. What to do if the changes in judgement are more serious?

1. What are changes in judgement?

Changes in judgement may include saying the wrong thing at the wrong time, acting inappropriately in a situation, or not understanding one's own limitations.

Usually these actions are not harmful, but they can be stressful or embarrassing for the person living with dementia or the carer. People with dementia are often looking for guidance or reassurance.



1. Activity

Did you ever notice that the person you care for sometimes has a change in their judgement?
If so, what did you observe? *Please describe this in the space below.*

How did it affect you as the carer?

Tip

Changes in judgement will increase as dementia progresses. In this lesson you can practice several ways of responding to changes in judgement and find out what may help.

2. How can you manage changes in judgement?

Let's go through an example

Ivan is in town visiting his aunt Isabel who has dementia. They are on their way to a restaurant for dinner. In order to get there, Ivan decides to hail a taxi. All of a sudden, the car pulls up alongside Isabel and startles her. Isabel, who is normally a very gentle woman, starts scolding the taxi driver.

1. Check your understanding



Managing changes in judgement.

What would you recommend to Ivan to help him deal with this situation? *Please select all correct responses.*

- Put his hand on Isabel's mouth in order to stop her scolding the driver.
- Walk Isabel back to her apartment and leave because what happened is embarrassing.
- Stay calm and reassure Isabel everything is alright.
- Accept the behaviour. If the taxi driver doesn't seem to notice, let it be. Find ways to adapt.
- Ivan could carry a business card that explains, 'My companion has dementia, please be patient with us.' and give this card to the taxi driver.

3. What to do if changes in judgement are more serious?

The last example was a brief and one-time experience for Ivan. However, what happens if the changes in judgement experienced by a person living with dementia are more serious? Here are three examples to help you learn how to react.

Mishandling finances

Sophie has dementia and lives alone. Her cousin Julia has come to visit her. Despite the fact that Sophie has always been organised, Julia arrives to find that there is a large pile of unopened mail on the kitchen table.

Julia wonders if Sophie has had some trouble paying her bills. She asks Sophie about her finances. Sophie cannot remember whether she has paid her bills or not, does not know when they are due, and cannot recall how much money she has in her bank account. Julia becomes quite concerned.

2. Check your understanding



Managing more serious changes in judgement (1).

What would you recommend to Julia?

Please select all correct responses.

- Stay calm and call Sophie's daughter.
- Go to the bank and ask for control of Sophie's finances.
- Leave because she feels uneasy.
- Ask Sophie if she would like some help in opening her mail.
- Try to find out whether Sophie has someone who handles her finances, like a family member or a professional.

Insisting on driving

Hugo is living with dementia. His neighbour, Pablo, notices that his car is parked very strangely one day, obstructing some of the other cars on the street.

Pablo walks out of his apartment, sees Hugo and attempts to start a conversation.

Instead of stopping, Hugo jumps in his car, speeds off and takes an illegal left turn out of the compound. Hugo returns quickly and nothing bad seems to have happened.

Tip



It is better if the decision not to drive comes from the person living with dementia. Giving up driving is typically a difficult time in the person's life where they are losing independence.

Alternatives such as offering regular rides, teaching the person how to use public transportation or arranging taxis will help the person stay active and involved in their community activities.

It is important that the person does not become isolated or lonely once they give up driving. More effort will be needed to keep them connected to the world outside their home.

3. Check your understanding



Managing more serious changes in judgement (2).

What would you recommend to Pablo?

Please select all correct responses.

- Immediately seize Hugo's car keys when he returns. This will prevent it from happening again.
- Stay calm and ask whether Hugo has any other places to go that day, and if so, offer him a ride.
- Ignore the situation because it is embarrassing.
- Ask Hugo if he would like some help figuring out transportation.
- Tell Hugo that he is concerned about his driving and suggest visiting his doctor to discuss it.
- Report the incident to Pablo's carer, friend or family member.

Inappropriate sexual advances

Mateo is in his late 70s, has dementia and lives with his family. Two days a week, an in-home aide, Camila, who is 22 years old, comes to help him take a bath and administer his medication. This arrangement has been working well for several months.

One day, while preparing for his bath, Mateo makes some sexual remarks and tries to pull Camila close to him. Camila is shocked and surprised. She runs out of the room and tells the family that she can no longer work there.

Tip



If the inappropriate advances continue, the family might want to consider hiring a male in-home aide instead of a female one which could prevent this behaviour. They also might seek help from a professional.

4. Check your understanding



Managing more serious changes in judgement (3).

What would you recommend to Mateo's family?

Please select all correct responses.

- Stay calm and tell Mateo that this behaviour is unacceptable. Explain who Camila is.
- Change the bathing situation. Perhaps Camila can set up a sponge bath and Mateo can do more himself.
- Change the environment. Put a towel or robe over Mateo's shoulders while he is being bathed to keep him covered for privacy.
- Shout at Mateo, shaming him for his conduct.
- Ignore the situation.

2. Activity



Let's look at your own situation

It is important to apply what you have learned to your own situation. Earlier, we asked whether the person you care for sometimes shows changes in judgement. After going through these examples, think again about your own situation. *The spaces below are for you, like a diary.*

Does the person living with dementia sometimes show changes in judgement?

In what way could you respond?

Take a moment to summarize the points that you have learned, which will help you deal with changes in judgment in the future.

Remember



Changes in judgement may hamper decision-making. If you want to know more, review **Lesson 3. Supported decision-making** in **Module 2**.

Let's review what you have learned

- Changes in judgement usually increase as dementia progresses.
- Changes in judgement can be very upsetting for the person living with dementia and the carer.
- It is important to reduce or prevent changes in judgement, whenever possible.
- Realize that there may be good and bad days.
- Remind yourself that this is a part of the disease.
- Take a deep breath and think about the best ways to respond that will be the least distressing to you and the person you care for.
- Plan for increasing levels of changes in judgement.



You finished this lesson, well done!

1. Check your understanding

*Managing changes in judgement.***What would you recommend to Ivan?**

- ✗ Put his hand on Isabel's mouth in order to stop her scolding the driver.

This response is not good because it may even worsen the situation and cause Isabel further agitation.

- ✗ Walk Isabel back to her apartment and leave because what happened is embarrassing.

This response is not good because Isabel may feel bad and isolated.

- ✓ Stay calm and reassure Isabel everything is alright.

This is a good response because it shows Ivan cares about Isabel. It may stop her from scolding the taxi driver and make her feel more relaxed.

- ✓ Accept the behaviour. If the taxi driver doesn't seem to notice, let it be. Find ways to adapt.

This can be an appropriate response if the behaviour is not harming anyone.

- ✓ Ivan could carry a business card that explains, 'My companion has dementia, please be patient with us.' and give this card to the taxi driver.

This is a good response because it relieves Ivan from explaining the situation to the taxi driver which may embarrass Isabel.

2. Check your understanding

*Managing more serious changes in judgement (1).***What would you recommend to Julia?**

- ✓ Stay calm and call Sophie's daughter.

This response is good because Julia shares her worries with Sophie's closest relative, her daughter, who might know more and can arrange help if needed.

- ✓ Go to the bank and ask for control of Sophie's finances.

This is not appropriate because it is Sophie's decision to appoint a person that she is comfortable with to help manage her finances.

- ✓ Leave because she feels uneasy.

This response is not appropriate. If Sophie has problems dealing with her finances, letting the situation continue could make things worse.

- ✓ Ask Sophie if she would like some help with opening her mail.

This response is good because Sophie may be able to pay her bills if given the right prompts, such as opening the bills in front of her and cueing her to pay one at a time.

- ✓ Try to find out whether Sophie has someone who handles her finances, like a family member or a professional.

This is a good response because Sophie may be at the point in her illness where she is no longer able to handle the finances on her own. If it seems that she is not getting any help with handling her finances, Julia may want to call her daughter to share her worries.

3. Check your understanding



Managing more serious changes in judgement (2).

What would you recommend to Pablo?

- ✗ Immediately seize Hugo's car keys when he returns because this will prevent it from happening again.

This is not a good response because Pablo cannot decide whether his neighbour should drive anymore, and Hugo may become angry.

- ✓ Stay calm and ask whether Hugo has any other places to go that day, and if so, offer him a ride.

This is a good response because it prevents Hugo from driving unsafely and provides safe transportation, so Hugo can run his errands.

- ✗ Ignore the situation because it is embarrassing.

This response is not good because Hugo's driving may cause harm to himself and others.

- ✓ Ask Hugo if he would like some help figuring out transportation.

This response is appropriate because Hugo may be able to safely ride a bus or walk, preventing any unsafe behaviour.

- ✓ Tell Hugo that he is concerned about his driving and suggest visiting his doctor to discuss it.

This is a good response as Pablo respects Hugo by being honest and raising a concern.

- ✓ Report the incident to Pablo's carer, friend or family member.

This is a possible response. Pablo may not know if Hugo has dementia and could be concerned about the risk of harm to Hugo and others.

4. Check your understanding



Managing more serious changes in judgement (3).

What would you recommend to Mateo's family?

- ✓ Stay calm and tell Mateo that this behaviour is unacceptable. Explain who Camila is.

This option is a good one. Mateo's family does not overreact because they remember it is the disease taking effect. They redefine the appropriate boundaries for Camila's safety.

- ✓ Change the bathing situation. Perhaps Camila can set up a sponge bath and Mateo can do more himself.

This is a good option. Letting Mateo do more himself will distract him. In this way, both Camila and Mateo's dignity are maintained.

- ✓ Change the environment. Put a towel or robe over Mateo's shoulders while he is being bathed to keep him covered for privacy.

This is a good response. Perhaps because Mateo is naked, he misunderstands the situation.

- ✗ Shout at Mateo, shaming him for his conduct.

This response is not good because as part of his dementia Mateo may not know that these advances are inappropriate. Therefore, try not to overreact.

- ✗ Ignore the situation.

This response is not good because Mateo may continue to make inappropriate sexual advances and cause distress to Camila.

Lesson 10. Putting it all together

Why is this lesson important?

Certain changes in behaviour can be particularly stressful for the person living with dementia and the carer.

How will this lesson help me?

This lesson will summarize ways to prevent, reduce or manage behaviour changes.

What will I learn?

1. The most important things to keep in mind when dealing with challenging behaviours.
2. Practical tips on not blaming yourself, sharing your feelings with others and making time for yourself.

1. The most important things to keep in mind when dealing with behaviour changes

- Behaviour changes can be stressful for the person you care for and yourself. This is quite common.
- Try to make the person you care for feel more comfortable.
- Look for ways to prevent or reduce behaviour changes that are stressful, for example by using memory aids.
- Try to distract the person you care for, don't argue.
- When one approach does not work, try another one.
- Realize that there may be good and bad days.
- Consult a medical doctor to identify any causes related to medication or illness.
- Identify whether the environment or your approach could be causing the particular symptom.
- Remind yourself that behaviour changes are part of the disease but other possible causes should be identified before accepting the disease as a cause.

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

Here are some tips from related lessons. If you did not take these lessons yet, you can complete them after finishing this one.

- Don't blame yourself or the person living with dementia for the problems that you encounter. If you want to work on ways to manage your feelings, take a look at the last page of **Lesson 3. Thinking differently in Module 3.**
- Share your feelings about your experiences as a carer with others. If you keep them to yourself it may be more difficult for you to look after your family member or friend. If you want to learn more about involving others, take a look at **Lesson 4. Involving others in Module 2.**
- It is essential that you make time for yourself. This will allow you to do the things that you value in life, such as spending time with others or enjoying your favourite hobbies. If you want to learn more about doing pleasant activities, take a look at **Lesson 2. Making time for pleasant activities in Module 3.**



You finished this lesson, well done!

Worldwide, carers of people with dementia should have access to information and support in order to effectively respond to, and manage, the physical, mental and social demands associated with caring for someone living with dementia. This iSupport manual has been developed to provide accessible, evidence-based training and information, tailored to carers' needs. It aims to improve knowledge and caregiving skills, such as carers' ability to cope with dementia symptoms and care for themselves. iSupport is also available online and can be accessed at www.isupportfordementia.org/en.



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