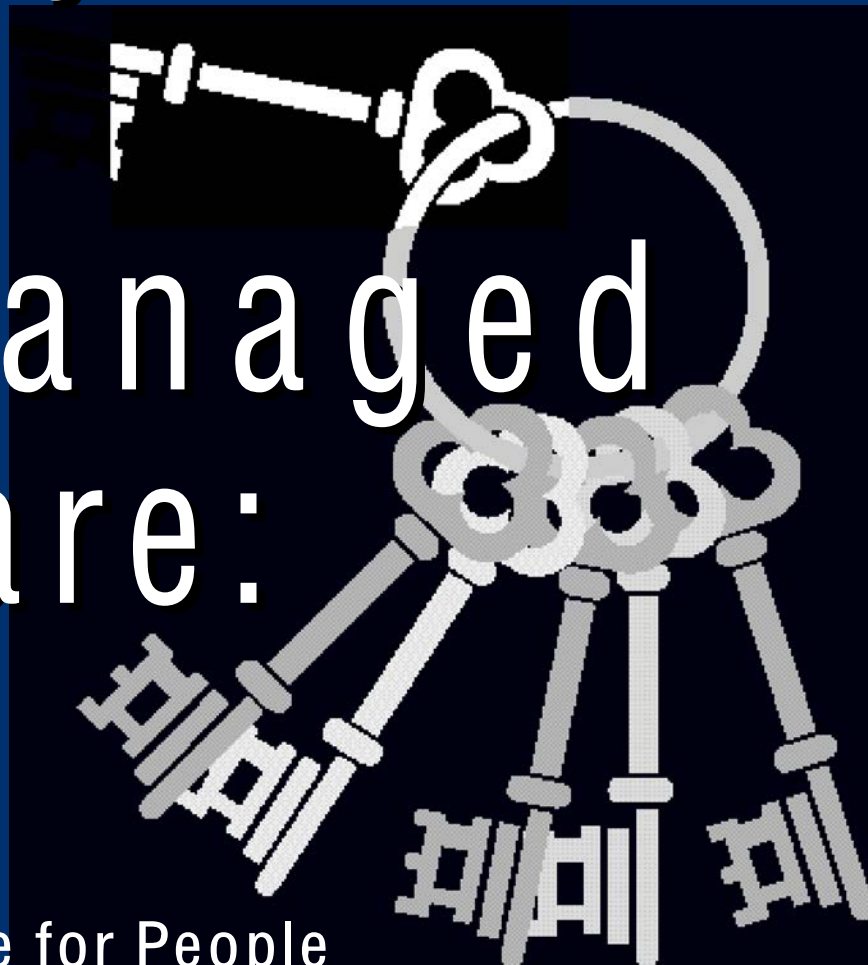


The Keys to Managed Care:



A Guide for People
With Physical Disabilities

National Rehabilitation Hospital
Center for Health & Disability Research
Washington, DC

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A Guide for People With Physical Disabilities

NRH Center for Health and Disability Research,
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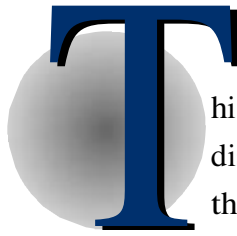
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his guide has been developed to help people with physical disabilities who are already in managed care plans learn how they can get the best healthcare possible. This guide was prepared by the National Rehabilitation Hospital Center for Health & Disability Research (NRH-CHDR), the Paralyzed Veterans of America (PVA), and the Eastern Paralyzed Veterans Association (EPVA) with input and careful review from a number of healthcare consumers and professionals. We wish to specifically acknowledge June Isaacson Kailes, disability policy consultant from Playa del Rey, CA, for her substantive review and her thoughtful assistance in developing the interview guides that led to the wealth of information at the heart of this guidebook.

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Introduction: The Keys to Managed Care

Managed care is a strong and growing force within the American healthcare system. The growth of managed care has changed the way people get healthcare. Understanding these changes is important for people with physical disabilities because they sometimes have complicated and urgent healthcare needs. This guide has been developed to help people with physical disabilities who are already in managed care plans learn how they can get the best healthcare possible.

The information and advice in this guide was collected by talking to people with disabilities. We chose people to talk with based on their success in getting the healthcare services they needed from their managed care plans. They shared their experiences with us in all areas of their healthcare. They also described the ways in which they obtained the healthcare services they needed. In speaking with these individuals, it became clear that they were all using a small set of specific strategies to get the services they needed from their managed care plans. These strategies will be described throughout this guide as the keys to getting better healthcare.

The goal of this guide is to explain and illustrate the “keys to getting better healthcare” from your managed care plan. Before these keys are discussed, the next section explains the basics of managed care.

What is Managed Care?

Until the 1980s, almost all healthcare insurance plans were fee-for-service plans. This type of plan typically allows you to see any doctor at any time. You are usually required to pay a monthly **premium***, a yearly **deductible**, and a percentage of the cost for each service you receive (typically 20%). Today, millions of people are covered by a different kind of plan, called a managed care plan. Managed care plans work very differently from the traditional fee-for-service plans. There are three main types of managed care plans, each with its own set of rules. This can make obtaining healthcare very confusing for people who don't understand their managed care plan. Later, we will describe these three different types of managed care plans, but first we'll outline some common themes among them.

Premiums charged by managed care plans are usually less than those charged by fee-for-service plans. Because managed care coverage is cheaper to purchase, it may be attractive to employers who provide healthcare coverage for their workers or to individuals who are responsible for obtaining their own coverage. Most managed care plans require you to select a primary care doctor from their **network** of doctors. This network is simply a list of doctors with whom your plan has an agreement. Once selected, your primary care doctor is responsible for coordinating all of your healthcare and acting as a **gatekeeper**. This means that you need to get a referral from your primary care doctor if you wish to use other healthcare services, such as see a specialist, receive physical therapy, or obtain a new wheelchair or a prescription medication.

*Words in blue and bold in the text appear in the glossary

Let's take a look at the three most common types of managed care plans. Your plan may be a little bit different than those described below, but these are the most common types of managed care organizations.

Health Maintenance Organizations (HMOs).

The **HMO** is probably the best known type of managed care plan and is also the least expensive and least flexible of the three types. An HMO will usually have a **network** of doctors from which you must obtain all of your healthcare and supplies. If you go to a doctor who is outside the network without a referral from your primary care doctor, your plan will not pay any of the cost. Most HMOs charge a small fee, or **co-payment**, for each service you receive.

Preferred Provider Organizations (PPOs).

Preferred provider organizations allow a little more flexibility than the HMO. You still have a limited network of doctors associated with the health plan, but you have more freedom to see doctors outside the network. The trade-off is that your plan will pay for more of the costs when you stay within the network than when you go outside the network. For instance, if you go outside the network for care without a referral from your primary care doctor, you will probably have to pay a deductible and a percentage of the total cost of your care. The premiums for this type of health plan are generally more expensive than for an HMO. So, while a PPO allows greater flexibility, it is also more costly.

Point of Service (POS) Plans.

Point of service plans are a cross between a fee-for-service plan and an HMO. Like the HMO, you are usually required to select a primary care doctor from a list of doctors in the plan's network. Also like the HMO, you pay a set fee, or co-payment, for each service you get from

KEY 1:



Know What
Kind of
Managed
Care Plan
You Have

doctors within the plan's network. In this type of plan, you can see doctors outside the network if you are willing to pay more out of your own pocket. Again, if you go to a doctor outside the plan's network without a referral, you can expect to pay a deductible and a percentage of the total cost of your care. However, if your primary care doctor refers you to someone outside the network, you'll probably pay the standard co-payment. This plan offers flexibility because the network of doctors is usually large and it allows you to get healthcare outside of the network. However, this type of plan also charges higher premiums than HMO.

The Good and Bad of Managed Care

Potential **ADVANTAGES** of Managed Care.

Managed care plans may have several advantages over fee-for-service plans: less out-of-pocket costs to you, less paperwork for you to file, lower co-payments for prescription drugs, greater focus on preventive care (regular check-ups and exams), and better coordination among your doctors. Preventive care and coordination of care are both especially important for people with disabilities.

Potential **DISADVANTAGES** of Managed Care.

Along with the good there is a bad side to managed care. One disadvantage of managed care is that you are often required to select your doctor from a list, which may not include the doctor that you want to see. In addition, since managed care plans require referrals from your primary care doctor for specialists, physical rehabilitation, and healthcare services, your access to these services may be limited. One of the main objectives of managed care plans is to provide appropriate medical care while keeping costs down. This may mean that you, as a person with a disability, will have problems getting access to the services you need.

KEY 2:



Know Who Covers Your Healthcare

Most people are covered by **Medicare**, **Medicaid**, or **private insurance**. In some cases, people may be covered by two or more of these **payers**. We'll talk about each payer and describe who is typically covered by each one. It is important to understand who your payer is, because this often determines the rights and benefits that you have as a member of your health plan.

Medicare

Medicare is the nation's largest health insurance program and is administered by the Health Care Financing Administration (HCFA). HCFA is part of the United States Department of Health and Human Services. Medicare provides healthcare coverage for people age 65 and over, some people with disabilities under age 65, and people with kidney disease.

Medicare has two parts: Part A and Part B. Part A is hospital insurance that helps pay the costs related to stays in a hospital or nursing facility, as well as home healthcare and hospice care. Medicare Part B helps to pay for doctor's services, outpatient care, physical rehabilitation services, and durable medical equipment (wheelchair, scooter, walker, crutches, braces, splints), as well as other services. Traditional Medicare does not pay for prescription drugs.

Traditional Medicare is fee-for-service health coverage. That is, you can see any doctor who accepts Medicare. Like other fee-for-service plans, you pay a premium (for Medicare Part B only), a deductible, and a percentage of the total cost. Many people covered by traditional Medicare purchase private insurance to supplement their Medicare coverage—these plans are commonly referred to as Medigap plans. **Medigap** plans cover some of the expenses that traditional Medicare does not, like the costs of prescription medications and the annual deductible for hospitalizations.

In addition to the traditional coverage, Medicare also has managed care coverage options. These options have the same benefits and drawbacks as all other managed care health plans. Medicare managed care plans may provide coverage of some prescription medications. The costs to you are less and you may get extra benefits that traditional Medicare alone does not offer—such as eyeglasses and hearing aids. The tradeoff is that you may have reduced access to specialty services that you need.

Medicaid

Medicaid provides health insurance coverage for low-income families and individuals and for people with certain kinds of disabilities. Each state administers its own Medicaid program and rules for eligibility and coverage vary from state to state.

Private Insurance

This type of insurance is typically received through an employer, or it can also be purchased by an individual. Each private insurance plan is different and there are thousands of private managed care plans in existence. To find out specific information about your health plan, you should contact your insurance company or your human resources department at work.

This handbook is designed to help you understand your managed care plan and how you can make it work for you. The following sections will outline in detail the strategies and tools people with disabilities have used to get the healthcare services they need from their managed care plan.

KEY 3:



Be a
Informed
Consumer

The most important “key” to getting the healthcare services that you need is to be a knowledgeable user of the healthcare system. Being a knowledgeable, informed consumer means:

- Knowing all that you can about your disability.
- Knowing about your own specific healthcare needs.
- Knowing the details of your managed care plan.

All of the keys described in this handbook depend on the knowledge that you have of your disability, your specific healthcare needs, and your health plan. Talk with other people with disabilities, do research, read articles, and ask questions. You will find a list of organizations in the back of this guide that are excellent sources of knowledge and information in these areas.

Be an Expert on Your Disability

When most people think of being a patient, they see themselves passively getting care, instruction, and advice from an all-knowing doctor. This image is no longer true, especially for people in managed care. For people with disabilities who often have conditions that are relatively uncommon—such as spinal cord injury, cerebral palsy, or multiple sclerosis—the passive patient role often leads to frustration and denial of needed healthcare services. It is difficult for most primary care doctors to have enough knowledge and experience to provide expert advice and care on all disabling conditions. This becomes more of a difficulty for people in managed care plans, since the few primary care doctors who are knowledgeable about your condition may not be in your plan’s network.

For a person with a disability, the more knowledge you have about your condition, the better off you will be. It is

“Keep yourself educated—and that’s a lot easier now than it used to be, if you have access to a computer.”

Marcus



is a 28-year-old algebra teacher and an assistant coach for his local high school football team. Marcus is also a paraplegic. He sustained a spinal cord injury at age 17 while playing football. Marcus has learned that to get the healthcare services he needs to stay healthy and productive, he has to be knowledgeable about his spinal cord injury and how it affects him.

Marcus explains that, “I have my primary care physician and a specialist related to my disability—a neurologist. They both told me during my first visits with them that I was the expert and that I needed to tell them what my health issues were. I was totally shocked by this. Before my injury, I just went to the doctor for things like strep throat and for a sprained knee. The doctors knew exactly what to do in those situations. I expected them to know everything about spinal cord injury complications, too.”

After realizing that it is difficult for most doctors to have a strong knowledge of spinal cord injury, Marcus read as much as he could about his condition. He joined a peer group for people with spinal cord injury, where he learned from others in his situation. He also paid more careful attention to his health. By making himself an expert on spinal cord injury and his own health needs, he is now able to work with his doctors to prevent pressure sores and urinary tract infections that used to limit his health and well-being.

“Being educated about my condition has been the key for me,” Marcus states. “Once I figured out that I couldn’t rely solely on my doctors to keep me healthy, I was able to educate myself and work with my doctors to get the services I need. Now I almost never have to take any sick days off from work.”

highly likely that you will be in a situation where you have to explain the specifics of your condition to your doctor(s). The knowledge that you have of your disabling condition and your ability to express that knowledge to your doctors will help you get the healthcare services that you need.

“I have to be an advocate for myself, as a person with a body and symptoms that doctors aren’t as familiar with.”

Be an Expert on Your Personal Healthcare Needs

In addition to the knowledge that you have about your condition, you also need to think of yourself as the expert when it comes to knowing your body and your healthcare needs. Being in tune with your condition, as it effects you personally, will allow you to work with your doctors to determine the health services that you need.

Some people with disabilities have a complex set of treatments and medications that they need to remain healthy. Become an expert in how your treatments and medications affect you and your health. If you understand why you are receiving specific treatments or medications, you will be better able to work with your doctors to tell if they are having the desired effect. Being in tune with your body and your healthcare needs will also allow you to better explain your needs to other health professionals in the future.

“Doctors don’t understand what they should be doing for people with my disability.”

Be Knowledgeable about the Specifics of Your Health Plan

If you have insurance through a managed care plan, you should carefully read all of the information that the plan gives you. It is very important to know what health services, equipment, and medications are covered by your plan. It is also important to know how often you can get services, equipment, or medica-

“I think being an informed consumer is paramount. Calling your insurance plan with an obvious knowledge of what is covered makes them a little more careful about denying you services.”

tions. The literature that the health plan gives you after you enroll is called the **evidence of coverage**.

Sometimes this information is complex and difficult to understand. If the literature that you receive from your plan is not as specific as you would like, or if you don't understand some of the information, be sure to call your plan to ask questions. For example, if you cannot tell from your health plan documentation how often you will be able to get parts for your wheelchair, it is important to call them to get clarification. Armed with this type of knowledge, you will be more successful working with your plan and your doctors to get healthcare services when you need them.

Putting It All Together

When you are knowledgeable about your specific health-care needs and the important details of your managed care plan, you will have the basic tools to help you get the health services you need. Your knowledge in these areas is the foundation for all of the other “keys” described in the following sections.

“I've got a spinal cord injury. Developing pressure sores is a real risk. I needed to do an awful lot of educating to let my doctor know what he should be looking for.”

KEY 4:



Find A Primary Care Doctor You Are Comfortable With

Another basic “key” to getting the best healthcare possible from your managed care plan is finding a **primary care doctor** with whom you are happy and comfortable. Because your primary care doctor plays a major role in your health and healthcare, it is important to look for a primary care doctor who:

- Knows about or is willing to learn about your specific disability.
- Communicates well with you.
- Is willing to serve as your advocate in the health plan.

Find a doctor who is willing to learn about your disability

Most doctors in your health plan’s network will not have a strong knowledge of your disability and the complications that may result from it. If you are not able to find a primary care doctor who is an expert on your disability, your best option is to find a doctor who is willing to listen to you and learn about your condition and healthcare history and needs. It is often difficult for doctors to allow you to be the expert and to learn. When you find a doctor who is willing to listen and learn from you, you know you have found a good healthcare partner and advocate.

“If you’re not happy with the doctor you have, find a doctor that you like. Get one that you trust and know is going to fight for you and support you.”

Find a primary care doctor who communicates well with you

The partnership you develop with your doctor has a direct impact on the quality of the healthcare you receive. Communication is a two-way street. In addition to being a good listener, your doctor should also be able to explain complex medical terms and procedures in an easy-to-under-

Jack



Due to a spinal cord injury acquired during a car accident, Jack Turner was unable to maintain his job as a construction worker. Since he no longer had health coverage through his employer, he decided to get his medical coverage through a Medicaid HMO.

Jack had trouble finding a primary care doctor that he liked. The first primary care doctor he signed up with was not mindful of how his spinal cord injury made him more susceptible to pressure sores. Jack also felt that the doctor rushed him through his visits and did not listen to him. During the year that Jack visited this doctor, he had two preventable pressure sores and frequent urinary tract infections (UTI).

Jack decided to change to a new primary care doctor. He got a list of all of the primary care doctors in his insurance plan. He also talked to other people with spinal cord injuries about their primary care doctors. He began calling and interviewing the doctors until he found one that he liked.

Jack knew he found the right doctor when he met with Dr. Jackson. “Dr. Jackson spent a long time with me asking me about my health, and it really seemed like she was interested in what I told her. She was taking lots of notes based on what I told her about my condition and the difficulties I had. Before I left her office on that first visit she screened me for hot spots and pressure sores, and took a urine sample to screen for UTI. We set up a regular schedule for visits and exams. I was completely relieved to have someone who listened to me and worked with me on my health.”

stand way. Your doctor should be open and honest with you and willing to explain all of your options for treatment that are both covered and not covered under your health plan.

Find a primary care doctor who will serve as your advocate within your health plan

When you develop a partnership with a doctor who is willing to learn about you and your healthcare history, that doctor will be more likely to work with you as an **advocate** within your health plan. When you need a healthcare service or treatment that your plan may not cover, you will be more likely to receive that service if your doctor can communicate to the plan why that service is important to your health and well-being.

How to find a good primary care doctor

The following paragraphs outline the tried-and-true strategies that other people with disabilities have found useful as they searched for a primary care doctor with whom they were comfortable.

An effective way of finding a primary care doctor is to talk to other individuals with disabilities about their primary care doctor. Get recommendations from other people with disabilities. These recommendations may help you narrow your search to doctors who are known to be good communicators or to those who have experience serving people with disabilities.

Another way to narrow your search is to contact your plan's member services department to find out which doctors in your plan have offices and equipment that are accessible to people with disabilities. Ask them which doctors have adjustable examination tables and scales that allow you to be weighed in a seated position. Your plan

“Try to choose a primary physician who you feel could serve as an advocate. The doctor needs to see him or herself as a collaborator, not as the expert.”

should know this information but many plans do not. If your plan does not have information about the accessibility of its doctors' offices, be prepared to make telephone calls to find out which offices are accessible.

You may also want to ask other healthcare providers that you are comfortable with to recommend a good primary care doctor. For example, if you have seen a specialist that you like, ask that specialist to recommend a good doctor from the list of doctors in your health plan.

“Interview your healthcare providers. Know that the doctor you pick is willing to take time with you. If you don't get a good feeling from them, get out and find another provider.”

You can interview as many primary care doctors in your plan as you want until you find a doctor who meets your healthcare needs. Take the time and effort to contact as many doctors as you can by telephone, to get an idea of whether or not you can communicate with them effectively. You may also need to make this assessment during your first visit, so set up a longer appointment time if you can. Ask them if they have experience serving people with disabilities. The

time that you spend contacting potential doctors will be well spent if you are able to find one that you are comfortable with.

If you have a primary care doctor that you are not happy with, you can switch to another primary care doctor. Your plan may restrict the number of times you can switch doctors, but do not hesitate to change primary care doctors as often as you can in order to find one that meets your needs.

Finally, once you have found a primary care doctor you are comfortable with, take an active role in building and maintaining your relationship. This means educating your primary care doctor about your disability and how it affects your life. Give your primary care doctor any information you feel will help him or her provide you with the best possible healthcare.

You should think of yourself as the central coordinator and record-keeper of the healthcare you receive. Many people with disabilities find that keeping detailed records of their complete healthcare experience is a very important key to getting the services they need from their managed care plan. Because your health plan is a large, complex organization, your medical records may not get transferred to and from the different doctors that you need to see.

Because of this, it is important to keep up-to-date copies of all of your medical records from all of the different providers that you see. Before you leave any medical appointment, ask for a copy of any records or paperwork that was filled out during that visit. (You may need to request copies in advance. There may be a fee.) Keep an organized notebook containing these records for future reference.

You should take your medical records notebook to any appointments or meetings with representatives from your health plan. Having personal copies of your medical records is important just in case there are problems with lost documents at your doctors' offices. For example, when your doctor gives you a referral form so that you can visit a specialist or get a piece of equipment, keep a copy of the referral form for your records. The specialist you have been referred to may not receive a copy of the referral form and will not be able to see you unless you have that form.

You should also keep a written or recorded diary of the health services you receive. This means keeping a detailed record of when you saw your primary care doctor, specialists, and therapists, and when you received equipment. You should also record what happened during each doctor visit

KEY 5:



Keep Copies of All Your Health Care Documents

“As a person in managed care, it is important to keep track of your medical procedures. Always get copies of all paperwork pertaining to any medical procedure that you have.”

Twyla



is a 58-year-old homemaker who has had severe rheumatoid arthritis for several years. Because she sees both her primary care doctor and her rheumatologist frequently, a large amount of paperwork must be recorded in her medical record—referrals, prescriptions, physician’s notes, and documentation of her symptoms and visits. Twyla found out the hard way that her doctors’ offices were not very good at maintaining this record of her healthcare history.

Twyla’s rheumatologist prescribed a front-wheel walker because walking was becoming difficult for her without regular support. Her health plan would not cover the purchase, claiming that there was not enough evidence that she needed the walker. When she asked her primary care doctor about this denial of coverage, she discovered that her medical record did not document many of her frequent visits to her rheumatologist. The notes that her rheumatologist made about the increasing severity of her condition were not included in her official medical record.

Twyla eventually got her complete medical record and was able to obtain the walker that she needed. In the meantime, though, she was unable to attend her nephew’s high school graduation and to be as active as she would like, because she was unable to walk or stand for very long without proper support.

After going through such a frustrating ordeal, Twyla decided to start keeping personal copies of all of her records. At the end of every appointment, she now asks for a copy of the notes, referrals, and prescriptions that her doctors make that day. “Now that I put myself in charge of keeping my own medical record, I feel a lot better about my healthcare situation.”

and the treatment plan that was recommended to you. It is also a good idea to record in your diary any other health experiences or concerns that you may have, such as your feelings during a particular visit or side-effects of a new medication. You can then raise these concerns the next time you meet with your doctor.

In addition to maintaining updated copies of your medical records, it is important to keep copies of all documents and letters that you receive or send to your doctors and health plan. Be sure to keep letters from your health plan that deny you from getting a health service that you need. You will need these letters to begin the appeals process to get needed services (see Key 10).

Keeping accurate, updated copies of your health records, as well as a health diary, will create a paper trail that can help you deal with any potential problems that may develop with your healthcare providers or managed care plan.

“Always keep a medical diary! Remember to write down every time that you go to your doctor. This will provide a log that you will be able to reproduce whenever it’s necessary.”

“Some day you may need to appeal, so it makes sense to be really meticulous about keeping accurate records.”

A m a n d a



a law student who has multiple sclerosis, is insured by an HMO. Because of her condition, Amanda often needs prescription medications, and her health could suffer if she were to run out.

Once, Amanda nearly did run out of her medication because she waited too long to get a refill. She needed a prescription from her doctor and had to wait 10 days just to get an appointment with him. This was very stressful and health-threatening because she was almost out of medicine. Also, since the pharmacy was not well-stocked with her relatively rare medication, she worried whether she would run out before they could fill the prescription.

Amanda's symptoms could have been exacerbated without her medications, leading to serious consequences. Missing her classes would have resulted in not being able to graduate on time. She had worked very hard in school and didn't want her health to set her back.

Luckily, she was able to get her medications just in time. After this close call, Amanda decided that she needed to take a different approach. The next time she needed a refill on medication, she started planning well ahead of time. Nearly a month before running out of her medication, she called her primary care doctor for an appointment. A week later, she had her doctor's appointment and got her prescription for the medication. This time she had her medication two weeks before she ran out of the old prescription.

Amanda says, "Being in a managed care plan means you have to be on top of things. You have to know what you need and think ahead. If you can do that, you can cut back on a lot of stress in your life."

KEY 6:



Plan Ahead

When it comes to using your managed care plan, planning ahead can save time, stress, and possibly your health.

Many people with disabilities who are in managed care plans say they have trouble getting the services, equipment, or medications they need in a reasonable amount of time. One way to be sure you get the things you need on time is to plan ahead. To avoid delays, try to anticipate your need for medications, equipment, supplies, and other services for which you must get a referral from your doctor. Be familiar with the prescription refill policy of your health plan. Then, take action to get the referral or prescription before you need it.

The first step in planning ahead is understanding that things take time, and in a managed care plan they may even take a little longer. Be aware of how long it usually takes to get an appointment with your primary care doctor so that you can get a timely referral from him or her. Also, be aware of how long it will take to actually get medicines or equipment after you get the referral. Once you know this, don't wait until the last minute to schedule an appointment with your doctor to get a referral. Request referrals far enough ahead of time to get the new supplies or medicines before you run out.

If you have durable medical equipment (wheelchair, scooter, walker, crutches, braces, splints) that needs repairs, start the process as soon as you notice a problem. If you let your doctor or health plan know as soon as you notice a problem, you can get the repairs done before they get worse. But, if you wait until after your equipment breaks, you will have to go through the referral process without your equipment. You may need to cite a specific problem (such as a problem with the wheels) in order for your doctor or health

“I think the big message in managed care is that the consumer has to be much more on top of it.”

plan to authorize repairs, but catching repairs early can mean less time that you have to spend with equipment that doesn't work properly or doesn't work at all.

You can do the same when you think you may need to replace a piece of equipment. If you feel you will be needing new equipment soon, talk to your doctor. He or she will probably have to write you a referral for the new equipment, so you shouldn't wait until the old equipment has completely broken down to bring up the subject. Find out what your health plan's policy is on replacing equip-

“Before I run out of a prescription, I start calling the office and the drug store, and I just keep calling them until I know that the doctor has called in the prescription. I used to assume that it was going to happen. Now I have to make the process happen.”

ment. Most importantly, find out how often you are allowed to replace equipment and under what conditions the new equipment will be approved. Make sure you know the procedure for getting new equipment before you need it, and talk to your doctor in advance about the possible need for a replacement.

Another important consideration for equipment users is knowing how many pieces of equipment your plan will cover. This may be important if you need to purchase or replace more than one piece of equipment. For instance, if your plan will only cover one piece of new equipment every 5 years, and you need more than one piece of equipment, you should try to plan ahead and get the most costly piece of equipment paid for by the health plan. That way, you'll pay less for equipment out of your own pocket. For example, many people own both a power wheelchair and a manual wheelchair. Since the power wheelchair is more costly than the manual model, you should plan ahead and purchase the power chair when it is most likely to be covered by your plan.

It also pays to plan ahead when you have been referred for services by your doctor. If your doctor has referred you

to another healthcare professional, you should always make sure that the right paperwork has been completed before arriving for your appointment. Call the office where you were referred to one to three days before your appointment to make sure all the necessary paperwork and records for your appointment have arrived. This may prevent you from making an unnecessary trip, only to find out the proper arrangements for your referral visit weren't made. You should also ask how many visits your referral is good for, and how long the referral lasts. Some referrals may be limited to a number of office visits or a limited period of time.

Plan ahead when you are going to an office that you haven't been to before—it may not be physically accessible. Make sure any specialists or other doctor's offices are accessible to you before you go. Call ahead to find out about curb cuts, widened doorways, thresholds, parking, inclines, ramps, exam tables, or other accessibility issues. If you are a wheelchair user and are going for tests or services that require special equipment, such as a Pap smear or mammogram, make sure they know you are in a wheelchair and find out if their equipment is accessible to you or if it can be made accessible. Be specific about what your needs are—for example, that you need assistance transferring to the examination table. The office staff may not know what you mean by accessible.

Getting prescription refills before you run out of them is also a way that planning ahead can help you avoid problems. Again, try to anticipate how long it will take to get a prescription from your doctor and then plan accordingly. If you use a mail order prescription service, know how long it will take them to deliver your prescription and order as far in advance as possible.

“If you're not sure if an office is accessible, call ahead and ask. Tell them very specifically what your accessibility needs are, because most people don't have the slightest idea what it means to be accessible.”

Megan



is a 38-year-old manual wheelchair user with a visual impairment. She works as a policy analyst, loves her job, and has been quite successful in getting the healthcare services that she needs. Until recently, she hadn't realized the importance of relying on a support system in a time of health crisis.

When Megan found out that she needed major surgery, she scheduled a pre-operative doctor's visit. She had always used public transportation to get to her doctor's office but wasn't feeling well enough to do this. Her sister, Emily, drove her to her appointment. Although the slight incline leading up to the office building usually wasn't a problem for her, because she was sick she lacked the strength to push herself. Fortunately, Emily was there and pushed her up the incline.

Emily's help before surgery also eased some of the stress and anxiety that Megan was experiencing. "My sister went in two days early and got all my forms. When I went in to the receptionist, Emily had told her of my visual impairment. I'd already read the forms, after enlarging them, but she went through the stuff that I needed clarification on, and on my chart she put 'legally blind.' Everybody who saw me thereafter was able to relate to the fact that they had to read whatever they were handing me. So that was positive, and Emily's support had a lot to do with that."

"My family support was critical here. I feel that one of the reasons I have been able to stay healthy is because of my strong personal support system." Even though Megan is usually able to get the healthcare services she needs on her own, she has learned that in certain situations it doesn't hurt to rely on friends or family. She also came to realize that without her sister's help her surgery and recovery would have been more stressful—both physically and emotionally.

KEY 7:



Develop and Maintain a Strong Support System

Having a support system of family and friends will help you get through certain healthcare experiences that can often be stressful. Family and friends can make it easier to get to your appointments by providing you with transportation to and from your provider's office. If you are not feeling well, they can help you remember information and communicate your needs to your healthcare provider more effectively than if you were alone. The situations in which you are sick, or nervous and anxious about a healthcare situation, are often when you need the best healthcare possible. Ask family members or friends who are familiar with your healthcare needs to go with you to your appointments during these situations.

Another important part of your support system should be your primary care provider. As was mentioned earlier, you should find a healthcare provider who understands your healthcare needs and makes you feel comfortable; one who will work with you and be an advocate for you. Your healthcare should involve a mutually respectful partnership between you and your provider. Make sure that you trust your provider and feel comfortable enough in your relationship so that you can be open and honest about your healthcare needs. Your provider should be open to your input and supportive and respectful of your healthcare choices.

Joining a support group can also be a good way to surround yourself with supportive, understanding people. Members of a support group may have faced some of the same healthcare issues as you and can offer understanding, compassion, and helpful advice. Becoming a part of a support group can be especially important if you don't have supportive family members or friends

“For me, my support system is critical. I’m proactive and I have a support system that goes with me to doctor’s appointments, not only for transportation, but to read the forms to me and be there if there’s an issue.”

“I do have an informal support group, but it wasn’t formed especially for medical reasons.

It’s a bunch of us who are mobility impaired, spend a lot of time together, and are pretty sharp. We keep each other informed and give each other advice.”

who live close to you. Support groups can keep you educated and up-to-date on new health services that are available. They can also recommend providers and accessible facilities in your area. Even if it’s not a formal support group, just spending time with others who have disabilities and have gone through some of the same experiences is helpful.

If you have a computer, or access to a public library where computers are available, the internet is another possible source of support. Through e-mail and internet chat groups and message boards, you can now connect with other people with disabilities in your home town, across the country, or even internationally.

In addition to your family, friends, and healthcare provider, your local Center for Independent Living is another resource that can offer support and information. Centers for Independent Living are good resources for many services that may be helpful. For example, they can help you find support groups in the area. Independent living centers may also have information on the accessibility of certain medical offices and can provide you with referrals to other resources and agencies for people with disabilities that are available in your community.

Finally, it’s a good idea to make sure that you have your own list of resources that you can use when you run into problems. This list should have the names and numbers of your health plan’s Member Services, as well as numbers for accessible transportation services. It is a good idea to have contact information for your local disability advocacy group or other outside advocacy group. You should also find other sources of support and assistance that you can refer to in times of need.

KEY 8:



Establish an Inside Connection at Your Health Plan

Every health plan has people on staff who work with individuals covered by the plan. Their job is to help you get specific information about your plan and the health services that it covers. It is beneficial for you to establish a working relationship with someone knowledgeable inside the plan.

Medicaid and Medicare HMOs often have people who are called **special needs coordinators**. These coordinators work with people who have disabilities or other long-term health conditions. Some private managed care plans often have someone called an **ombudsman** who works with individual consumers to answer questions or address the problems people are having with their healthcare. Health plans also have **case managers** to help you coordinate the health services you receive.

Contact the **Member Services Office** at your health plan to find out whom you can talk to if you ever have any questions or concerns. It is helpful to contact the Member Services Office before you have a specific healthcare issue that you need to address. When you contact an ombudsman, special needs coordinator, social worker, or case manager by phone, find out her or his name, telephone number, and extension for your future use. Introduce yourself and explain to this person that you have a disability that may someday require immediate attention—for example, a speedy appointment with a specialist or a quick repair of equipment. Ask this person any specific questions that you have about your health insurance plan and say you will be calling back in the future.

A plan's case manager, ombudsman, or special needs coordinator gets paid to work with you. Don't hesitate to call your inside contact often if you have questions or concerns about your health plan.

Sheila



is no longer shy about calling people at the HMO that insures her. In fact, she is now on a first-name basis with many people who work there. Sheila, a 41-year-old florist, has cerebral palsy (CP).

About four years ago, Sheila sought a referral to a physical therapist because she felt she was slowly losing the ability to work effectively with her arms and hands. She received a referral, but it was only good for three visits. “I was very frustrated by this 3-visit referral,” states Sheila. “My doctor understood that I needed regular therapy visits to maintain the strength and flexibility I had, but he was not authorized by the HMO to give me that kind of open-ended referral.”

Sheila spoke with people in the HMO’s Member Services Department—who referred her to the HMO’s case management service. After numerous calls with a case manager named Franklin over a number of weeks, she was eventually authorized for more therapy visits at regular intervals. “As a florist, I need to be able to work with my hands. My regular physical therapy visits allow me to maintain my ability to do that.”

Another important benefit that she received from this experience, though, was the understanding that she could call Franklin, her case manager, whenever she had a question or concern about her coverage. “Whenever I need something—like a scooter repair or a referral to an orthopedist—I call Franklin first.”

KEY 9:



Be Persistent, Assertive, and Vocal

Another key to getting the healthcare services you need is to become your own advocate and take an active role in your healthcare. Be proactive and plan ahead and try to foresee problems before they become a reality. Become an active, informed participant in your healthcare. Work to make sure that you are involved in all decisions concerning your healthcare.

Remember that you also have a right to voice your complaints about your healthcare. If you have to wait too long to get an appointment, call your provider or your plan's Member Services department. Let them know that the delay is unacceptable and that you need an earlier appointment. If your provider's office does not have accessible equipment for a specific health service that you need, call your plan and your provider's office to let them know. Tell them what your specific needs are for the visit. By being vocal, you bring more attention to the barriers and problems that you and others are experiencing. It's important to let providers and insurance companies know that these problems exist and are directly affecting the healthcare you receive.

For many people, being assertive and proactive when dealing with healthcare professionals is uncomfortable. Don't be afraid to be assertive. Remember, "the squeaky wheel gets the grease."

Be assertive and let your healthcare provider know what your health concerns are. Call your provider's office before an appointment to make sure that equipment and an accessible room are available and will meet your needs for your visit. Take an active role with your healthcare provider by making suggestions and providing input about your own healthcare. Think of your relationship with your doctor as an equal partnership.

"I always recommend the "Three P's" when you are dealing with bureaucracies: patience, persistence, and politeness."

Sam



is a 54-year-old wheelchair user whose persistence and assertiveness have helped him obtain needed healthcare services. Recently, Sam had to be tested for a UTI, and when a urine sample was requested, he found that the doorways to the restrooms in the urologist's office weren't wide enough for his wheelchair. Because of this, he had to use restrooms on another floor. Since it took him longer to get to the accessible facilities, it cut down on the amount of time that Sam had to discuss other healthcare concerns with his urologist. He left his doctor's office feeling that all of his healthcare needs weren't addressed.

Sam decided that he had to become more assertive if he wanted to have more productive follow-up visits. As he says, "My experience with a lot of these situations is, if you don't do it yourself, it isn't going to get done." He began by requesting a portable commode in the examining room when he scheduled the appointment. But, the information wasn't relayed from the appointment desk to the office staff. Once again, a trek through the building to an accessible bathroom used up most of the time he should have been consulting with his doctor.

When he scheduled another follow-up visit, he also called the doctor's office directly and spoke with the front desk receptionist to make the request with her. He called again the day before his visit to speak with one of the nurses to make his request again. Finally, on the day of his visit, he spoke to the receptionist one more time to remind her of his request. His persistence and assertiveness paid off. When he arrived for his visit, there was a portable commode for his use in the examination room. As a result, Sam had more time to discuss his concerns with his urologist and left his visit feeling satisfied.

When dealing with medical equipment companies, it's just as important to be persistent and assertive. Let them know ahead of time that getting certain repairs or supplies quickly is essential to your daily living and functioning. If you're immobile while you're waiting for wheelchair repairs, insist that you get your repairs done more quickly and ask that they loan you the equipment you need while yours is being repaired.

In addition to knowing what you'll need in advance and ordering or requesting things before you need them, you should be prepared to call to check on the progress. If you think things are taking longer than they should, call your doctor, call the pharmacy, call whoever you need to, to see if there is a problem and what is causing the delay. If you only rely on others to contact you when there's a problem, your equipment repairs or replacement may end up being delayed. Take matters into your own hands and be persistent. Call your medical equipment company as often as is needed to get your services as soon as possible.

Being persistent with insurance companies is especially important, since they are large, complex organizations. Paperwork may get lost and getting reliable information from a knowledgeable person may be difficult. Make sure that you are educated about your plan so that you will be able to deal with your insurance company more successfully. This will help you get the services that you need. Let them know that when the services you need have been denied or delayed, your health and well-being suffer. Be specific when explaining the reasons for your needs and use personal examples of how you are being affected. For example, if you need a new seat cushion for your wheelchair, let your plan know that you

“Begin by being positive but firm, positive not argumentative. But then stand your ground if you don't get cooperation, and feel free to file complaints up the line if you need to.”

“Don't assume the person you're talking to is the last source to speak to you or the most knowledgeable.”

“Be your own best advocate,
and your own militant
advocate. Don’t take “no” for
an answer and don’t be afraid
to stand up for your rights.”

are more likely to develop pressure sores
without it, which could result in hospital-
ization. Continue to call, and keep
fighting to get your services approved.
Try not to let the system wear you down.

Take your healthcare into your own hands by being
persistent, assertive, and vocal. Become an active partici-
pant in your healthcare and insist on getting the services
you need. Keep a cool head, and don’t be intimidated by
authority. Know how the healthcare system works and
complain to those who can influence change and make
things happen. Take it upon yourself to write letters, file
appeals, and make phone calls to voice your concerns,
register your complaints, and express your needs.

“Those who are vocal and who
keep on the case are the ones
who get what they need.”

Your health plan may decide that it will not pay for a specific healthcare service that you or your doctor ask for. For example, your health plan may not pay for a new wheelchair or for physical therapy that you need to maintain your strength. This is called a **denial of coverage**. When you are denied coverage, you can often file a formal appeal, which requires the plan to reconsider its decision.

Depending on who covers your health insurance and which plan you have, the steps that you take to appeal health plan decisions are different. If you are in a Medicaid managed care plan, the state that you live in has rules that define what decisions may be appealed. If you do not already have information about appeals under your Medicaid plan, call your plan or the Medicaid office in your state capital to get more information.

If you are enrolled in a private health plan or a plan provided by your employer, read your Member Handbook or evidence of coverage to learn how to file an appeal. Don't hesitate to call your plan to get additional information.

If you are enrolled in a Medicare HMO, consult the instructions given to you when you enrolled. You can also call (800) **Medicare** (that is, (800) 633-4227) to get instructions on how to file an appeal.

In sum, if your health plan decides that it will not pay for a health service that you or your doctor feels is important or necessary, there are formal avenues for you to follow to get your plan to reconsider. The appeals process can be long and sometimes difficult, but it can be made easier if you are knowledgeable about the terms and conditions of your plan (see Key 3) and you have a good relationship with your doctor(s) (see Key 4) or with a caseworker or special needs coordinator at your health plan (see Key 8).

A number of resources are listed in the following section. Some of these organizations can assist you with the healthcare appeals process; others provide assistance and support in other areas of health and life.

KEY 10:



Be Prepared
to File an
Appeal

KEY 11:



Join Forces With Others

It is important to know that you are not alone in your efforts to get appropriate healthcare services. There are millions of people with physical disabilities living in the United States. Many of them have created or are involved in disability advocacy and support groups. Advocates and advocacy groups are an important resource for individuals with disabilities.

Approaching your healthcare in the ways described in this book can help you get the health services you need. These approaches, though, can sometimes be time-consuming and difficult. Sometimes these approaches do not work. It is during these difficult times that advocacy and support groups can be most helpful. By becoming involved in disability advocacy and support groups before you need assistance, you will be in a better position to get the health services you need.

Joining an advocacy group or becoming an advocate may not only be helpful for you, but for others as well. You can help someone else who is having a hard time getting needed services. Others can learn from your experiences, just as we hope that you learn from the experiences of others by reading this guidebook. Get involved when it comes to healthcare so you can be a more informed consumer—for your own health and the benefit of others!

Following is a list of resources with telephone numbers and web page addresses. These resources include advocacy and support groups that you might want to think about contacting, as well as organizations that you can contact with questions about your managed care plan or health insurance issues in general.

Families USA

www.familiesusa.org
(202) 628-3030

Families USA is a clearinghouse of information on healthcare issues in the United States. Their website contains a wealth of information on managed care.

Health Care Financing Administration (HCFA)

www.hcfa.gov

HCFA is the branch of the federal government that oversees the Medicare and Medicaid programs. Their website contains useful information about the Medicare and Medicaid programs and phone numbers of HCFA officials in your region of the country.

Independent Living Resource Utilization (ILRU)

www.ilru.org
(713) 520-0232,
TTY: (713) 520-5136

ILRU maintains a list of Independent Living Centers from around the country. Contact them to find the Independent Living Center nearest you. ILRU's website also contains a wealth of information on managed care and disability.

Medicare

www.medicare.gov
(800) MEDICARE (633-4227)

This telephone number and website contain extensive information on the Medicare program, including answers to the most frequently asked questions.

National Organization on Disability (NOD)

www.nod.org
(202) 293-5960,
TTY: (202) 293-5968

NOD is a national advocacy organization. Their web-site contains useful and interesting information on national issues of interest to people with disabilities.

Paralyzed Veterans of America (PVA)

www.pva.org
(800) 424-8200
TTY: (800) 795-4327

PVA is a membership organization for military veterans with spinal cord dysfunction. PVA staff can provide you with information about national and state healthcare programs such as Medicare and Medicaid. Service officers around the country work with individual veterans to secure their healthcare and other benefits from the Department of Veterans Affairs.

Eastern Paralyzed Veterans Associated (EPVA)

www.epva.org
(718) 803-3783

EPVA is a chapter of Paralyzed Veterans of America headquartered in New York with offices in New York, New Jersey, and Pennsylvania.

GLOSSARY

Advocate:

One who pleads the case or cause of another, or one who defends or pushes for a cause. Being one's own advocate when obtaining healthcare from a managed care plan involves arguing for certain services when needed and defending oneself against denials of services.

Case Manager:

A healthcare professional who works to coordinate the care that a person receives from a variety of doctors. Case managers can be especially helpful to people with complex healthcare needs.

Co-payment:

A specific dollar amount that you pay each time you receive a healthcare service or see a doctor. For managed care plans, the amount of a co-payment is usually between \$5 and \$15.

Deductible:

The amount that you must pay each year before your health insurance company will pay for your remaining healthcare expenses. For instance, a person with a \$200 deductible has to pay for the first \$200 charged for healthcare received in a given year. After that, the insurance company will pay a percentage of the remaining charges (usually 80%).

Denial of Coverage:

A situation in which your insurance plan will not pay for the costs of health services or equipment. For example, an insurance plan may not pay for a new scooter if it feels that the equipment is not "medically necessary."

Evidence of Coverage:

The documentation that you receive from your health plan when you become a member of a plan. It specifically describes health services that your health plan will pay for.

Gatekeeper:

The person who is responsible for coordinating your healthcare, and who authorizes referrals for other doctors, services, equipment, or medication. Your gatekeeper is usually your primary care doctor and is a common part of managed care plans.

Health Maintenance Organization (HMO):

A type of managed care plan in which people can only see doctors who are a part of their HMO network. Referrals from your primary care provider are required in order to see specialists or to get other services from within the network.

Medicaid:

The federal health insurance plan for low-income families with children, low-income elderly, and people with disabilities. The federal government runs the Medicaid program in cooperation with individual states, so each state has different Medicaid guidelines.

Medicare:

The federal health insurance plan for the elderly (age 65 and over) and people with disabilities. Traditional Medicare is comprised of Part A and Part B. Part A has no premium and covers hospitalization. Part B has a monthly premium that an enrollee must pay and services covered include doctor visits and outpatient hospital services. Most Medicare beneficiaries now have the option of enrolling in a managed care program.

Medigap:

Private insurance purchased by individuals to supplement Medicare coverage.

Member Services Office:

The department within a health insurance plan that provides customer support and fields questions from people covered by the plan. Member services offices will have a telephone number that you can call with questions or concerns about your health plan.

Network:

A group or listing of doctors who will provide healthcare under your insurance plan.

Ombudsman:

A person employed by your health plan who investigates complaints and then acts to resolve the issue with the health plan.

Payer:

The company or organization that is financially responsible for your healthcare after you become a member of your plan. This may be a government agency such as Medicare or Medicaid, or a private insurance company such as Blue Cross / Blue Shield.

Point-of-Service (POS) Plan:

A managed care plan in which people can see network doctors at a reduced cost, but also have the option to use out-of-network doctors. If you want to see a specialist within or outside of the network, you must first get a referral from your primary care doctor. POS plan enrollees have more choice of doctors, but using out-of-network doctors means that a person must pay a deductible plus a percentage of the cost of the service received.

Preferred Provider Organization (PPO):

A PPO combines the features of an HMO and fee-for-service plan. A PPO is more similar to a fee-for-service plan because you do not usually need to get a referral from your primary care doctor before seeing another doctor in the network. Healthcare costs are less if enrollees see providers who are part of the plan's network, but enrollees can also refer themselves to providers outside of the network at an increased cost. PPO premiums are usually higher than premiums for HMO and point-of-service managed care plans.

Premium:

The amount you pay monthly to your health plan to receive coverage of healthcare services.

Primary Care Doctor:

In a managed care plan, this is the doctor that you consult with for healthcare. Primary care providers also play the gatekeeper role—you must consult with them before you are allowed to visit other doctors or get equipment or medications.

Private Insurance:

Health insurance available through a variety of private entities such as for-profit companies and nonprofit organizations. Each private insurance company has different benefits and options that are available to you.

Special Needs Coordinators:

Employees of a health plan who assist people with complex healthcare coordination needs. These people are sometimes called case-managers.

To obtain additional copies of this guide visit www.nrhchr.org,
www.pva.org, or www.epva.org



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