

## CHAPTER 12

# The Caring Experience: Developing a Partnership

Estelle R. Klasner, Ph.D., Kathryn M. Yorkston, Ph.D., BC-NCD,  
and Kurt L. Johnson, Ph.D., C.R.C.

---

### A PERSPECTIVE ON CARE AND CAREGIVING

The term “care” has a number of different meanings. Care can mean that you pay special attention to something of value (e.g., “I’m going to take care when I finish this important project”). It can mean to have a high regard for something or someone (e.g., “I truly care for my husband”). “Care” can also mean a worry or responsibility (e.g., “He is troubled by the many cares in his life”). At one time or another, all of these different meanings may describe your thoughts about multiple sclerosis (MS). Multiple sclerosis is a progressive disease, meaning that, over time, it can worsen. You may reach a stage in your disease when you will need other people to care for you. Both needing and giving care are complex roles filled with a whole host of emotions. Providing care may be stressful and frustrating, but it also can present opportunities to discover hidden strengths and feel new joys.

Usually, being someone who requires care or becoming a care provider are not roles that people choose on their own. As a rule, the need for a care provider comes about when someone has a chronic illness, like MS, that interferes with that person’s ability to perform activities and tasks independently, on a daily basis. This chapter’s purpose is to provide an overview of the issues that must be considered as you begin to establish and maintain a caring partnership between yourself and the family members and/or friends who are helping you. This chapter offers advice to the person with the illness who needs care and the family members and friends who provide care. The term “family,” as it is used here, distinguishes between caregivers who are family members and/or friends and those individuals who are paid to give care.

---

## FAMILY CAREGIVERS: WHO YOU ARE AND WHAT YOU DO

Family caregivers are men and women who assist loved ones who have MS. Most often, they are spouses, but they also can be children, parents, or friends. The family caregiver usually assists the person with MS in his or her own home and community, so that the person can maintain a familiar, safe, and secure environment. If you are a family caregiver, you might be involved in a number of activities with the person who has MS. You may assist with shopping, making appointments, driving, and household maintenance. You may also provide companionship and encouragement on a continual basis.

As time goes on, you may be asked to help with such matters as bathing, dressing, and feeding. Your role is very important. You may be the reason a young mother can continue to care for her children, or the reason someone with MS is able to remain in his or her own home. Providing care and support in a kind and compassionate manner, although certainly challenging, can be a rewarding experience.

Recently, the term “caregiver” has come under scrutiny in both the professional and popular press. Some professionals in the field of chronic illness, particularly in Great Britain, have stated that the term implies a one-way relationship, i.e., that the person with MS is getting care and not playing an active role in the relationship. For this reason, the term “carer” has become popular in European countries. In the U.S., the term “care partner” is becoming widely used to refer to both the person with MS and the person giving care. The term “care partner” implies just that, a partnership between two people in which both partners make a contribution. We hope that the information in this chapter will be helpful to you, as you establish your own caring partnership.

---

## THE SPECIAL CASE OF MS

Multiple sclerosis is a disease with some unique characteristics that can have an influence on the caring partnership. First, it is important to note that MS affects more women than men. Because of this, men are more likely to take on the role of the care partner who provides assistance. Traditionally, men have not often taken on caring responsibilities. Research has shown that men approach the caring partnership differently than women (Good, Bower, and Einsporn 1995). Men are less likely to ask for outside help, and they are reluctant to express their feelings about the caring situation. Problems may arise because of the lack of communication and/or insufficient help.

Fortunately, there are solutions for these problems. For example, it should be possible to structure communication situations so that the male caregiver can begin to feel more comfortable sharing his thoughts and feelings. This may require the female care partner to initiate such discussions fairly often.

In another example, outside help may be arranged so that others who are familiar with caring demands can assist. Women are accustomed to assuming a caring role more often than men. However, they are also less likely to take breaks from the care situation, and they often neglect their own health. Becoming aware of the types of issues that may arise allows care partners to set up contingency plans before problems become acute.

Women who provide care might schedule some time each day to take part in health-promoting activities for themselves, like exercise. And they should schedule regular doctor’s appointments to monitor their own health. They can also prearrange respite care, so that they will be more inclined to take breaks for rest and relaxation for themselves.

Because MS is a disease that primarily occurs between the ages of twenty to forty years, children or parents can also be care partners. Asking children to take on care responsibilities needs to be carefully

considered. Tasks should be appropriate for the age of the child. Certainly, children can contribute to household maintenance, but asking a child to give medications or to carry out personal care tasks such as toileting may be ill-advised. It is very hard to preserve the parent-child relationship when children and parents do not maintain preestablished boundaries.

Most likely children will be eager to help, but parents should clearly delineate the limits of the care they accept from their children. Often, the parents of adult children also act as care partners in many situations. Although this may seem like a natural role for the parent to assume in this situation, caution should be taken to avoid burdening an aging parent. Also, parents need to remember that their “child” is now an adult and should be treated accordingly. It may be wise to have a discussion about “parent-child” roles to avoid the pitfalls that can occur.

Two of the hallmark features of MS are the unpredictability of symptoms and the course the disease takes. Some of you have described having MS and caring for a person with MS as similar to walking on sand; everything shifts and changes all the time. The unpredictable nature of MS makes it essential for care partners to be flexible and able to adapt to changing needs.

For example, you may be able to walk to the mailbox one day, but on the next day, you may only be able to sit on the front porch. This means that care partners must take and give back responsibilities for tasks on a consistent basis. Care partners need to develop an understanding that allows both of the people in the relationship to give and receive the assistance they need.

---

## THE JOURNEY OF CARING

A care partnership cannot be created overnight. It is a dynamic process, and like most other relationships it goes through a series of stages. A number of researchers have investigated the caring partnership and have recognized a series of steps that generally take place. One group of researchers (McKeon and Porter-Armstrong 2004) has defined these steps as *rejecting care*, *resisting care*, *seeking care*, and *accepting care*. Both care partners can be engaged in a number of these steps.

**Rejecting care.** Care is usually rejected at the beginning of the caring partnership. At this stage, both of you as partners refuse outside offers of help in order to maintain independence, protect each other from the changes that MS may bring, and preserve the family as it was before MS.

**Resisting care.** The next step, resisting care, happens when the care partner without MS acknowledges that he or she may need help but is reluctant to ask for it. He or she gradually takes on more responsibilities and this becomes the “norm.” Many care partners, especially spouses, feel that they should be doing all of the care all of the time, and asking for help is not an acceptable option. Neither of you wants to be viewed by others as unable to cope, and asking for help may signify an inability to cope for some people.

**Seeking care.** Often, the next step in the caring partnership is to seek care. Frequently, this occurs during a period of crisis when you, the person with MS, may be experiencing both an exacerbation and a change in your ability to be independent. At this phase, outside or paid help on a temporary basis is usually sought.

**Accepting care.** Often, accepting care is the last step for care partners. Both care partners acknowledge that the situation has evolved to the point where it is necessary to obtain additional help. Care partners may increase their reliance on other family members or they may make a more permanent arrangement with paid-care providers.

Being aware of the stages that a caring partnership may undergo allows both partners to practice patience and realize that their partnership will change and shift in sympathy with the care needs of both partners.

---

## CARE PARTNERSHIP BASICS: FIRST THINGS FIRST

Even when a spouse or other close relative has provided care for someone he or she has lived with for a number of years, the establishment of a caring partnership in the face of MS is a new venture. Some issues must be addressed early on to ensure a successful partnership. Becoming educated about MS, deciding on a primary care partner, and establishing house rules are some of the basics that need to be put in place at the start of the partnership and they should continue to be monitored throughout the care process.

### *Become Educated About MS*

Research suggests that caregivers who view themselves as prepared and knowledgeable about the disability experience less strain than those who feel less prepared (McKeon and Porter-Armstrong 2004). It is important for care partners to first gain a full understanding of MS and all of the symptoms that may occur. Information is available from a number of resources including your doctor, nurse, books, and the Internet. Becoming aware of all of the aspects of MS that may occur can help you, as care partners, to develop plans for care and goals that are logical and realistic. Also, you may wish to share this information with your family and friends, so that if a situation arises in which that friend or family member is to provide care, he or she will know what to expect.

New developments in the treatment of MS are occurring at a rapid rate. It is necessary to keep abreast of these developments and discuss them with your healthcare provider(s) to determine whether the new treatment might be appropriate for the person with MS. Chapter 1, *Optimizing Your Medical Management*, and chapter 6, *Alternative Therapy Considerations*, are excellent places to start educating yourself about MS.

### *Decide on a Primary Care Partner*

One person should be chosen as the primary care partner. The primary care partner is the person who is responsible for organizing all of the care that is needed. As a primary care partner, you work out schedules with the person who has MS and you communicate with all of the other care partners. In addition, the primary care partner knows all of the important medical information such as doctor's name, allergies, and medication schedule. He or she also knows where things are stored and how the home is organized. As the disease progresses, the primary care partner also may have to become aware of new medical and daily routines. The primary care partner and the person with MS make all major decisions and plans for the inevitable changes that occur as a result of MS.

Establishing a primary care partner is a good way to avoid poor communication. One person acting as the primary resource allows the other caregivers to know how and where to access important information. It also allows other caregivers to feel confident that the care they provide was designed in conjunction with the person who has MS. If and when problems arise, the other caregivers can be assured that decisions will be made by the primary care partner and the person with MS.

## ***Establish House Rules***

Most people have particular ways they like things done in their own home and ways they prefer to be approached and treated. It is essential for care partners to establish rules early on in the caring partnership. Rules regarding personal care and household tasks should be decided on from the outset of the partnership. For example, care partners may decide that only the primary care partner should administer medication. Housecleaning, cooking, and pet care may be other areas in which rules need to be set. Care partners also must decide about daily routines such as times for meals, exercise, treatment, and bedtimes.

If children are living in the home, schedules are of the utmost importance. Having an organized daily routine will ensure allowing enough time to help children with their schoolwork and any other tasks they need to perform. This type of organization allows for care partners to take on as many duties as they wish to, while capitalizing on each other's strengths and being aware of each other's limitations. It also provides an opportunity for care partners to discuss expectations and remain realistic about what can be accomplished. See chapter 2, *Getting Things Done: Managing Your Time and Energy*, for details about planning and carrying out preferred activities.

---

## **DIFFERENT VIEWS: CARE PARTNER PERSPECTIVES**

Each care partner comes to the relationship with his or her own set of personal qualities and experiences. These distinctive qualities often add richness and a unique level of understanding that is vital for a successful caring partnership. To benefit from each other's differences, these differences must be recognized and respected by each of you. In addition, the complex nature of your partnership must be acknowledged, and care partners need to recognize that the partnership will go through "good" and "bad" times. Care partners should acknowledge differing viewpoints, the potential for both positive and negative feelings, and the time required to adjust to the changes brought about by MS.

### ***Recognizing Your Care Partner Differences***

Care partners will inevitably have different views on a number of issues. If you have MS, you see the care partner relationship from "inside" the disease. You must make constant adjustments to your new role and be willing to accept care. You must also come to terms with the changing roles that MS has imposed on you. For example, a husband who was the sole breadwinner may now have to share this responsibility with his wife and he may need to spend more time on tasks at home such as helping children with homework and preparing meals.

When you are the primary care partner, you must view the partnership from "outside" of the disease. A care partner may have to assume a number of extra responsibilities. He or she may have to adjust work schedules and take on more household tasks.

The different perspectives you have as care partners can create different priorities for each person. If you are the person with MS, at times, you may want your care partner to be available at all times, and or you may feel resentment toward the person without MS. If you are the care partner providing care, you may also feel resentment about life adjustments, decreased financial security, and increased responsibilities. Both of you care partners need to "take stock" on a regular basis and monitor both sets of needs and

expectations. You need to ask yourselves if demands are reasonable, and acknowledge the challenge of each other's position in the caring partnership.

### ***Feelings: Positive and Negative***

A caring partnership is filled with emotion. Often, spouses, children, parents, relatives, and friends are kind, compassionate care partners, and are invaluable resources. However, dealing with MS on a daily basis can be difficult. Adjustments to role shifts, loss of intimacy, loss of privacy, an increased sense of vulnerability, and living with uncertainty are often necessary. These changes will frequently cause feelings of resentment, anger, and jealousy.

At the same time, care partners may discover hidden strengths and resources. You may also find new activities to share. Whether positive or negative, emotions should be discussed in an open manner if that is at all possible. One way to facilitate conversations about challenging issues is to set aside a time for discussion. It is nearly impossible to come to any resolution if discussions take place during a trying or difficult situation. Emotions are generally high and care partners need time away from the situation to decide on a reasonable and realistic plan for dealing with difficult matters. It may be necessary to seek outside professional help such as a counselor, religious advisor, or mental health professional to help you, as care partners, to talk about your problems. Seeking outside help should be done sooner, rather than later, to avoid escalation of negative emotions, which if left unchecked, can turn into abusive situations.

### ***Care Partners Need Time to Adjust***

If you have MS, you also may have ongoing, ever-changing emotions about having the disease. You must deal with the knowledge of having a progressive illness and that this illness will be a major influence on your plans for your life. Because of the changes that MS causes, those having the disease must cope with loss of function and possibly loss of control over certain situations on an ongoing basis.

If you are the primary care partner, you must also deal with change and loss. You may need to work outside the home and give up staying at home during the day to care for the children. You, too, may have to change your life plans because of MS. For example, you may have to choose to turn down a promotion because the new position entails a great deal of traveling. You may have a hard time juggling care responsibilities, work, and children. Care partners may have to learn how and when to ask for help. You may require time to adjust to your new life situations. Respect between care partners for each other's situation is one of the most helpful ways to cope with adjustment issues and to prepare for the future.

---

## **GIVE AND TAKE: THE NEEDS OF CARE PARTNERS**

Throughout this chapter, we have emphasized the "partnership" involved in caring for a family member with MS. It is critical that both partners be cared for. While care partners are busy with the duties involved in the caring partnership, it must be remembered that you both have individual needs. Both of you need time to care for yourselves. And both of you will benefit from time away from each other to pursue other activities and interests that have nothing to do with your roles as care partners. Maintaining social and leisure interests is essential to staying balanced and content in any partnership.

## *Taking Care of Yourself*

Maintaining a sense of well-being is one of the most important things that care partners can do for each other. Care partners must strive to keep a healthy balance between the physical, emotional, and social aspects of life. Because much of this book focuses on the person with MS, this chapter will emphasize the need for a primary care partner to take care of him- or herself. For the primary care partner, physical well-being involves eating a nutritious diet, exercising whenever possible, getting enough rest, and tending to personal medical needs. When providing assistance, primary care partners often neglect their own needs and do not receive necessary medical attention. One of the greatest gifts that you can give to your family member with MS is taking care of yourself on a regular basis.

Maintaining your emotional well-being can be a juggling act. At times, both care partners are bound to feel depressed, angry, and anxious. However, it's important for care partners to recognize when these negative feelings may become problematic, that is, it's important to recognize when these feelings may pose a problem. For example, care partners may experience depression that goes unrecognized. (See chapter 5 for a discussion of ways to deal with depression and other emotional challenges.)

It's also important for care partners to maintain their social well-being. Care partners often feel trapped and isolated in their situation. Becoming isolated can happen so gradually that both care partners may not be aware of the situation for some time. Maintaining social connections is vital to a balanced partnership. Both care partners should continue to engage in activities they have always enjoyed, separately and together.

If going out is difficult, having an occasional potluck dinner may provide much needed social interaction. Friends can gather at one care partner's home and bring dinner with them so that neither care partner is burdened with transportation or cooking duties. Other social activities might include listening to music, renting movies, playing cards or board games, visiting art galleries, museums, or libraries, if possible, and learning something new like a foreign language or new computer program.

## *Respite Is Both Needed and Necessary*

Both care partners will benefit from frequent and regularly scheduled respite from each other. Time away creates a sense of security for both care partners. You, having the disability, acknowledge that other people can provide competent care. Your primary care partner acknowledges that it is possible to delegate his or her caring responsibilities to other people. You may need a break from your primary care partner often in order to feel confident that you can get along with someone else's help and spend time with others. This allows you to maintain a social network with previous friends and relatives.

Obviously, the primary care partner also benefits from regularly scheduled respite. Primary care partners often report experiencing social isolation due to fatigue resulting from the demands of taking care of someone else and decreased interaction with others.

Respite also allows the care partner to take care of his or her own health issues and spend leisure time with family members or friends. Respite lets the primary caregiver enjoy some unscheduled time that allows him or her to "recharge" his or her energy. When both care partners take some time away from each other, that permits them to engage in a period of reflection and then they may both be able to bring new ideas back to each other for solving difficult situations.

Arranging alternative care should be done in advance and both care partners must be comfortable with the alternative care plans. If family members or friends are not available to provide respite care,

services in your community are likely available. Check with your physician or local healthcare center about respite services in your area.

## *A Word About Paid Respite/Care Help*

Although this chapter was written for family caregivers and their loved ones, there may be times when paid-care help is needed. Once the decision has been made to hire someone to assist with care, care partners should consider the available choices very carefully. The level of outside help needed should be discussed.

Several levels of paid help are available, including domestic help, personal care assistants, therapists, certified nursing assistants, and registered nurses. Both care partners should decide which type of care is needed so that an appropriate person can be hired. Care partners also need to discuss financial and privacy issues as they relate to the paid-care provider. Expectations relative to paid assistance should be clear for both care partners.

### Finding Paid-Care Help

Going through a licensed agency is one way to hire paid help. Agencies handle all the bookkeeping duties and they are responsible for screening potential employees. Agencies also have the capacity to provide backup care if someone falls ill or care is needed in an emergency. However, agencies also control how many hours care providers can work and the tasks they do. Hiring someone without going through an agency allows for greater control over wages and duties, and may be less costly, as long as there is a reasonable quality of performance.

Churches, synagogues, and other religious facilities may be able to find reliable personnel at modest hourly rates. It is unlikely, however, that religious facilities will conduct background checks or take care of accounting tasks. These will become new responsibilities for both care partners in the event that paid-care help is obtained through religious or community facilities. Moreover, if someone is ill or an emergency arises, substitute care providers will not be available.

In addition to discussing where to hire help and the type of help that is needed, care partners also may want to revisit their house rules and make some changes to feel comfortable with paid help in their home. When your home is open to others on a consistent basis, private information may be inadvertently left out in the open. For example, you both may decide to keep important documents or valuable possessions in a safe-deposit box or fireproof safe in the home to ensure your desired level of privacy. The best way to establish and maintain the desired level of privacy is to take the necessary steps to ensure that privacy. This can go a long way in avoiding embarrassment and unpleasantness between care partners and paid-care helpers.

## *Informal Support Networks*

Family members and friends are often invaluable resources to support care partners. If possible, friends and family can be relied on to help with household projects, running errands, pleasure outings where extra help may be needed, or caring for others in the household, such as children. In addition, care partners often discover that an informal support system already exists in their neighborhood that was formed by everyday contact with members of their community. Frequently, care partners engage in

ongoing interactions with postal workers, pharmacists, grocery clerks, neighbors, and other people in their neighborhood.

As time passes, service providers in the neighborhood become aware of the needs of the care partners and can provide support and assistance in recurring situations. For example, a pharmacist may know that because of your disability, you need to sit down while signing for your prescription, and he or she will have a chair available for you. The postal worker may knock on your door and personally deliver packages to you because he or she knows about the difficulty you experience when navigating your way to the mailbox. The grocery store clerk may keep certain items in stock to ensure they are available because you buy them on a regular basis.

Many people in your community will often be interested in providing assistance in any way they can, so that you, as someone with a disability, can continue to live in your own home and neighborhood. These small measures can go a long way to making life easier for care partners. Members of your community often provide more direct support. Some communities have established “telephone trees” to support those with severe disabilities who live in those communities.

For example, if you live at home on your own, neighbors can organize a schedule of calling you periodically to check in and find out if you need any assistance. Telephone trees of support have worked miracles in providing reassurance to care partners. You, as someone with MS, can rest assured that there are people available to provide help, if needed, and the well care partner can go to work or do errands with the confidence of knowing that help will be provided if it becomes necessary. Please remember that it is okay to ask for this help in different life areas.

### *Maintaining Your Previous Relationship*

Often, primary care partners become so focused on the caring routines that they forget they were in another kind of primary relationship with the person with the disability, e.g., husband and wife or parent and adult child. This prior relationship inevitably will weather some changes while the care partnership becomes firmly established. Being able to delegate tasks to others like housecleaning or yard work, on a regular or even occasional basis, will free up time to spend nurturing loving relationships and sharing enjoyable activities.

Activities may involve taking a break from the routine and devoting some time to pleasurable outings such as going to a movie, visiting friends, or taking a scenic drive. This time away from home will provide a much-needed break for you as care partners and also help you to maintain your previously established relationships. You may not be able to engage in pleasurable activities with the same degree of spontaneity that you once enjoyed, but with careful planning both care partners certainly can enjoy leisure time together.

---

## **MAKING THE REWARDS OUTWEIGH THE WORRIES: A SET OF GUIDED EXERCISES**

At this point, some general issues related to developing a care partnership to deal with MS have been identified. We’ve outlined the challenges as well as the rewards you may experience. The following section offers a set of guided exercises designed to help the primary care partner make the rewards outweigh the worries.

First, let's take an inventory of your current situation. Go to worksheet 23 and list your five biggest worries regarding your role as primary care partner. Be honest about your areas of concern. Put down whatever comes to your mind. There are no right or wrong answers. Your worries may include many different topics: "How can I get the help I need?" "How can we manage financially?" "What if the MS progresses very quickly?"

After you've completed writing down your five biggest worries, then turn to the rewards section of the worksheet. List five things that you consider the most rewarding aspects of your role as a primary care partner. As with the worries you just listed, there are no right or wrong answers here. Rewards can vary from person to person and include things like feeling a sense of accomplishment, feeling closer to your partner, or having the opportunity to learn new skills.

## **WORKSHEET 23: TAKING AN INVENTORY OF YOUR WORRIES AND REWARDS**

List your five biggest worries regarding your role as primary care partner:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

List five things that you find most rewarding in your role as primary care partner:

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

After you have listed your worries and rewards, ask yourself this question: "Do the rewards outweigh the worries?" If your answer is "My rewards do not outweigh my worries," then you may find the following exercises helpful. These exercises are designed to help you reduce the strain you experience in your caring role. They are based on research that suggests that caregiver strain can be reduced by at least three factors: preparedness, easing task difficulty, and seeing eye-to-eye with your partner (Archbold and Stewart 1990).

## Preparedness

We will start with preparedness. Being prepared means getting ready beforehand. It may involve becoming educated (for example, knowing what drugs are recommended for the management of MS) or developing a plan (for example, working out the details of what you and your family will do in an emergency). Go to worksheet 24 and ask yourself the questions about how well you are prepared for a number of issues related to MS.

As you answer the questions in worksheet 24, other issues may come to mind where you may think that more information or a better plan would be helpful. Jot down those issues as well. When you review your answers, pay particular attention to the items where you need more preparation. For those items, jot down potential sources of information or help you could use to develop a plan. The goal of this exercise is to help you feel more prepared to deal with day-to-day challenges of MS.

<b>WORKSHEET 24: PREPAREDNESS FOR THE PRIMARY CARE PARTNER</b>			
<b>How prepared are you to</b>	<b>Well-prepared</b>	<b>Need more preparation</b>	<b>Potential ways to be more prepared</b>
Understand what MS is?			
Understand how MS is treated by your healthcare providers?			
Understand how drugs may affect the course of MS?			
Understand how rehabilitation can help your family member function better?			
Take care of your family member's physical needs?			
Take care of your family member's emotional needs?			
Get the help you need?			
Have a handle on emergencies?			
Manage the finances?			
Arrange for health care?			
Identify resources and supports you have?			
Keep yourself emotionally/physically healthy?			
Other issues:			

## Easing Task Difficulty

The next exercise involves identifying ways to make your tasks easier. Worksheet 25 contains a long list of tasks you might be doing for your partner. The list comes from research on those who provide care to family members with disabilities (Archbold and Stewart 1990; Archbold, Stewart, and Hornbrook 2001). You may not be doing all of these things, but on the other hand, there may be things you are doing that are not listed. Be sure to add them to the list.

First, check all of the activities that you assist with and then add any others that are not already on the list. Next, put a checkmark in the column labeled “Difficult” if you feel that the activity is not easy for whatever reason. Finally, for those difficult items, think about how they could be made easier. Sometimes this would involve more education. For example, if helping to transfer your family member from a bed to a chair is difficult, then having a physical therapist teach you proper techniques may make this activity easier.

In another example, many of the tasks might be easier if you had the help of a volunteer or paid caregiver to assist with driving, bathing, dressing, and so forth. Once you have completed the worksheet, you may see a pattern. Where, for example, would your life be easier if you had help with household chores or if you had expert advice about finances or access to needed services? Getting help with a few difficult tasks may remove a considerable burden from your shoulders. Think “outside of the box” and of all the resources that may be helpful here (e.g., church groups, United Way volunteers, community volunteer Web sites, and so on).

<b>WORKSHEET 25: MAKING YOUR TASKS EASIER</b>			
<b>Activity</b>	<b>Do you help?</b>	<b>Difficult?</b>	<b>What is needed to make it easier?</b>
Help him/her getting outside the house			
Assist with medications			
Help with eating			
Lift or transfer him/her from place to place, e.g., bed to chair			
Assist with bathing			
Assist with dressing			
Drive the car for your care partner			
Take part in leisure activities with him/her			
Help with bowel/bladder care			
Write for him/her			

Prepare meals			
Do the shopping			
Manage medical equipment, e.g., feeding tube			
Take care of his/her skin care			
Take care of finances			
Take care of legal matters			
Deal with his/her fatigue			
Deal with his/her emotional ups/downs			
Take him/her to doctors' appointments			
Take care of household maintenance			
Help him/her move around the house			
Assist in filling out forms, e.g., Social Security, insurance			
Handle his/her physical pain			
Assist with grooming			
Help him/her use the phone			
Help to handle medical emergencies			
Arrange for paid help in the home			
Help him/her to the bathroom during the night			
Other issues:			

### Seeing Eye-to-Eye with Your Partner

For this final exercise, go to worksheet 26. At the top of the worksheet there is a place for you, the primary care partner, to list the top five results that you would like to come out of this caring partnership. Do this without consulting your partner. Then, have your partner with MS do the same thing. After each of you has individually listed your priorities, compare your lists. Are they alike? If not, how are they different? After you have compared them, work together to make a list that you both can agree upon.

**WORKSHEET 26: SEEING EYE-TO-EYE WITH YOUR PARTNER**

For the **primary care partner**, what are the top five results that you would like to come out of this caring partnership?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

For the *partner with MS*, what are the top five results that you would like to come out of this caring partnership?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

After discussing your individual lists, what are the top five results that you mutually would like to come out of this caring partnership?

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_
5. \_\_\_\_\_

---

## Conclusion

Care partners are unique individuals who face ongoing challenges. Experienced care partners become experts in receiving and providing care for people with MS. The path for care partners may be bumpy and, at times, frustrating; but it also provides opportunities for joy and many of life's hidden rewards. We hope that some of the perspectives that you may have arrived at by working through this chapter may ease your journey.