







Decision Making for Dementia





























Making decisions is an important part of managing one's life with dementia.

• The progressive course of dementia implies continuous changes in the lives of people with dementia and their informal caregivers.

• It causes various problems that require decisions both medical and social, both major and minor









1. Support in decision-making is important for dementia patients because as the disease progresses, they may experience cognitive decline that can affect their ability to make decisions independently. Dementia can affect a person's memory, attention, language, and reasoning abilities, which can make it difficult for them to process information, understand their options, and weigh the pros and cons of different choices.









2. Additionally, dementia can affect a person's emotional well-being, leading to increased confusion, anxiety, and frustration. These emotions can further complicate decision-making and make it harder for the person with dementia to communicate their preferences.









3. Support in decision-making can help dementia patients navigate these challenges by providing them with information, guidance, and resources to help them make decisions that align with their values and preferences. This support can come from healthcare professionals, family members, and other caregivers who can work together to identify the person's needs, preferences, and goals and provide the necessary support to help them make decisions.









4. Some examples of decision-making support for dementia patients may include providing clear and simple explanations of options, involving the person in discussions about their care and treatment, offering visual aids or other communication tools, and respecting the person's autonomy and right to make decisions, even if they may not fully understand the implications.









So, we need to response to these needs







Studies show that people with dementia want to participate in decision-making about their situation as long as possible, although they realize it will become difficult as the illness progresses

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Clinical Investigations

Patient Participation in Medical and Social Decisions in Alzheimer's Disease

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Abstract

Objectives

To analyze the preferences of people with amnestic mild cognitive impairment (aMCI) and mild dementia in Alzheimer's disease (AD) regarding different aspects of healthcarerelated decisions, to correlate these findings with different measures of decision-making capacity, and to explore the views of relatives and referring physicians.



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Being central to decision making means I am still here!: The essence of decision making for people with dementia

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Abstract

The ability to make choices and decisions, and to have those decisions upheld, is central to self-determination. For people living with a diagnosis of dementia, however, it can be difficult to remain involved in decision making. While many studies show that people with mild or moderate dementia have the ability to participate in decision making, there

How to make decisions in someone's best interest for individuals with dementia (1)

Making decisions in the best interest of someone with dementia requires a personcentered approach that considers the individual's needs, preferences, and values.

Here are some tips for making decisions in someone's best interest

- Understand the person's wishes: It is important to understand the person's wishes and values before making any decisions on their behalf. This can be achieved by talking with the person directly (if possible), reviewing any advance directives they may have created, or consulting with family members or other caregivers who know the person well.
- Involve the person in the decision-making process: Whenever possible, involve the person with dementia in the decision-making process. Even if they cannot fully understand the situation or the choices, allowing them to participate can help them feel more in control and respected.

How to make decisions in someone's best interest for individuals with dementia (2)

- Consider the person's safety: When making decisions for someone with dementia, it is
 important to consider their safety and well-being. This may mean making decisions that limit
 their independence or restrict their activities, but ultimately, the goal is to keep them safe
 and secure.
- Respect the person's autonomy: People with dementia have the right to make decisions about their own care, as long as they are capable of doing so. It is important to respect their autonomy and involve them in decision-making to the extent possible.
- Consult with family members or other caregivers: Family members and other caregivers can
 provide valuable insights into the person's preferences and needs, as well as offer emotional
 support during the decision-making process.
- Review decisions regularly: As the person's condition changes, it may be necessary to revisit
 decisions and make adjustments as needed. Regularly reviewing decisions can ensure that
 the person's needs and preferences are being met over time.

As dementia progresses, individuals may experience difficulty in making everyday decisions.

Here are some ways to support someone with dementia in making decisions:

- 1. Involve the person in the decision-making process: It is important to involve the person in the decision-making process as much as possible. This can be done by asking open-ended questions, giving choices, and allowing the person to express their preferences.
- 2. Simplify the decision-making process: Complex decisions can be overwhelming for someone with dementia. It is important to simplify the decision-making process by breaking down the decision into smaller, more manageable steps.
- 3. Provide visual aids: Visual aids, such as pictures or diagrams, can be helpful in aiding decision-making for someone with dementia.
- 4. Minimize distractions: Distractions, such as loud noises or interruptions, can make it difficult for someone with dementia to concentrate on the decision at hand. It is important to minimize distractions during the decision-making process.
- 5. Respect the person's autonomy: Even if the person with dementia is having difficulty making decisions, it is important to respect their autonomy and involve them in the decision-making process as much as possible.





How to support someone with dementia in making complex decisions?





How to support someone with dementia in making complex decisions?

Supporting someone with dementia in making complex decisions can be challenging,

but there are strategies that can help.

Here are some suggestions:

- 1. Allow plenty of time: When discussing complex decisions, it's important to allow the person with dementia plenty of time to process the information and make a decision. Avoid rushing them, as this can cause stress and anxiety.
- 2. Simplify the information: Try to simplify the information as much as possible, using clear and concise language. Use visual aids or diagrams if necessary to help the person understand the options.
- 3. Encourage involvement: Encourage the person to be involved in the decision-making process as much as possible. Ask them for their opinions and preferences, and try to incorporate these into the final decision.
- 4. Consider their values and beliefs: When making complex decisions, it's important to take into account the person's values and beliefs. For example, if the decision involves medical treatment, consider their beliefs about healthcare and the role of doctors.
- 5. Seek professional advice: In some cases, it may be helpful to seek the advice of a professional, such as a social worker or a geriatric care manager. They can provide guidance on complex decisions and help navigate any legal or financial issues that may arise.



Remember, supporting someone with dementia in making complex decisions requires patience, empathy, and a willingness to listen. With the right support and guidance, it is possible to make decisions that are in the best interests of the person with dementia.

Supporting the Decisions of Caregivers of Family Members with Dementia is research that proposes a decision support system (DSS) to help family caregivers of individuals with dementia make complex decisions related to caregiving.

The DSS uses a mathematical model to simulate the dynamic decision process and provides recommendations to the caregiver based on their values, preferences, and available resources.

Explains that caregivers face numerous complex decisions related to the care of individuals with dementia, such as managing symptoms, determining appropriate levels of care, and addressing end-of-life issues.

The decisions are complicated by the progressive nature of dementia and the varying needs of the individual with dementia.

- The DSS is designed to provide support to caregivers throughout the caregiving process.
- The DSS takes into account various factors, such as the caregiver's emotional state, the individual's cognitive and functional abilities, and the available care options. It also provides information on the potential outcomes of different decisions and the associated risks and benefits.

 The DSS has the potential to support caregivers in making complex decisions related to the care of individuals with dementia. The system can provide personalized recommendations and help caregivers navigate the dynamic decision process, improving the quality of care for individuals with dementia and reducing caregiver burden.



Living arrangement

- · Decision aids
- · MacCAT-T
- · API



Financial

- · ACED
- · DMI
- · FCI



Feeding

- · Decision aids
- · LSPQ



Treatment

- MacCAT-T
- · CCTI
- HCAI
- · API



Exercise/ADL

- . Decision aids
- · DMI
- + ACED





Medical Treatment Decisions



End of life care

- Decision aids
- · CCTI
- · PFC



Care plan

- · Decision aids
- · LSPQ
- · Interviews



Driving

- · Decision aids
- + MacCAT-T
- · API



Research participation

· MacCAT-CR

Decisions

Carers have to focus on overarching key areas of decision-making towards their relative with dementia:

- 1) ensuring everyday wellbeing of the person with dementia
- 2) managing eating and drinking difficulties
- 3) managing changes in care, including transitions in place of care
- 4) managing healthcare and treatment
- 5) managing financial and household affairs.
- 6)a diagnosis, using dementia-related health and social services,
- 7) supervision and assistance in daily living,
- 8) Admission to a nursing home, legal and financial matters

Focusing to Carers Making-decision

The aim of involving relatives is to reach decisions that people with dementia can identify with, regardless of who eventually makes the decisions.

Decision-making is thus defined as a complex process in the context of dementia care networks that involves people with dementia and their informal and professional caregivers

Decision-Making Models

The Classical Approach

- Have complete or "perfect" information about the situation.
- Distinguish perfectly between the problem and its symptoms.
- Identify all criteria and accurately weigh all the criteria according to preferences.
- Know all alternatives and can assess each one against each criterion.
- Accurately calculate and choose the alternative with the highest perceived value.
- Make an "optimal" choice without being confused by "irrational" thought processes.

The Administrative Approach

Bounded Rationality (Herbert Simon)

• The boundaries on rational decision-making imposed by one's values, abilities, and limited capacity for processing information.

Satisfice

• To stop the decision-making process when satisfactory alternatives are found, rather than to review solutions until an optimal alternative is discovered.

Checklist 3.1 The Decision Making Process

- Define the problem.
- Clarify your objectives.
- Identify alternatives.
- Analyze the consequences.
- Make a choice.



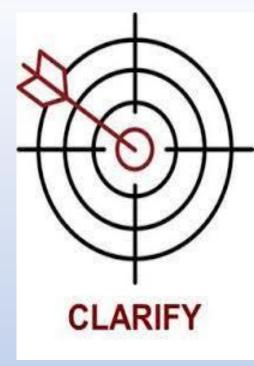
Step 1. Define the Problem

- 1. Start by writing down your initial assessment of the problem.
- 2. Dissect the problem.

- What triggered this problem (as I've assessed it)?
- Why am I even thinking about solving this problem?
- What is the connection between the trigger and the problem?

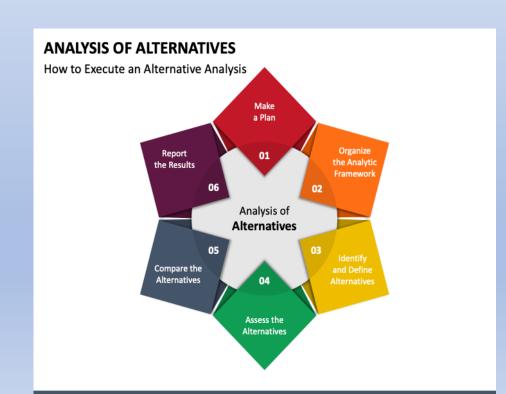
Step 2. Clarify Your Objectives

- 1. Write down all the concerns you hope to address through your decision.
- 2. Convert your concerns into specific, concrete objectives.
- 3. Separate ends from means to establish your fundamental objectives.
- 4. Clarify what you mean by each objective.
- 5. Test your objectives to see if they capture your real target.



Step 3. Identify Alternatives

- 1. Generate as many alternatives as you can yourself.
- 2. Expand your search, by checking with other family carers, also, including experts.
- 3. Look at each of your objectives and ask, "how?"
- 4. Know when to stop.



Step 4. Analyze the Consequences

1. Mentally put yourself into the future.

Process Analysis

- Solving problems by thinking through the process involved from beginning to end, imagining, at each step, what actually would happen.
- Eliminate any clearly inferior alternatives.
- 2. Organize your remaining alternatives into a table (matrix) that provides a concise, bird's eye view of the consequences of pursuing each alternative.

Step 5. Make a Choice

Analyses are useless unless the right choice is made.

- Under perfect conditions, simply review the consequences of each alternative, and choose the alternative that maximizes benefits.
- In practice, making a decision even a relatively simple one like choosing a computer
 usually can't be done so accurately or rationally.

How To Make Better Decisions

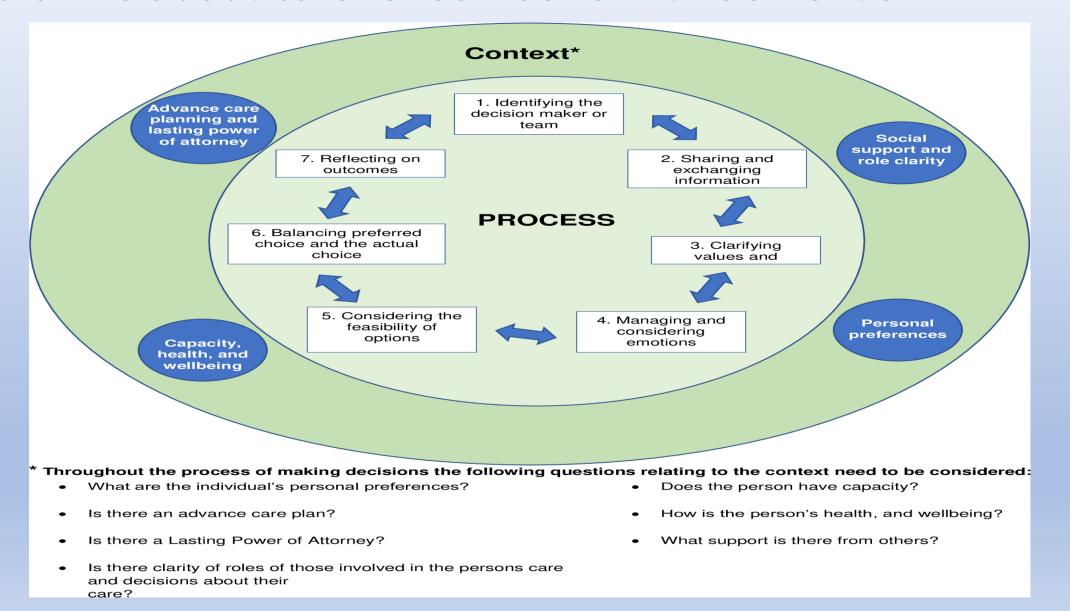
- 1. Increase Your Knowledge
- 2. Ask questions.
- 3. Get experience.
- 4. Use consultants.
- 5. Do your research.
- 6. Force yourself to recognize the facts when you see them (maintain your objectivity).
- 7. Use Your Intuition
- 8. A cognitive process whereby a person instinctively makes a decision based on his or her accumulated
- 9. knowledge and experience.

However....

There are four contextual factors that influenced the process of making decisions by carers:

- 1) personal preferences
- 2) advance care planning and Lasting Power of Attorney
- 3) capacity, health and wellbeing of the person with dementia
- 4) support from others and clarity of roles.

Developing an applied model for making decisions towards the end of life about care for someone with dementia



BRADFORD DEMENTIA GROUP GOOD PRACTICE GUIDES

Ethical Issues in Dementia Care

Making Difficult Decisions

Julian C. Hughes and Clive Baldwin



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Original Articles

Awareness in dementia: Ethical and legal issues in relation to people with dementia

Bob Woods Professor ≥ & Rebekah Pratt

Pages 423-429 | Received 03 Feb 2004, Accepted 10 Sep 2004, Published online: 19 Oct 2010

Full Article

Figures & data

References

66 Citations

Metrics

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Abstract

Our improved understanding of the experience of people with dementia provides a new impetus to address legal and ethical issues. This paper explores emerging issues in relation to awareness in dementia and its impact on legal and ethical matters. The different approaches and principles demonstrated in relation to ethical issues are discussed, with an exploration of the concepts of



Dotor L Whitehouse

Sum up!

- Making these decisions can be challenging for caregivers, as they may feel overwhelmed, stressed, or uncertain about what the best course of action is. Some factors that can impact caregiver decision-making include their level of social support, their own health status, and their beliefs and values.
- To support dementia caregivers in making decisions, healthcare professionals can provide education, counseling, and resources to help them understand their options and make informed decisions. They can also help caregivers build a support network, access respite care, and connect with other caregivers who have similar experiences.

