

Decision-Making: Respecting Individual Choice

BACKGROUND

Making decisions and controlling one's own life are important for each of us. It is no different for the person with Alzheimer's disease or other dementias. However, the extent to which a person with the disease can make simple or complex decisions varies greatly and will depend on the person's personality and the extent to which the disease has progressed.



THE ISSUES

For people with Alzheimer's disease or other forms of dementia:

Opportunities to make decisions: A diagnosis of dementia, in itself, does not mean that a person is immediately incapable of making decisions. However, as the disease progresses, a person's decision-making abilities will change. With this change in abilities, caregivers may choose to make all decisions and not present people with dementia opportunities to make decisions of their own. This may occur not just with simple day-to-day decisions but also decisions relating to a person's future care and support.

Respect for the person's wishes: Sometimes those making decisions on behalf of the person with the disease do not use the person's wishes as a guide and put their own interests first.

For family members and caregivers, substitute decision-makers and health-care professionals:

Assessment of abilities: Those who provide assistance and support may be unable to determine the extent of a person's decision-making capabilities and may prematurely begin making decisions on that person's behalf. Alternatively, family members may find it difficult to confront the person about the loss of decision-making abilities. They may choose not to take action even though they know that the person is making poor decisions.

Decision-making strategies: People who provide care may not be aware of strategies that help make it easier for people with dementia to make many of their own decisions. Or perhaps caregivers find the strategies time-consuming. Also, they may not realize how important decision-making can be to maintaining a person's confidence and self-esteem.

Challenges of substitute decision-making: As a person loses decision-making capabilities, decision-making will involve others, such as family members, substitute decision-makers and health-care professionals. It can be difficult and highly stressful for them to make decisions on another person's behalf. This is particularly so when the values and wishes of the person are unknown, unclear or impossible to follow. Also, the wishes of the person may conflict with those of the substitute decision-maker, family or society. For example, a person could express a wish to live at home, but unsafe smoking could put that person and neighbours at risk of fire. Also, if several caregivers are involved in decision-making, they may not be able to agree on what the person's wishes are.

PREFERRED CHOICES

Recognize abilities

Recognize that the person still has abilities. These abilities should be respected and encouraged. Caregivers and family members should support the person in making decisions independently, and involve the person in decision-making while capable. As well, it is important to draw up a plan for the time when the person will not be able to make independent decisions.

Plan for the future

While able, the person with the disease and the substitute decision-maker should ideally take the opportunity to discuss openly and frankly issues relating to future health care, personal care and financial decisions. Wherever possible, legal paperwork should be completed to ensure that the wishes of the person are recorded and a substitute decision-maker is named. Laws about advance directives and substitute decision-making vary from province to province.

Adjust to changing abilities

As the disease progresses, those involved in care should identify what abilities the person still has, break down complex tasks and decisions into more easily-managed options, and respect the person's choices.

Respect the person's values and wishes

When the time comes that a person is no longer able to make decisions, the substitute decision-maker should follow the expressed wishes of that person. When these wishes are not known, the substitute decision-maker should make the decision based on what is thought the person would want. As well, depending on the type of decision, the substitute decision-maker may have to weigh the risks and benefits of the decision, and assess how it will affect the person's quality of life and well-being.

STRATEGIES TO FACILITATE DECISION-MAKING

Personal involvement

Feelings of independence and self-esteem are encouraged when people are able to control or have a say in the day-to-day details of their lives. As the abilities of the person with dementia change, those who provide care and support need to ensure that the person continues to be involved in making as many decisions as possible. Strategies to achieve this include:

- Reducing the number of options at any one time. For example, ask, "Would you like to have your bath now or later?" rather than, "When do you want a bath?"
- Providing step-by-step guidance. "Would you like to go for a walk now?" "Would you like to wear your blue or red sweater?" "Shall we go to the garden or park?"

- Listening and being sensitive to messages that a person with dementia can convey by facial expression, tone of voice and body language. Feelings and emotions remain intact long after words have lost their meaning. The person can communicate meaning to anyone who learns to read the emotional signals conveyed.

Open discussion

Most people are not comfortable about making plans for a time when they will be unable to make decisions and have control of their own lives. Discussing personal values in relation to illness and death, finances and living arrangements, for example, is difficult. But silence on these issues can result in people being denied the opportunity to express and realize their wishes about their own care.

While able to make decisions, people should be encouraged to discuss their choices and who their substitute decision-maker will be with their family members. Family members and substitute decisions-makers should be aware of what the person values and how the person defines quality of life. Discussion of these matters helps give the person a sense of control over future decisions, and provides support and reassurance to future substitute decision-makers.



Substitute decision-making

Substitute decision-makers should be selected. It could be one person. Or, it could be someone for health-care decisions and someone else for financial decisions. In choosing substitute decision-makers, consider their availability to take on the role, understanding and respect for the values and wishes of the person with the disease, ability to work with others, and ability to resolve conflicts. Once the substitute decision-maker is chosen, the person with the disease and the substitute decision-maker may want to talk about how disputes might be resolved if they arise. Laws about substitute decision-making vary from province to province. Contact your local Alzheimer Society for more information.

Advance directive

The person's values and wishes can be written down in an advance directive. This is a document that records a person's wishes about the preferred type of future care. Should the person become incapable of making decisions in the future, the advance directive will provide direction. Other terms used for an advance directive in Canada include living will, or enduring or durable power of attorney for health care. Laws about advance directives vary from province to province. Contact your local Alzheimer Society for more information.

Competency assessment

For some major decisions, it may be necessary to have experts assess the person's ability to make that particular decision. Regulations governing competency assessment vary from province to province. Contact your local Alzheimer Society for information about the relevant regulations in your province.

When decision making becomes difficult

If the time comes that a substitute decision-maker is called upon to make a decision on behalf of the person, the expressed wishes of the person must be followed whenever possible. If conflict develops, or, if the person's wishes are not known, are unclear or

are impossible to follow, there should be a review of the decision based on:

- the values of the person with dementia;
- the weighing of risks and benefits of the decision to the person, caregivers, family members and others who may be affected;
- the effect on the physical and emotional well-being of the person;
- the effect on the quality of life of the person, caregivers and family members.

If there is disagreement between the needs and wishes of the individual and those expressed by family members, caregivers and/or health-care professionals, an impartial, trusted third party should be consulted to assist in resolving the issue. With some decisions, a resolution may take some time.

SOME TOPICS FOR DISCUSSION

Future health care

What kind of treatment would the person want for other major health problems, such as heart disease or cancer? Would elective surgery, such as cataract removal, be considered? Decisions should take into account the effect the treatment would have on the person's physical and cognitive health.

End-of-life care

The chart outlines different approaches to treatment that need to be understood when making decisions for care in the later stage of the disease. Knowing in advance the person's wishes for these difficult situations can ease the burden of making decisions. However, health-care professionals may never offer some choices if they would be ineffective or may cause more harm than good.

Finances

Person responsible: Has someone been named to look after the person's financial interests? This may or may not be the same person responsible for decisions relating to health and personal care.

Financial documents: Are financial and legal documents, such as wills, insurance policies and bank accounts, gathered together in a safe location?

Financial priorities: Have financial priorities been set? For example, a person with dementia might indicate that the top priority for financial resources be the promotion of the person's comfort and well-being.

Personal care

Language: What language should be used in communicating with the person with the disease?

Food: Is there a specific type of diet the person wishes to follow? Examples: vegetarian, kosher.

Hygiene: Is keeping well-groomed important? Are there specific routines that the person wishes to be followed? Examples: hair dyeing, beard trimming.

Clothing: Are there specific garments the person wishes to dress in? Examples: a favourite sweater, prayer shawl, turban.

Daily routines: Are there daily habits to be followed? Is the person a morning person or a night person? Examples: having tea before breakfast, watching the news every evening.

Health routines: Are there any practices related to health that the person wishes to be continued? Examples: taking daily vitamins, special dental care.

Activities: Does the person want to continue to pursue certain activities? Examples: daily walks, golf, quilting, music.

Fears: Is there anything the person is especially afraid of? Examples: dogs, storms, loud noises, spiders.

Provision of care: When extra help is needed, are finances available to provide this? When living at home is not possible, what type of care facility would the person prefer? Examples: small, large, culturally-specific.

APPROACH TO TREATMENT	WHAT IT MEANS
Aggressive Medical Care	<p>Goal: To prolong life using all available types of treatment.</p> <p>This could happen in either the hospital or at home. For example, using tube feeding when swallowing is no longer possible, or keeping a person on a respirator when no longer able to breathe properly.</p>
Conservative Medical Care	<p>Goal: To maintain or improve current health status.</p> <p>Care that is considered routine or usual practice. For example, using blood pressure medication to treat high blood pressure, giving insulin for diabetes or antibiotics for an infection, or setting a fractured hip.</p>
Comfort or Palliative Care	<p>Goal: To provide active and compassionate care when cure is not the goal.</p> <p>The priority is symptom and pain control, as well as meeting the physical, emotional, spiritual, social and cultural needs of the person and the family.</p>

IN CLOSING...

Recognizing the abilities of the person with dementia is the key to supporting decision-making that respects the person and offers opportunities to promote independence and self-esteem. When the person can no longer make decisions, the individual's values and wishes need to be respected. These needs and wishes may have to be balanced with the needs and wishes of families, substitute decision-makers and health-care professionals. Keeping the balance is not always easy. Considerations such as family relationships, the number and availability of caregivers, legal, cultural, religious and financial factors may influence the decision-making process.

RESOURCES:

Contact your local Alzheimer Society for province-specific information on:

- Substitute decision-making for health care and finances
- Advance directives
- Competency assessment

The Moral Challenge of Alzheimer Disease. Ethical Issues from Diagnosis to Dying (2nd ed.). Stephen Post, The Johns Hopkins University Press, 2000.

For ordering: www.press.jhu.edu.

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