

## CHAPTER 15

# Support for caregivers



Everyone needs help sometimes. It is rare that we can go through a day without getting help from—or giving help to—family members, neighbors, or even strangers. It is human nature to help each other.

A disabled woman often needs assistance in a daily, ongoing way. When she gets the help she needs, she can live a healthier and happier life, and can contribute to her family and community.

Assisting a woman with disabilities can be rewarding work, but it can also be stressful, especially if she needs a lot of care. This chapter is mainly for families and others who assist women with disabilities in caring for themselves. It will also help disabled women better understand the needs of the people who help them.

## MAKE DECISIONS TOGETHER

Above all, anyone who assists a woman with a disability must remember she is a grown woman and not a child. If she can, let her tell you what she needs help with, and then together you can decide the best way to do it.

As much as possible, the disabled woman should be in charge of her care and her life. Caregivers should encourage the disabled woman to regard herself as the captain of the 'team.' That way she can get the help she needs, and not assistance given in a way she finds unnecessary, not helpful, or lacking respect.

As far as possible, talk with the disabled person about what she expects. Ask her what responsibilities she can share, and what a caregiver needs to do or not do. She may not feel good asking for help to do things she would rather be doing herself. It will be easier to give good care if you and the woman can talk about this openly. If that is not possible, try putting yourself in her place and imagine what she might be feeling.

**If she is deaf** and uses sign language to communicate, make sure you learn how to sign with her as soon as possible.

**If she is blind**, let her tell you how she wants you to help her find her way around. Do not just take hold of her arm or hand and start to lead her. Let her take your arm first. Also, if she uses a stick or cane to find her way around, make sure it is always close by her side.

*Ramola tells me what help she needs. She is the one in charge!*



### ***What women with disabilities can do***

If you are a woman with a disability and you need help with daily activities, such as bathing, dressing, eating, or getting up from lying down, talk with the person who will assist you before they begin to help you. Make sure they understand how much assistance you do or do not need.

**Be patient.** It may take time for the person to realize there are many things you do not need help with.

**Caregivers need respect.** Most caregivers and assistants work very hard. They need a little time to themselves every day as well as a whole day off at least once a week. If your caregiver is rested, he or she will be better able to assist you.

**Make decisions together.** Although you know best the sort of assistance you need, listen to the ideas the caregiver may have. Sometimes her ideas may work better.

**Meet with other disabled women** to share ideas about the best way to use the help of a personal caregiver.

# The community must value caregivers

Both women with disabilities and caregivers—whether they are family members or paid assistants, whether they are men, women, or children—are valuable members of our communities. They need to be supported in real and warm relationships within the families and communities where we live, work, and share our joys and suffering. But like most domestic work, assisting women with disabilities is seldom valued, appreciated, or seen as important. Sometimes a helper feels that even the disabled woman herself takes the assistance for granted!

## Women as caregivers

Most often, women and girls assist family members who are sick or have a disability. And they do this while they continue to do their other work at home and in the community. For many women, their daily work begins before dawn and is not done until late in the day. When women are also helping care for another person, they have even more work to do.

*There's too much to do. As soon as I send the children to school, I must give Mary a bath. And then I have to wash our clothes and cook a meal. When will I have time to plant the cassava? I never finish everything.*



## Children as caregivers

It is easy to forget that children—especially daughters who assist their mothers—have their own needs. Children need to spend time with other children, to learn and to play.

Instead of always relying on their daughters, mothers with disabilities can also get help from other adults. If the mother can explain to everyone the help she needs, perhaps the entire family can work together as a team to assist her.

## Men as caregivers

Sometimes it is the man or boy in a family who is the caregiver for a wife, sister, or mother. If so, he may need help from other women in the family, as well as the person he is assisting, to understand why life for a woman with a disability might be different than it is for a man. The differences between male and female bodies are important, but the differences in the ways men and women are raised and treated in the family and community are even more important.

## PAID PERSONAL ASSISTANTS

Sometimes a woman with a disability can pay a personal assistant whose work helps her have more freedom and be more independent. In some communities, the government provides money for people with disabilities to hire someone to assist them with daily care or will pay family members and friends to assist them. Sometimes a disabled woman gives her assistant food or a place to stay.

Although the work that assistants do, such as taking care of daily hygiene including bladder and bowel care, is very important to a person's health, it is usually considered a low-status job and often pays very little. Many personal-care assistants say that family members sometimes want to control them and make unreasonable demands on their time, or dismiss them without explanation. And if disabled people are isolated, they may not understand how badly the attendant is being treated.

Paid caregivers, like other workers, need fair wages, time off, vacations, and sick leave.

Organizations and community groups that train and provide jobs for personal assistants can:

- help set standards for working conditions.
- educate about ways to prevent and reduce conflicts.
- offer training in counseling skills to better meet the emotional needs of women with disabilities.
- teach skills for lifting, helping someone exercise, and preventing infection.

*No one bothers to be polite to me. If only Christine would realize that I need a little time to myself during the day, and a day off from work.*



### ***Community workers make time for caregivers***

In Ghana, a group of community workers who help older people gathered a group of caregivers together to talk about how to make things easier for them. They started the group because when the community workers traveled to different villages in Ghana, looking in on older people and assisting them with everyday tasks, they realized that in addition to helping older people, they also needed to look out for the people who help the older people every day. Now, whenever a community worker goes to visit an older person, she also makes time to talk to the person's caregivers. She listens to their feelings and problems. She also helps them with their tasks if they need it, and makes sure the caregiver gets a break for a little while.

# Caregivers need help too

## UNDERSTAND YOUR FEELINGS

Caregivers stay busy trying to make things better for the person with the disability. They often focus on how that person is feeling. But, if you are a caregiver, it is also important to take time to notice your own feelings. Even if you are glad to assist a woman with a disability, you will sometimes get tired, experience stress, or feel frustrated or upset. As a caregiver, you may work in many different ways—as a nurse, a counselor, a driver, a cook, an accountant, and a housekeeper—all at the same time. If you look after a person who is very ill or depressed, you may experience more stress.

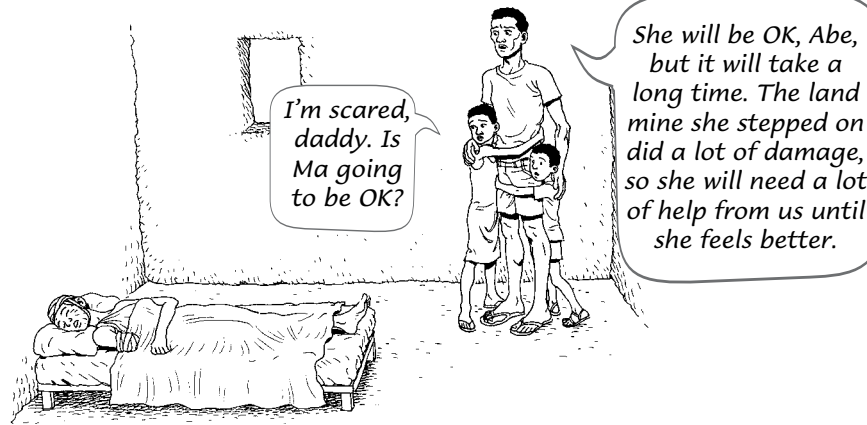
It is natural for family members and others who assist women with disabilities to feel ashamed or guilty for being frustrated, tired, angry, or upset. Even a person who cares for a close relative or a spouse can experience uncomfortable feelings and strong emotions. Do not feel guilty or ashamed for wanting to get away sometimes.

If you can notice and think about what makes you feel angry, frustrated, or helpless, then you can try to find a way to change the underlying causes of your feelings.



*If I knew more about Li Peng's disability, I could help better. Neither of us knows what she needs. It makes me feel very frustrated and sometimes I don't feel like helping her.*

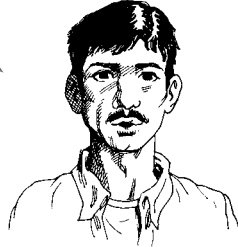
### ***A sudden disability affects the whole family***



When someone close to you becomes disabled suddenly, because of an accident or an illness, everyone gets injured in a way. The unexpected change in your life can be frightening, and can cause you and other family members to feel very sad or angry.

Understanding your feelings can move you to actions that make both your life and the life of the woman with disabilities better.

*I love my wife and I want to support her. But since her accident, my life has become so difficult. I have to do everything for her. It makes me feel angry with her sometimes.*



**Feeling angry** may give you energy to help organize a group of caregivers and others to persuade the government to make it easier for women with disabilities to get good health care, transport, and access to public buildings.

**Feeling frustrated, helpless, or lonely** may help you reach out to other people in your community who live with women who have disabilities, or who are themselves disabled. They may be able to help you.



*People in my village do not treat women with disabilities well. I wish I could change that and make life better for Sita. It makes me feel so sad and helpless.*

### Healthy ways to talk about feelings

When people who spend a lot of time together do not talk about how each other feels, they can become frustrated and angry with each other. Even if talking cannot find a way to change the underlying reasons for your feelings, it can help both of you to change how you act on them.

People show their feelings in different ways. There are healthy ways of expressing feelings and unhealthy ways. For example:

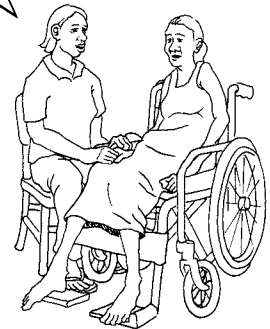
*You're an ungrateful woman! I don't know why I bother to try to help you.*



This is a dangerous and unhealthy way to talk about feelings.

*When you tell me all the things I'm doing wrong, and never talk about anything I'm doing right, I get angry because you don't seem to appreciate my help.*

This is a safe and healthy way to talk about feelings.



### ***A mother in Nigeria tells how she cares for her disabled daughter***

My daughter is a polio survivor. When she was a young girl, we could not afford to buy a wheelchair or to employ anyone to help us. So I used to carry her on my back to school every day, even up to the 12th grade. It was hard for me and I would get very tired as she got bigger and heavier. When she got to university she also got a wheelchair, and now she even has her own car. So I can rest more compared to what it was like a few years ago.

But now she needs emotional help because she becomes erratic in her behavior sometimes. I understand that this has to do with what she is going through, so I try to help her. But if I could afford to employ someone to help her become more emotionally stable, then I would be able to look after myself better and not be so exhausted all the time.



## **Take care of yourself**

Some caregivers devote themselves completely to fulfilling the needs of the people they care for. They get so good at helping other people that they forget to take care of their own needs. Sometimes they sacrifice their own well-being and their enjoyment of life. After a while, helpers who never think about themselves may begin to get frustrated and angry at the people they help. This can hurt both the helper and the person she assists.

If you do not take care of yourself, you stop having energy to help others. To take good care of someone, you must get enough sleep and rest, look after your own physical needs, and continue to have fun and other relationships.

Practice traditions that calm the body and mind and build inner strength such as yoga, prayer, meditation, T'ai Chi, and others. Practicing these traditions regularly can help you cope with the stress of caring for someone.

### **Take care of your own health**

- Eat good food so your body stays strong.
- Get enough sleep so you will have enough energy during the day.
- Get more exercise than just your work as a caregiver.
- Massage can help you relax your body. It can also help relieve stress and upset.



yoga

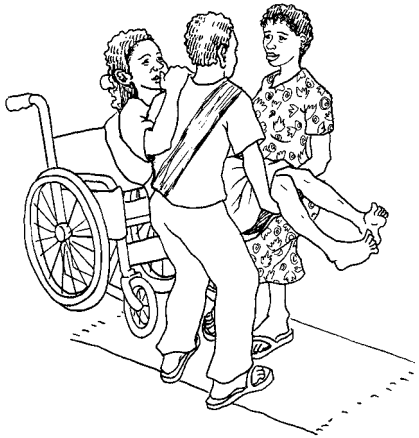


prayer

Make time to put your work aside and do something you enjoy. It is important for a woman with a disability and her caregiver to both have friends and interests away from each other. To have a full and satisfying life, each of you needs to spend time with other people.

### ***Be careful not to injure yourself***

The job of caring often involves physical work, such as lifting the person you are helping. This can cause injuries to your back. To lift or carry someone or something safely:



- Use your leg muscles, not your back muscles. When you lift something heavy from the ground, kneel or squat to pick it up rather than bending over.
- Keep your back, shoulders, and neck as straight as possible as you straighten your legs.
- Ask someone to help you lift the person you are caring for. It may seem quicker to do it yourself, but if you injure your back, later on you may not be able to help at all.

## **ASK OTHERS FOR HELP**

Being a caregiver can be isolating. When a disabled person relies on just one helper all the time, everyone else may feel that the 'expert helper' is the only person who knows the right way to assist. But no one should be a disabled woman's only helper. Other family members, friends and neighbors can assist by bringing or cooking a meal, going to the market, cleaning, or just coming to visit. This will help you rest and have more energy later.

## **GIVING AND RECEIVING HELP**

Look for ways a disabled woman can do things as part of the family's daily routine. Then, she can give help instead of just receiving it. Have good, realistic expectations. Expect a woman to be the best she can be. Encourage her to try new things and develop her skills.

*Qin Cheng does all the accounts for our family's poultry business. You can say she's our resident manager!*



## Start a caregiver's group

One important way to improve health for caregivers is to talk with each other. Both caregivers and people with disabilities need support from others who have similar experiences. Talking with others about your needs and feelings can help you feel less isolated. You can also share ideas with other caregivers about how to make things easier and build support systems for you and all the disabled people you assist.

If there is not a group already, and you know there are other caregivers in the community, it may be up to you to start one. Some of the strongest and most active groups began because of one person's idea. A group working together can solve problems and do more than if they each work alone.

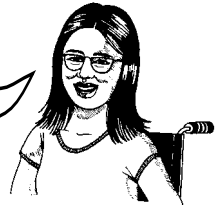
### To start a group:

Find 2 or more caregivers who want to start a support group. If you do not know any families in which someone is disabled, a health worker may know of other families in nearby communities.

Plan when and where to meet. It helps to choose a place where everyone will be comfortable talking, perhaps a room in a health center, community center, cooperative, or place of worship. At the first meeting, discuss why you are meeting and what you hope to do.

Probably one person will be the leader of the first few meetings. But it is important that no one person makes decisions for the group. Everyone should have a chance to talk. Try to keep the discussion focused on the main reasons for the meeting. After the first few meetings, take turns leading the group. Having different people lead each meeting will help shy members participate.

*I need care all the time. I have a group of attendants and friends who have formed a "take care of Mai" network. They talk to each other, help each other feel better, and support each other. They all like me, and I like them. It's like a great circle.*



*We found out that all of us have the same kind of problems.*



*I can talk about my problems openly and get advice on what to do.*

### ***Together we help our children and ourselves***

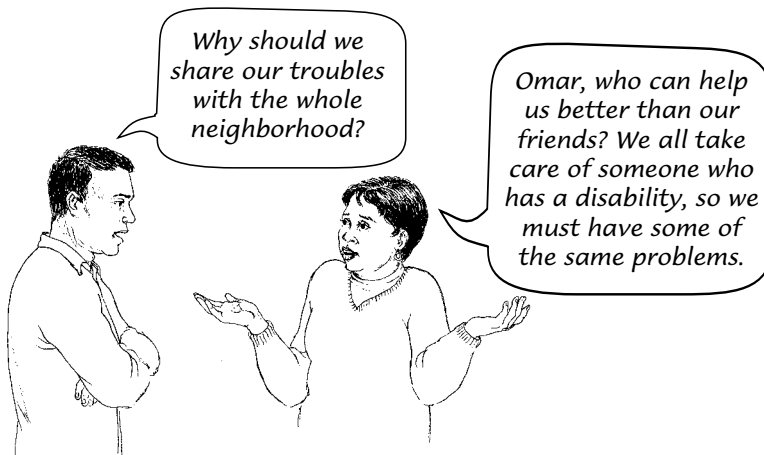
In a poor community in Bangalore, India, several families of disabled children and adults have formed a support group. They meet once a week to talk and to make plans to promote and demand services in the community for persons with disabilities. They also own and operate several auto-rickshaws (3-wheel motorcycle taxis) to take children with disabilities to and from school.



### **LEARN TO SUPPORT EACH OTHER IN THE GROUP**

Often, people who are always assisting others are too busy to think about their own feelings. Or they think they have no right to feel upset, or that only the woman with a disability should feel upset. Even when people know each other well, it may take time to feel comfortable talking about feelings, experiences, and the challenges of being a caregiver.

It is easier for some people to speak in a group than it is for others. But speaking is not the only way people can express their thoughts and feelings. Try different activities, such as singing songs, creating poems, or telling stories to help each person participate in a way that feels comfortable for them. Some people may best express themselves by drawing or painting pictures.

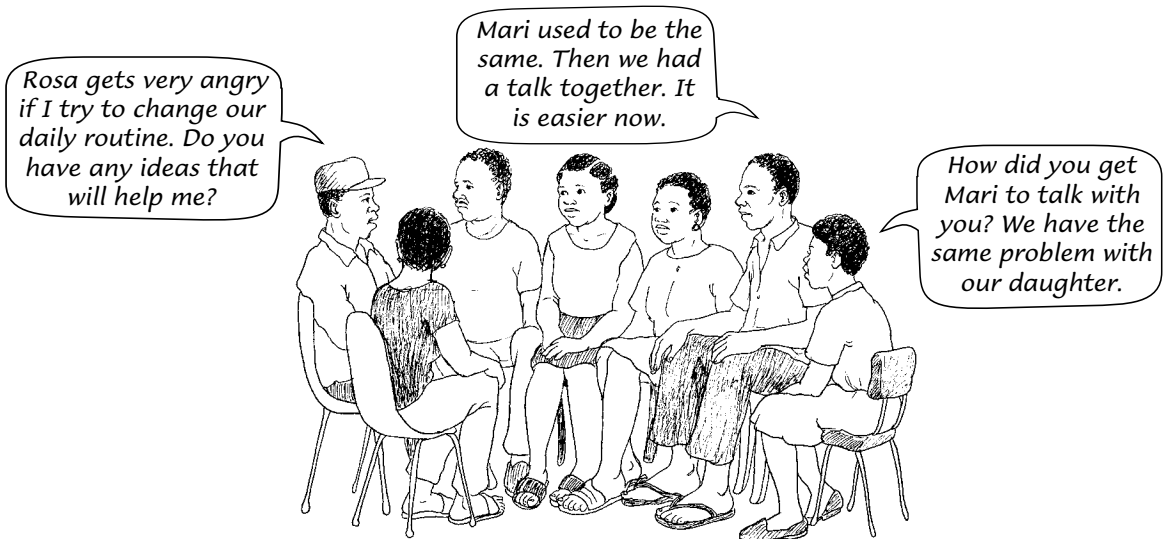


Here are some suggestions to help group members feel comfortable and trust each other:

**Listen to what others say.** Think about how you want others to listen to you, and then try to listen to them in the same way.

**Try not to tell other people what to do.** You can help others understand how they are feeling, and share your own experiences. But everyone must make their own decisions about the best way to assist people with disabilities.

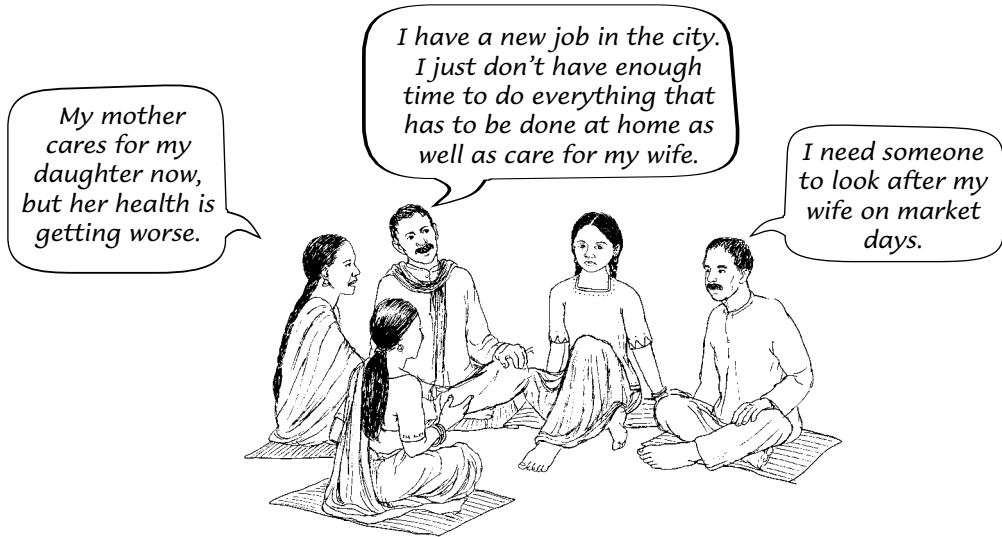
The support group can be a place where a caregiver can show anger or cry from frustration. By sharing experiences and ideas, you can help each other find ways to change the causes of these feelings.



## PLANNING FOR ACTION

A group working together can take action to solve many problems. Here are some useful steps for taking action.

1. Choose a problem that most people in the group feel is important. Although many changes are probably needed, your group may be more effective if it works on one problem at a time. At first, pick a problem that your group has a good chance of solving quickly. Then, as the group learns how to work together, you can work on more complicated problems.



2. Decide how you want to solve the problem. List many ways the problem could be solved and pick the one that best uses your group's strengths and resources.



3. Make a plan. Members of the group will need to do different things to get the job done. Try to set a date when each should be finished.

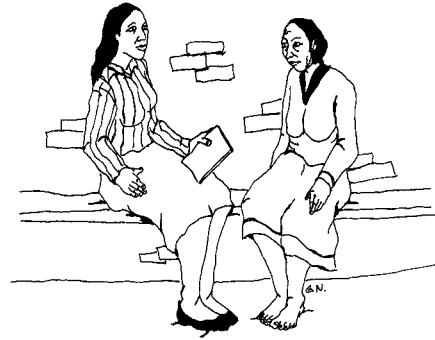


4. When you meet again together, talk about how the work is going. Adjust your plan as needed if difficulties arise.



**To the health worker:**

Health workers can help caregivers. When you treat a woman with a disability, try to discuss with her the relationship she has with her caregiver. If her caregiver comes with her, talk with them both about their relationship and about what each needs from the other.



Talk with the caregiver to see if she has any problems you can help her with.

Encourage the caregiver to talk about her own feelings. Listen to the caregiver and let her talk. Do not scold her for feeling frustrated or upset. Assisting another person is hard work. Remind the caregiver that it is natural to sometimes feel sad, angry, or frustrated.

Ask the caregiver about her own needs. Encourage her to take care of herself as well as the person she helps.

Try to find someone who can give the caregiver a break. Everyone needs some time for themselves. See if you can find another person in the family or in the community who could help out for a little while.

If necessary, teach the caregivers in your community any health care and counseling skills they may need to take better care of the woman with a disability they are assisting.

**IMPORTANT** There is a difference between a person feeling frustrated, and hurting the person they help. Sometimes caregivers get so stressed and angry that they are dangerous to the person they are taking care of. Always be alert for signs of abuse when you examine a disabled woman (or any woman), and try to talk to her alone to make sure she is not being abused by her caregiver in any way. See Chapter 14 for more information about abuse and violence toward women with disabilities.



*I have learned a lot from the women with disabilities I have assisted. I am so inspired by their determination. They have taught me by example that we can all overcome the barriers we face to live a full and rich life.*