

Australian version

iSupport For Dementia

Training and support manual
for carers of people with dementia



Unit 5. Creating an enjoyable day

Why is this unit important?

It is important to maintain routines and activities that are familiar to a person with dementia to help create a sense of safety, routine and an enjoyable day. Activities help to sharpen focus and can ease agitation.

How will this unit help me?

By learning how to adapt routines and activities as the abilities of the person with dementia change. A good routine, with meaningful activities will slow decline and create the best lifestyle possible.

What will I learn?

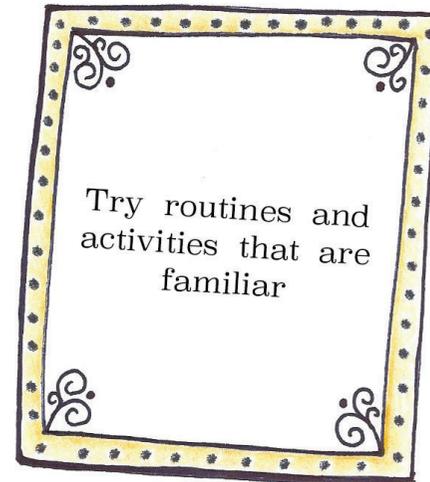
- To establish routines for the person living with dementia for morning time, during the day and bedtime.
- To keep routines similar to the ones the person living with dementia had before developing dementia.
- To adapt routines to the changing abilities of the person living with dementia.

Maintaining routines and activities is important

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

This is also true for you and the person living with dementia.

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 the person living with dementia does every day or almost every day.

It is important to try and continue the person living with dementia's routine for as long as possible. This is reassuring and can promote less stress at home. It is important to be aware of **[his, her]** usual routine. If there has not been a routine, for example for the evening, then it is helpful to develop one and to follow it regularly - such as drinking a cup of tea, listening to restful music, usual time for bed. Maintain a sense of structure and familiarity by having consistent times for activities such as waking up, mealtimes, bathing, dressing, receiving visitors and bedtime.

Doing chores and preparing for activities on your own might be easier, but try to involve the person living with dementia in daily activities as much as able. Use your best judgment as to what is safe and what they can handle.



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 teeth, getting dressed and then sitting down to breakfast. As dementia progresses, the person living with dementia will need help with each of these things, 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 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 prior interests and current abilities.

In the early stages of dementia, the person may be able to do things the person likes to do with minimal guidance. However, as the disease progresses, activities will need to be changed or modified so that the person can still do them with enjoyment and pleasure. Explain activities beforehand and consider if they will be able to do an activity to avoid frustration. If the health of the person permits, an increase in daily physical activity may be beneficial. It's important to be flexible and creative in figuring out the routines and then adapting them as needed over time.

Back to routines

Let's look at an example

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

Check your understanding



Back to routines

What suggestions do you have for Penny?

Mark all that apply.

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

Check your understanding



- ✓ **If Penny suggests keeping to the routine by taking tea first, it is likely that Martha will go for a walk afterwards.**
Right! It will help keep to Martha's routine.
- ✓ **Penny should ask Martha what activities she is used to and what order she would like to do them in.**
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 good because it may make Martha feel agitated and upset as it changes her usual routine.



Tips



Keep in mind that:

- It is important to try and keep the routines (something the person 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 maintain the person's dignity. Think for a moment how you might feel if your routines were changed or planned by another person.

Adaptations of routines during the disease process

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

Here are some common routines to establish during the day for a person with dementia. How have you adapted the person's routine at home?



IN THE MORNING

- Wake up at the same time every day

Adaptation: Help might be needed to wake up the person because the person may not be able to set the alarm correctly.

- Have breakfast at a fixed time. In the earlier stages of dementia, the person might be able to make the person own breakfast. Remember to let the person help as much as able.

Adaptation: the person may need someone to put out ingredients. Later on the person may need more help with preparing and eating breakfast.

- Doing grooming activities, such as brushing teeth, bathing/showering, and getting dressed. In the early stages, the person may be able to do all of these things with a little prompting and without help.

Adaptation: Tools, such as toothbrush, paste, etc., can be laid out in the bathroom in plain view to prompt the activity of bathing or brushing teeth. In the later stages it may be necessary for someone to do these things for or with the person.

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 with dementia change.

During the day

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

How to continue prior activities and interests?

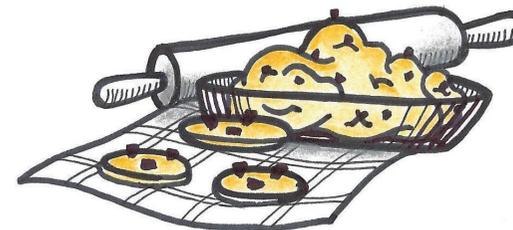
An example:

Martha loves baking and used to prepare special cakes and biscuits for family gatherings. Now that she has dementia, she sometimes forgets the ingredients and which order to put them in. At first, Martha used a cookbook to help her to continue baking, but she found this increasingly difficult. The cakes and biscuits did not taste very good and had to be thrown away. Penny wants to help her mother keep up this activity.

Check your understanding**What suggestions do you have for Penny?**

Mark all that apply.

- 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 biscuits, '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 with her mother to do baking and cooking together.



Check your understanding



- ✗ **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 biscuits, '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 with her mother to do baking and cooking together.**
This is an excellent plan for the future. It allows Martha to continue her routine with support as needed.



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 caregivers. The exact causes of sundowning are not yet clear, but a loss of routine might be one of the reasons. Try to have something meaningful to do at this time of day. Also try to discourage too much daytime napping and inactivity as this can lead to unsettled behaviour in the evening.

Let's look at another example from Penny and Martha

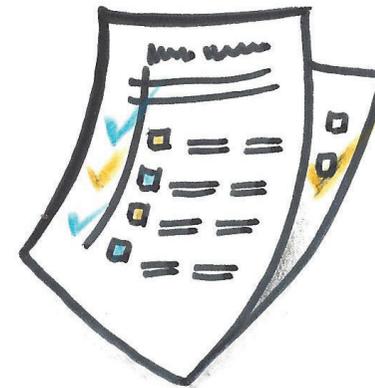
Martha likes to go to a community centre every day from 12 noon until 3 pm. There she has lunch and meets with friends to do some activities together. At first, she walks there by herself, but as her memory loss becomes more frequent, she cannot find her way to the centre anymore. Penny asks another family member to take Martha to the centre and bring her back home again. 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.

Check your understanding



What suggestions do you have for Penny?

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



Check your understanding



- ✓ **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 the routine and adapts to Martha's changing abilities.
- ✓ Penny could ask other people outside the family to walk with Martha to the senior centre such as a neighbour.
This is a concrete task you could ask for help with.
- ✗ Penny could tell her mother to do a quiet activity in the afternoons like watching TV 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 she enjoys. It might be a better solution in the later stages when Martha's abilities change, but not for now.

Keep in Mind



- It is important to respect the current daily routines of the person and continue them as long as possible.
- When this is no longer possible, adapt the routine the best you can so that the key activities important to the person 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 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.

Check your understanding



What suggestions do you have for Penny?

Mark all that apply.

- 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 books on tape (sometimes called audiobooks) for Martha.

Check your understanding



- ✓ **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 the importance of reading to Martha. Penny should recognise that she and her mother can share this routine still, it just needs to be adapted.
- ✓ **Penny should get some books that have more pictures than words or books on tape (sometimes called audiobooks) for Martha.**
This is a helpful adaptation for people in the later stages of dementia who liked to read but find they aren't able to read books with lots of words anymore.



Let's review what you have learned

- Establishing routines is important for people living with dementia. That also holds for the person.
- Try to keep routines similar to the ones the person had before developing dementia.
- Limit choice so the person with dementia does not become overwhelmed. Yes/No questions are also good, for example asking if they would you like to go for a walk will help decision making to be easier.
- Be prepared to adapt routines as necessary as the abilities of the person living with dementia change.

RELATED LEARNING UNITS

- Module 1 Unit 1 Introduction to dementia
- Module 4 Unit 1 Eating and drinking - more pleasant mealtimes
- Module 5 Unit 1 Introduction to person-centred approach

Further Information

- **Carer support groups**

Carer support groups can offer you a safe place to talk about your role as a carer. They can put you in touch with other carers who may be experiencing similar things to you so you can share advice and suggestions to support each other.

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, read about caring for someone with a particular need or call My Aged Care on 1800 200 422. **The National Dementia Helpline** can also put you in touch with support groups. The groups let you share experiences, learn from others and discuss issues and emotions in a safe environment.

- **Dementia Australia**

The Dementia Australia website produces a series of help-sheets for carers of people with dementia, including a useful safety checklist.

- **Dementia Behaviour Management Advisory Service**

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 sundowners, wandering and aggression. Visit the DBMAS website or contact them on 1800 699 799 (24 hours a day) to find out more.



You finished this unit, well done!