

Going Home after Rehab: A Family Caregiver's Guide

Discharge from a rehabilitation (rehab) facility to home can be hard for all involved. Your family member may still need a lot of assistance even though he or she no longer needs to be in a facility.

In the Rehab Facility: Planning for Discharge

Start by asking the rehab team how long your family member is likely to be receiving services in the facility. While it isn't possible to give an exact date, rehab staff usually have a general idea of when someone will be ready to go home. When patients leave the rehab facility, they might be discharged to:

- ▶ Home, with no services needed
- ▶ Home, with help needed from a family caregiver
- ▶ Home, with follow-up care at an outpatient rehab clinic
- ▶ Home, with help needed from a home care agency



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.

Know Who Is on the Discharge Team

Many people help planning for discharge and they are often referred to as a “team.”

The team members include:

- ▶ **The doctor.** He or she approves (authorizes) the discharge.
- ▶ **The therapists** (physical, occupational or speech therapists working with your family member). They evaluate your family member’s progress and assess future needs.
- ▶ **A nurse or social worker.** This person coordinates the discharge, making sure that everything happens when it should.
- ▶ **You, the family caregiver.** You likely are the one who knows your family member best.

Tell the nurse or social worker that you are the family caregiver. Meet with this person 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 some or all of the needed care
- ▶ Whether you need to, and can, take time off from work
- ▶ Health problems, 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 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).

Next Step: Getting Ready to Go Home

There is a lot to think about as you get ready for your family member to go home.

Equipment and Supplies

Make sure to get all the needed equipment and supplies. Find out what the facility or home care agency provides and what you must get.

Here are some good questions to ask:

- ▶ Does my family member need a hospital bed, shower chair, commode, oxygen tank, or other equipment? If so, where do I get these items?
- ▶ What supplies do I need? These may be diapers, disposable gloves, and skin care items.
- ▶ Do I get them from the facility 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?

Medication Management

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 medication will my family member take?
- ▶ How long should he or she take this medication?
- ▶ 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 along with my family member’s other prescriptions, over-the-counter medications, vitamins, and herbal supplements listed on the medication management form?
- ▶ Do I get this medication from my family member’s pharmacy or the rehab facility?
- ▶ 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

Health Care Tasks

When your family member is at home, 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 the facility.** You can do this by watching rehab facility staff as they do these tasks and asking them to watch as you try these tasks yourself.

Sometimes, rehab facility staff will not teach these tasks until closer to 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 facility, a home care nurse, or another health care professional.

Speak up if you are afraid of doing certain tasks (such as wound care) or can't 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 team needs to know what tasks you can and cannot do so they can plan for any needed help.**

Home Space

Your family member's home should be comfortable and safe, and a good place for care. Ask the 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.
- ▶ Remove items that can cause falls such as area rugs
- ▶ Make sure that electric cords are out of the way
- ▶ 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 drawer.

Special Foods

Ask the 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 foods, 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.

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 phone numbers for people on the rehab team 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 limits or restrictions on what your family member can do? For example, your family member may not be able to take a bath, lift heavy things, or walk up and down stairs.
- ▶ Is it safe to leave your family member alone? If not, what should you do when, for instance, you need to go work?
- ▶ 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?



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.

Arrange for Follow-Up Care

Your family member may have one or more new health professionals once he or she is home. Even if no new health care professionals are involved after discharge, **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:

- ▶ 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 transportation arrangements need to be made?
- ▶ 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 rehab facility?

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 medical 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 facility 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 facility staff 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 by going to the Medicare website at www.medicare.gov/contacts/static/allState-Contacts.asp
- ▶ If your family member has Medicare, you can contact the Medicare Rights Center. You can call 1-800-333-4114 and ask to speak with a Medicare specialist. You can also check online at www.medicarerights.org.

Taking Care of Yourself

Being a caregiver is a big job whether your family member is in the hospital, the rehab center, 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.