

Fact Sheet - Making Choices About Everyday Care (for Families)



Family Caregiver Alliance

The diagnosis of a dementing illness marks a new stage in your life and your family's life. Challenging decisions and important choices arise, along with uncertainty and often confusion, anxiety or fear. Some decisions might need to be made right away. Others lie ahead. The best future for you and your family depends on understanding what is most important to each of you. Recognizing and communicating your personal values about everyday care enables you and your family to make the right choices, one by one, as the situation changes.

Choices in Care

Today, in many communities, resources exist to assist you and your family now and in the future. For example, support groups, counseling services and volunteer programs can help with the emotional impact of the disease or disorder and enable you to stay involved and active. Assistance with daily living can be provided through structured day programs, in-home support, short-term respite and other community programs. Legal and financial advice can guide you and your family in planning for the future. Experienced professionals can assist by providing information and arranging for services you may want.

Recognizing Your Values and Preferences

When it comes to everyday care, what are your wishes? The first step in exploring your options is to be sure that you know what is most important to you. Those who are close to you also need to understand what you want. Projecting into the future is difficult, but it is important to educate yourself about choices and communicate how you feel about these.

Some of these questions may help you and your family think and talk about values and preferences:

- How much are we 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 we need right now? What do we think we might want in the future?
- Can we get used to having a stranger in our home to help us? Can we adjust to someone who speaks a different language?
- Do we want some out-of-home care provided? What kind? How often? How long?

Small and very personal choices also can make a big difference. For example:

- How often do you want a bath? Is a shower all right? In the morning or at night?
- 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? Or do you prefer being inside, near a window?
- Would you rather be alone most of the time or have company?

Communicating Your Wishes

Both the one who is ill and the one who provides care try to make decisions that are in the best interests of the other person. Family members who provide care find it more satisfying if everyday care matches the values and preferences of the one receiving care. Sadly, family caregivers – especially adult sons or daughters – sometimes do not know as much as they would like about their parents' wishes for daily and nursing home care. That uncertainty adds stress.

Recent research confirms that ongoing, meaningful communication about daily care choices and preferences is quite possible. Dementing illnesses need not keep a person from expressing life-long values and wishes for care now and in the future. Even if serious memory problems affect work and home life, or lead to changes in behavior and mood, one still can participate in care decisions.

Until there is a need, few of us consider how we feel about care issues or life choices such as stopping driving or no longer cooking. Starting a discussion about this subject may be hard, but most people respond positively to a conversation that involves planning for the future.

Here are some tips that may help your family communicate about these issues:

1. Start talking about preferences for everyday care and handling daily activities, such as finances and living arrangements, before problems arise or a crisis occurs. The sooner you discuss such questions, the better prepared you will be to make difficult decisions later on.
2. Choose a time when you all are relaxed. Try to focus on understanding what each of you needs and prefers, recognizing strengths but not making assumptions.
3. Don't be surprised or discouraged if you get resistance the first time you bring up this topic. That is normal. Try again at another time.
4. Don't assume that the illness prevents making many personal decisions. A person with dementia may be able to make some decisions and not others. Also, it may be easier to express decisions at one time of day than another. Keep trying at different times.
5. Recognize your loved ones' rights to make their own life choices even if you do not agree with them. If health or safety is at immediate risk, or you need help in talking about these issues in a family meeting, do get a skilled professional to assist you in reaching agreement.

Knowing your individual styles of communication can help. A diagnosis of dementia may upset and overwhelm members of a family. Some cope by taking immediate action. Others withdraw to absorb the unexpected situation. Both responses may block good communication. A trained counselor or facilitator can be helpful in improving family communication about care preferences and decisions.

Finally, by all means express your preferences when your family explores care possibilities. For example, it may be more important for you to consider who provides a service rather than the cost of the service. For your family, it may be more important to consider what is included in the service and what it will require of them or of you. In either case, make your wishes and preferences known! In the long run, a clear understanding of what is most important to you will help you and your family now and in the future.

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.

Resources

Family Caregiver Alliance

180 Montgomery St., Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
Web Site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating brain disorders that strike adults.

Alzheimer's Association

225 N. Michigan Ave., Ste. 1700
Chicago, IL 60601-7633
Phone: (800) 272-3900
www.alz.org

National Stroke Association

96 Inverness Dr. East, Suite 1
Englewood, CO 80112
(800) 787-6537
info@stroke.org

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