



The First Step in Care: Becoming a Family Caregiver

The United Hospital Fund's Next Step in Care guides (www.nextstepincare.org) are designed to help family caregivers and health care providers work together to make transitions in patient care easier and safer. Transitions occur when a patient moves from one care setting to another. To make the best use of the guides, you first have to understand that you are in fact a caregiver.

You are a caregiver if you:

- ▶ **Take care of someone** who has a chronic illness or disease.
- ▶ **Manage medications or talk to doctors and nurses** on someone's behalf.
- ▶ **Help bathe or dress someone** who is frail or disabled.
- ▶ **Take care of household chores, meals, or bills** for someone who cannot do these things alone.

If you are a new caregiver, this guide will help you understand your new challenges. If you have been caregiving for a while, this guide will help you look at your responsibilities in a new way.

Big events in life are often marked by ceremonies and rituals. A wedding makes you a spouse. A naming ceremony celebrates the birth of a child. A graduation acknowledges your educational achievements. A funeral marks the loss of someone you love.

But when you become a family caregiver, there are no ceremonies or rituals. No one congratulates you. No one sends presents. No one even asks if you want to become a caregiver, or tells you what it might mean. You may not even have realized that you have taken this life-changing step. And even if you do know that something big has happened, you may not realize what it means or how to adjust.

Why It Is Difficult to Call Yourself a Caregiver



Child, spouse, lover,
cousin, neighbor, friend –
as people take on a
caregiving role, it is
important to know that,
no matter what your day-
to-day responsibilities are,
the heart of your
relationship will always
remain. You will always
be the child, or spouse,
lover, cousin, neighbor,
or friend.

Many people say, “I’m not a caregiver, I’m a daughter, son, partner, or wife.” They may be afraid that if they acknowledge their caregiving role, their basic relationship to their family member will mean less to both of them.

This fear is understandable, but not realistic. You will always be a daughter, son, husband, or wife.

Some people talk about caregiving as “becoming a parent to your parent.” But that’s not really true either. Whatever you do for your aging mother, she will always be your mother. Thinking of her as your child is not helpful for either of you.

Another objection to being called a caregiver is that you are not doing anything special. You are just taking care of someone you love, as you promised or feel obligated to do. **But the reality is that “taking care” in today’s complicated health care world goes far beyond what any family member had to do in the past.**

Why It Is Important to See Yourself as a Caregiver



Some state Medicaid programs allow patients to pay family members for daily care instead of using a home care agency.

Being a caregiver gives you some rights and authority when dealing with health care and social service agency staff.

- ▶ As a family caregiver, you have the right to get information about your family member's condition.
- ▶ You have the right to be involved in decision making about your family member's care.
- ▶ You are an essential partner in the health care team and have the right to be trained to provide care.
- ▶ As a caregiver you can find support services that you might otherwise miss.
- ▶ In some states, being a caregiver can protect you from job discrimination.

Still, it's an emotional as well as practical transition. There are ways to make the transition less stressful and, equally important, help you cope when caregiving ends.

When Does Caregiving Start?

The transition to becoming a caregiver is often not the event itself, which may be an emergency, but what happens after the emergency. The moment of realization may come when a hospital discharge planner assumes that you will provide your father's extensive needs for care at home. Or it may be when a nurse tells you that your husband will be unable to feed himself after a stroke. Or perhaps the close family members you counted on for help are unable or unwilling to provide day-to-day care.

It is hard to accept that your family member is going to need help from now on. It is also hard to accept that you will need to provide that care or find other people to do it. But once you have accepted the reality, you can begin to deal with it. Here are a few things to remember:

- ▶ **Think before you act.** Your first thought may be to quit your job, move your family member into your home, or sell your own home to pay for care. Take time to think about all big



The moment you realize that you are a family caregiver may come after years of a parent's gradual decline, or suddenly after a spouse's stroke.

There is nearly always some event that forces a change. It may be an event that involves the police – a fire, driving accident, wandering – or the health care system – a serious fall, a diagnosis of a chronic disease, a hospitalization.

decisions. What you do now will affect your future and the rest of your family too.

- ▶ **Set limits on what you can do.** No one can do it all. You will need to get help from many people—professionals, people you hire, other family members, friends, and community services.
- ▶ **Let go of guilt.** Sometimes other people make you feel guilty - a nurse or doctor who criticizes you because your father does not do his exercises, a sister-in-law who spots the one room you haven't cleaned recently, your mother who wants you and only you by her side all day. Most guilt, however, comes from your own feelings of not being a good enough caregiver, parent, spouse, or employee. If you are doing your best to keep up with the many demands of caregiving, there is no reason to feel guilty. **If you realize that even your best is not good enough to meet all the needs, it's time to change the situation and ask for help.**

First Steps for Family Caregivers

Learn all about your family member's condition. Find out about your family members medical condition, and the risks and benefits of the treatment choices, and what is likely to happen in the future. You may have to speak with several different doctors to get all the information, and you may have to ask lots of questions.

Sometimes different doctors focus on just one part of the picture and assume someone else is taking care of the rest. You need the whole picture. Some treatments must be done immediately, for example, for a heart attack or stroke, but many can wait until you can sort out the options.

Find out what your family member's insurance pays for (and what it doesn't). You may not even know exactly what insurance your family member has when you become a caregiver. You may not know whether he or she is eligible for some public programs, such as Medicaid. The insurance company's brochure is only the beginning. You will need to get more information about the specific doctor or other bills insurance will pay for and other limits to the plan.



If you are responsible for providing, managing, or paying for care, you have the right to medical information, unless your family member objects.

For more information about your rights under the law, review the [Next Step in Care guide to HIPAA](#).

Review or create legal documents. Perhaps you and your family member have talked about what to do in case of serious illness or disability. Maybe you even have some legal documents that put this in writing. Most people do not want to talk about this possibility. If you do not have legal documents that outline your family member's wishes, you should get these documents in order.

At the very least, **your family member should sign an advance directive and health care proxy if he or she is able to do so.** An advance directive tells health care professionals what kinds of care your family member wants or does not want if he or she cannot participate in a discussion. A [health care proxy](#) names someone to make treatment decisions on the person's behalf in those situations. Every state has different rules about advance directives (sometimes called "living wills"). Wherever you live, make sure you can easily find the documents so that you can give them to doctors and hospitals.

You may also need a durable power of attorney for financial affairs if your family member cannot pay bills or make financial decisions.

He or she should have a will if there are assets like a house or bank account. It is best to have an attorney advise you if there are other people in the family who will be affected by the way the money is spent or divided up.

Consult with other family members. Make every effort to get other family members involved. Consider holding a family meeting. This works well if you have the kind of family that is used to problem-solving together. If not, you can talk to individuals separately to find out their feelings about your family member's:

- ▶ Medical care,
- ▶ Living arrangements,
- ▶ How the caregiving tasks can be divided, and
- ▶ How to pay for what insurance doesn't cover.

Try to find a way to include everyone, even if the final arrangement isn't exactly "fair" in the sense of someone (probably you) will be doing more than others. You may need to balance cultural traditions --the oldest or unmarried daughter is the caregiver or only men can make decisions -- against the



Being a family caregiver is difficult. Other family members may not live up to your expectations or their own promises.

Being resentful and angry will not change the situation, nor will it help your family member. Even if you can't help feeling this way, try to keep everyone informed about important changes in your family member's condition or decisions that have been made. Keeping communication open will help when decisions have to be made later on.

realities of your life. Community organizations that provide caregiver support services may be able to provide a social worker or counselor to hold a family meeting if you have or foresee family conflicts.

Find out what is available in your community for your family member and you. Nearly every community has some kinds of help available for you. The [“Links and Resources” section](#) of the Next Step in Care website can get you started.

There may be:

- ▶ Adult day care for your family member,
- ▶ Meals on Wheels,
- ▶ Limited financial support,
- ▶ Respite (a break from caregiving), and
- ▶ Other services.

Local religious or community-based organizations often provide support of various kinds, such as transportation, friendly visiting, simple home repairs, and others. Disease organizations and other groups offer support groups where you can talk to other people in similar situations. Perhaps some family member or friend can do some research for you to find the options.

Try to continue some of your previous activities. You may get pleasure from singing in a choir, meeting the garden club, bowling, going to a baseball game, or just having lunch and a movie with friends. These activities keep you in touch with the non-caregiving world. **It is not selfish to take time off to do these things. It is a way to keep caregiving from overwhelming you.**

Think about how you will manage your job and caregiving. Half of all caregivers are employed full- or part-time. If you have a job, you will have to figure out how to balance employment and caregiving. Some jobs are flexible, making it easier to keep up with your work. Other jobs require the employee to be at a certain place at a certain time. Some employers will work hard to make accommodations for you, but others set rigid rules.

Look into the provisions of the Family Medical Leave Act to see if they apply to you (remembering that leave under this Act is unpaid). A few states, such as California and New Jersey, have paid family leave.

There is no easy answer. It's best to address the changed situation with someone you trust at work. Even though you may be worried about caregiving, make sure you continue to do your best at your job.

Pace Yourself for the Long Term

Many family caregivers expect their caregiving to last a short time, only to find that it goes on for years instead of months.

Many people find it easier to respond to an emergency than to adjust to a long-term situation. You need to pace yourself, know your strengths and limitations, and be flexible.

Time Out Moments. Most caregiving situations change over time:

- ▶ Your family member's condition may improve or get worse.
- ▶ New complications may arise.
- ▶ If your family member has memory problems, he or she may not be safe alone anymore.
- ▶ A new hospitalization will mean new medications and new treatment plans.

Perhaps your daughter has a new baby and needs your help. Maybe your job has changed and you need to work extra hours. Perhaps your financial situation has improved, and you can afford to pay for more help. Or perhaps it has become worse, and you cannot continue to pay for costs not covered by insurance.

This is a "time out" moment, when you, your family member, and others need to reconsider the arrangements. Is it time for your family member to move in with you? Would assisted living be a good choice? Is it finally time to consider a nursing home? Remember, let go of guilt. If a move to a facility seems the best decision overall, you will still be a caregiver. What you do for your family member will change but you will still be a major source of emotional support. You will also become an advocate for your family member in the new setting.

Your Own Health. "Take care of yourself" is the most common advice you will get from professionals and friends. And it's good advice. It's just hard to get a good night's sleep, eat healthy



Each of these transitions is an opportunity for you to revisit your own ability to provide the level of caregiving you have become used to.



Activities like exercise or support groups give you a chance to be with other people while taking action on some of your own health needs.

foods, exercise, and go to the doctor regularly when caregiving seems to take every minute of every day.

There is no answer that works for every caregiver. Try focusing on the one area that makes you feel most at risk. Seeing a doctor regularly and following his or her recommendations is most important if you have a chronic health problem. If you are generally healthy, but feeling seriously depressed, you need to consult a doctor or therapist.

When Caregiving Ends

In one sense, caregiving never ends. The experiences you have had—both good and bad—will stay with you forever. You may have been exhausted physically but gained a stronger spiritual awareness. You may have learned new skills, gained new self-respect, or found a new world of advocacy.

But of course, with the death of your family member, the day-to-day experience does end. Grief is natural. So is a sense of relief. Perhaps your family member's last days were peaceful and dignified; if so, you can feel pride in having helped accomplish that through your care. If not, then you know that you did your best and can think about your own wishes if you were in a similar situation.

Many former caregivers find that they miss not only the person they loved and cared for but also caregiving itself. Some found caregiving rewarding and miss the satisfaction of knowing that they were making a difference in their family member's life. Some became so committed to the daily routines that they don't know how to cope with the emptiness. It is impossible to go back; it is hard to go forward.

How you coped with caregiving makes a difference. It will be easier to start whatever comes next if you were able to maintain a reasonable balance between caregiving and all the other important parts of your life. There is life *after* caregiving. What it will be depends in part on how you lived *through* caregiving.