

When Short-Term Rehab Turns into a Long-Term Stay



Even if your family member moves to a long-stay unit, he or she may be able to return home later -- if there is more progress, the home is prepared, and needed services are in place.

Like most family caregivers, you hope that your family member can go home after being a patient in a short-term rehab (rehabilitation) unit in a nursing home. But this does not always happen. Sometimes a short-term stay turns into a long-term stay. This is likely to result in a move to a long-stay unit in the same facility or a move to a different nursing home.

Most family caregivers and patients do not want or expect this move to happen. This guide can help you learn more about this transition. It can also help you make this move as smooth as it can be.

Why Going Home May Not Be Possible

During rehab, physical therapists and other staff members set initial (starting) treatment goals for patients. These are based on a person's condition and what he or she needs to learn or relearn to do. For instance, if your mother was in the hospital because of a hip fracture, then an initial rehab goal might be to teach her to walk safely. Or if your father had a stroke, an initial rehab goal might be to help him relearn how to dress and feed himself.

Sometimes patients make slow or little progress toward initial goals. There are many reasons why this can happen. For example, patients may be too weak or not able to do all needed exercise and therapy. Or they may be too sick. And sometimes, no matter how hard patients try, they do not respond to treatment right away.

How much progress your family member makes toward meeting his or her initial goals may also affect insurance payment for rehab services. Most insurances pay for rehab based on how well patients meet initial goals. Insurance coverage for intensive therapies might stop if patients do not make enough progress. If this happens, and your family member is not able to manage at home, your family member may have to move to a long-stay unit. The services there will not include as many or as intensive rehab sessions (such as physical therapy, occupational therapy, or other therapies).

Here are some other reasons why going home may not be possible:

- ▶ **Dementia.** Sometimes rehab staff notice signs of dementia (memory loss and disorientation) that you may not have seen at home. Rehab staff may then tell you that your family member cannot safely go home.
- ▶ **Environmental barriers.** This means that your family member's house or apartment is not set up for people who have problems getting around or managing on their own. For instance, your father's apartment building may not have an elevator and he now uses a wheelchair. Or your mother's house may have more steps than she can climb because of her heart condition. Sometimes bathrooms and kitchens are not arranged in ways that patients can manage safely on their own. Sometimes these problems can be fixed so that the patient can come home later.
- ▶ **Home care services.** Your family member's insurance may not pay for all needed home care services. For instance, Medicare does not pay for long-term home care.
- ▶ **Depression or isolation.** If your family member is feeling very sad or has no one nearby to help, going home can make these feelings worse.
- ▶ **Your limits.** You may not be able to give your family member as much time as he or she needs. Or you may have your own physical problems, responsibilities, or other limits on what you can do.



You have the right to be at the care planning meeting and should plan to attend. Family caregivers are expert about their family member's behavior and attitudes.

Finding Out That Your Family Member Must Move

Your family member's progress in rehab is discussed at a "**care planning meeting**." This takes place about 3 weeks after admission to rehab. At this meeting, staff members talk about your family member's initial treatment goals and what he or she needs for ongoing treatment and follow-up care. It may be clear by this meeting that your family member cannot go home safely.

You may have concerns or questions about your family member's progress even before this first care planning meeting. You do not need to wait before talking with staff.

Planning for the Move

Planning should start as soon as you know that your family member is going to a long-term setting. This can be a very hard transition for patients and family members.

There is a lot you now need to think about and do. Ask for help and advice from nursing home staff and others.

- ▶ **Deal with feelings about this move.** You and your family member may be very upset that his or her physical problems are not getting a lot better.
- ▶ **Take care of finances (money issues).** Your family member may need to apply for Medicaid. This is because Medicare and most private insurance do not pay for long-term nursing home care. You can ask the social worker on the rehab unit to help you with the paper work. This process can take many weeks.
- ▶ **Choose a nursing home.** This may or may not be the same place where your family member is now. Think about its location, program, and staff. Is this where you want your family member to live? If yes, then the move might be quite easy. If no, now is the time to look for other long-term stay options.

Learning About Long-Term Care Options

Choosing a long-term setting for your family member can be as hard as accepting that it is needed. There is a lot to think about, including: location; quality of care; medical and rehab services; finances (what insurance covers and what you need to pay for).

Take time to learn about your options and get comfortable with your choice. Ask family members, friends, and other health care professionals what they suggest. You can also contact groups that know a lot about long-term care. They include:

- ▶ **Area Agency on Aging (AAA).** These local agencies are part of the US Administration on Aging. They can provide information about local nursing homes and other long-term care options. To find your local agency, go to the AAA website at <http://www.n4a.org/about-n4a/?fa=aaa-title-VI>.
- ▶ **FRIA.** This is a one-stop resource for questions and concerns about long-term care and nursing homes. To learn more, go to the FRIA website at <http://www.fria.org> or call 212-732-4455.
- ▶ **National Long Term Ombudsman Resource Center.** An ombudsman is an advocate for residents' rights and quality of life. Ombudsmen can provide information about how to find a long-term care setting and how to get quality care. You can locate your state's local ombudsman and learn more at <http://www.ltombudsman.org> or call 202-332-2275
- ▶ **American Association of Homes and Services for the Aging (AAHSA).** This group offers tips about finding nursing homes and other community-based services. To learn more, go to <http://www.aahsa.org/article.aspx?id=3786> or call 202-783-2242.
- ▶ **The National Consumer Voice for Quality Long-Term Care.** This group offers a guide about choosing a nursing home. You can access its guide by going to http://www.nccnhr.org/uploads/File/guide_to_choosing_a_n_h_-_july07.pdf. To learn more and find other fact sheets, go to their website at <http://www.nccnhr.org> or call 202-332-2276.

- ▶ **Centers for Medicare and Medicaid Services (CMS).** This federal agency sponsors a website with detailed information about the quality of services at all Medicare- and Medicaid-certified nursing homes in the U.S. To learn more, go to www.Medicare.gov/NHCompare.

Getting Ready to Move

A move to a long-stay setting can be very stressful for you and your family member. Here are some ideas about how to get ready.

- ▶ **Visit where your family member will live.** Do so, even if it is the same facility as where he or she is now. Try to go on this visit with your family member. Ask to see all the units (floors, areas, or sections) where your family member might stay. Talk with staff about which might be best for your family member. This often depends on the type and amount of care your family member needs. You may not have all the options you want. If there is no open room now on the unit you want, ask if your family member can move there later on.
- ▶ **Prepare yourself. Many people get upset or depressed when visiting long-stay units.** Many residents (people living there) are sick, frail, or have some form of dementia. Look for those you think your family member would like to be with. If your family member does not speak English, then look for residents and staff who can communicate in his or her language.
- ▶ **Know that the pace is slower.** There will be some activities but perhaps not as many as in rehab.
- ▶ **Say goodbye to friends and staff in rehab.** Your family member may have become quite friendly with other patients on the rehab unit. He or she may also have good relationships with staff. It can feel like yet another loss saying goodbye to these people -- but it is important to do.

Being Prepared for Many Changes

There are many changes if your family member moves to another facility. But even if he or she stays in the same facility and moves to a long-term care unit, there still will be things that are new. Here are some changes to expect and prepare for when getting settled on the unit:

- ▶ **Words and terms.** In the rehab unit, your family member was a “patient.” In the long-term unit, he or she is a “resident” because this is now home.
- ▶ **Orientation.** A nursing assistant or other staff member will orient (show) your family around the new unit. If you cannot be there, ask someone to show you around later.
- ▶ **Staff.** There will be new staff to meet even if your family member moves to a new unit at the same facility. New staff includes nurses and nursing assistants. Your family member may also have a new doctor, social worker, dietitian, and recreation specialist.
- ▶ **Medical records.** Your family member’s medical record will be sent from rehab to this unit, or to the new facility. New staff will add their own assessments (reports) about care they think your family member needs.
- ▶ **Daily routine.** This routine may be somewhat different than at rehab. For instance, meals may be at other times. Laundry may be picked up and returned on new days. There may be a washer and dryer you can use to do your family member’s laundry. Residents may get showers or baths only on certain days. If so, tell staff about whether your family member preferences a shower or bath, how often, and at what time of day.
- ▶ **Therapy.** Rehab services do not always end just because your family member goes to long-term care. He or she may get rehab as long as there is progress. But the amount of therapy may be less. For instance, your family member may have rehab 2 or 3 days each week, rather than daily as before.

Making Your Family Member's Room Feel More Like Home

- ▶ **Roommate.** Most residents share a room with a roommate. This can feel awkward and takes time to adjust. You can help by learning about the roommate and what he or she enjoys. For instance: Does the roommate like the TV on or off? Will he or she wear earphones? What about listening to the radio? Does the roommate like the room hot or cold? What time does he or she go to bed and wake up? It is best when you, your family member, the roommate, and maybe the roommate's family, solve problems together.
- ▶ **Bedroom.** Many residents want rooms that feel somewhat like home. Talk with your family member about bringing in photos, books, games, bedspread, or blanket. Ask staff if you can bring in a favorite chair, bookcase, or other large item.
- ▶ **Privacy.** Find out if there are rooms where you can visit that are more private than your family member's shared bedroom.
- ▶ **TV and radio.** There will be some TVs on the unit. If your family member wants his or her own then you likely will have to bring it. It is good to have TVs and radios with headphones. This way, roommates do not have to listen too. Likewise, you might suggest the roommate also use earphones.
- ▶ **Telephones.** The unit may have a telephone for your family member to use but at an extra cost. Or you might need to arrange for your own phone service. Ask the social worker what you need to do and how much it should cost.

Ways to Make Your Family Member's Stay More Enjoyable

- ▶ **Calendar of activities and other points of interest.** All nursing homes post lists of events. These include movies, music programs, and other special events. They also include more routine activities such as special meals and birthdays. Ask staff where they post this calendar. Many facilities also have special rooms such as a greenhouse, chapel, and library. Help your family figure out how to get to activities and places that he or she might enjoy.
- ▶ **Things to do and places to visit nearby the facility.** Ask whether you can take your family member outside the facility. This could be to a nearby park, library, movie theatre, restaurant, or other place of interest. Staff will likely know of good places to go to.
- ▶ **Newspaper or magazine.** Does your family member like to read the newspaper or magazines? If so, ask if you can have it delivered to the unit. Expect to pay extra for this.
- ▶ **Food.** Food can be very important to your family member now. Help your family member talk with the dietitian or other staff about foods he or she enjoys. Talk also about any foods to avoid. The nursing home should be able to respond to most food requests. Find out whether you can bring in special food from home or a restaurant. If so, ask where to keep this food, how it needs to be packaged, what to write on the label, and whether it is okay to share with other residents.
- ▶ **Internet access.** Ask whether there is a computer that can be used to access the internet if this is important to your family member.

Being an Active Caregiver after the Move is Made

Your family member's move to a long-term unit can be hard for you, too. This is a big change in your role. Staff members now help your family member with medication, treatment, bathing, dressing, eating, and other daily tasks.

You can still be an active caregiver. Here are some ways:

- ▶ **Be with your family member at the time of the move.** Ask how you can help.
- ▶ **Get to know the staff.** They are often very busy taking care of a lot of residents, but you will be able to get to know them with time. Thank staff for caring for your family member – a kind word and smile are always welcome.
- ▶ **Advocate (speak up) for the needs of your family member.** These can be medical care needs and general needs and likes such as bathing times and food choices. This will help make your family member's stay more comfortable.
- ▶ **Talk with nursing staff or a social worker if you notice any problems or have concerns.**
- ▶ **Participate in care plan meetings.** Each resident has a "care plan." This is a meeting to discuss your family member's medical condition, rehab, diet, activities, and other important information. A full care plan is made once a year with updates every 3 months. Residents and their family members are always invited to these meetings. Ask when they will happen. If you cannot attend, ask if it can be held at another time or if you can join in by phone.
- ▶ **Attend Family Council meetings.** Many facilities have these types of meetings to discuss issues about living in the nursing home. There are also Resident Councils that are open just for residents. Ask when these councils meet if you or your family member want to attend.
- ▶ **Visit your family member as often as you can.** Try to visit at different times so that you can see how well your family member is doing. This is also a good way to get a sense of the quality of care.

Being a family caregiver of a long-term care resident is an important role. You will want to make sure your family member gets all the medical care he or she needs. You should provide a lot of support, too. Family and friends can assist by visiting your family member and helping you with other tasks. Working with others can help you make your family member's move to a long-term care unit as smooth as it can be.

Notes and Questions
