

How to support everyday
decision-making for people living
with dementia in residential aged care:

A guide for care workers



Dr Jo-Anne Rayner, Dr Deirdre Fetherstonhaugh and Dr Michael Bauer

Australian Centre for Evidence Based Aged Care (ACEBAC),
La Trobe University

This booklet was developed in consultation with consumers including carers and people living with dementia.

Funding Acknowledgement: This project was funded by the Dementia Collaborative Research Centre - Carers and Consumers, Queensland University of Technology as part of an Australian Government initiative.

Copyright Statement: La Trobe University, as represented by the Dementia Collaborative Research Centre - Carers and Consumers (2020).

ISBN: 978-0-646-82126-9 (Hard copy)

ISBN: 978-0-646-82129-0 (ebooklet)



DCRC
Dementia Centre for
Research Collaboration



Australian Government

National Health and Medical Research Council

Contents

| | |
|---|-----------|
| About this booklet | 1 |
| Living with dementia and making decisions | 1 |
| Why people with dementia should be supported with everyday decision-making and have choices? | 2 |
| How do you know that a person with dementia can make decisions? | 3 |
| How can you support residents with making everyday decisions and making choices? | 5 |
| Communicating with people with dementia to assist in decision-making | 6 |
| Assisting decision-making about clothing and personal appearance | 8 |
| Assisting decision-making about when and what to eat | 9 |
| Assisting decision-making about who to spend time with | 10 |
| Assisting decision-making about participation in lifestyle activities | 11 |
| Assisting decision-making with showering or bathing | 13 |
| Assisting decision-making with going to bed and getting up | 13 |
| How other facility staff can support residents with every-day decision-making? | 15 |
| Key points | 15 |
| Some Useful Resources | 16 |

About this booklet

This booklet has been written to help you understand why it is important for you to support people with dementia make everyday decisions. There are practical examples in this booklet of how to do this.

All people want to be treated in a way that is consistent with their own wishes and preferences. People want to make decisions based on information they have been given and their personal experience where possible. Being involved in decisions and making decisions is part of being a 'person'. Everyone has the right to be acknowledged and respected as a person.

Living with dementia and making decisions



For most people being able to make decisions is a part of everyday life. Decisions can be about everyday things such as deciding what to wear or what to eat. Decisions can also be about important life changing things such as where to live, or whether to agree to a medical treatment. When someone has dementia, the ability to make decisions will eventually be affected. A diagnosis of dementia can make people feel insecure and lose confidence in themselves and their ability to keep making decisions. People with dementia may feel

they are no longer in control and they may not trust their own judgment. They may also be treated differently by other people because of their diagnosis. All of this can have a negative impact on self-esteem and the person's ability to make decisions. Eventually people with dementia will lose their ability to make the important life changing decisions and someone else will have to take over. Even when this happens however, they will still be able to participate in making everyday decisions. You need to encourage and support people with dementia to do this.

Why people with dementia should be supported with everyday decision-making and have choices?

- Everyone has the right to participate in decisions about themselves.
- However, choice is often removed for people with dementia because others assume they cannot make their own decisions.
- People with dementia living in residential aged care facilities need to be given opportunities to participate in everyday decisions about their life. This is an important part of person-centred care.
- You have a legal responsibility to involve residents in making decisions and support them in doing this.



Remember

This is an important part of person-centred care.

How do you know that a person with dementia can make decisions?

- Remember that changes in the brain that happen with dementia are not the same in every person.
- You should always assume that a person can make everyday decisions.
- As the person's dementia gets worse, the decisions they are able to make, and when they are able to make them, will change. Being able to make decisions can change over the course of a day. For example, you might find that it is harder for a person with dementia to make decisions late in the day when they are feeling tired.
- Even people with advanced dementia may still be able to respond to questions about preferences (likes and dislikes).
- When residents are not able to talk, watching their behaviour and body language for signs that may show their decision or choice is important. Sometimes behaviour or body language is a sign that they are agreeing to something, or, wanting to do something. This is called *assent*. Signs of assent may be the resident being happy and cooperative, showing enjoyment through participation in an activity, or looking relaxed.
- Behaviour and body language can also be signs that a resident does not agree to, or, want to do something. This is called *dissent*. Signs of dissent can include the resident being agitated, aggressive or restless, looking angry or anxious, making noises, or being withdrawn.



Remember

Always assume that a person can make everyday decisions.

- Residents with dementia may need you to help them make decisions and they should be supported in doing this for as long as possible.
- Even if you disagree with the decision, or the decision seems unwise, this does not mean the person cannot make their own decision.
- When you support a resident with dementia to make a decision it is important to consider any risks to them or others. For example, wearing a t-shirt on a cooler day is of little risk to the resident when the facility is warm, but if they go on an outing in cool weather in a t-shirt they may get sick. This places other residents at risk of becoming sick as well.

How can you support residents with making everyday decisions and making choices?

A residential aged care facility should promote quality of life for the people who live there. Part of this is helping residents make, or participate in, decisions. Residents should always be supported to make everyday decisions about things that personally affect them such as:

- what to wear each day
- when to eat meals and what food to eat
- what activities they want to participate in
- who they want to spend time with
- when to shower or bathe
- when to go to bed.



Communicating with people with dementia to assist in decision-making

Communication can be difficult for some people with dementia. So, knowing if a person with dementia can make a decision or choice may not always be easy.

The following suggestions may help you to support residents to make decisions and choices:

- Make sure you have read and understand the resident's care plan. The care plan should document their likes and dislikes which will help you support their decision-making.
- To help residents to make a decision, make eye contact with them when talking to them. You should also reduce noise and other distractions.
- Make sure you have a resident's full attention before communicating.
- Make sure they have their glasses on so residents can see the choices that are available.
- Speak clearly using short, simple sentences, and listen carefully to what the resident has to say. As we age we can have some loss of hearing.
- Make sure your body language and facial expression match what you are saying. A person with dementia may be able to read your body language. Sudden movements, or a tense facial expression can upset or distress the resident and can make communication more difficult.



- Having someone who can speak the resident's own language helps to support their everyday decision-making.
- Make choices simple. Ask one thing at a time. Do not give them lots of things to think about at the same time. For example, do not ask them about what they want to wear for the day and when they want to eat breakfast, in the same sentence.
- Ask the resident if they understand what you have asked.
- Give the resident time to respond before asking the next question.
- Don't pressure the resident to make a choice.
- Always look for body language and behaviour as a sign of assent or dissent. Expressions such as smiling may suggest the resident is happy with the choice. If the resident becomes agitated or restless, this may show that they are not happy.



Remember

Make choices simple. Ask one thing at a time.



Assisting decision-making about clothing and personal appearance

We all have preferences about how we want to look. How we look and how we feel about ourselves are connected. Personal appearance is just as important to residents with dementia and how they feel about themselves. Let residents decide what to wear and how they want to present themselves for the day. Help them to choose their clothes and help them with their grooming. Supporting residents in this way will help them express their own identity and personal style.

- Ask the resident questions about how they would like to look each day. Give them choices. Ask them what clothes and shoes they would like to put on and how they would like their hair done. Ask if they would like to put on aftershave or perfume, makeup, jewellery, or a watch.
- Offer only a few choices at a time. A wardrobe full of clothes can make decisions difficult, as there is too much choice.
- If you know a resident's favourite clothes, put these where they can easily choose. Accept unusual clothing or personal appearance choices. It is not up to you to judge what the resident has decided to wear or how they have decided to look.
- Allow enough time for residents to make their decisions and choices. Help residents to dress in their preferred clothes and attend to their personal grooming and care.



- Always observe body language and behaviour as a sign of assent or dissent. Expressions such as smiling suggests the resident is happy with the choice. If the resident becomes agitated or restless, this may show that they are not happy.
- Document a resident's choices in the care plan and communicate their preference to other staff, BUT do not assume that they will want to make the same decisions or choices every day. A person should be able to change their mind and their preferences.



Assisting decision-making about when and what to eat

What people like to eat, how much they eat and when they eat varies greatly. Older people generally do not need as much to food as younger people, but they do need more protein. Some people have strict cultural or religious food habits which should be documented on the care plan when they move into the residential aged care facility. If the person cannot tell you this, ask their family and friends. Other people may have dietary restrictions related to a disease such as diabetes, which should also be documented on the care plan.

- Some people do not like noisy and busy dining rooms and may prefer to eat by themselves. Always offer residents the choice to eat their meals in the dining room with other residents, or in their rooms. However, remember that eating is a social activity. Research tells us that eating with others, can help prevent weight loss.
- Ask residents if they are hungry at mealtimes. If they are not hungry, offer to put a meal aside so they can eat when they are hungry.
- Know the person's individual dietary restrictions and food habits. Tell residents what is on the menu and ask them what they would like to eat and how much food they would like.

- Ask residents if they would like their meal cut up and help with this if they do.
- Never assume that residents want to sit at the dining table with the same person for every meal. Ask residents who they would like to sit with and observe how they get on with other people at the table.
- Always look for body language and behaviour as a sign of assent or dissent. If the resident is withdrawn and not eating they may need assistance with their meal or they may not like the food.



Assisting decision-making about who to spend time with

People generally like to be with other people and relationships and connections with others are important. However, not all people may get along and some may not want to be in the company of others all the time. Some people may prefer to spend most of their time on their own.

- The physical environment of residential aged care facilities should ensure that residents can be either alone in their room, or with other residents in the dining or lounge room. If you know of residents who like the company of others, ask them if they would like to spend some time together and assist them to do this if this is what they want.
- Remember social interaction between residents can happen without them having to talk to each other all the time.

- Always look for body language and behaviour as a sign of assent or dissent. Expressions of enjoyment such as smiling or talking suggests residents like spending time with each other. Withdrawal, avoidance, agitation or restlessness may show they do not.



Assisting decision-making about participation in lifestyle activities

Too often, people with dementia living in residential aged care facilities do not have enough to do and are not engaged in life in the facility. Activities should be of interest to the resident, hold their attention, and connect with their interests. Activities that the resident has decided to participate in are more likely to bring enjoyment and create opportunities for interaction with others. They will also more likely bring about physical exercise, improved sleep, and less disruptive behaviours.

- Ask residents or their family and friends, about what activities they like. Activities should be individualised to each resident where possible.
- Offer a range of activities taking account of differences in residents' age, sex, culture and their cognitive and physical abilities.
- Offer appropriate activities that will motivate, stimulate or challenge the resident, such as physical exercise, artistic pursuits, activities that will entertain, be fun, and encourage memories.



- Change activities; many people do not like to do exactly the same thing every day.
- Always look for body language and behaviour as a sign of assent or dissent. Expressions of enjoyment such as smiling or talking suggests the residents like spending time with each other. Withdrawal, avoidance, sleep, agitation or restlessness may show they do not.



Remember

Change activities, many people do not like to do exactly the same thing every day.



Assisting decision-making with showering or bathing

When, how often, and how we wash, is generally an individual choice. Not all people like to shower or bathe in the morning. Some people like to do this before they go to bed each night, some like to shower or bathe before breakfast; some after eating.

- Individual preferences about bathing should be documented in a care plan when a person moves into the residential aged care facility. Ask the resident, or their family, or friends about personal preferences.
- If the resident appears to need a shower or bath, offer them the choice of changing their routine. When assisting a resident with bathing ask them about the water temperature that they prefer. Remember older people often have less body fat and may feel extremes in temperatures more easily.
- Always ensure privacy when assisting a resident to bath or shower.



Assisting decision-making with going to bed and getting up

People's sleeping patterns differ greatly. People with dementia in particular, often have trouble sleeping. Offer residents some choice in what time they go to bed in the evening and when to get out of bed each morning.

- In the evening, if residents are asleep in chairs in front of the television, wake them gently and ask them if they would like to go to bed. If they want to stay where they are and sleep in the chair, make sure they are safe, warm and comfortable.

- If they want to go to bed assist them to their rooms and help them with toileting and to get into their pyjamas. Make sure they are warm and comfortable. Before leaving the room always ask them if they want the light left on, or, turned off.
- Always knock on the door before entering a resident's room each morning and avoid opening the curtains straight away. Look at the resident and ask them if they slept well. Ask them if they would like the curtains opened. Ask the resident if they would like to get up and wait for their response before opening curtains or taking the bed clothes back.



Remember

People's sleeping patterns differ greatly.

How other facility staff can support residents with every-day decision-making?

It is important that all staff working in residential aged care work as a team. Managers and nurses can assist care staff to support resident decision-making through good management practices, flexible work schedules, open communication, staff education and the implementation of policies and procedures that encourage and maintain resident decision-making.

Key points

- Being involved in decisions about things that affect you is a human right.
- People with dementia can be supported to make decisions about everyday things that affect them.
- Residential aged care facilities must have a commitment at all levels to support and assist residents with dementia in everyday decision-making.



Some Useful Resources

Charter of Residents Rights and Responsibilities

<https://www.agedcarequality.gov.au/consumers/consumer-rights>

The Australian Quality Care Principles

<https://www.legislation.gov.au/Series/F2014L00830>

Alzheimer's Australia

Dementia and your rights: Quality Dementia Care Standards

https://www.dementia.org.au/files/20070200_Nat_QDC_QDC2QualDemCareStandards.pdf

DCRC Dementia Centre for
Research Collaboration