

Australian version

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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The World Health Organization (WHO) developed iSupport for Dementia, a comprehensive online dementia education and skill training programme for informal carers of people living with dementia [1]. This programme has been adapted into the Australian social context [2]. Flinders University funded the research activities leading to the current version of Australian iSupport for Dementia. The research team members who contributed to the adaptation of the WHO iSupport for Dementia programme and to the new learning module in the programme entitled 'My engagement in consumer directed care' are:

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1. World Health Organization; (2019). iSupport for dementia. Training and support manual for carers of people with dementia. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO.
2. Xiao, L. D., McKechnie, S., Jeffers, L., De Bellis, A., Beattie, E., Low, L. F., per, B., Messent, P., & Pot, A. M. (2021). Stakeholders' perspectives on adapting the World Health Organization iSupport for Dementia in Australia. *Dementia* (London, England), 20(5), 1536-1552.

MODULE

1

INTRODUCTION TO DEMENTIA

Unit 1. What is dementia?

Unit 2. Timely diagnosis of dementia has many benefits

Unit 3. Using memory aids in your care activities

Unit 4. How to respond to repetitive behaviour

Unit 5. How to avoid conversations that may trigger changed behaviour

Unit 1. What is dementia

What is dementia and how does it affect someone?

Why is this learning unit important?

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

How will this learning unit help me?

This learning unit will help you to understand the basics of dementia, what it is and how it affects someone. This information is essential when you are a carer. It will also guide you as to what help and resources are available to you.



What is dementia?

Dementia occurs as a result of a disease process in the brain and there are many causes, both known and unknown. Dementia affects a person's thinking, memory, behaviour and their ability to perform everyday tasks. It is present in all groups in society and is not linked to social class, gender, ethnic group or geographic location. Dementia can happen to anybody, but it is more common after the age of 65. Three in ten people over the age of 85 and almost one in ten people over 65 have dementia. There are lots of types of dementia and the most common will be discussed later in this module.

What causes dementia?

Dementia is caused by a number of diseases which produce gradual changes and damage in the brain. The diseases cause brain cells to degenerate and leads to a decline in a person's mental and sometimes physical abilities. Although there is no cure for dementia at present, if it is diagnosed in the early stages, there are ways it can be slowed to help maintain mental function.

Types of dementia?

Alzheimer's Disease

Alzheimer's Disease is the most common form of dementia and accounts for 60-80% of dementia cases. The disease destroys brain cells and disrupts the transmitters which carry messages in the brain, particularly those responsible for storing memories, but eventually it affects all areas of the brain. Alzheimer's Disease was first described by Alois Alzheimer in Germany in 1906.

For more information about Alzheimer's Disease visit:

Brain Tour: https://www.alz.org/braintour/3_main_parts.asp

or:

Information sheet:

https://www.dementia.org.au/files/helpsheets/elpsheet-AboutDementia13-AlzheimersDisease_english.pdf





Vascular Dementia

Vascular dementia is a common type of dementia caused by reduced blood flow to the brain and as a result brain cells die. 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 dementia cases. Vascular dementia tends to get worse over time, although it's sometimes possible to slow it down. The main symptoms of vascular dementia include slowness of thought, difficulty with planning and understanding, and problems with concentration. These problems can make daily activities increasingly difficult and someone with the condition may eventually be unable to look after themselves.



For more information about vascular dementia visit:
<https://www.dementia.org.au/about-dementia/types-of-dementia/vascular-dementia>

Dementia with Lewy Bodies

Dementia with Lewy Bodies is similar to Alzheimer's Disease in that it is caused by the degeneration and death of nerve cells in the brain. This type of dementia is characterised by visual hallucinations and fluctuating cognition (or having 'good days' and 'bad days'). Dementia with Lewy Bodies is named after the doctor who first wrote about them and is caused by a forming of abnormal deposits of protein in the nerve cells of the brain. It may account for around 10% of all cases of dementia.

It may be hard to distinguish Lewy Body disease from Parkinson's Disease, and some people with Parkinson's Disease develop a dementia which is similar to that seen in Lewy Body disease.

For more information about Dementia with Lewy Bodies visit:
<https://www.dementia.org.au/about-dementia/types-of-dementia/lewy-body-disease>



Frontotemporal dementia

Frontotemporal dementia (FTD) is the name given to dementia when it is due to progressive damage to the frontal and/or temporal lobes of the brain. These lobes are involved in mood, social behaviour, attention, judgement, planning and self-control. Damage can lead to reduced intellectual and language abilities and changes in personality, emotions and behaviour. In contrast to other dementias, memory often remains unaffected. It was first described 100 years ago by Arnold Pick and was previously referred to as Pick's Disease.

For more information about Frontotemporal dementia visit:

<https://www.dementia.org.au/about-dementia/types-of-dementia/frontotemporal>

Rarer causes of dementia

There are many other rarer causes of dementia, like alcohol-related dementia, Downs Syndrome and dementia due to HIV and AIDS.

What causes dementia?

The diseases that cause dementia are all similar in that the brain does not work like it did before. The exact causes of dementia are not clear. More research is needed to learn about the disease and the most effective ways to prevent, identify and treat it. To learn more about these diseases and problems with memory, thinking, behaviour or emotions, please visit:

<https://www.dementia.org.au/about-dementia/types-of-dementia>

Check your understanding



1. What happens to people with dementia?

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

- ☐ TRUE
- ☐ FALSE

ANSWERS - What is dementia?

Check your understanding



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

✓ True: This is the correct answer.



RELATED LEARNING UNITS

- Module 1 Unit 2 Timely diagnosis of dementia has many benefits
- Module 1 Unit 3 Using memory aids in your care activities
- Module 1 Unit 4 How to respond to repetitive behaviour
- Module 2 Unit 1 The journey together
- Module 3 Unit 3 Thinking differently
- Module 4 Unit 5 An enjoyable day
- Module 5 Unit 1 Introduction to person-centred care approach
- Module 6 Unit 1 Introduction to consumer-directed care

Keep in Mind



- Dementia affects a person’s brain.
- Dementia is common, especially in older people.
- Dementia is a disease, not a part of normal ageing.



For additional care and support, see
Dementia Australia in your state,
<https://www.dementia.org.au/> or call
National Dementia Helpline on 1800 100 500.

Tip



You finished this unit, well done!

Unit 2. Timely diagnosis of dementia has many benefits

Why is this learning unit important?

People with dementia can be diagnosed in a timely manner. Timely diagnosis of dementia has many benefits for person living with dementia and for you as the carer.

How will this learning unit help me?

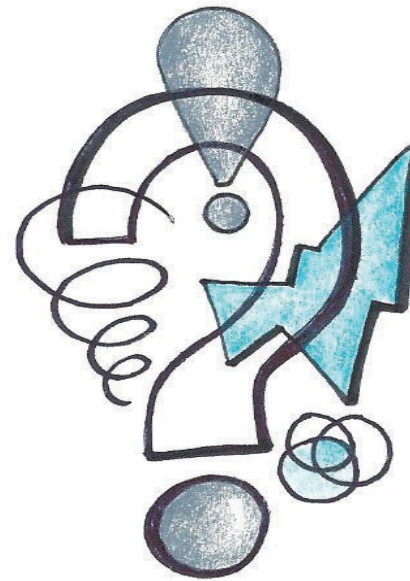
This learning unit will help you to understand the symptoms and stages of dementia and the ways to get help for diagnosis and for care services.



What happens to people with dementia?

Every person is unique, and dementia affects people differently.

Not only the brain damage, but also other factors, including an individual's personality, life course, general health and functioning and living environment, are all important in determining how dementia affects someone.





Activity

Here are some common things that may happen to people living with dementia.
Do you think any occur with the person you care for? Please click on any that apply:

Have trouble remembering things that happened minutes before?	<input type="checkbox"/> <i>Forgetting recent events</i> <input type="checkbox"/> <i>Repeating questions</i>
Find it difficult to perform daily activities?	<input type="checkbox"/> <i>Money management</i> <input type="checkbox"/> <i>Shopping</i> <input type="checkbox"/> <i>Preparing dinner</i>
Struggle to identify the time or place as they did before?	<input type="checkbox"/> <i>Forgetting the date and time of appointments</i>
Communicate differently than they did before?	<input type="checkbox"/> <i>Difficulty expressing oneself</i> <input type="checkbox"/> <i>Difficulty finding the right words</i>
Misplace things?	<input type="checkbox"/> <i>Not finding common objects, such as keys</i> <input type="checkbox"/> <i>Suspecting things are stolen</i>
Withdraw socially?	<input type="checkbox"/> <i>Showing decline in social activity</i> <input type="checkbox"/> <i>Lacking urge to do something</i>
Show changes in feelings or personality?	<input type="checkbox"/> <i>Having a lot of ups and downs</i> <input type="checkbox"/> <i>Becoming more anxious than before</i>

What happens to people with dementia?



So, you think the following occur with the person living with dementia:

Have trouble remembering things that happened minutes before?	<div><input type="checkbox"/> <i>Forgetting recent events</i></div> <div><input type="checkbox"/> <i>Repeating questions</i></div>
Find it difficult to perform daily activities?	<div><input type="checkbox"/> <i>Money management</i></div> <div><input type="checkbox"/> <i>Shopping</i></div> <div><input type="checkbox"/> <i>Preparing dinner</i></div>
Can't identify the time or place as they did before?	<div><input type="checkbox"/> <i>Forgetting the date and time of appointments</i></div>
Communicate differently than the person with dementia did before?	<div><input type="checkbox"/> <i>Difficulty expressing oneself</i></div> <div><input type="checkbox"/> <i>Difficulty finding the right words</i></div>
Misplace things?	<div><input type="checkbox"/> <i>Not finding common objects, such as keys</i></div> <div><input type="checkbox"/> <i>Suspecting things are stolen</i></div>
Withdraw socially?	<div><input type="checkbox"/> <i>Showing decline in social activity</i></div> <div><input type="checkbox"/> <i>Lacking urge to do something</i></div>
Show changes in feelings or personality?	<div><input type="checkbox"/> <i>Having a lot of ups and downs</i></div> <div><input type="checkbox"/> <i>Becoming more anxious than before</i></div>



Where can I get help?

Step 1: See a general practitioner.

If you think that the person living with dementia may have dementia, a good first step is to make sure the person living with dementia sees the general practitioner (or GP). The GP will take a detailed history of the person living with dementia 's health, do a physical examination and question how [Name] 's brain is functioning.

It is important to rule out whether the person living with dementia 's memory problems are caused by other treatable conditions like depression, urinary infection, medication side effects, vitamin deficiency or other brain problems.

It is important to sort out whether the memory problems of the person living with dementia are really part of dementia or are part of something else. Only a medical doctor can do this, not this program.

Check your understanding



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

Call a friend or relative.

- ☐ TRUE
- ☐ FALSE

Use iSupport alone for help.

- ☐ TRUE
- ☐ FALSE

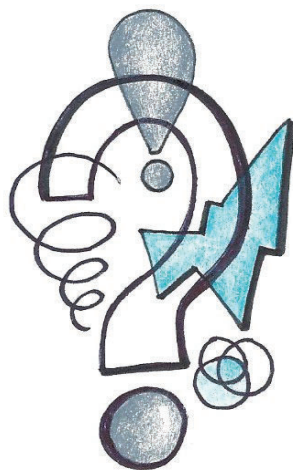
Call the general practitioner (GP) and make an appointment.

- ☐ TRUE
- ☐ FALSE

The person has been to a medical doctor already and has been diagnosed with dementia.

- ☐ TRUE
- ☐ FALSE





To learn more about stages of dementia, click here:
https://www.dementia.org.au/files/helpsheets/Helpsheet-AboutDementia14-ProgressionOfAlzheimersDisease_english.pdf



- ✗ **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.

Step 2: Reach out for help.

The diagnosis of dementia enables the person to receive Australian Government funded aged care and dementia care services. It is important to realise that you, alone, are not going to be able to provide all the care the person living with dementia needs, especially when things become more complex overtime. So, we encourage you to reach out to family members, friends and professional organisations or services for help.

In Australia, there are services available that offer education and care support including respite care. For assistance to live at home or care for someone in their home, please refer to www.myagedcare.gov.au or call My Aged Care on 1800 200 422 Monday to Friday 8am to 8pm and Saturday 10am to 2pm. All home care packages are delivered on a Consumer Directed Care (CDC) basis. This means you (and the person you care for) have more choice and control over what services are delivered and where and when they are delivered.

For more specific information, please go to 'Learning module 6: My engagement in consumer directed care'.

Please also contact Dementia Australia in your state for the information, support and care that is available in your area and could be of benefit for the person living with dementia and you.

Dementia Australia can provide details of local supports and resources - Contact the National Dementia Helpline 1800 100 500 or <https://www.dementia.org.au/>



Step 3: Understand support for carers. Being a carer

The diagnosis of dementia also enables you as a carer to be formally recognised as a carer and receive support. You may look after the person for years. It is very important that you look after yourself as well. There are many free care services for carers funded by the Australian Government that may be suitable for you. Please contact Dementia Australia (Phone: 1800 100 500 or <https://www.dementia.org.au/>) and/or Carers Australia (Phone: 1800 422 737 or www.carersaustralia.com) to find out about support available.



Step 4: Understand your rights as a carer. Legal considerations of being a carer

The Australian Government has created an Act to increase recognition and awareness of carers. Most states and territories also have legislation that sets out your rights as a carer.

It's important to know your legal rights when you are an unpaid carer which include:

- being recognised by health providers as a contributor to the health of the person being cared for
- being heard and treated with respect
- using services to support the person living with dementia without discrimination
- being able to comment on services provided to the person being cared for
- acting in the best interests of the person being cared for.

For more details regarding 'Legal considerations of being a carer', please go to 'Module 6 Learning Unit: Carer support'.



Check your understanding

?

Carers of people with dementia need to apply for carer support groups from My Aged Care.

☐ TRUE
 ☐ FALSE

Check your understanding

?

Carers of people with dementia need to apply for carer support groups from My Aged Care.

✗ False: This is the incorrect answer.

The right answer is that carers of people with dementia need to apply for carer support groups from Dementia Australia and/or Carers Australia.



Keep in Mind



- As a first step for dementia diagnosis, it is important to see a general practitioner or GP.
- It is important that you take care of yourself.
- The iSupport program is to support you as a caregiver.
- There are services and support available to help you and the person living with dementia.



RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 1 Unit 3 Using memory aids in your care activities
- Module 1 Unit 4 How to respond to repetitive behaviour
- Module 2 Unit 1 The journey together
- Module 3 Unit 3 Thinking differently
- Module 4 Unit 5 An enjoyable day
- Module 5 Unit 1 Introduction to person-centred approach
- Module 6 Unit 1 Introduction to consumer-directed care

Tip

For additional care and support for the person living with dementia and you, see Dementia Australia in your state, click here. <https://www.dementia.org.au/> or call National Dementia Helpline on 1800 100 500.



You finished this unit, well done!

Unit 3. Using memory aids in your care activities

Memory loss

Why is this learning unit important?

Memory loss can be frustrating for the person with dementia and result in repetitive behaviour including repetitive vocalisations. As a carer, you may feel frustrated when reacting to repetitive behaviour.

How will this learning unit help me?

In this learning unit 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?

- Memory loss is common in people with dementia
- Different ways to deal with memory loss
- Not to blame the person with dementia because memory loss is part of the disease.

What is memory loss?

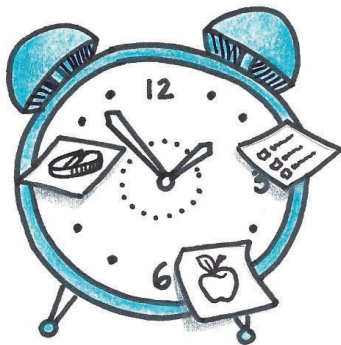
People with dementia will increasingly lose their memory over time.

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, like childhood memories, are often preserved for a longer period of time.

Does the person you care for forget things sometimes?

If so, what kinds of things does the person you care for forget?



Check your understanding



Forgetting to buy groceries

Anne often forgets what she needs to buy from the shops. Anne is living with dementia, and she has a daughter named Maya. When Maya goes to visit Anne's house, she notices that the fridge/cupboard is empty. Anne often forgets what she needs to buy from the shops. Maya becomes worried.

Check your understanding



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

Pick from the list below all the responses you think are appropriate and drop them to the box at the right.

- ☐ 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 Anne needs to buy, and put that in a prominent place, so that the list is easy to access.
- ☐ Go out and buy groceries immediately.
- ☐ Ask: 'Mum, 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.



ANSWERS - Using memory aids in your care activities

Check your understanding



How would you advise Maya?

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

This might be helpful if the neighbour is happy to help Anne. Anne will have groceries and a nice visit with the neighbour.

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

It addresses Anne’s memory loss and may become a weekly shared pleasant activity.

- ✗ **Go out and buy groceries immediately.**

This is a short-term solution. Further action will be needed to address the problem long term.

- ✗ **Ask: ‘Mum, what’s wrong with you, there is no food in the house?’**

Anne cannot help that she forgets to buy food, if critiqued, she 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.**

Maya is addressing her mother’s needs. However, she might first want to try another approach. For example, with a list of groceries her mother may still be able to go shopping without help.

Tip

People with dementia often find barriers when shopping. Below you will find some of the problems people with dementia may have with possible solutions.

Problem shopping: Getting to/from the shop on their own

Possible solutions:

Arrange for help with transport such as a friend to go with the person or a taxi service. The person may be eligible for Community Transport and other Commonwealth Home Support Program services or a Home Care Package. For further information call My Aged Care on 1800 200 422.

Problem shopping: Feeling overwhelmed by the people, the size of the shop, the number of aisles and variety of choices.

Possible solutions:

Choose a shop that is smaller; shop on a less busy day (i.e., not Saturday or Sunday); ask for help from a staff.

Problem shopping: Difficulty counting change.

Possible solutions: Ask for the check-out staff to help with the change or use a direct debit or credit card.

Problem shopping: Difficulty remembering what to buy.

Possible solutions: Take a shopping list that is in the order of the aisles in the shop.

Check your understanding



Forgetting daily activities

the person living with dementia might forget other things. The same goes for Anne. Have a look at the next example.

Maya and Anne are talking on the phone. Maya notices that Anne often forgets what she has planned for the day. Maya is impatient with Anne and tells her mother 'This is getting worse'.

Maya feels frustrated when her mother forgets daily activities.



What do you think Maya's response should be?
Please select all the responses you think might apply.

- ☐ Tell her mother what to do over the phone.
- ☐ Tell her mother what day of the week it is and remind her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the shops.
- ☐ Go straight over and take charge of the situation by ordering her mother around.
- ☐ Plan to visit Anne each week and write on a calendar or blackboard the program for the week.
- ☐ Call My Aged Care on 1800 200 422 to find out care services to help Anne.

ANSWERS - Using memory aids in your care activities

Check your understanding



Forgetting daily activities

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

This response may help if Anne can respond to the directions.

✓ Plan to visit Anne each week and write on a calendar or blackboard the program for the week.

This may help Anne to remember.
- ✓ Tell her mother what day of the week it is and remind her mother what she usually does on that given day. For example, Monday is wash day; Thursday is going to the shops.

This response may be a good one because Maya can use this information to remind her mother or write up a diary of daily chores for her mother to refer to.

✓ Call My Aged Care on 1800 200 422 to find out care services to help Anne.

This is a starting point to help Anne check her eligibility for aged care services and apply for care services to enable her to stay at home as long as possible.
- ✗ Go straight over and take charge of the situation by ordering her mother around.

This disempowers Anne and does not solve the problem long-term.

Check your understanding



Forgetting medications

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

Anne forgets medications.

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



How do you think Maya should respond to this situation?
Select all Maya's responses that you think are appropriate.

- ☐ Maya says, 'Mum, how could you forget your medications?', and 'You know you really need them to stay healthy!'
- ☐ Maya goes over the medications with her mum as she has time to help her mum. She purchases a pill box and puts the tablets in the box at the right day/time and calls her mum every day to instruct her to take her medications.
- ☐ Maya can set medication reminders on Anne's smart phone or program an electronic alarm clock at Anne's home to remind her to take her medication.
- ☐ Maya goes through the medicine cabinet, sits down and cries about her mother's memory loss.
- ☐ Maya could arrange with Anne's chemist to place her tablets into a medication organiser called a webster pack, some chemists provide this as a free service, others charge a small fee.

ANSWERS - Using memory aids in your care activities

Check your understanding



Forgetting medications

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

Anne cannot help that she forgets to take her medications. Memory loss is a disease symptom of dementia.

✓ Maya goes over the medications with her mum as she has time to help her mum. She purchases a pill box and puts the tablets in the box at the right day/time and calls her mum every day to instruct her to take her medications.

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

✓ Maya can set medication reminders on Anne's smartphone or program an electronic alarm clock at Anne's home to remind her to take her medication.

This is a good response because this memory aid might help Anne to take medications at the right day/time if Maya has a job where she can't call Anne at the right time.

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

It is ok to be upset, it can be difficult looking after someone with dementia. However, it doesn't resolve the problem of Anne forgetting to take her medications.

✓ Maya could arrange with Anne's chemist to place her tablets into a medication organiser called a webster pack, some chemists provide this as a free service, others charge a small fee.

This is a good response because this will support Anne to take the right tablets at the right day/time.

Activity



Let's look at your own situation

It is important to relate what you have learnt to your own situation.

You wrote that the person you care for forgets the following:

Activity



Let's look at your own situation

How could you respond to help the person you care for to deal with memory loss?

This box is for you, like a diary.



Keep in Mind

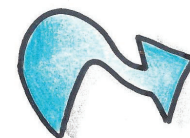


Let's review what you have learnt

- Memory loss is very common for people with dementia.
- Memory loss can be stressful for everyone to deal with.
- In case of memory loss, try a memory aid like a note, calendar, diary, list, pill box, prompt/alarm etc.
- If possible, involve the person living with dementia to find the best way to support them in developing a solution for their memory problems.
- It is important to remember that the person with dementia is not to blame, because they can't help that they forget.
- If one approach doesn't work, try another one.
- Realise 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 least distressing for you and the person you care for in the case of memory loss.

You finished this learning unit, well done!

Would you like to try the following relaxation exercise?





Number counting

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

This is how you do it:

- Sit or lie down comfortably in a quiet place.
- Breathe slowly.
- With each breath, take at least three seconds to breathe in and at least six seconds to breathe out.
- Focus on your breathing and your lower abdomen 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 you 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 do this exercise again, but close your eyes.

Further resource

Dementia Australia, <https://www.dementia.org.au/>

The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.

My Aged Care <https://www.myagedcare.gov.au>

Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or, call My Aged Care on 1800 200 422.

RELATED LEARNING UNITS

- Module 3 Unit 3 Thinking differently





You finished this unit, well done!

Unit 4. How to respond to repetitive behaviour

Repetitive behaviour, things a person does over and over

Repetitive behaviours can include repeating a sound, a word, a question or an action (for example, tapping fingers).

Why is this learning unit important?

If a person repeats things over and over it can be stressful for the person with dementia and the carer. We refer to this as 'repetitive behaviour'.

Understanding the reasons behind specific behaviours can help carers cope.

How will this learning unit help me?

This learning unit will help you to understand why this happens and how to respond and reduce it.

What will I learn?

- Repetitive behaviour is common in people with dementia.
- What may increase repetitive behaviours and how to change this.
- Different ways to comfort a person with dementia who maybe using repetition in response to a particular issue or situation.

What is repetitive behaviour?

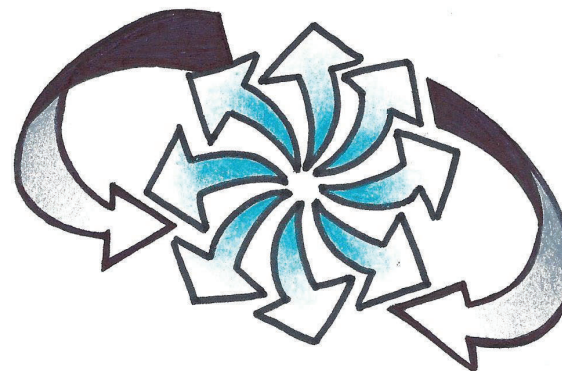
A person with dementia may forget what he or she has said, heard or has done from one moment to the next, leading to repeated questions and actions.

Usually doing things over and over is not harmful in itself to the person with dementia, if the carer knows how to deal with it.

If not, the person with dementia can become anxious, aggressive or depressed and the carer can become stressed.

As a result, carers may respond inappropriately, for example by yelling, which often makes them feel guilty.

- Does the person you care for ever do or say things over and over again?
- What does the person you care for repeat?



Say things over and over again

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.

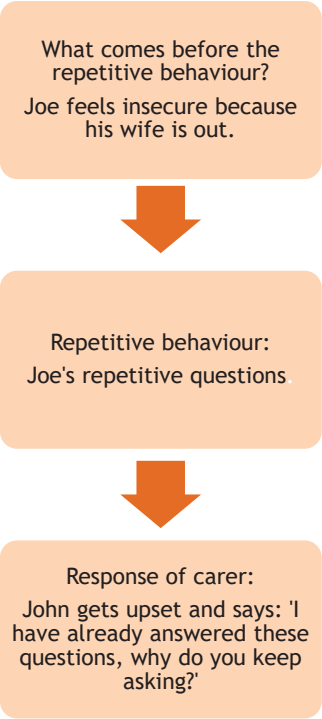
John and Joe eat lunch together. Sometime after finishing lunch, Joe asks: 'When is lunch?' and 'What are we having for lunch?' John does not think much of it at first.

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 he is doing this and gets more and more worried about his father.

John continues to answer the questions but becomes a bit frustrated and raises his voice. John responds loudly, 'I have already answered these questions, why do you keep asking?'

Take a look at the boxes at the right.



Check your understanding



What would you recommend?

What would you recommend to John?

Click on any responses you think are appropriate.

- ☐ 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 with 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 father a snack or a drink.



ANSWERS - How to respond to repetitive behaviours

Check your understanding



Let's look at your answer

- ✗ **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 he can't help.
- ✓ **Stay calm and reassure his father that his wife will be home soon.**
This is a good response because 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 with 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 and 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.**
Perhaps if it is just repetitive questioning, by remaining calm the behaviour may decrease.
- ✓ **Offer 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.

Activity



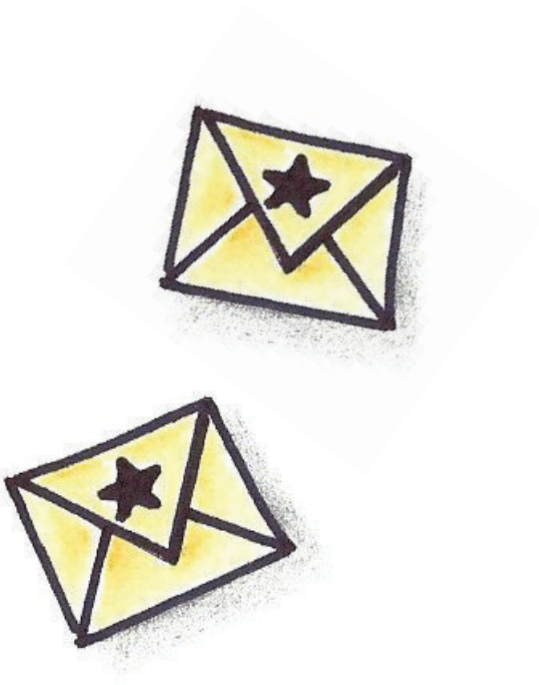
Let's look at your own situation

It is important to relate what you have learnt to your own situation.
These boxes are for you, like a diary.

Has the person with dementia been repeating things lately?

What could you do to help reduce this?

What could you do to change your response to this?



Keep in Mind



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 increase comforting the person you care for.
- Try to identify what comes before that may increase this and try to change it; try to identify how you respond and change that also.
- Realise there are good days and some bad days.
- Remind yourself that repetitive behaviour is part of the disease.
- Use memory aids (write notes, make signs, use large clocks and calendars) to help orient the person.
- Take a deep breath and think about the best ways to respond that will be least distressing for you and the person you care for in case they do or say things over and over again.

Additional resources

Dementia Australia, <https://www.dementia.org.au/>

The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.

My Aged Care <https://www.myagedcare.gov.au>

Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or, call My Aged Care on 1800 200 422.

RELATED LEARNING UNITS

- Module 2 Unit 1 The journey together
- Module 3 Unit 1 Reducing stress in everyday life
- Module 5 Unit 6 Walking and getting lost



You finished this unit, well done!

Unit 5. How to avoid conversations that may trigger changed behaviour

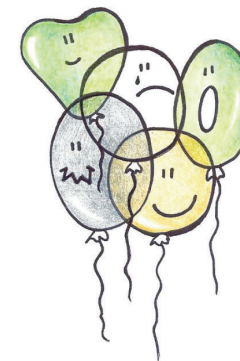
Changed behaviour of the person with dementia can be triggered by the carer through everyday conversations.

Why is this learning unit important?

If a person with dementia demonstrates changed behaviour, it can be stressful for the person and the carer. Understanding how to avoid conversations that may trigger changed behaviour can help carers cope.

How will this learning unit help me?

This learning unit will help you to understand why this happens and how to respond and reduce it.



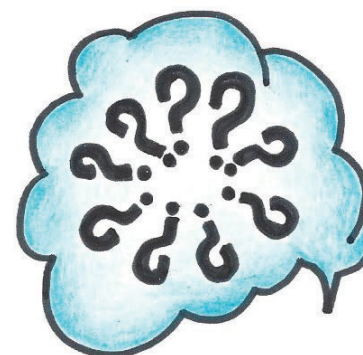
Memory loss that triggers changed behaviour

Kayla has dementia. Her husband, Howard, is taking care of her.

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 becomes very angry and yells when Howard questions her.

As a result, Howard feels frustrated and yells back at Kayla.



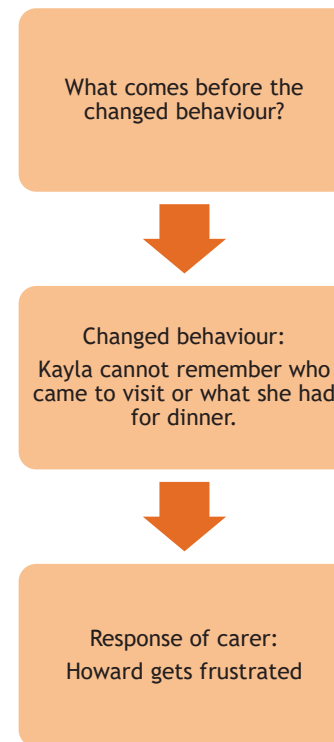
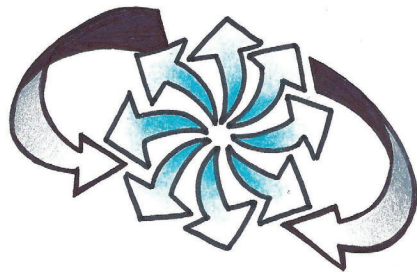
What comes before the changed behaviour?

The three boxes show what's happening:

What comes before the changed behaviour?

Why is it important to examine what comes before the changed behaviour?

Sometimes you can reduce or even prevent changed behaviour. If you pay attention and figure out what comes before the behaviour, this can help you to reduce or prevent the changed behaviour.



Let us analyse Kayla's situation:

- Howard asks questions Kayla cannot answer
- The tone Howard asks these questions makes Kayla feel nervous.

1. Activity



Now you try the next one. Please fill in your ideas on what comes before Kayla's changed behaviour.

Check your understanding



What are some of the things Howard could do differently?

Here are some responses, some are good, others are not. Please indicate what you think could be good responses. Howard could:

- ☐ Show that he is frustrated.
- ☐ Take a deep breath.
- ☐ Remind himself that his wife has dementia and cannot answer these questions he asks. She is not forgetting on purpose.
- ☐ Remember next time that asking Kayla such questions might lead to frustration for himself and also upset his wife.
- ☐ Work with Kayla to record significant family and social events in a family diary.

ANSWERS - How to avoid conversations that may trigger changed behaviour

Check your understanding



Let's look at your answer

- | | |
|--|---|
| <p>✗ Show that he is frustrated.
Showing that he is frustrated may even make the behaviour of the person with dementia worse.</p> | <p>✓ Remember next time that asking Kayla such questions might lead to frustration for himself and also upset his wife.
This is a good response, because it may prevent this frustrating situation.</p> |
| <p>✓ Take a deep breath.
It shows that Howard is trying to calm down, if he calms down Kayla might too.</p> | <p>✓ 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 together to have a sense of being loved by family members and friends.</p> |
| <p>✓ Remind himself that his wife has dementia and cannot answer these questions he asks. She is not forgetting on purpose.
Howard recognises that Kayla is living with dementia.</p> | |

Activity



Now relate to your own situation

It is important to relate what you just have learnt to your own situation with the person you care for. These boxes can be used like a diary by you to keep records that may help you in the future.

What were the most changed situations you experienced as a carer in the last month?

What could you do differently to prevent these changed situations?

Keep in Mind



Let's review what you have learned

- People with dementia have memory loss.
- It is 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 to situations that will be the least distressing for you and the person you care for.
- Try different responses and approaches, as the first one does not always work.
- Look after yourself during and after challenging situations and, if necessary, seek support from someone you trust to talk about the incident.

RELATED LEARNING UNITS

- Module 2 Unit 1 The journey together
- Module 3 Unit 1 Reducing stress in everyday life
- Module 5 Unit 6 Walking and getting lost

Additional resources

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The National Dementia Helpline 1800 100 500 is open nationally from 9.00am to 5.00pm Monday to Friday excluding public holidays. A message service is available if you call outside operating hours.

Dementia Support Australia, <https://www.dementia.com.au/>

The Dementia Behaviour Management Advisory Service (DBMAS) offers people with dementia and their carers support in managing behavioural and psychological symptoms of dementia, such as wandering and aggression. Contact them on 1800 699 799 (24 hours a day).

My Aged Care <https://www.myagedcare.gov.au>

Carer support groups can sometimes be organised around specific caring roles and the situation of the person you care for. For information about these groups in your area visit the website or call My Aged Care on 1800 200 422.



You finished this unit, well done!