



Family
Caregiver
Guide



The best time to start planning for discharge is just after your family member is admitted.

While it may seem too soon to think about going home, planning gives you more time to prepare.

Rehab-to-Home Discharge Guide

In Rehab: Planning for Discharge

A good way to start planning for discharge is by asking the doctor how long your family member is likely to be in the rehabilitation ("rehab" or "subacute") facility. The doctor or physical therapist may have a general idea when the admission begins. But they may not know how long your family member will continue to improve, which is a requirement under Medicare and other insurance. Once improvement stops or significantly slows, insurance will discontinue payment, which may make discharge very rapid. Insurance may have other restrictions as well.

When patients leave rehab they might be discharged to:

- ▶ Home, with no needed services
- ▶ Home, with help needed from a family caregiver
- ▶ Home, with help needed from a home care agency
- ▶ A long-term care setting (such as in a nursing home or assisted living)

Know Who Is on the Discharge Team

Many people help plan a rehab discharge, and they are often referred to as a “team.” The team members include:

- ▶ **A doctor.** He or she authorizes (approves) the rehab discharge.
- ▶ **A nurse.** Often this is the head nurse of your family member’s unit, who will coordinate any education regarding medications and other nursing issues.
- ▶ **A social worker.** This person coordinates the discharge, making sure that everything happens when it should. He or she also takes care of many details about rehab discharge.
- ▶ **A physical or occupational therapist.** He or she is responsible for evaluating your family member’s progress in accordance with both professional standards and insurance requirements, as well as providing the therapy.
- ▶ **You, the family caregiver.** You likely are the one who knows your family member best.

Tell the team that you are the family caregiver. Meet with the social worker as soon as you can to talk about discharge. This is a good time to discuss:

- ▶ How much time you can devote to being a family caregiver
- ▶ Whether you will provide all or some of the needed care
- ▶ Whether you can continue to work at your job or must take time off
- ▶ Whether you have any health problems or other limitations, such as not being able to lift heavy weights
- ▶ Whether you have other commitments, such as caring for young children
- ▶ All your other questions and concerns about being a family caregiver



Your family member should not leave the rehab facility until there is a safe and adequate discharge plan. This means that the plan meets your family member's needs and that you can do what's expected of you.

Help Decide about Discharge

You may feel pressure from the rehab team to take your family member home. Your family member might also pressure you to go home as soon as possible. Being home might be better for everyone involved. But it needs to make sense for both your family member and you. This means that the home to which your family member will be discharged is safe, has a telephone, and does not need a lot of repair. It also means thinking about how to pay for care and balance caregiving with your other commitments.

This is a lot to think about. You may need time to figure out how to manage it all. **Tell the team if you are not ready or able to care for your family member after discharge. They will try to help you solve the problem(s).**

Appeal a Rehab Discharge Decision (if needed)

Sometimes the rehab program makes a discharge plan you do not want, agree with, or feel is safe. You have the right to appeal (ask for another review) this decision. By law, the rehab program must let you know how to appeal and explain what will happen. Make sure the rehab program provides you with contact information for the local Quality Improvement Organization (QIO) that reviews such appeals. You can find a list of QIOs by state at <http://qiossynergy.org/default.aspx?ID=qios>.

Appeals often only take a day or two. If the appeal is denied, then insurance will not pay for those additional days. Also, your family member will have to leave the facility immediately.

Next Step: Getting Ready to Go Home

There is a lot to think about as you get ready for your family member's transition from rehab to home. Here are some important issues to keep in mind:

Equipment and Supplies

Make sure to get all the needed equipment and supplies. Find out what the rehab program or home care agency provides and what you must get. Here are some good questions to ask:

- ▶ Will my family member require a cane, wheelchair, walker, special cushions, grab bars, or other assistive devices? Who will adjust them to fit my family member properly? Who will teach my family member and me to use them correctly?
- ▶ Does my family member need a hospital bed, shower chair, commode, oxygen supply, or other equipment? If so, where do I get these items?
- ▶ What supplies do I need? This may be diapers, disposable gloves, and skin care items.
- ▶ Do I get these from the rehab program or a home care agency, or will I need to buy them?
- ▶ Where can I find these supplies if I have to buy them?
- ▶ Will my family member's insurance pay for them?
- ▶ My family member already has this (or similar) equipment at home. Can it be used again?
- ▶ What do I do with the old medications left at home? Do I keep them or get rid of them? If I get rid of them, what is a safe way to do it?

Home Space

Your family member's home should be comfortable and safe, and a good place for care. Ask the rehab team if you need to do anything special to get ready. This might be to:

- ▶ Make room for a hospital bed or other large equipment.
- ▶ Move out items that can cause falls such as area rugs and electric cords.
- ▶ Arrange a safe place to store medications.
- ▶ Create a place to sit near your family member.
- ▶ Have a place for important information, such as a bulletin board, notebook, or a drawer

Health Care Tasks

You will likely do certain tasks as part of giving care. It is important that you know how to do these safely. **Try to learn as much as you can while your family member is still in rehab.** You can do this by watching the physical and occupational therapy staff as they do these tasks and asking them to watch as you try these tasks yourself.

Sometimes, rehab staff will not teach these tasks until the day of discharge. This may not be a good time to learn if you feel rushed or overwhelmed. Learn what you can, and ask who to call if you have questions at home.

You might be told to call someone from the rehab program, a home care nurse, or other health care professional.

Speak up if you are afraid of doing certain tasks (such as wound care) or cannot help with personal hygiene (like helping your family member take a shower or go to the bathroom). Some caregivers are okay with changing their family member's diapers while others feel very uncomfortable about doing this task. Think about your own feelings as well as your family member's. **The rehab team needs to know what tasks you can and cannot do so they can plan for any needed help.**

Special Foods

Ask the rehab team if there are certain foods your family member can or cannot eat. This might include specific foods such as milk or meat, or general types of food, such as very soft food or liquids. If your family member needs any special foods, try to buy them before discharge when it is easier to shop.

Medication

One of your jobs as a caregiver may be “medication management” — making sure your family member takes the right medication, at the right time, and in the right amount. Here are some questions to ask that can help you do this job well:

- ▶ What new medications will my family member take?
- ▶ For all new medications, how long should he or she take them?
- ▶ Should this medication be taken with meals? At certain times each day?
- ▶ Does the medication have any side effects?
- ▶ Can it be taken with other medications?
- ▶ Is this new medication listed in the *Medication Management Form*, along with my family member’s other prescriptions, over-the-counter medications, vitamins, and herbal supplements?
- ▶ Do I get this medication from my pharmacy or the hospital?
- ▶ Will my family member’s insurance pay for these medications? If not, are there other medications that work just as well and cost less?

A Medication Management Guide and a form that can help you organize your family member’s medication information, is available on www.nextstepincare.org.

At Home: Giving Care

Know Who to Call and What to Do

You may have a lot of questions during the first few days at home. **Make sure you have the phone number for the social worker at the rehab center, as well as any home care agency involved with your family member's care.**

Make sure you know what to do for your family member's care. This includes knowing:

- ▶ Are there any symptoms that you must report right away, such as fever, intense pain, or shortness of breath? If you notice these symptoms, who do you call, and what should you do?
- ▶ Are there limits or restrictions on what your family member can do? For example, your family member might not be able to take a bath, lift heavy things, or walk up or down stairs.
- ▶ Is it safe to leave your family member alone? If not, what should you do, for instance, when you need to go work?

Arrange for Follow-Up Care



You should find out about local resources. Many communities have resources that can help you and your family member, such as: Help with transportation or financial assistance, and friendly volunteer visits for your family member, counseling, support groups, and respite care (time away from caregiving) for family caregivers.

Your family member may have one or more new health care professionals once he or she is home. Even if no new health care professionals are involved, **your family member should have a follow-up visit with his or her doctor.**

Here are some questions you can ask about follow-up care before leaving the hospital:

- ▶ What health professionals does my family member need to see?
- ▶ Who should I call to make these appointments?
- ▶ Where will the appointments be? In an office, at home, or somewhere else?
- ▶ What should I do if I cannot get an appointment within a certain time?
- ▶ How will my family member's doctor learn what happened in the hospital and the rehab program?



Being a caregiver is a big job whether your family member is in the hospital, getting ready to go home, or already at home. You need to take care of yourself, not just your family member. This means paying attention to your feelings as well as physical health. It also means taking time for yourself—even for just a short while each day.

Plan for Routine Care

Even though all days are not the same, it helps when you have a plan for routine care. This means knowing what tasks are done each day and who will do them. If you are working with a home care agency, find out what jobs they and you will each need to do.

Paying for Care

You will have to deal with your family member's rehab bills at some point. **Make sure to read these bills closely, and make sure that your family member received all the listed services. Let the rehab or insurance company know if there are any problems.**

Dealing with these bills can be difficult, and some caregivers ask other family members to help. You may also have to deal with other financial and insurance issues. Each time you speak with a representative about these issues, write down who you spoke with, and what you discussed. Sometimes you may hear that Medicare or other insurance will not pay for a needed service. If so, check the facts for yourself.

Here are some ways:

- ▶ Talk with the rehab team who planned your family member's discharge. They may be able to arrange ways of paying for home care services.
- ▶ Call your State Health Insurance Assistance Program (SHIP). You can find contact information for SHIP programs in other states by going to the Medicare website at www.medicare.gov/contacts/static/allStateContacts.asp
- ▶ If your family member has Medicare, you can contact the Medicare Rights Center. You can call 800-333-4114 and ask to speak to with a Medicare specialist. You can also check online at www.medicarerights.org.