

Making Choices for Everyday Care

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:

- 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.
- 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.
- 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.
- Don't assume that the illness prevents your relative from making many personal decisions. A person with memory problems 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.
- 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.

Acknowledge Values and Preferences

When it comes to everyday care, what are your wishes as a caregiver? 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.

Before starting a family discussion, knowing individual styles of communication can help. A diagnosis of a chronic condition or dementia can upset and overwhelm members of a family. Some cope by taking immediate action. Others withdraw to absorb the unexpected situation. Both re-

sponses may block good communication. A trained counselor or facilitator can be helpful in improving family communication about care preferences and decisions.

Some of the following 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 the 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?

Your loved one may have strong preferences regarding their care. Some of these personal choices may surprise you. Keep in mind that the current generation of older adults may not be comfortable receiving help with everyday tasks such as cooking, cleaning, or laundry, viewing this as a failure on their part to lead independent lives. Including your relative in discussions of their care will show that you recognize their need for independence and will allow them to retain a sense of control over their care.

Just because a family member needs help with their care, does not mean that they cannot make basic decisions about their daily life. For example you may want to ask:

- 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?

Steps for Making Decisions

So many issues are involved in deciding on the care of your relative, and it may seem that

there are so many decisions to be made. By breaking big decisions into these separate steps, you turn a potentially overwhelming problem into manageable pieces of problem-solving:

- Find the biggest problem within the problem.

For example:

A problem that affects someone's health or safety.

The problem which, when solved, will produce the greatest positive changes overall

- Figure out what goal you need to accomplish.

What specific goal do you want your decision to achieve?

Which specific results will tell you how well the solution working?

- Get information.

Four basic kinds of information about your loved one are essential to consider:

1. physical functioning - health and ability to perform everyday activities
2. psychological functioning – mental health and memory problems
3. financial information
4. social information

Care decisions also depend on information from other sources as well. It is important not to overlook the help from professionals in the community, such as geriatric care managers and elder law attorneys. Care managers are familiar about resources in the community, such as senior centers, adult day health and social programs, home care agencies, residential facilities, and local, state, and federal assistance for the care of your loved one. If your relative is not able to live independently, it is wise to consider the need for a durable power of attorney, so that you can act and make decisions on their behalf. Elder law attorneys can assist with this and protecting your loved one's finances.

- Examine alternatives.

Have your family brainstorm without limiting the alternatives. When all ideas are on the table, weigh them against each other. What's the possible good from each one? The possible harm? How acceptable does it sound to the people it will most likely affect?

The most successful alternative will probably be the one that:

1. Has the fewest undesirable consequences.
 2. Appeals most strongly to the person most involved (usually the caregiver or receiver).
 3. Has the most family members' support.
- Make an action plan.

Make a list of which steps to take, in which order, and who should take them. Figure out which specific criteria will tell you whether or not the plan is working, and how much time you should allow to find out.

- Give your decision time to work.
How long should that trial period last?
 - Long enough for the people involved in the new plan to at least start adjusting to it.
 - Long enough for potential or unexpected problems to surface, but
 - Short enough to correct mistakes early.

- Evaluate how well it's working.
Has the plan actually changed things?
Who's better off than before, and how? And who's worse off, and how?
Has progress been made towards achieving the stated goals? Is there enough progress?
Have unexpected obstacles arisen? Unexpected benefits?
Should we give the plan more time? Or start working to change or replace it?

Write all these steps down, and use your written list as a checklist. Go through the entire

process step by step, without skipping. And remember that it is simply not possible to do it all in one sitting; some steps will take time—particularly information-gathering and giving your solution time to work.

Communicating Your Wishes

Both the one who is ill and the one who provides care try their best 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. Even dementing illnesses need not keep a person from expressing life-long values and wishes for care now and in the future. If serious memory problems affect work and home life, or lead to changes in behavior and mood, one still can participate in their own care 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 Caregiving Decisions, Family Care America, Inc, Revised 2005.

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