

CHAPTER 15

Tapping Available Community Resources

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FINDING YOUR WAY

Living with multiple sclerosis (MS) can be a demanding, sometimes overwhelming task if you try to do everything by yourself. Fortunately, there are many community resources available to you. The trick is to learn what services there are, where they are, and how best to use them. Until they are needed, you may not realize how many no-cost/low-cost resources there are in your community.

In this chapter, we discuss four subjects. First, we talk about how to find useful information. This is probably the most important part of our discussion. We try to help you figure out how to find out about services (or anything else) you want. Second, we have a short discussion about the Internet. This is really a continuation of our discussion on finding information. We try to demystify the Internet and we talk about how to use it efficiently. After all, if computers were not really “user-friendly,” most people wouldn’t be using them. Third, we provide a list of ideas about exploring possible resources in your community. This is meant to be a “brainstorming” list, not an exhaustive directory or even complete list. Fourth and last, we provide you with some tips and ideas for evaluating the information and agencies you find. This is sort of a “quality control” section. It reminds you, the reader, that it is important to be a wise consumer!

GETTING INFORMATION

Let’s start with how to get information. You may not get the services you need simply because you haven’t figured out how to get the right information about them. Furthermore, getting the right information is

sometimes difficult. For instance, try looking up “garbage collection” in your telephone book. In many phone books, it is listed under “solid waste disposal.” How would you know this if you were from a different country or even a different city? If you don’t know the right terms to use (or someone who does), your garbage might never get picked up. Most information about nearly every aspect of our culture is listed somewhere. The trick is finding out where it is and the easiest way to get it.

Libraries

Thanks to Benjamin Franklin (and Andrew Carnegie), public libraries are one of the most useful and most user-friendly sources for information. Libraries are not just collections of books, videos, and CDs. They are good resources for finding out about community services, if you know how to go about it. Fortunately, you don’t have to be a library expert to use a library. Librarians and library staff are in excellent locations for finding out about community resources, and they enjoy working on information requests and helping people to use library tools. The sister of one of the authors of this chapter is a librarian. She convinced us to start our discussion about community services by talking about libraries first, because libraries provide the most consistently valuable resource for information for everyone in our country.

Some large libraries, such as those in Seattle, Boston, and Baltimore, actually have whole departments exclusively devoted to providing people with information over the telephone. The program in Seattle is called “Quick Information” and is nationally known for its excellence. People call these libraries to ask any informational question that is important enough to them to want an answer. A large portion of these calls are requests for how to find help through service agencies or other local sources, e.g., “I need to find a support group for people with Parkinson’s condition” or “Can you help me find information about employment discrimination?” Even if a library close to you doesn’t have a department devoted specifically to providing callers with information, it’s more than likely the librarians will be good at helping you find what you need. Sometimes, all you have to do is know how to ask for what you need.

It’s been our experience that almost all of the librarians and support staffs with whom we work enjoy helping others to explore new areas of information. It’s also a good idea to let library staff know how much you appreciate their help. Those of us who work with library personnel see them as part of our support network and we let them know how much their help is valued. After all, what better people can you think of to help you find information than the professionals who specialize in disseminating information?

County and Municipal Information Sources

In many instances, especially in more rural areas, you’ll have to think out of the box a bit to find formal and informal networks that might have answers to your needs. Your local Chamber of Commerce can be an excellent resource, as can many local religious facilities. Most cities and towns have a social service office that can explain your needs to other municipal departments that, in turn, can help you if you have special concerns. Many agencies and government departments have specialized services for senior citizens (people over the age of fifty-five), veterans, or people with physical disabilities or other limitations.

Don’t neglect fraternal organizations or service organizations, like the Rotary, Lions, or Kiwanis clubs. Ask a member to take you to a meeting and make your need known. Some of these fraternal groups run small grant programs for health, vision, or dental care and other types of aid. Don’t forget to check

out your area newspapers, free throwaway weeklies, or end-of-the-week supplements with calendars that list events and activities. You can find anything in these from classes on job-seeking to free services, to announcements of upcoming plays, and so on. Finally, don't forget informal forums, such as the local barbershop, gas station, hair salon, coffee shop, and so forth. These meeting places provide very valuable and, at times, the only local human networks.

Of course, getting information doesn't help you very much unless you are able to store it in a format where you can get to it quickly when you need it. So, here is a short checklist that you can use to quiz yourself about important strategies for storing and keeping information:

Checklist 14: Saving Information Records

- Do I have a plan for recording all of my agency contacts by date? (See the Format for Record Keeping below.)
- Do I have permanent storage for all records I make?
- Do I keep duplicate records of important information?
- If I am using a computer, do I back up my information (that is, on a floppy disk or tape)?
- If I am disorganized and can't keep track of my papers and affairs, do I have a close friend or family member who is willing to check or keep duplicate backup records for me?

Do you already have a format for storing or organizing important information? The following checklist provides the points to consider when you are organizing information and offers a useful structure for storing it.

Checklist 15: Format for Record Keeping

1. **Important instruction:** When you decide on a record keeping format, make sure you always keep and file your records in the same way, each time you add something to a file. For records of your dealings with social service agencies, the following items should always be recorded and kept on file:
 2. Date of agency contact
 3. Name of agency
 4. Mailing address/physical address (not always the same)
 5. Electronic addresses: e-mail address; Web site; fax number; and telephone number
 6. Name of specific contact person (first and last names)
 7. Brief comment about results
 8. What to do next? (very important)

USING THE INTERNET

Now, let's move on to the Internet, also called the "Web" or the "Net." Looking for information on the Internet is sometimes called "surfing the Net." We don't have the space to teach you how to surf the Net. We can, however, offer some suggestions about using a computer to find community resources.

First, if you don't know how to use a computer, the good news is that it is fairly easy to learn how to operate one. Second, if you don't have a computer, many libraries offer free computer access to people who have library cards. It wouldn't be fair to ask library staff to teach you how to use the computer, but when we researched this article, it became clear that the library is an excellent place to find out where inexpensive or free computer classes can be located in your area. In rural areas (or even in some urban areas), if the librarian has the time, you may get some free lessons. Using a computer is just like learning to drive: once you learn the basics, the rest is just practice.

How to Do a Computer Search

Suppose you want to do a computer search about a subject that interests you. First, of course, you have to know the basics, like how to turn on the computer, and how to find a search engine to conduct your search. If you are using a public computer as at a library, you probably won't even have to turn it on. Often, the librarian or a staff member will guide you in this procedure. Once the computer has been turned on, you need only do the following:

1. Open a search engine, which is a free service that helps you look for information. Currently, the name of the most well-known search engine is "Google." If you are using a library computer, it's more than likely the computer will have Google available for your use. It's very easy to learn how to use. Remember, if the computer were not user-friendly, it would not be used by so many people.
2. Enter some "key words" into the search engine. Key words are words that are likely to be included in information you are seeking. For example, if you're looking for alternative medical approaches to multiple sclerosis, you would type in the words "alternative medicine" and the words "multiple sclerosis."
3. Usually, it's best to insert quotation marks (" ") around the words that belong together. This way, the computer will search for and find only the combination of the words you want. In the example above, you want to find every instance of the term "alternative medicine." You don't want to find every instance of the word "alternative" and every instance of the word "medicine."
4. After you enter your key words, hit the Enter key and your search has begun.

While we were writing this chapter, we followed the steps outlined above. The computer found 331,756 different articles when we used "multiple sclerosis" and "alternative medicine." We didn't look at each article, but the first twenty-five or thirty were very interesting.

Just for fun, we also entered the words without using quotation marks. We got back more than half a million different articles. Some of them were interesting, but some didn't have anything to do with multiple sclerosis or alternative medicine. That was because the computer looked for every article that contained the separate words "medicine," "multiple," "alternative," and "sclerosis" instead of just the combinations "multiple sclerosis" and "alternative medicine." We hope that knowing these facts about the ease of doing computer searches will encourage you to do some searches on your own to find the resources and services you may need in your own community.

SPRINGBOARD RESOURCE LIST

Now, let's look at some resources that should be available to you in your community. This following is a list of agencies you might find helpful to contact for aid in dealing with any of the many issues that MS may have brought into your life.

The National Multiple Sclerosis Society (NMSS). This is probably the best MS-specific contact in the United States. See the Resources section at the back of the book for their Web address. This organization can provide general and specific information about MS. For example, they can supply you with information about employment, life planning and independence, facts for the newly diagnosed, educational and training programs, local support and educational groups, and MS-related literature. Through their local chapters NMSS offers referrals to neurologists who specialize in MS and other healthcare services, social services, legal services, and they can help you to access local government agencies, such as state rehabilitation and state employment offices. You can use NMSS as a resource for questions concerning medication, assistive devices, counseling agencies, and so forth. They can help you find practitioners of physical, occupational, speech, recreational therapies, and similar resources.

Other Web sites of interest to those with MS are also listed in the Resources section at the back of the book.

Local not-for-profit MS agencies. In addition to local chapters of NMSS, many areas also have other MS agencies that provide a variety of services. These may be statewide agencies, or agencies that focus on a smaller local area, such as a county or a region.

Legal aid/attorneys' associations. These organizations sometimes provide no-cost ("pro bono") or low-cost legal services for people who need legal help but cannot afford it. Unfortunately, these organizations are more readily available in urban areas than in rural or semirural places. But don't be afraid to call a local lawyer to ask about free consultations (pro bono work), sliding-scale fees, or a payment plan for legal services if you really need them.

Credit and debt counseling agencies. As someone with MS who may have been caught in mid-career with high credit-card debt and expensive mortgage payments, who would benefit from negotiated lower rates, consolidated debt payments, extended payment schedules, and so forth, these agencies can be invaluable to you. There are even nonprofit agencies of this type that may have no fees or low fees. **Note:** It is very important to understand the fee structure if there is one.

Federal and State Agencies

The intent of this section is to give you brief profiles of some state and federal agencies that can assist you as they have others with MS. Again, your local librarian or a search on the Internet can help you find even more options of this type.

Equal Employment Opportunity Commission (EEOC). Workers who believe that no effort was made by their employer to provide suitable accommodations for them on the job so that they would have been able to continue working in spite of having MS, or perceive that they were otherwise discriminated against should contact the EEOC. The agency representative will decide if your case has a legal basis before the EEOC engages in actual litigation. Many private lawyers won't take a discrimination case unless a finding of discrimination is made by the EEOC. This can be a time-consuming and lengthy process if you use only federal lawyers; on the other hand, if you have the resources or a new job, why not pursue it? In some cases, employment discrimination cases can be handled more expediently by a state human rights commission (or an agency with a similar title).

U.S. Department of Justice or Office of Civil/Human Rights. Clients can be referred directly to this agency for diverse types of human rights violations and discrimination issues. Depending on the volume of cases, and other matters, local county or city human rights agencies may be better at expediting a case more quickly.

AmeriCorps. This agency offers a stipend to its participants, who generally work in schools or not-for-profit agencies involved in a variety of social service enterprises. This program is very similar to the earlier federal VISTA program. The stipend is approximately \$850 per month, but it can vary.

Participation in the AmeriCorps program does not count as substantial gainful activity (SGA) with respect to Social Security Disability Income (SSDI) payments. So if you receive some SSDI income, AmeriCorps can provide some useful supplementary income. The accompanying educational benefits, which can reach up to \$4,725 annually (in early 2005), can be applied to further your education. Examples of AmeriCorps positions might include a high-school volunteer coordinator, a nonprofit agency marketing position, an elementary school literacy counselor, and so forth.

Vocational rehabilitation. The goal of state vocational rehabilitation agencies is to help those with disability barriers to employment become employed or reemployed. They can provide access to a variety of educational, training, and counseling services, as well as assistive technology and other services related to becoming employed. In the United States, each of the fifty states has a state rehabilitation agency. See chapter 7 for a fuller discussion of this agency.

State health and human services agencies. As with vocational rehabilitation, these agency offices are usually accessible with local offices. They provide varying amounts of basic financial subsidies, food stamps, and medical coverage if the client has no other means of support and during the long wait for Social Security eligibility to be determined.

Housing authorities. These agencies vary as to their availability on a county or city level, but they may have low-income housing available provided by the city or under Federal Section 8 availability. Rent for Section 8 housing is assessed on a graduated scale, which is determined according to the person's income. If housing will be needed in the future (i.e., if you are anticipating the loss of your home or difficulty with your rent payments), application should be made as soon as possible as a long wait period is often experienced for desirable low-cost housing.

Aging and disability services. Although the title may vary, this type of state agency usually provides different critical support services, such as “meals on wheels” deliveries, in-home care, daytime recreation programs for seniors and for those of you with significant disabilities. If you have a limited income, this type of agency can be critical both in keeping you healthy and in helping you to live independently.

Additional Service Resources

Transportation. These types of services are usually more available on a city or county level. Transportation can be a very critical service if you can no longer drive or afford the upkeep of a car, and so forth. Transportation services range from a deeply discounted bus pass to specialty van or small bus pickup services. Some communities issue taxi script that can be used in place of cash to pay for transportation by taxi.

Faith-based agencies. Islamic, Jewish, Catholic, other Christian, Mormon, and various other religious communities frequently have well-developed social service programs, funded by their respective congregations. The Church of Latter Day Saints, for instance, offers a variety of social services, often including vocational services, through the local bishop. Our experience has been that many of these religious groups have been generous in providing services for nonmembers as well as members. Services have even included emergency rent and short-term help with utility payments (e.g., the Salvation Army and St. Vincent de Paul). Don’t forget this option. It can be extremely helpful.

Previously, we discussed organizing and storing information. In the following checklist, we offer some suggestions about how to approach the agencies we’ve described throughout this chapter to maximize your experience.

Checklist 16: Contacting Agencies

- Have I called and made a specific appointment for services?
- Will I arrive on time or early?
- Am I prepared? Do I have accurate, appropriate background information about my medical condition, financial needs, job résumé, and so on, relating to the purpose of my visit?
- Will I record exactly with whom I spoke and contact information for that person?
- Do I know the next steps for myself and for the agency person? Timelines?
- Do I understand the costs for these services, if any?
- If I am being teamed up with a special program (e.g., advocacy, vocational, etc.), have I checked out their references and outcomes? Can I talk to others who received this service?

QUALITY CONTROL: BEING AN INFORMED CONSUMER

Let's say you are getting quite skilled at finding potential services. You must also remember the saying, "Don't believe everything you read (see, hear, find on the Internet)." A famous saying during the Revolutionary War was: "Trust in God, but keep your powder dry." This suggests the importance of your responsibility to look out for yourself. Quality control is an important responsibility you need to accept. Not every information source has the best information, or even your best interests at heart.

You need to be more than a consumer. You need to be an informed consumer. An informed consumer is one who is good at evaluating the resources that she or he finds. This way you are more likely to avoid making poor decisions about services or having anyone take advantage of your lack of experience in choosing services. Most people would probably agree that federal, state, and other governmental agencies are usually providing services in good faith (even if they make political jokes). This may not always be the case with, for example, private-for-profit agencies or even some nonprofit agencies.

Specialists who provide rehabilitation services have had the experience of working with clients with MS who enrolled in expensive vocational programs that did not provide the expected result (a job, or marketable skills). It has even happened that services were knowingly provided that were not likely to benefit the client. It doesn't really matter what went wrong if you are stuck with a large debt for services that did not improve your life.

The more of your money and time involved, the more important it is to take your time when making decisions, whether your decision is in regard to a consumer debt agency or a training program. This statement also holds true for organizations that allow you to pay "part now, part later" or that help you get private or government loans to cover their high fees. Some "advocacy" agencies that you may think provide a free service actually can involve legal fees—to be paid by you. Even programs or agencies that do not present themselves as a fee-for-service business may have hidden costs.

The following checklist will give you some ideas about how to screen different agencies to see whether they are the best agency for you to approach.

Checklist 17: Contacting Agencies—Additional Information

1. Is this a government agency or a nongovernmental agency? ____
2. Is it a nonprofit or a for-profit agency? ____
3. Have I asked about fees and costs? This is important no matter what kind of agency (profit, nonprofit, government, nongovernment, etc.). ____
4. If the agency asks me to sign a contract, can I take it home to read carefully and discuss with friends or family? ____
5. If I sign a contract for services (i.e., like training classes), do I have to pay the full fee if I drop out early? What allowances are made? ____
6. If I am working with a "for-profit" agency or individual, have I been a good consumer by comparing options and reviewing my choices with a close friend or relative? ____

Conclusion

In this final chapter, we've talked about services in the community that may be available to those of you with MS. We discussed how to find information about these services. The Internet was specifically discussed because this is a very efficient way for people to find information. The Resources section at the end of the book provides many useful Web sites. We also talked about how to store information and how to organize it. Finally, we reviewed strategies for evaluating different agencies and making sure that the agency or individuals that you approach will provide you with the services you want. Researching and storing information about the services that may be available to you (on a computer, in a notebook, etc.) is one excellent way to plan ahead and give you more control over the life problems that sometimes occur with MS.