AGING PARENTS
Helping When Health Fails

A Pacific Northwest Extension Publication
Oregon  •  Idaho  •  Washington
PNW 246  •  July 1984
Mother is becoming more forgetful and confused. She doesn't remember to take her medication, doesn't prepare nutritious meals, and forgets to turn off the stove. What can I do?

Should Dad be forbidden to drive? His vision had one minor accident. Still, he seems to drive the four blocks to the store okay.

Mom needs 24-hour supervision. The only choices we have are for her to live with us or in a nursing home. Mom says she would rather die than live in a nursing home. I can't stand to live alone when we live together.

Situations like these are difficult for families. Yet, the decline of a parent's health or intellectual capacities often requires adult sons and daughters to become involved in decisions about a parent's life.

Dealing with such age-related changes in older parents is a relatively new phenomenon. In 1900, for example, one out of 25 people was age 65 or older; today one out of nine people is in this age group. During this century, life expectancy at birth has increased from 47 years to 74.5 years. A male reaching age 65 can expect to live another 14 years; a female, 18 more years.

The most dramatic increase is in the "old-old" population—persons over 85. This is the fastest growing age group and is expected to increase by 200 percent in the next 20 years.

The older people are, the more likely they will face increasing health problems, frailty, and the need for support and assistance from family and community services. Furthermore, it is no longer unusual for a 65-year-old to have a parent still living.

Many people never face major concerns about aging parents. Their parents remain physically and mentally active until death and need little or no assistance. However, for some older persons, poor health, limited financial resources, or loneliness present serious problems.

Few guidelines exist for dealing with the transitions that occur when a parent confronts age-related changes. Moreover, most of us lack the experience to make the necessary decisions. These decisions are not easy and there are no simple solutions. Each older person and family is unique. The right answer for one family may be inappropriate for another, although the situation and decisions may be similar. There is no "pat answer."

This publication provides general guidelines to consider if you face the dilemma of what to do about aged relatives.
before a crisis

Have you spent time planning for the part you might play in your parents' old age? Most of us avoid thinking about the possibility that someday one or both of our parents won't be self-sufficient. As a result, most families are unprepared to handle a parent's increased dependency.

The best approach is to talk with your parents before a crisis develops and discuss future "what ifs." For example, ask your parents what their wishes would be if they could no longer live at home. It's important to explore options and to have more than one plan. Circumstances at the time of crisis may require flexibility. Alternate plans can provide some insurance against making unsatisfactory decisions you'll regret later.

Talking with parents about "what ifs" may not be easy, especially if you and your parents have avoided frank discussion of emotion-laden issues in the past. Look for "natural" opportunities to talk. For example, when a parent says "When I die...," listen and encourage expression of feelings.

Don't discourage discussion by saying things such as "Don't be morbid," or "You'll probably outlive all of us." Other natural times for talking may be when an older family friend suffers a health crisis, enters a nursing home, or moves to the home of an adult son or daughter.

coping with feelings

The increasing frailty of elderly parents can become a daily reminder of their mortality (and our own mortality). We may need to adjust our perceptions of our parents. Making this change can be emotionally painful. It's not easy to accept that "my father is no longer the strong and powerful man he once was," or "my mother, who was an excellent cook, no longer desires (or remembers how) to cook." Most painful may be the realization that the parent you depended on is now increasingly dependent on you.

If you can, express your feelings to someone who will listen and understand—a friend, family member, minister, or health care professional. Sharing your emotions can make it easier to deal with the pain.

Remember, too, that your parent is likely to have similar feelings. It's difficult for most people who have been self-sufficient to accept increasing dependency. Any loss of independence or control—qualities highly valued in our society—can be a blow to an older person's self-esteem. Most older people will fight to keep their independence as long as possible. Some will deny or mask their dependency. They'll insist they can manage very well, will refuse their offers of help, or will even attempt to control the lives of other family members.

Encourage discussion with your parent about his or her lifestyle changes and feelings of dependency. Share your feelings; it might help your parent to express his or her feelings. Statements such as the following encourage honest discussion:

"I'm feeling a little overwhelmed by all these changes, Mother. I can imagine that it's especially painful for you right now."

"It must be difficult, Mom, to leave your home of 40 years and to decide what you'll take to the small apartment and what you'll give away."

"Dad, I know you've always prided yourself on being very independent. I feel it's very difficult for you to ask me for any assistance now that you can't drive anymore. Is that right?"
Regardless of the quality of your lifetime relationship with a parent, a crisis is likely to create stress. Some families find that crisis and increased parental dependency bring them closer together. In other families, unresolved conflicts between the "child" and aging parent revive. Such conflicts are usually difficult to resolve under stress.

Unresolved negative feelings often result in unwise, inappropriate decisions. When unresolved feelings direct relationships, negative behavior often results. Examples of such behavior are:

- Never visiting or contacting parents.
- Being oversolicitous—spending an abnormal amount of time doing things for a parent or creating undue dependency.
- Faultfinding with others who provide care to a parent.
- Denying a parent's problems or need for help.
- Blaming the parent for one's own difficulties.
- Becoming a martyr—making unreasonable demands on oneself and not letting others help with caregiving.

If possible, acknowledge and resolve negative feelings about a parent prior to crisis. Come to terms with early experiences and feelings, forgive a parent for past mistakes, and accept the parent as she or he is today. It often helps to realize that parents are individuals with their own needs, limitations, strengths, and life histories. Most parents have tried to do their best.

You and your parent can improve a poor relationship, but it takes willingness from both generations to try to understand the other, to not judge, to forgive, and to accept each other as adults.

**crisis: reducing strain**

Adults often find an aged parent needs support at a time when their own lives and responsibilities are the most complicated. If you are in your 30's, 40's, or 50's you may feel pulled in several directions—raising your children, being supportive to a spouse, helping aged parents, and/or working—all at the same time. It's not unusual to wonder "Why me?" or to ask yourself, "What about my life?"

If your parent is 80 or older, you are likely to be in your 50's, 60's, or 70's and may be adjusting to your own age-related changes—retirement, reduced income, widowhood, or decreased health—and may not be able to provide the assistance your parent needs.

If your parent's health and/or living situation should deteriorate and you face decisions about your parent's life, the following guidelines may help to reduce the strain.

**Communicate openly.** Open, honest communication helps build and maintain effective relationships. Oftentimes, family members are not honest or direct enough with each other. Adult sons and daughters don't always tell the truth; sometimes they say only what they think their parents want to hear or what they think won't upset their parents. This tends to create mistrust and wastes energy as family members "walk on ice" with each other.

"I" messages promote communication. With "I" messages, the individual speaks from personal feelings and identifies both the specific behavior or situation of concern and its effects on him or her. An example of an "I" message is, "Mom, because of your recent falls, I'm concerned about your safety living in this house alone; I'm afraid you'll fall again and not be found for several hours—or even days." Mother is much more likely to be willing to discuss the situation if you
communicate feelings directly instead of with a "you" message ("You must move, Mom; this home just isn't safe for you.").

We send people many "you" messages about their behavior. These messages sound dictatorial, create defensiveness on the part of the person to whom we are talking, and create a resistance to change. "You" messages are usually orders or commands ("You must eat;" "Stop doing that;"), blaming or name-calling statements ("You drive me crazy;" "You never cared about me;"), or statements that give solutions or deny a person's feelings ("You should move to a retirement home;" "You shouldn't feel... "). The worst "you" message is the "if...then" threat ("If you don't... then I will...").

Adequately expressing your thoughts and feelings to another person is only one part of effective communication. You also need to actively listen and empathize—sense and understand the feelings and emotional needs of another. The worst thing to say to a person is "You shouldn't feel..." or "There's no reason for you to feel..."

If you listen actively, the person to whom you are listening feels your care and concern. When older parents experience changes and losses, they may experience many feelings—fear, anger, grief, helplessness, and frustration. Having an adult son or daughter who is willing to listen and understand such feelings makes it easier for parents to talk openly about their situation, concerns, and feelings. An example of an active listening response is, "I sense you're feeling angry and disappointed because neither Bob or I came to visit you last week."

Active listening is not the answer to long-term problems in a relationship. No one thing can readily solve such problems. Nevertheless, the acceptance that you give through active listening may help to break down old barriers and allow a new relationship to develop.

Inaccurate interpretation of messages often causes needless misunderstandings and conflict between parents and adult sons and daughters. If you receive unclear or conflicting messages, request clarification using statements such as, "I'm not sure what you mean by..." or "Is my understanding of what you said... correct?"

Involving your parent in decisionmaking.

When considering what is best for your mother or father, be sure to ask your parent's opinion. Too often the older person is not included in planning and decisionmaking. Family members may fail to tell the person what is happening or the decisions being considered. This contributes to feelings of isolation, helplessness, anxiety, and perhaps despair. Change can cause anxiety, but not being involved in decisions about a change creates even more anxiety.

Shared decisions usually produce the best results. Aged parents have a legal and moral right to participate in plans affecting their lives and to make their own decisions whenever possible. You may not always agree with their choices.

Only if your parents experience reduced mental capacity and/or there is evidence they are endangering the lives of others, should you
question their ability to make decisions. For example, if your father doesn’t see well and has had several minor accidents but still insists on driving, then the family has a responsibility to take preventive action. (In certain situations, a family member could be held legally responsible for damage or injury.) In such cases, you may need to dictate or overrule a parent’s decision. Do this with kindness and explain the situation honestly to your parent.

If you must set limits, involve your parent in decisions about how to implement these limits. For example, say to your father, “Dad, driving isn’t a possibility any longer, so why are other ways you might be able to get around?” Work together to identify the choices available to your parent.

To relieve stress between you and your parent, you may want your parent’s physician to participate in the decision-making. Some people will accept their physician’s suggestions more easily than the same suggestions given by a family member.

A parent who is excluded from decision-making is most likely to become angry, demanding, helpless, or withdrawn. Plans are also more likely to backfire. Involvement in decision-making provides greater assurance that a person will accept and adapt to a change, even if the change is not the individual’s preferred choice. A person who feels railroaded into a new situation usually makes a poor adjustment. Regardless of age, feeling in control of one’s life is important.

In the case of progressive mental decline, make plans with your parent as early as possible. Delays in decision-making may preclude the elder’s active participation in decisions about his or her life. As a family member, you are likely to find the burden of decision-making easier if you’ve discussed plans earlier with the person for whom you must make decisions.

**Explore options.** Carefully explore various options before making a decision. It’s important not to have preconceived ideas about what is “the best solution.” Identify all implications of a change or decision under consideration. Consider the effects on your parent, yourself, and other family members.

Evaluate your parent’s economic situation. Talking about finances may make you feel uncomfortable and make your relative feel you’re meddling; nevertheless, such discussion is crucial to effective planning. Consider your parent’s income sources—such as Social Security, pensions, benefits, and income-producing assets—in addition to current and potential expenses.

Inform yourself about possible financial support. It’s helpful to know your state laws and regulations concerning assistance in advance of need. Find out what your parent’s health insurance policies—including Medicare—cover. Medicaid may be another resource if
your relative receives Supplemental Security Income (SSI) or other public assistance or qualifies as "medically needy."

Contact your local public assistance or welfare office for eligibility requirements in your state. The Internal Revenue Service can supply you with information about tax breaks available to older people and to families who provide care and support to older relatives. Other people who can help you plan for the future are your lawyer and/or tax consultant.

Avoid making irrevocable decisions. Keep options open. Set a definite trial time for any decision and then re-evaluate it. This is sometimes hard to do, especially if you want to resolve a difficult situation and not face more decisions. Approach your judgment from the perspective of "This seems like the best decision for now. Let's see how it works for four weeks. Then we'll reassess the situation."

Too often, families make decisions based on inadequate information. Find out about available community services and how they can help you. Sources for information include senior services divisions; area agencies on aging, information and referral; and senior citizen centers. Don't forget friends and neighbors either. Many are willing to help, especially on a short-term basis.

Know the family's resources. This will help you to evaluate alternatives. Talk with various family members to identify what each can contribute. In one family, for example, the adult children split their mother's chores three ways: one daughter shops; another daughter launder's clothes; and a son keeps the accounts and business records up-to-date.

Avoid unrealistic expectations of family members. Remember, your brothers, sisters, children, and spouse each have a unique relationship with your parent. Sometimes, individual family members are experiencing stress in their own lives—a troubled marriage, problems with teenage children, uncertainty about a job or finances—which may limit the support they can give. Your perceptions of a family member's situation or assets may not be accurate. Therefore, encourage each family member to share concerns and explore the family resources together.

Don't criticize other family member's contributions; remember that your nonjudgmental attitude may help build family solidarity.

Hold a family conference. A family conference can provide a forum for open communication among family members. Include the elder, siblings, spouses, and other relatives who are concerned or will be affected by decisions under consideration. Include young children, for example, who would be affected by a grandparent's move into the home.

Don't exclude concerned family members because of personality, limited resources, or distance (use telephone calls or letters to inform and involve anyone who's absent).

It is just as important to include a brother or sister who is argumentative or "never visits or seems to care" in the family conference as the brother or sister who provides financial and/or emotional support. This helps to avoid later undermining of the decision by those not included.
Create a safe environment for expressing feelings and concerns. If possible, hold the family conference in a neutral place; don’t use the home of the “favorite” child, for instance.

Be honest, share feelings, and focus on the current problem—not past rivalries—to open communication for a successful family conference. If anxiety, family friction, or hidden resentments prevent rational discussion, seek professional guidance. A professional can provide an objective view to help your family deal with emotions and conflicts, thus enabling you to identify and resolve problems more effectively.

You can locate a psychologist, social worker, mental health professional, or counselor skilled in working with elders and their families through senior centers, hospitals, mental health facilities, or home health agencies.

Barbara Silverstone and Helen Hyman, in You and Your Aging Parent (1982 edition), offer an excellent eight-step process for planning and conducting family conferences. Chapter 10 would be beneficial for all family members to read before a family conference.

Too much loving protection can undermine an aging parent’s self-esteem. The desire to overprotect an increasingly frail parent is natural; however, it’s usually the last thing an older person wants or needs.

The goal is to strive for a balance in caring. Don’t overestimate your parent’s needs; it can be destructive to both of you. If you assume responsibility for functions that your parent can still perform—even if only with difficulty—you’re likely to make your parent angry, depressed, or more dependent. People resent forced dependency.

Don’t make assumptions such as the following about your parent’s abilities, feelings, or needs:

Mother would be happier if she moved. There are just too many memories of Dad in the house.

Father should not live alone because he can’t see very well.

The best place for Mom would be a retirement complex where she’ll have to interact with people.

In fact, Mother’s adjustment to her husband’s death is likely to be more difficult if she is forced to move from her home. Father may have learned to compensate for his loss of

allow parent to risk

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sight. He may function very well in his familiar home environment, as long as family doesn't attempt to "organize his clutter." Mom, who has never been people-oriented, may find living in a retirement complex too crowded and "social" for her tastes.

Also, do not assume that your parent is mentally incompetent just because he or she seems eccentric or refuses to do what you think is "best." Mental incompetency needs to be assessed by professionals.

Before asking or forcing a parent to make changes in his or her life, ask yourself these questions:

- Am I contemplating a protective environment for my parent's sake or my own?
- Are the dangers real or would I just feel more comfortable and worry less knowing my parent is safe?
- Would I feel too guilty if I let my parent take an occasional risk to live independently?

Although your parent's safety is important, it isn't the only factor to consider in making a decision. Reflect on the type of life your

parent has lived and your parent's perceptions of the situation. It is just as important to focus on parents' strengths and remaining abilities as on their limitations. Too often focus is only on "What Mom or Dad can no longer do." Limitations should not get in the way of seeing the whole person.

Don't force your values on your parent. What one thinks is "bad" or "best" for a parent is not always true. Sometimes adult sons and daughters are concerned with a parent's "quality of life" whereas the parent is concerned with "quantity of life." If your mother or father is mentally competent and chooses, for example, to remain at home even though you feel he or she would be safer in another living situation, that's your parent's right and choice. If you are worried, express your concern by using "I" statements.

Avoid promises and "shoulds"

Don't make promises such as "We'll never put you in a nursing home, Mom" or "You can always live with us, Dad." You may not be able to live up to them. What may seem like the "best" solution now may not be best five or ten years from now when your parent's health or circumstances—or your own—change. Unfulfilled promises often result in feelings of guilt, mistrust, and disappointment.

If your parent's health or living situation deteriorates, you may find yourself bombarded with "shoulds," such as:

- A caring son should invite a parent to live in his home.
when providing care

Providing care to a frail older parent can be stressful and rigorously demanding, regardless of family commitment. For many, it can be the equivalent of a full-time job or more. Your sleep patterns may change, outside activities you enjoy may be drastically reduced, and you may feel overwhelmed by tasks and responsibilities. The aging person may add to the stress because of care demands, a difficult personality or changes in personality due to illness, annoying personal habits, and in some cases, alcohol or drug abuse.

Previous ways of interacting with the frail person may change. An adult son or daughter, or the healthy spouse of the frail person, may need to become more assertive. This can be particularly difficult if the caregiver has been the passive person in the relationship. These role changes can cause fear, conflict, and confusion for everyone. Frail older persons often resent the burden they create, feel anger and frustration in relinquishing roles, or become demanding in an attempt to regain the control they feel slipping away.

After weighing all the concerns, you may decide that it's best at this time to assume the role of caregiver for a frail parent. It may be a temporary arrangement or it may be long-term. Here are basic guidelines to help you guard against common caregiving pitfalls.

**Balance your responsibilities.** Caregivers can easily become overburdened in trying to meet obligations and responsibilities to the ill person, to other family members, and to themselves. Before assuming caregiving responsibilities, carefully assess the impact on everyone—children included.

Look at the sacrifices everyone will need to make—as well as the benefits. Don't assume caregiving at the expense of your relationship.
with your spouse, your own physical and emotional health, or the welfare of your children. You need time and energy to maintain quality relationships with your spouse and children, whom may be unintentionally neglected.

**Meet your own needs.** People in a caregiving role frequently place their own needs “on the back burner.” Don’t ignore your own needs; it’s detrimental to yourself and to the person who needs your care. It will lead to “burnout”—a depletion of your physical, emotional, and spiritual resources.

Set limits on what you can do. Most importantly, communicate your needs and what you can and cannot do to your parent and other family members. It’s unrealistic and unfair to expect other people “to know” when you need help.

Avoid the “I can do it alone” attitude. It will place you at greater risk for physical and mental illness. Eliminate less critical tasks. Delegate tasks. Ask family members to pitch in, but be positive with your requests and use “I” messages. Ask friends, neighbors, and members of your church or other organizations for help. Seek assistance from volunteer or public agencies that provide services to elders and their families.

Schedule some time for yourself everyday, if only for a half hour or a longer time at least once a week. This isn’t always easy to do, but it’s important. Leisure time improves morale and energy.

Many people feel guilty about leaving an ill person and enjoying themselves because they have been taught that to focus on one’s own needs when a family member is ill is selfish. There is nothing selfish about it. Without breaks in caregiving, you may jeopardize your own health, efficiency, and effectiveness. Your ability to provide loving care will diminish. If you become physically and/or emotionally exhausted, you will find your susceptibility to illness increasing, your problem-solving ability decreasing, your frustrations mounting, and your emotions getting out of control—all warning signals of burnout.

**Plan ahead.** Realize that the decision to be a caregiver is not a permanent one. There may come a time when you are no longer able to provide care. Consider options—including nursing home or adult foster care—in advance of need.

Be aware of legal matters which need attention and seek professional advice prior to crisis. Make plans for the care of the ill person in case you become ill or die. Involve other family members in these decisions to ease some of the burden.

briefly...

There is no easy or “right” solution to the problems people face concerning their aging relatives. Each situation must be treated on an individual basis. It’s important to consider the feelings, desires, and needs of everyone. Look at what is best for all and don’t let guilt guide decisionmaking. Involve all family members in decisionmaking, especially your older parent. Build on family strengths; then seek help when needed.
Answers to difficult situations sometimes require a professional. A counselor, physician, financial advisor, lawyer, or social worker may be helpful. Involvement in a family support group may also provide answers to problems of caregiving and reduce social and emotional isolation. Sharing with others who are living through the same experiences can promote a sense of “I am not alone” and provide both a source for learning practical skills and an opportunity to vent feelings with others who understand.

Though changes in the later years may be dismaying at times, you can ease the transition by learning about life’s stages. We need education to successfully negotiate late-life transitions not only for aging kin, but for ourselves in our own old age. Learning about aging is truly a family affair.

resources

Many publications, available through bookstores and libraries, can help you deal with concerns about aging relatives. These include the following:


Silverstone, Barbara and Helen Hyman, You and Your Aging Parent; New York, Pantheon Books, 1982.