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Fact Sheet: Dementia and Caregiving

Helping Families Make Everyday Care Choices



The best everyday care choices for the person diagnosed with a dementing illness, and for loved ones giving care, depend on an understanding of values and care preferences. Examples of everyday care choices include when to stop driving, how to manage money, whether to purchase or use support services, when to accept care from family members and, at a more personal level, when to bathe and what activities to do.

Some families need professional help to identify and communicate their personal values about daily care. Health and social service practitioners can be of great help, both to the person with dementia (i.e., care receiver) and the family caregiver, by working with them together.

Multiple Decision Makers and Interests

A diagnosis of a dementing illness brings in its wake a complex decision-making process. Few individuals make decisions entirely on their own. Usually family members are part of the picture and their interests are at stake, too. Under the stress of providing care, family caregivers may not see that discussing the care receiver's wishes is a priority. Effective advance planning can lessen emotional and financial strain over time. That planning relies on communication and understanding of the cognitive-ly impaired person's values and preferences for care.

Some practitioners believe that persons with cognitive impairment cannot make informed decisions and lack the ability to make valid statements of wishes, values and preferences. Research shows the contrary:

- A person with mild to moderate dementia can express life-long values and wishes for care now and in the future. Most can participate in care decisions. They can state preferences consistently and explicitly delegate responsibility for making everyday decisions. They can identify whom they want to make decisions for them about health care, finances, personal care, social activities, living arrangements and the possibility of living in a nursing home.
- A cognitively impaired individual may have "task specific competence," i.e., be able to make some decisions and not others. Also, ability to express decisions may be better at one time of day than another and vary day to day.
- Most spouses, and adult children and their parents, respond positively to a conversation that focuses on values and preferences for care and involves planning for the future.

Research also shows that caregivers gain more satisfaction if everyday care matches the care receiver's values and preferences. Both the one who is ill and the one who provides care seek what is in the other's best interests. Family caregivers -especially adult children- sometimes do not know as much as they would like about the care receiver's wishes for daily and nursing home care. This uncertainty adds strain to an already stressful situation.

The practitioner's challenge is to hear and respect both voices: take into account the views and preferences of the person with cognitive impairment and the needs and situation of the family caregiver. By listening to both the care receiver and caregiver, the practitioner usually can reduce dissonance, provide helpful strategies and skills, and increase family members' feelings of confidence and ability to cope.

Practice Guidelines

Structured discussions between the family caregiver and care receiver, facilitated by a trained clinician with experience in conducting family meetings, may bridge the communication gap, lead to a better understanding of the care receiver's preferences and help resolve conflicts between the two. To assist families in making the best choices for everyday care:

1. Focus expressly on values and care preferences as part of the assessment process to facilitate mutual understanding of what care receivers and caregivers need and prefer.
2. Start talking as soon as possible about preferences for everyday care and for handling daily activities, such as finances and living arrangements-before problems arise, a crisis occurs or the person with cognitive impairment becomes unable to express wishes.
3. Support the active participation of the person with cognitive impairment in developing the care plan. Whenever possible, involve family members in the assessment process and in developing the care plan.
4. Recognize the strengths of the person with cognitive impairment and encourage him or her to express his or her own values and preferences, rather than rely solely on information from the proxy or surrogate, who typically is the family caregiver.
5. Keep in mind that persons with memory loss and other cognitive impairments can often make decisions about their care or state specific preferences for everyday activities even though they are unable to answer seemingly simple questions about themselves (e.g., number of children, birthdate).
6. Recognize the family caregiver's need for information, emotional support and practical help. Time constraints, sadness over loss and the stress of new and difficult tasks can be a great burden to the family member involved in care. The caregiver must provide hands-on care and supervision, try to determine what the care receiver wants and then balance these new roles and situations with other work and family responsibilities.
7. Enter into the discussion among family members with an open mind. Take into account the wishes and preferences of the person with cognitive impairment and the needs and situation of the family caregiver.
8. Encourage all family members to recognize one another's rights to make their own life choices even if there may be disagreement about these choices. If health or safety is at immediate risk, assist the family to reach agreement.

Questions that may help family members talk about values and preferences include:

- How much is your family willing to spend for paid care?
- Who in the family will take charge of caregiving and/or make the arrangements for care?
- What sacrifice of money or time is too much?
- What kind of help do you need right now? What do you think you might want in the future?

- Can you get used to having a stranger in your home to help you? Can you adjust to someone who speaks a different language?
- Do you want some care to be provided outside of the home? What kind? How often? How long?

To encourage expressing daily care wishes of a more personal nature, consider asking:

- When do you like to bathe? Is a shower all right?
- Would you rather have someone you know help with bathing or someone you don't know?
- Do you mind if someone of the opposite sex helps you with baths?
- What do you like to wear at home? When you go out?
- Do you like to exercise? How often?
- Do you like to go outdoors? Do you prefer being inside, near a window?
- Would you rather be alone most of the time or have company? Do you like conversation? Radio or television? News or music?

Although initial resistance is not unusual, assessment of values and care preferences and discussions about decision making are rewarding as well as challenging to undertake. Communication of values about everyday care enhances the family's decision-making skills, promotes maximum autonomy of the person with cognitive impairment, improves caregiver well being and betters the whole family's quality of life.

Credits

Early-Stage Alzheimer's Disease: Fact Sheet, Family Caregiver Alliance, Revised 1999.

Making Hard Choices, Respecting Both Voices: Final Report, Feinberg, L.F., Whilatch, C.J. and Tucke, S. (2000). Family Caregiver Alliance, San Francisco, CA.

Recommended Reading

Early-Stage Alzheimer's Disease: Fact Sheet, Family Caregiver Alliance, Revised 1999.

Show Me the Way to Go Home, Larry Rose, 1996, Elder Books, P.O. Box 490, Forest Knolls, CA 94933, (800) 709-COPE.

Alzheimer's Early Stages: First Steps in Caring and Treatment, Kuhn, Daniel (1999). Hunter House Inc., P.O. Box 2914, Alameda, CA 94501, (800) 266-5592.

Fairhill Guidelines on Ethics of the Care of People With Alzheimer's Disease: A Clinical Summary, Post, S.G. and Whitehouse, P.J. (1995). Journal of the American Geriatrics Society, 43, 1423-1429.

Resources

Alzheimer's Association

919 North Michigan Ave., Ste. 1000

Chicago, IL 60611-1676

(312) 335-8700

(800) 272-3900

www.alz.org

National Stroke Association

96 Inverness Dr. East, Suite 1

Englewood, CO 80112

(800) 787-6537

Email: info@stroke.org

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