

## A Guide for Families Family Questions: The First Thirty Days

### EMOTIONAL ISSUES: INTRODUCTION

#### *I feel so relieved - and so guilty for feeling that way. Are my feelings normal?*

Guilt. Resentment. Confusion. Relief. All of these and more are common and understandable reactions to a family member moving into a nursing facility. Whether the move was long overdue, or the result of a sudden illness or a drastic change in circumstance, such a major change in the life of a loved one resonates throughout a family, creating concern not only about the care their loved one will receive, but also about the many emotionally-charged issues that the move does not seem to resolve.

Questions most frequently asked by relatives of new residents are answered simply and directly. Some questions reflect the emotional turmoil common to the adjustment phrase, Like, "Did I make this decision for selfish reasons?" Others will address more practical matters like laundry and special diets.

This information is provided to help guide you, as a family member of a new resident, through what can be like an emotional roller coaster in the first few weeks. Questions have been provided by people who have themselves admitted family members to nursing facilities. Answers have been provided by experienced social workers who assist families daily in dealing with this life change.

The importance of your role in the success of your relative's adjustment to nursing facility life cannot be stressed often enough. You are one of the most knowledgeable members of your family member's caregiving team - you cannot give the other team members too much information, or ask too many questions about your relative's care.

Finally the nursing facility industry is currently undergoing a period of major transitions. What was once referred to as an "old folks home" is now a state-of-the-art health care facility sometimes combining short-term rehabilitation services with long-term skilled nursing care. For the purposes of this document, we refer to the people who use short-term services as "patients," and long-term services as "residents." For the families of both patients and residents, the emotional turmoil - and the questions it gives rise to - can be much the same. But for questions specific to short-term residency, refer to *Issues Unique To Short-Term Patients*.

### HELPING YOUR LOVED ONES ADJUST

#### *How can I help Dad settle into his new home?*

You might help your family member settle into life in the nursing facility best by remembering that he's not just moving into a home, but into his new home. Ask your father how he would like his home decorated and arranged. You can help him make that home as comfortable and personal as possible.

Although it's important that any decorative item not interfere with the caregiving mission or policies of the nursing facility, thoughtful decorating can help the nursing facility meet its goals of caring not just for the body, but for the mind and spirit of its residents as well.

**Don't** forget to discuss with staff members you and your father's decorating ideas. Some of the best ideas for brightening up a family member's room can come from the staff who see them every day.

Consider the following:

- You can help restore some sense of a home environment by decorating your father's room with things brought from his home. In borrowing from the former home environment, try to go beyond just moving items from the old into the new. Instead, try also to capture and recreate the same mood, texture and tone.

- Bring things your dad's made or collected. Bring items that have always been important to him, like a chair, picture, or coffee table.
- Provide photos of yourself or your family. Get the children involved in creating handmade items for all occasions. Create collages of children's photos, and bring or send wall decorations to commemorate holidays. In most cases, the brighter and more cheerful, the better
- Stimulate all the senses. Borrow decorating ideas from Mother Nature - nothing can be as refreshing as a bit of the outdoors brought indoors. Find flowers, colorful leaves, and other reminders of the seasons to help brighten his room.
- Provide paintings or prints of his favorite subjects, or of religious or other familiar scenes.
- If your father is able to enjoy them, supply magazines, books and newspapers for him; if not, bring tape-recorded books or music. If he subscribed to the daily newspaper, keep it coming.
- Provide a telephone or TV if his room can accommodate them.

***Mother's still angry and keeps saying she wants to go home. Will she ever adjust to the move?***

If you've ever moved yourself, especially out of town, you've already experienced a part of what your mother is going through. But add to that the stress she's experiencing from the loss of her cherished independence, from living in unfamiliar surroundings with scores of strangers, and from trying to accept you in the unnatural role of caregiver, and you'll begin to understand just how major a life change this can be.

Suffice it to say that the first 30 days may be uncomfortable for both of you. Don't be surprised if during the early days of your mother's residency, the whole family experiences some degree of guilt, tension, fear or fatigue. Your mother is likely to do or say things that will upset you and make you feel guilty. She may express either verbally or non-verbally her dissatisfaction with the new arrangements and her desire to go home. She may act mad or hurt, or berate or ignore you.

Remember that these behaviors - and your reactions to them - are perfectly normal under the circumstances. Adjusting to their new living arrangements is a process that all residents go through in their own way, and at their own speed. The adjustment won't be accomplished overnight, but as the days turn into weeks, you'll find your mother talking less about her old home and more about her new. In the meantime, the staff is always there to help see you through the peaks and valleys of this very emotional experience. Don't be afraid to ask for a little moral support.

**COPING WITH GUILT AND RESENTMENT**

***Mom and I chose this nursing facility because we thought it was the best thing for her, but she treats me like I'm abandoning her to pursue my own selfish pleasures. How can I remind her that we have her best interests at heart?***

The decision to admit a family member to a nursing facility setting is never an easy one. But whenever you begin to doubt the decision, remember the many advantages a nursing facility offers your family member:

- 24-hour care, with medical assistance always available.
- A roommate, with whom many residents form a deep and lasting bond that proves both invigorating and supportive.
- A sense of community and activity, which can encourage residents to get up, dress and get out to enjoy a community meal in the dining room or an organized activity in the recreation room.

- Staff members who become attached to the people in their care, and work to make their lives as comfortable and interesting as possible.
- Regular clergy visits and religious services.
- Activities, educational programs, group discussions and outings.
- Personalized physical, occupational, speech and restorative therapies.
- Trained nurses who teach skills and promote self-care.
- Medical staff that tracks the individual progress of each resident, as well as his medical needs, on a daily basis.
- Tasty and nutritious hot meals on a regular schedule, with help for those who need it, and special attention for those whose diets need to be monitored.
- Finally, more satisfying relationships with family members who, with the stress of routine daily care transferred to home staff, now have sufficient energy and time to devote to the emotional needs of their family member.

***I know my mother should be here, but I promised her years ago that we'd never put her in a nursing home. I feel like I've gone back on my word.***

One of the most difficult situations a person can face in life is having to move an elderly family member into a nursing facility after having promised - often years before - not to.

The decision can lead to guilt and self-doubt, and, if it's not resolved, even to depression. If you've had to break such a promise, whether it was expressed or only implied, it's important to take some time to separate what you feel about your decision from what you *know*. For example, even though you might feel as though keeping that kind of a promise is very important, you might know that it was no longer safe for your mother to live alone.

Remember:

- As circumstances change in your life, so too, do your options. The “best” solution to a problem ten years ago might not be the best solution today. If you did make a promise not to institutionalize your family member, it was probably made at a time when home care and independent living were practical options. If they are no longer practical options, they should not be considered just because they seemed like good solutions years ago.
- All you can give is your best. If you've considered all the options and made the best decision you can, you have nothing to feel guilty about. The guilt that often accompanies placing a family member in a nursing facility can actually debilitate you or drive you to give more than you can possibly give.
- Doing the impossible to keep your family member at home is precisely that: impossible. Few people can provide the 24-hour care a nursing facility can provide. Your family member needs you for more than lodging, meals and medication. She needs your love, something that can be hard to provide when you're constantly drained, both physically and emotionally. Often the only way to do your primary job right is to turn your secondary over to another.
- Try to listen to your head. It's very difficult to get over the emotional reaction of admitting a family member to a nursing facility. Remember though, that being relieved of the daily physical and emotional stress of a practically impossible home care situation can enable you to enjoy your relationship again. And the time it frees up can be used constructively with your own family or in taking an active role in nursing facility activities, both of which will provide support for your own adjustment.

- You're not alone. At the heart of almost all guilt suffered from placing a family member in a nursing facility is the unspoken doubt that a promise has been broken. Talk to someone who has made a similar decision and share your conflicting emotions. Then ask them to share with you how they coped with the guilt, and how they feel about their decision in retrospect. If your nursing facility has a family council, visit with some of the members. See *Family Councils*.

***Even though I was killing myself trying to take care of my Mom and family both, since she's moved to the home I've felt even worse. Instead of appreciating all the staff does for her, I resent them for caring for Mom better than I could, and guilty for being so childish. What is wrong with me?***

Nothing is wrong with you, anymore than there is something wrong with the young mother who is crushed when her only child comes home in love with his kindergarten teacher. There comes a point in all of our lives when we cannot provide our loved ones with everything they need to be happy - when we discover that at this stage in our loved one's life, our best efforts are not as successful as our best efforts combined with those of another. Sure you feel resentful, and probably a little left out. You used to be the center of your mom's universe, and now you feel like an orbiting planet, at best.

Don't fret. This too shall pass. Soon you'll get to know the staff, and realize that they're not taking your mom away from you. Moreover, you'll discover that what you can offer your mom, no one else can provide.

In the meantime, share your feelings either with someone on the staff, or someone whose been in a similar position like a Family Council member. Don't worry about sounding silly. Your reaction is more common than you think.

***When my wife and I lived together, I was there for her every minute of every day. How can a nursing facility provide that kind of care?***

It can't. On the other hand, it can provide a lot of things you couldn't, and the tradeoff might prove healthier for everyone involved. Granted, your wife may have to wait a couple of minutes for help to get to supper. On the other hand, she'll have people her own age to eat and talk with, and a diet tailored to her needs. And while she won't have you there to help plan her day, an entire staff of professionals with years of experience with her age group will be scheduling activities for the entire community to enjoy.

Moreover, she'll still be getting what she needs most from you, frequent visits full of gossip and confidences, trips out to her favorite hairstylist - in short, the kind of individual attention only a family member can provide. But one type of care doesn't preclude the other. Take the opportunity to visit with the staff about your wife's likes and dislikes. The quicker they get to know her, the sooner they can try to personalize the attention she will be receiving.

***As the only relative in town, I feel I have too much responsibility for Mom, while my sisters out of town feel guilty for not helping more. How can we share the load more equitably?***

Your mom is only the first of many family members that will find this life change stressful. Admitting a close relative to a nursing facility brings to the surface all kinds of life issues that we often keep on the back burner. If not handled right, it can also stir up old resentments, sibling rivalries and control issues that you thought were buried years ago. Remember, this dramatic development in the life of the new resident is also a watershed in the lives of her family members, for the event forces each to come face to face with a new family role, accept the new limitations of other family members, and grapple with the reminder of her own mortality.

Often, the caregiver who has assumed the major responsibility for the decision has become the primary caregiver by default, as the only close relative in proximity. By the time the decision is actually made, she may feel exhausted and depressed, as well as resentful of all the responsibilities.

At the same time, she will undoubtedly have made the best decision she could, and be both resentful of criticism and possessive of future decision-making. On the other hand, out-of-town relatives who only see their family member rested, medicated, and dressed for "company," may argue for care options that they would realize were unrealistic if

they were the primary caregiver for just a day. All family members need to make a concerted effort to empathize with others' points of view and the needs and conflicts they face.

For the primary caregiver, it's crucial to remember that failure to keep other family members informed on developments only makes the transition harder for all involved. Out-of-town relatives who are only informed of major decisions may feel they are lurching from disaster to disaster, with no control or input.

But the primary caregiver can help put them back “in control” of their lives by providing them with regular progress reports and suggestions as to what to send or when to plan their visits. She can also help by preparing them for what they will see, since changes in a nursing facility resident's appearance will seem more drastic to them than to her.

If appropriate, the primary caregiver might even review possible future scenarios, soliciting feedback *before* a decision has to be made, and subtly informing out-of-towners what might have to be considered in the future.

For the distant caregiver, it's important to empathize with the extra demands placed on the nearby family member in her role as primary caregiver. In addition to caring for the nursing-facility resident, she still has to manage her home, her family, her job, etc.

Try to keep family discussions of options and decisions as open and uncritical as possible. Everyone should feel free to express opinions and suggestions without fear of emotional retaliation. When it comes down to the nitty gritty of decision-making, strive for consensus, but don't force it. Try to get only those commitments from family members that can be given honestly and realistically. If that leads to nothing decisive or realistic, try to agree on a temporary or trial measure, recognizing that some family members do not favor the option, but that as yet no other solution has presented itself. Put all involved family members on the mailing list so everyone gets the same correspondence from the facility.

Remember, too, that it's unreasonable to expect a better relationship between family members than they had before the nursing facility decision. And keep in mind that you and your family members will not always be in the role of caregivers for an elderly relative. Trying to squeeze a family member into a caregiving role that doesn't fit may ultimately do more harm than good.

#### **MAKING YOUR VISITS COUNT AND VISITING BY MAIL**

***Dad and I never did talk much, and now conversations are even harder. What can I talk about that won't make us both uncomfortable?***

Often relatives and friends find it painfully difficult to visit a family member during the early days of his residency. They may feel it their “duty” to keep the conversation light and to avoid any discussion topics that might make everyone uncomfortable.

But talking about the “uncomfortable” things can be therapeutic for nursing facility residents - and for their family members. And if he can't talk frankly with you, his family member, who will he be able to “talk it out” with?

Knowing that you won't flinch from difficult issues might help your dad grapple with them all the sooner. You can help make your conversations more productive in other ways as well:

- Often conversations in the early days of residency revolve around the decision to admit the family member to the home. When discussing it, avoid loaded terms like “helpless” and “incompetent” - terms that strike at the heart of your family member's self-concept. Instead, stress the more objective side of your case: “Your condition requires that you have 24-hour nursing care.”
- Use your conversation to lovingly motivate your family member. Saying, “You can't even get out of your wheelchair by yourself,” is in essence saying he might as well give up. But if you know he can do better and you say, “After you can transfer from your wheelchair to a chair maybe we can plan an outing in the car,” you're inspiring him to achieve.

- Finally, remember that the most important part of any conversation is the time you spend listening. A relative who says, “I want to go home,” wants to feel that you care. Turning away from his honest expression of emotion because it makes you feel uncomfortable will only make further communication more difficult.

Instead, encourage him to talk about home and the things he misses. Then listen! Listen as you would to your boss or your spouse - carefully and patiently. Accept the fact that at first a lot of his conversation will cover the same ground over and over, but don't feel as though the conversation is pointless.

Realize, instead, that your family member is “working through” a major life change in the best way available to him, and he needs your help.

### ***How can visits seem like they used to be at her home?***

Geriatric care providers recognize that sometimes the best therapy in the world is a visit from a loved one. Unfortunately, visits can sometimes be an emotional challenge for family members - and instead of tackling the challenge, too often they give up altogether.

Successful visiting is like any other social skill - it can be improved upon with a little bit of work and some practice. The payoff will be more enjoyable visits for both you and your resident. Consider these tips for better visiting:

- Plan ahead. You can help avoid the “duty” visit by remembering why you used to visit your relative *before* she became a resident. Then fill the visit with similar activities. If you shared a passion for jigsaw puzzles, bring one along and help her get it started. If you're both big readers, start a book aloud that you can read a chapter out of each time you visit.

Write letters for her, take her out to lunch, meet her new friends, or brag about the kids - with grade cards, photographs, school projects, and even videotapes to back you up! The possibilities are endless, but the point is to think ahead.

- Remember this is a visit to your family member's new home, not a hospital room. Fill the visit with things you felt comfortable doing before she entered the home. Touch, if it feels natural to do so, and talk as you used to. Take her for lunch and to the mall, or out to get her hair done. Ask your family member for a tour of the home. Don't feel pressured to entertain; instead, if she's able, let her be hostess to you.
- Don't fear reminiscing. Gerontologists are showing that such “life review” is an important adjustment mechanism that helps elderly people put their situation into perspective and deal with lingering conflicts.
- Remember you're an important link to the outside world. If she wants to gossip, then gossip. Keep her involved in the family, the community, and the church. Don't be afraid to seek the same amount of advice and comfort from her as you did before she moved into the home.

Sometimes you'll have to let her vent her anger and frustration at the situation, and at her new limitations. But remember, you don't have to remedy the problem in order to be of some help, you just have to listen.

- Get to know the staff. These care providers are part of the extended family that constantly works to improve the overall quality of life for your loved one. Fill them in on your family's favorite stories about your resident, and about her personal idiosyncrasies, to help them understand her individual needs. Volunteer to help in the facility's group activities to get better acquainted.

### ***My kids can sometimes be a handful. Should I bring them on visits or will they just wear Dad out?***

Bring them. It's easy to underestimate the importance of a connection between children and elder family members, but studies show that the relationship between grandparent and grandchild is second only to that of parent and child.

For the elder person, grandparenting is an opportunity to satisfy a natural wish to continue in a family role. It allows him to pass on feelings and attitudes to another generation - to share what is important in his life with someone whose life is important to him.

- If your family member can communicate, let the child and family member play games like Tic-tac-toe or Hangman, simple card games, checkers or dominoes. Share coloring books and drawings. Think of games from your own childhood or, better yet, help your family member think of games from his childhood to share.
- Don't be concerned about the commotion that always accompanies kids. It can be a welcome change to the usually sedate home environment, and studies show that even unrelated elderly people enjoy seeing children at open parties or public activities.
- Encourage physical intimacy between children and elderly family members, particularly if the resident can't speak. Kids can tend to be bashful in this kind of situation, but model eye contact, hand-holding, back-rubbing and hugging for them. Simply holding a baby is often therapeutic for residents who can't interact well.
- Occasionally bring, or send ahead of time, a small gift for the family member to give to the child.
- If you have problems managing the visit, take only one child at a time. But allow enough time for a fruitful visit.
- If the resident is not actually your children's grandparent, show your appreciation for his willingness to take on the grandparenting role. If he is, reserve to him as many of the traditional rights and privileges of a grandparent as possible. For example, make sure that except for the immediate family, he's the first to see grade cards, dance costumes, etc.
- Be sure to visit on days that are special for the children, such as Halloween (in costume), the first day of school (in uniform), etc. It helps keep your family member involved in the children's lives. Try to continue or build new family traditions: "It's what we always do when we visit Grandpa."
- Encourage older kids to pursue their so-called "living history," in which older family members bring history alive by telling children their unique role in the public events of their lifetime. Encourage the elderly family member to open up by providing the child with questions like: What was it like learning in a one-room schoolhouse? What was the Depression? How did people get along? What was life like during World War II? You lived on a farm? You milked cows? Give adolescents a small recorder and plenty of tapes and start an oral history of your family.

***Mom's nursing facility is two towns over and I can't always visit. Should I send mail?***

Few things can brighten a resident's day more than receiving mail. Whether you use it to stay in touch with a family member between visits or to remember a distant family member you can't visit as often as you'd like, don't ignore these therapeutic benefits of regular letters and notes to your family member:

- Start small. A bright and cheerful greeting card can be as welcome as a long letter - sometimes better. A simple, short note is better than nothing; the importance of mail is the connection, not necessarily the content.
- Take note of special occasions like St. Valentine's Day, Mother's and Father's Days, holidays, family birthdays and anniversaries. Relay children's news regarding school, vacation, Scouts, and Little League.
- Since mail can double as decoration for your family member's room, select bright, colorful note cards, scenic postcards or page-a-day calendar classics that she'll enjoy seeing on her walls.

- Send photos featuring the activities and accomplishments of you and your family: show her your garden, the kids after a day at the beach, a newly decorated room, a pet, or your new hairstyle.
- Invite the kids to contribute a finger painting or a handmade card. Mail appropriate wall decorations to commemorate holidays. Send an envelope of colorful leaves in autumn.
- If your family member has moved from your community, clip the local newspaper for class reunions, school activities, engagements and births, local elections or other items of interest to her. If she has trouble reading the small print of the paper, recopy the stories in large print, or enlarge them on a copy machine. Don't forget gift subscriptions to her favorite magazine. (Some even have large-print editions.)
- Remember that it will often be a staff member who receives and directs your letter, so address it fully - including the family member's full name - and add your return address. Date the letter. Identify all people in photographs you send. When you mention people by name, include a brief reminder of who the person is.
- If you know your family member will be reading the letter himself, make it easy on his eyes. Print in large letters with a dark ink on light paper. If your family member is capable of writing in return, make sure she has a supply of stationery, pre-addressed envelopes and postage stamps - and don't forget that even postage stamps come in a huge variety now.

#### FINDING HELP WHEN YOU NEED IT

#### *Dad seems to be getting all the support he needs, but what about me? Where can I go for some encouragement and feedback?*

To the person responsible for caring for a family member, it may sometimes seem that there is no lack of support for the elderly, but very little support for the caregiver. Check out some of these resources for caregiver support:

##### *Outside the nursing facility*

- Many local phone directories now include an index of “helpful numbers” which may include a category for aging or elderly care. Look for state and local offices on aging, plus local programs sponsored by nursing facilities, hospitals or civic organizations.

If phone numbers are not indexed in that way, check the county and city listings for a local office on aging, the Area Agency on Aging, the health department or local senior facilities.

- Monitor the health section of your local newspaper and the community calendar. Visit the local library and talk to the librarian. Information on support for the elderly and their caregivers often funnels through these sources.

##### *Inside the nursing facility*

- Talk with the nursing facility administrators, social workers and staff. They can often sort out and identify the conflicting emotions you may be experiencing, as well as provide some practical solutions for some of the more mundane problems you are facing. Remember that many of the same issues plague all family members in the early days of a new residency; even when you most feel like it, you are not alone!
- If you can find no support group for caregivers, consider starting one of your own. The structure of the group may be as formal or informal as you wish, but you should try to meet at least monthly, even if you're only starting out with a few members.

Choose a place and time convenient for all and try to develop a particular theme for each meeting. Keep names and addresses of the people who do attend, and ask your nursing facility administrator for names of

others who might be interested in attending. Give and take support liberally within the group - sharing with your peers is often the best resource of all.

- The nursing facility may also have a family association or family council that YOU could join. These groups usually meet on an ongoing basis, and feature programs, speakers, family issue forums, social events, and fundraisers.

***What is a family council?***

A family council in a nursing facility is, in effect, a consumer advocate group, comprised of relatives and friends of the facility's residents. A typical council meets monthly at the facility, is run by the relatives and friends of the residents, and focuses its energies on several established goals and objectives. Usually a staff member of the nursing facility serves in an advisory capacity to the council, but is not actually a member of the council.

***What is the purpose of family councils?***

A family council has two main goals: to protect and improve the quality of life in the facility and within the long term care system as a whole, and to give families a voice in decisions that affect them and their residents.

Family councils can be responsible for organizing everything from spring clean-ups at the facility, to staff appreciation events and welcome visits for families of new residents.

They can also serve as important sources of information and support to families of new residents who are still struggling with both the practical and the emotional ramifications of their relative's new living arrangements.

***I want to do more than simply visit my husband in the nursing facility. Do homes ever need volunteers?***

Yes, nursing facility administrators are usually delighted at the prospect of a new volunteer, especially one whose family member is a resident. But there are other ways of getting involved as well.

- Ask about participating in one of the various councils the facility may offer, like the Dietary Council, Program Council, Family Council, etc.
- During your visits, don't confine yourself to your family member's room. Get to know the staff, the daily routine, the programs available, etc. Make a point of telling the staff how you appreciate any extra things they do for your mother - remember that she might be unable or unlikely to provide them with the kind of feedback that makes their job more rewarding.
- Find out what services and support groups are available in your area. Contact the nursing facility's administration, the American Association of Retired Persons, the Alzheimer's Association, and other organizations with chapters in your area.
- Inform yourself on political issues and candidates related to the aged on both the local and national level. Write or call legislators about your concerns.

**VISITING POLICIES AND TRIPS OUT OF THE HOME**

***Can I take Mom out sometimes?***

Of course. Residents are encouraged to go on outings as much as possible. Plan outings for your relative, especially on Sundays, holidays, and family birthdays and anniversaries. If overnight outings are planned, check with your facility regarding the policy on overnight stays.

***If I take Mom out, does she need to be back by a certain time?***

Not usually. However, the nursing staff needs to know when you are leaving and the estimated time of return. Medications may be given to you for your mom.

#### **CLOTHING AND LAUNDRY**

##### ***What personal items should I pack for my wife?***

First ask your wife what clothes and special items she wants to bring. Then ask your facility for its recommended clothing list and if your wife's situation warrants additional items.

##### ***Should I send Mom's personal items and valuables with her?***

Ask your mother if she would be upset if an item was broken or lost. If the answer is "yes," don't send it. Leave expensive jewelry, cash, credit cards and valuable collector's items at home.

##### ***Is there someone in the home I can leave some cash with, so Dad will have money if he needs it?***

Your father may need cash for the gift shop or the barber shop. See the business office manager about setting up a personal account that he can access to cover these personal expenses.

##### ***How will my wife's clothing be laundered and how often?***

Find out how the laundry is handled on the floor your wife is assigned to. There may be a particular bin or room for dirty clothes, and in the beginning it might help if you made sure your wife's clothes get there. Also, make sure she has plenty of clothes to wear while her dirty clothes are being laundered. If she is incontinent, she may need additional clothes.

##### ***How can I help keep Mom's clothes from getting lost?***

A facility the size of a nursing facility is responsible for laundering clothing and linens for scores of people, and it can be a challenge to keep everything straight. Upon admission, the staff will begin an inventory of your mom's items that will be kept on her chart. After admission, you'll need to let the facility know if additional items are brought in or removed. It won't be long before staff members recognize her clothes themselves. Don't panic if something turns up missing. First check to make sure it wasn't taken home by another family member, then report the missing item to the staff.

##### ***How should I mark Dad's clothing?***

Since markings can wash out with repeated launderings, the best way to mark his clothes is with sewn-in labels, especially if the clothes are dark. Check his clothing periodically to see if the name tag is still legible, and be sure to get all clothing marked before it comes into the home.

##### ***Can I do my husband's laundry at home?***

Probably, but check with the nursing facility. Make sure there's an adequate supply of clothes available to your husband while you're laundering his dirty clothes at home.

#### **FOOD**

##### ***Will Dad be made to eat food he doesn't like?***

No, but the staff cannot be expected to know what those foods might be unless you or he tell them. The staff will try to encourage your father to try different foods, and will help him order and season his food the way he likes it as soon as they learn his preferences. Many nursing facilities now offer more of a selection so that each resident can choose what he or she feels like eating from two to three selections.

***Who will help my aunt eat?***

Every one who needs assistance in eating receives it. Your aunt will be encouraged to feed herself if at all possible, because eating can be a very important part of physical or occupational therapy. Special equipment may be used to help her eat independently. If she is unable to do so, however, someone will help her.

***Can I stay to eat supper with Dad occasionally?***

Certainly! Your dining with him will add to his pleasure. Since each nursing facility has its own policies on guest meals however, ask to meet with the dining services manager for details on advance notice, meal times, cost (if any), and any other services the facility might provide. For example, some facilities offer a special menu and a special dining room so that you can take your father "out to eat" without leaving the facility. Or he can take you and your family "out"!

***Grandpa's supposed to be on a low-salt diet. Who will make sure he sticks to it?***

There are really two issues here. One is that your grandfather is on a sodium (salt) restricted diet for health reasons. The other is that he has the right to choose whether or not to follow that diet. No one can force him to follow it. He will be provided with meals that are planned to meet the dietary restrictions ordered by his physician and that will also be nutritionally adequate. If he asks for food that is not allowed on his diet, or obtains food from other sources that is not allowed, he will be counseled on the potential negative consequences of not following his diet. You can assist by encouraging him to follow his diet.

***I'd like to surprise my mother-in-law with some of her favorite foods occasionally. Is there any reason I can't bring her treats occasionally?***

No, but discuss it with the dietitian or dining services manager first to make sure the item does not conflict with her diet. Each time you bring in an item, let the dining services manager or nurse know. Also try to time your visits so that your mother-in-law can eat the item. The facilities have strict regulations to follow on storing and refrigerating foods to keep them as safe as possible. If you bring in something for her to keep in her room that can be stored at room temperature, also bring in an airtight container to store it in (provided that the facility's policies allow this).

**PERSONAL CARE**

***How fast will Mom's call light be answered?***

Almost immediately, especially if the staff is aware of some problem your mother is experiencing, for example shortness of breath while she's fighting a cold. Moreover, the staff does not rely solely on residents' signals for help. The staff checks everyone on a regular basis, whether they have requested assistance or not.

***How involved is my husband's doctor?***

The nursing facility staff is in regular contact with your husband's doctor. Family members are encouraged to keep in close touch with the physician themselves, but must remember that it is the nursing staff that will be carrying out the medical orders that come directly from the doctor. If you're not sure that something got passed on to your husband's nurse, be sure and ask her about it.

***My uncle is supposed to take half a dozen pills at all different times of the day. Will someone make sure he keeps to his schedule?***

Yes, you can rest assured that medications are monitored very strictly in the nursing facility, and that the medical staff is continually checking and double-checking medication schedules.

***How many people work a given shift? Is the weekend staff adequate? What is the staff-to-resident ratio?***

Staffing requirements are set by federal guidelines designed to provide enough staff for the appropriate care level at all times. Ask the nurse in charge of your family member's floor for the specific statistics for your nursing facility.

***Does the staff take everyone to group activities, or only those who express an interest? I know my mother-in-law would enjoy some of them, but I'm not sure she'll think to ask.***

All residents able to attend activities will be encouraged to do so. In fact, the staff is required to have a personal plan of care for each resident that includes activities and programs. This plan of care will be personally tailored to your family member's physical and cognitive abilities. If your mother-in-law wishes, you can attend care planning meetings, usually held quarterly, and any group activities.

***Who will be taking my grandmother to the bathroom and how often? Will someone get her up at night or will she use a bedpan?***

The facility maintains appropriate staffing 24 hours a day, seven days a week. Members of that staff will continually check on your grandmother to monitor bathroom needs. At night, and depending on her condition, your grandmother may choose the bathroom or prefer a bedpan to getting out of bed. Some residents, of course, will require a bedpan.

***Who will do my father-in-law's hair, teeth and nails? Is that up to the family?***

No, this kind of care is also strictly mandated by federal guidelines. Hygienic guidelines are very specific, and nursing facility staff are fully responsible for making sure your father-in-law's body, hair and teeth are clean.

***How frequently will my father be bathed, and by whom?***

Your father's nurse should be able to answer this question for you but as a rule, residents are bathed once weekly, usually by an aide, but sometimes by a nurse. Individual needs may dictate a more frequent schedule, however, so check to see whether your father falls into this category.

***Do residents receive any attention during the night, or only if they wake up and signal for help?***

The nursing staff conducts regular rounds to check on each resident during the night. Check with your nurse to see how often they do this for your family member.

***Will my wife's therapies continue on weekends?***

Not usually. Most therapies are planned for Monday through Friday.

## COMPLAINTS

***How should I handle complaints?***

If your family member complains, remember:

- Never hastily dismiss a family member's complaint. Even if the complaint appears petty or simply a way to register dissatisfaction with his new limitations, ignoring complaints will only further damage your relative's morale.
- In many cases, all the complainant wants is for you to listen, support and comfort him as he adjusts to his new environment.
- Try to really listen to what he is trying to say. (See *Helping your loved one adjust*.) Don't prejudge the validity of the complaint, and pay particular attention to his verbal cues, body language, facial expressions, posture and gestures. All can help you determine the seriousness of his complaint.

- Complaining is not limited to verbal expression. The onset of depression, an increase in anxiety, or the development of a tendency to withdraw into hostility and unresponsiveness can themselves be forms of complaint.
- Always respond to complaints, whether they are well founded or not. Use facial expressions, gestures, statements, questions and comments to show you're listening. Don't get upset and don't be condescending or patronizing. Treat your family member as an equal in the conversation.
- If you do feel a complaint could be warranted, bring it up to a staff member you're comfortable dealing with. Lingering or more serious complaints should be taken up with the home's administration. Most homes have a specific complaint procedure. If you're uncertain, ask.
- Be sure your relative is kept informed that everyone is working on the complaint and give him status reports.
- Although you should always bring complaints to the attention of the staff first, you should also be aware of the other avenues available to you for resolving problems. Amendments made in 1978 to the Federal Older Americans Act set up an ombudsman program in each state to help family members who have complaints about nursing facilities and long-term care facilities. Residents or relatives should be encouraged to report any unresolved complaints to this or similar programs in their area.

## INSURANCE

### *What does Medicare cover?*

Medicare is a short-term federal program providing funds according to medical need. To qualify, the resident must meet strict medical guidelines requiring a skilled nursing facility. Your facility will determine if your family member qualifies and will fill out the forms. When your family member is on Medicare, his case is continually monitored by a team of staff members to make sure he qualifies. The home will notify you when Medicare benefits will end.

### *What is Medicaid?*

Medicaid is a federal program administered by state agencies, based on financial need, and the medical necessity for nursing facility care. Although the benefits last indefinitely, the state reviews all Medicaid residents periodically to make sure they continue to qualify both financially and medically.

### *What does supplemental or long-term insurance cover?*

Insurance coverage is available to cover certain costs of nursing facility care. Some plans will supplement Medicare or Medicaid coverage and cover expenses beyond what these plans cover. Others pay for a portion of daily expense for a set amount of days in a nursing facility. These policies may be in the form of supplemental or long-term insurance.

If your family member has such insurance coverage, bring a copy of the policy to the attention of the nursing facility. Work with the administrative staff to discuss how they want to file claims to get the best benefits.

## ADVANCE DIRECTIVES

### *What are Advance Directives?*

Advance directives are documents which permit an adult to convey health care instructions in the event the person subsequently loses the ability to make or communicate decisions.

Although there are some language and provision differences between states, the two most common forms of advance directives are a Living Will (LW, or a Directive to Physicians), and a Durable Power of Attorney for Health Care (DPOA).

***What is a living will?***

A living will communicates health care preferences should an individual ever suffer from a terminal condition and be unable to indicate those preferences for himself. Before a living will can go into effect, not only must the patient's attending physician document both the terminal diagnosis and the patient's inability to make his own decisions, but a second physician must make an independent assessment of the patient and concur on both the terminal condition and the decisional incapacity. Living wills are used most often to indicate preferences about life sustaining treatment when death is imminent.

***What is durable power of attorney for health care?***

A durable power of attorney is a document in which a person names another individual to make his health care decisions for him, should he ever become incapable of making them himself. Like the living will, the durable power of attorney cannot be invoked unless the patient's attending physician - as well as a second physician or, in some states, an accredited psychologist - documents the patient's decisional incapacity.

***What does this mean in terms of self-determination?***

The sole purpose of advance directives is to ensure a person's right to make his own decisions regarding his health care options. For example, even after all the requirements have been met to activate a living will, if the patient regains decisional capacity, even temporarily, his wishes take precedence over any previously executed advance directive.

As the 1990 Patient Self-Determination Act makes clear, the law requires that in the case of an individual's mental incapacitation, his physicians and family are not to make the decision they consider best for the patient, but rather to determine what the patient's own preferences would be, and to act accordingly.

It is important to remember that no one is required to have advance directives. Furthermore, healthcare providers are required to take a neutral position regarding their merit. In fact, advance directives have advantages and disadvantages. If you are interested in having advance directives for yourself, it may be useful to consult with your physician and a health care attorney to help ensure that your concerns are adequately addressed.

**ISSUES UNIQUE TO SHORT-TERM PATIENTS**

**What to Expect from Therapy**

***How long will my wife be in therapy? How soon before we see some improvement? Are you sure she'll improve enough to go home?***

The person who can best answer these and other questions pertaining to your wife's stay in the short-term care unit of the nursing facility is the social worker assigned to her case. Although much depends on the progress your wife makes in the days ahead, many of your questions will center on "hows" and "whys" that come up all the time. Social workers are trained to handle both the issues that arise during your relative's stay at the nursing facility, and the ramifications of her return home.

**What to Expect at Discharge**

***What happens when Grandma's discharged?***

Just as your grandmother's progress is monitored continually, so too is her potential for discharge. The social worker will keep your grandmother informed as to when she's likely to be released, and will also inform you and other family representatives of what that will entail.

Once her physician can estimate a release date, the nursing facility staff will get with your grandmother to plan her discharge. Some facilities even have discharge planning teams to smooth the transition back home.

***When we take Dad home, who is responsible for arranging for home health care and medical equipment?***

The social worker assigned to your father will discuss with him his upcoming discharge. In cooperation with the nursing facility staff, she will schedule any in-home therapy that is prescribed, as well as make arrangements for any medical equipment your father may require.

***Dad is really depressed. How can I help him realize that he's only here for a little while?***

If you're certain he will be returning home soon, motivate your father-in-law by linking his achievements with going home. For example, praise the 30 steps he takes without his cane as a major step toward his total rehabilitation.

***Mom seems so unsteady. Is she really ready for home?***

Your mother's physician will not release her until he feels she's ready. That does not mean that further therapy is not in order, or that she'll feel up to snuff as soon as she gets back home. It does mean, however, that based on a careful assessment of your mother's condition and on the progress she has made since her admission, he feels she will make better progress at home.

**Making The Transition From Short- To Long-Term Care**

***Can we bring my mother back if we discover after discharge that we just can't take care of her at home?***

Every state has different admissions requirements. Contact the administrator of the nursing facility to see whether your mother's situation meets the criteria. You might also contact her primary physician, since a recommendation from a doctor is a prerequisite for admission.

***If my aunt never recovers sufficiently to go home, will we eventually have to move her somewhere else or can we just switch her from short- to long-term care?***

Your aunt's medical condition will determine whether she qualifies for admission to the long-term care section of the nursing facility. Since her health has been monitored since the moment of her admission by her attending physician, her social worker, and the nursing facility's staff, any of the three should be able to discuss your aunt's options with her.

**ISSUES UNIQUE TO SPOUSES OF RESIDENTS**

***I just admitted my wife in a nursing center and I'm beside myself. I just wander through the house, trying to think of something to do. It's as if she were dead!***

The hardest thing some spouses of nursing center residents have to face is their own fear of being alone. When suddenly a lifelong companion is no longer there, it's easy to panic and feel anxious and disoriented yourself. The best thing to do to combat these feelings of loneliness and anxiety is to keep busy. If you're employed, don't take too much time off right away. Work will keep you busy, and won't give you as much time to worry.

If you don't work, look into short-term volunteer work. Choose an area where you might eventually like to volunteer permanently. Whether it be community service, a political campaign, or just helping out with a neighbor's kids, find something to keep your hands - and your heart - busy during these early days.

***A girlfriend has invited me over for dinner since John moved into the nursing center. It just doesn't feel right to go out and enjoy myself without him. Am I doing the night thing?***

Socializing alone may make you feel awkward - even guilty at times - but interaction with people is important for your mental well-being. Men, in particular, have trouble seeking out new friends, but the first rule of thumb is to accept any and all invitations extended to you - this is one instance in which friends usually do know what's best. If you and your spouse often socialized with other couples, you might find it awkward or even painful to be included in future couples events. Participate if you want to, but if not, look on this as an opportunity to forge some new friendships.

***Tom and I were happy with him handling all of our legal and financial matters while I took care of the home. Now all of a sudden I'm buried in medical and financial paperwork that I don't understand.***

There's help available as near as your public library. Start there, but check out other community resources as well. There are many groups organized to assist seniors in tax preparation, advanced directives, etc., and even if you don't qualify as a senior, your special circumstances will no doubt be taken into consideration.

As a last resort, you can always hire someone to come assist you with some of your paperwork, but you'll probably find upon closer examination that the documents that are so intimidating to you now will be merely a tiresome chore in a month or so.

***My son's anger and my daughter's depression have left me feeling lower than ever. Why are they being so selfish and unrealistic about this?***

You may no longer be your husband's primary caregiver, but you'll always be your children's mom. Realize that they have no one else to take out their fears and frustrations on, and that this brush with their father's and, by extension, their own, mortality is very frightening for them.

Despite the developments that have affected their relationship with their father, you are still the same mom they have always known, they are looking to you for reassurance and stability. Try to ignore their reactions for now. As both you and your husband will eventually adjust to the new situation, so too will they.

If pressed, sit them down individually and calmly explain to them how you perceive their behavior. If asked to articulate their particular grievance, as well as a better solution to your husband's care problem, they will hopefully begin to realize that they are unjustly displacing their anger and anxiety onto you.

***Jim's children from his first marriage have been great about visiting their dad, but things are very strained with me. How can I explain to them that, like it or not, we're all in this together?***

Spouses of a second or third marriage can have it particularly hard since they might have to deal with the fears and frustrations of children not even their own. If possible, start by having your husband explain to his children why you and he made the decisions you did, making it clear to them that this was his choice as well.

If that is not possible, maybe it's best at first to let your actions speak for you. When they see how often you visit their father, how concerned you are about his care, and how difficult an adjustment the arrangement is for you as well, they'll probably reconsider.