

You've got
to be a savvy
consumer to
make sure your
needs are met.

Going to the Doctor



Getting the most out of health care services requires you to be an active and vocal consumer. If you feel intimidated, uncomfortable, or forget to ask questions when you visit a provider, you are not alone.

Visiting a provider can be highly stressful. Being prepared and having faith in your life experience and common sense will help you avoid feeling intimidated by places and providers who may appear cold and distant.

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Expect that providers will not know everything they need to about your condition or disability. The information explosion in health care makes it difficult to keep current. Providers cannot be experts on everything. Plus, the fact that your condition or disability often represents a small percentage of a provider's practice means it is important that you educate yourself and then your providers.

Be informed about the health conditions that are of most concern to you. This helps you participate as a partner in your health care. It will also improve the quality of your decision-making.

Anticipate that some health care providers may not be free of the common negative stereotypes of disability. Unfortunately, people working in medical settings may reinforce these stereotypes because they are exposed to only people with disabilities who are indeed sick. Medical students report that little is taught about disability during their four years in medical school.

Consider taking an advocate or friend who can listen, take notes and help ask questions. This is especially important if you tend to forget your questions, freeze, or become less effective as a self-advocate when dealing with health issues. If you take an advocate or friend:

- Choose a support person who has the skill to think objectively, is able to listen and remember accurately, and who can offer you emotional support.
- Ask her or him to be there for you and assist you but not take over.

During an appointment, take notes on important information. At the end of a visit, always check your understanding by briefly repeating what you heard the provider say. Consider taking a tape recorder if

you don't want to worry about taking notes.

Ask open-ended questions. Avoid leading questions. Leading questions can force providers to give the answer you want even if it's not true.

Leading question:

"I'm going to be OK, aren't I?"

Open-ended questions:

"What are the chances of my recovery?"

"What is the outlook?"

"What are the implications of the treatment?"

Never be afraid to say, "I'm having trouble understanding. Could you describe the problem in plain terms?" Don't pretend you understand if you don't.

Sometimes what you hear may surprise, shock, or upset you. Don't hesitate to ask for more time to make a decision that could affect your life. Ask if delaying your decision will affect the outcome of your treatment. Speaking up is the most powerful tool you have for protecting yourself, and protecting how you want to live your life.

People often hesitate to get a second opinion. It's your health; get one if you think you need one, particularly if:

- You feel uncomfortable with your provider or the treatment recommendations.
- You feel what you are being told doesn't make sense or isn't right for you.
- You are concerned about a procedure (especially a surgical one).
- Your provider isn't sure or doesn't seem to know what the appropriate course of action should be.
- You are dealing with a life-threatening condition or risk of increased disability.



When the second opinion differs from the first, you may feel justifiably confused and decide you want a third opinion. Get one or use a trusted provider to review the differing recommendations.

When you visit any specialist, make sure the physician goes over all your options and answers all your questions to your satisfaction. Since it may be difficult for you to sort these issues out alone, having a primary care provider can be beneficial.

If your care is not coordinated through a primary care provider, it may be more difficult to sort out recommendations that are given to you by specialists about complex medical problems.

An additional consideration is that the advice and opinions people with disabilities get for everyday conditions are often not put through a disability filter. For example, at times the provider may attribute a symptom to your disability when the two are unrelated. Conversely, a symptom that may in fact be an early warning sign for another condition could be a typical characteristic of your disability.

Selecting a provider

You can increase your chances for quality care by establishing a long-term relationship. In fact, research confirms that people who are more active in their relationships with their physician have more positive results. As providers get to know you, they're able to see you as an individual rather than a textbook or theoretical case.


Talk to your friends, especially those who have disabilities similar to your own, to see if they are familiar with any of the physicians that participate in your health plan. Call the offices of different practitioners about the types of patients they see.

This will help you pick a primary care provider that will have at least some familiarity with disability-related issues.

Providers practicing in rehabilitation settings tend to have a stronger knowledge base related to health needs of people with disabilities and often know providers who offer primary health care for people with disabilities. Primary care providers can coordinate the referrals to subspecialists who may be able to address your more complex problems.

Experienced primary care providers are usually familiar with specialists from many different disciplines and they have knowledge regarding the competence and expertise of such physicians. This awareness comes from having referred patients to these specialists on previous occasions and from having evaluated the quality of their consultations.

The experience and familiarity of the primary care provider with various experts will help to lessen concerns you might have about biased or inappropriate recommendations. Recommendations are usually sent to the primary care provider for review. If the recommendations do not seem appropriate to you and your primary care provider, get further advice and consultation.

Being a savvy health consumer does take time and planning. Follow some of these visit strategies and remember—you have the right and responsibility to ask: Why? Why not? What? How? When? 

By June Isaacson Kailes, Disability Policy Consultant, excerpted from her book, *Be a Savvy Health Care Consumer: Your Life May Depend On It*. To learn more about her other publications or to order this book, visit www.jik.com/.



Echinacea comes from coneflowers.

DON'T FORGET TO TELL DOCTOR ABOUT HERBS

Herbal supplements are popular, and they're taken for conditions ranging from depression to migraine to memory problems. However, these herbal remedies often have active ingredients and may have dangerous side effects, especially when combined with prescription drugs.

Be sure to tell your doctor and your pharmacist which herbal supplements you are using so they can advise you of any potentially harmful combinations with your prescription drugs.

Before combining alternative therapies and standard pharmaceuticals, it is prudent to learn if they are compatible. Neither prescription drugs nor dietary supplements provide much information about interactions on their labels.

Well before any surgery it is crucial to discuss medications, over-the-counter drugs, herbs and dietary supplements with the surgeon and anesthesiologist. It's especially important for your surgeon to know of any herbal remedies you're taking prior to a surgical procedure in case the herbs affect your blood-clotting capabilities.

One of the more complete Internet sites about herbs, over-the-counter medicines and home remedies is Joe and Terry Graedon's People's Pharmacy at www.peoplespharmacy.com

IMPROVING ACCESS TO BREAST HEALTH FOR WOMEN WITH DISABILITIES

Women with disabilities often have less access to breast health services than any other group of women, according to the National Women's Health Information Center. Overall, women who are not disabled receive mammograms 11 percent more often than women with considerable limitations.

Even if women with disabilities schedule mammograms or clinical breast exams, many cannot receive either service because of inaccessible health care facilities and medical equipment. Medical and societal biases also prevent treatment. These barriers may contribute to the delayed diagnosis of breast disease in women with disabilities, according to the Breast Health Access for Women with Disabilities program (BHAWD) in California.

Although many women with disabilities are familiar with the guidelines for breast cancer detection, a variety of issues preclude the ability of many to pursue the widely recommended methods of breast screening such as, monthly breast self-exam (BSE), annual clinical breast exam and mammograms. Various physical impairments may affect abilities to perform all methods of breast screening. Women with limited hand and arm function, with lack of sensation in their fingertips, and with low vision may have difficulty performing BSE according to recommended procedures.

Many women who use wheelchairs cannot transfer themselves or be transferred onto standard ex-


"Mammogram—are you kidding? I'll never go through that ordeal again—I can't balance or hold still long enough for them to get a good picture!"

— quote from web site of Breast Health Access for Women with Disabilities

aminating tables. Similarly, women using wheelchairs may be unlikely to find accessible mammography machines to accommodate them in their chairs. And women (including seniors) who have tremors, who experience spasms, or who lack the stamina to stand at an imaging machine also should be seated for accurate screening.

The National Women's Health Information Center reports that healthcare providers who focus on the area affected by the disability might not encourage women to regularly examine their breasts. Also, women with disabilities are often not identified as an underserved population for breast-cancer screening. Thus, they are not specifically targeted in education and outreach efforts by breast cancer organizations.

One community partnership working to overcome such barriers is Breast Health Access for Women with Disabilities (BHAWD). It provides breast education and accessible breast screening for women with physical disabilities and vision impairments in Alameda and Contra Costa Counties, California.

BHAWD's goal is to call attention to the breast-screening needs of women with disabilities, the numerous barriers that impede their access to screening and the serious neglect of this special population in local, state and national programs designed to improve screening utilization. 

For more information, contact:

Breast Health Access for Women with Disabilities

Alta Bates Herrick Medical Center
2001 Dwight Way, Room 2362
Berkeley, CA 94704

BHAWD's home page is
<www.bhawd.org>

Email <info@bhawd.org>

Phones:

Voice: 510-204-4866

TDD: 510-204-4574

FAX: 510-204-5892

Other information sources

MammaCare® Breast Self-Examination Program for Deaf and Hard of Hearing Women

The MammaCare Learning System uses a special life-like breast model with videotape instruction for women to learn to do a thorough breast self-examination at home.

Phone: 800-MAMCARE

Email: <info@mammacare.com>

Home page:

<www.mammacare.com/>

National Women's Health Information Center

Women With Disabilities page:

<www.4woman.gov/wwd/>

Note: This article includes excerpts from the web sites of BHAWD <www.bhawd.org/index2.html> and the National Women's Health Information Center <www.4woman.gov/>.

MEDICARE COVERAGE FOR MAMMOGRAMS

Medicare Part B pays for most of an annual screening mammogram for women with Medicare who are 40 and older.

A screening mammogram is a preventive service for women with no signs or symptoms of breast cancer. You will pay the usual 20 percent co-payment, and Medicare will pay the remaining 80 percent even if you have not met your annual Part B deductible, according to *Medicare and You 2001*, published by the Health Care Financing Administration. Find this online at <www.medicare.gov>.

Medicare Part B also helps pay for diagnostic mammograms as prescribed. A diagnostic mammogram is ordered to help diagnose where there are signs or symptoms of breast cancer.

Diagnostic mammograms are subject to a 20 percent co-pay and the Part B deductible. The Part B deductible is \$100 for 2001 and is subject to change each calendar year.

For more information, call
800-MEDICARE
(800-633-4227)
or check out the web site
<www.medicare.gov>

"As a disabled woman, access is difficult for me. I wait until the last minute to go to a doctor because it is embarrassing. I have to look at the location, parking, doors, and waiting room. When I get there, it always seems like I am inconveniencing the staff. I do not require accessibility by choice."

"Many times I don't get a full physical because I can't get on the table. . . . Physicians are reluctant to do a pelvic because I can't hold my legs up. It is humiliating. I miss information because I never have a good physical."

"Every office has been inaccessible in one way or another. It would be great if some of the [examining] tables would go up and down. Having tables that go up and down so women in wheelchairs can transfer would be helpful to them as well as the elderly, shorter women—it's a basic comfort for all."

"Providers need to see us as women. Women who need the same preventive guidance and services that all women receive."

EDUCATE YOUR DOCTOR



Are you frustrated by the lack of accessibility and appropriate equipment at some health-care facilities?

Do you ever feel uncomfortable because you need additional assistance from medical staff

to do things that should be simple, such as getting weighed?

Are there barriers, other than physical ones, that keep you from going to the doctor?

If you are unsure about how to address these issues with your physician, then take a copy of *Removing Barriers to Health Care: A Guide for Health Professionals* with you to your next doctor's appointment.

This 20-page booklet, produced by the Center for Universal Design at North Carolina State University and the NC Office on Disability and Health, provides useful tips and easy-to-read diagrams for making health-care facilities more accessible by meeting ADA requirements and incorporating universal design principles.

In addition to providing health-care professionals a better understanding of how to improve the physical environment, *Removing Barriers to Health Care* also discusses how to improve personal interactions with patients with disabilities.

So don't let inaccessibility keep you from obtaining the quality health care you deserve. Become an educated consumer—and educate your healthcare professionals, too. Work in partnership with your healthcare providers to make their facilities and services universally accessible for everyone.

For your free copy of *Removing Barriers to Health Care: A Guide for Health Professionals*, call the NC Office on Disability and Health at 919-966-2932 or email <bogues@mail.fpg.unc.edu>. *Removing Barriers to Health Care* can also be downloaded in PDF or HTML format or ordered from the NCODH web site at <www.fpg.unc.edu/~ncodh>.

By Sally McCormick, writer, Woodward Communications

Quotes from *Women with Disabilities in North Carolina: Their Views on Health Care*, by the NC Office on Disability and Health.

BECOMING A PARTNER IN CARE



Annette Lauber shares her advice

Here is some sage advice on going to the doctor from one of our *Orchid* contributors, Annette Lauber of Raleigh:

THINKING AHEAD

I always ask if there is accessible parking and how far it is from the building.

I suggest to the receptionist/nurse that it will probably take more time so they should schedule to accommodate that. I ask if there is a better time for them since the appointment may take longer.

I talk with the nurse first to clarify my questions for the doctor. I have found that the nurse can be key to good communication with the doctor, especially if you are calling with follow-up questions or need the doctor to call you back.

ACCESSIBILITY

In the waiting room, I look for space to maneuver and a place to sit in my wheelchair so I am not blocking pathways and others don't have to walk over me.

I tell the receptionist that I use a wheelchair and will need assistance in the exam room.

THE DOCTOR

The doctor always asks what medications I take. I include vitamins. If you're not sure that you will remember, take your medicines with you.

Ask what hospitals the doctor uses because they can affect your insurance.

Develop a partnership with your doctor and nurses. Good communication is essential; it's the key to good health.

It is always a good idea to get a second opinion, especially if you have any concerns. A doctor shouldn't have problems with a second opinion—that is your prerogative.

Find out the policies of your insurance company on second opinions. For some surgeries it may be required.

RESPONSIBILITY

You have to do your part to stay healthy. That means watching your diet, staying active, getting regular check-ups, and not ignoring changes in your health.

ANNETTE LAUBER

CAREER

I had to choose a college based on accessibility. There were only two on the east coast that met my needs.

I was a Special Education teacher for 12 years and worked as staff development specialist at Murdoch Center in Butner for 5 years.

Now, I am a funding specialist with the NC Assistive Technology Program, working with individuals and groups to identify funding sources for assistive technology.

COMMUNITY ACTIVITIES

I am active in my church; I work with high school kids teaching confirmation classes.

ATTITUDE

My disability doesn't determine who I am. Having the disability determines how I go through the world, not what I do.

BIGGEST CHALLENGE

Figuring out how I'm going to make my disability work in my everyday life so that it doesn't stop me from doing something I want to do. It has never kept me from ultimately doing what I wanted to do.

BIGGEST ACCOMPLISHMENT

Making a life for myself that I really enjoy—work that I believe in doing and enjoy doing. I've got a really good life.

Americans with Disabilities Act

KNOW YOUR RIGHTS

Problems with accessibility? Wonder if your rights have been violated?

Enacted in 1990, the Americans with Disabilities Act (ADA) is a comprehensive anti-discrimination law for persons with disabilities that extends to virtually all sectors of society and most aspects of daily living, work, leisure, travel, communications and more.

It gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, sex, national origin and religion.

It guarantees equal opportunity for individuals with disabilities in employment, public accommodations (such as restaurants, hotels, theaters, doctors' offices, pharmacies, retail stores, museums, libraries, parks, private schools and day care centers), transportation, state and local government services and telecommunications.

Under ADA, employers must ensure their employment practices do not discriminate against qualified persons with disabilities in hiring, advancement, training, pay, discharge and any other terms of employment.

Employers can not refuse to hire a qualified person with a disability if that person, with or without reasonable accommodations, can perform the essential functions of the job.

The ADA also requires that phone companies increase the availability of interstate and intrastate telecommunications relay services to individuals with hearing and speech impairments.

All "public accommodations" are expected to remove barriers when it is "readily achievable" to do so, according to the ADA. Barriers that are considered readily achievable to remove are those that can be changed easily and carried out with little or no expense. Removing barriers can often be done through simple changes to the environment.

Examples include: creating designated accessible parking spaces; making curb cuts in sidewalks; installing ramps; repositioning shelves; rearranging tables, chairs and vending machines; repositioning telephones; adding raised markings on elevator control buttons; widening doors; installing flashing alarm lights; installing grab bars in toilet stalls; rearranging toilet partitions to increase maneuvering space; insulating lavatory pipes under sinks to prevent burns; installing a raised toilet seat; installing a full-length bathroom mirror; and removing high-pile carpeting.

If you feel your rights under the ADA have been violated, you can file a complaint with the Equal Employment Opportunity Commission. Call 800-669-4000 (voice) or 800-669-6820 (TDD) to reach the field office in your area.

Complaints about accessibility should be filed with the Department of Justice:

Disability Rights Section
Civil Rights Division
U.S. Department of Justice
Post Office Box 66738
Washington, DC 20035-6738

For more information:

ADA web site

<www.usdoj.gov/crt/ada/adahom1.htm>

The Access Board

An independent Federal agency that develops and maintains accessibility requirements for buildings, transit vehicles, telecommunications equipment, and electronic and information technology. They also provide technical assistance and training to individuals and organizations on these guidelines and enforce accessibility standards for federally funded facilities.

1331 F Street NW, Suite 1000
Washington, DC 20004-1111
800-872-2253 (voice)
800-993-2822 (TTY)
202-272-5447 (fax)

Email: <info@access-board.gov>

Website: <www.access-board.gov/>

Southeast Disability & Business Technical Assistance Center (DBTAC)

One of ten regional centers on the Americans with Disabilities Act, funded by the National Institute on Disability, Rehabilitation, and Research. Southeast DBTAC can respond to questions from individuals or organizations about the ADA and has publications and videos as resources.

Suite 208 North
1776 Peachtree Rd.
Atlanta, GA 30309-2351
800-949-4232 (Voice/TTY)
404-888-9091

Website: <www.sedbtac.org/>

Insurance:

Do you know what you need to know?

PEOPLE WITH DISABILITIES often have health care needs that vary in type and intensity over time. The challenge for you, as a consumer, is to find a health care plan that best meets your needs. This requires understanding how the health insurance that you choose will work for you and your family members.

Medicare, Medicaid, Worker's Comp, an HMO, PPO, or traditional health plans all come with a policy. Some plans are traditional fee-for-service programs with few restrictions on choice of doctors, while some are preferred provider organizations (PPOs) that require the equipment or treatment to come from specified providers. Others are health maintenance organizations (HMOs) that restrict your choice of providers.

With the various insurance plans, some rules you're likely to encounter may include:

- Required letters of medical necessity
- Required pre-approval, exclusion of certain equipment
- Yearly deductibles (the amount of money you have to pay before insurance will cover costs)
- Limits on care provided out-of-state

It's important to know the rules ahead of time in order to choose the best plan for you. And as one savvy consumer put it, "Don't expect Cadillac coverage from a Chevy policy." Do your homework and know what your policy covers.

One claims representative emphasized that policies have rules. "We don't buy sports chairs; we don't buy multiple chairs; we don't buy hearing aids; we don't buy vans; we're not liable for quality of life things. Our guidelines clearly state that equipment must address functional capacity and activity of daily living."

To get more information about selecting a health plan:

TALK to others with a similar disability or health condition for advice.

CHECK the NC Institute of Medicine web site at www.nciom.org/hmoconguide/backh.html

CALL the NC Department of Insurance at 800-622-7777 or 800-546-5664.

This article includes excerpts from NC Institute of Medicine web site, "Questions to Ask Your Plan: People with Special Health Needs" www.nciom.org/hmoconguide/qu2.html



Dianne Tyson staffs the Special Needs Helpdesk for the NC Division of Public Health

When choosing a health insurance plan, consider the following questions:

- Are pre-existing conditions covered?
- Do I need to choose a primary provider to coordinate my care, or can I obtain care from any provider?
- How will the health plan treat my health condition? What are the plan's clinical protocols regarding the treatment of my particular condition?
- Can I go outside of the health plan network to seek care from a non-network provider?
- Will I have to pay a co-payment or deductible for visits to my provider? For tests? How much?
- Will the plan pay for the prescription drugs I need?
- If I need care in a hospital, which one does the plan use? How much of the cost is covered?
- Can I see a specialist when needed? How do I do that?
- Does the plan cover allied services like therapies?
- Does the plan cover medical equipment, medical supplies, orthotics, prosthetics and assistive technology?
- If I have a problem with the plan, what is the process for handling my complaint?

“I have MS, and we are assigned levels of severity.

Insurance denies medical prescriptions because it is not for my assigned level. The physician thought it was the right thing to address my current needs, yet I cannot have it because the insurance company says no.”

“In order to have physical therapy, we need to show physical progress to continue. That doesn’t happen with chronic disease—therapy helps you maintain function. Insurance companies need to realize that maintenance can be more important than improvement.”

“I have an education and want to work, but the problem of pre-existing conditions and losing my Medicare keeps me home and on assistance.”

— Women with Disabilities in North Carolina: Their Views on Health Care, NC Office on Disability and Health

APPEAL DENIALS

Richard Holicky, writing in the March 2000 issue of *New Mobility*, said, “Medical insurance, regardless of who provides it, can be a source of stress. Most of us have been there, trying to deal with the logic of being denied a shower/com-mode chair because it’s not ‘medically necessary.’ It’s a jungle out there, and what once was the domain of medically trained and knowledgeable personnel is now the dominion of bean counters entrusted with cost containment.”

Many decision-makers are far more focused on dollars and cents and medical necessity than on active living or quality of life. That replacement chair or backup ventilator that’s a top priority to you may seem like a frivolous convenience to a case manager holding the bottom line.

“Form letters just don’t work anymore,” according to a hospital counselor who advocates for patients. What gets funded is dependent on the wording of the policy and the wording of the requests. People are usually more successful if they use medical terms to justify their requests. “getting out of bed” becomes “skilled transfer” or “posture positioning,” when a “bowel program” becomes “administering of medications (suppositories),” when “bathing” becomes “monitoring for skin integrity,” case managers tend to be more receptive, the counselor said.

Another valuable tactic is to point out the long-term prevention aspects of both care and equipment. For example, explain the cost of skin-flap surgery when requesting a replacement cushion. Work with your provider to write a letter of medical necessity for what you need.

Once you understand that a denial is simply a business transaction, you won’t let it discourage you. Keep a key statistic in mind: 70 percent of denials are never appealed. And it’s likely for things out of the ordinary to be denied after the first claim.

No matter whom you talk to, one piece of advice always comes through loud and clear: always appeal denials. And if you feel you’re on sound footing, don’t stop with simple appeals to the insurance company. You have other options. Write letters; make phone calls; put your tax dollars, public employees, and elected representatives to work. Write your state insurance commissioner. Exhaust all avenues.

Say it with me: “Always appeal denials.”

Annette Lauber with the NC Assistive Technology Program offered these survival tips:

- Policies are different. Know your policy, its limits, inclusions, and exclusions. Make sure you know if you have a fee-for-service or HMO plan.
- Justify and document the medical necessity of all requests.
- Be polite and businesslike, and don’t take denials personally.
- If your claim is denied, find out why it was denied; then appeal it. Include letters of medical necessity from your provider.
- It is not unlikely for things out of the ordinary to be denied after the first claim.
- Refer to your insurance benefits materials, which will outline the appeal process.

By Richard Holicky, health counselor and free lance writer, excerpted from “Insurance Tips,” in *New Mobility* magazine, March 2000.



CENTER
FOR
RESEARCH ON
WOMEN WITH
DISABILITIES

The Center for Research on Women with Disabilities (CROWD)

focuses on issues related to health, aging, civil rights, abuse and independent living for women with disabilities.

Current studies are examining health promotion and violence against women.

To learn more, call 800-44-CROWD or visit their web site at <www.bcm.tmc.edu/crowd>

CROWD publications include:

Serving Women with Disabilities: A Directory of Abuse Intervention Services

Serving Women with Disabilities: A Guide for Domestic Abuse Programs

Working with Abuse Survivors: A Guide for Independent Living Centers

HELP FOR VIOLENCE PROBLEMS

If you or someone you know is affected by domestic violence, call the confidential National Domestic Violence Hotline (Linea Nacional sobre la Violencia Domestica) at 800-799-SAFE, TDD: 800-787-3224. The web site is <www.ndvh.org>

MAKING THE MOST OF YOUR 15 MINUTES

According to the American Society of Internal Medicine, 70 percent of a correct diagnosis depends solely on what the patient tells the provider. Giving providers as much information as possible about your health can help them make faster, more accurate decisions about your conditions and treatment.

If providers don't ask, tell them things about your disability they should know. Give them relevant information about how your disability affects your health care. If you prefer that certain information not go beyond your provider, request that it not be written down. Once information becomes a part of your medical records, it may become available to insurance companies and others.

A provider has limited time. Become an effective self-reporter. For example:

- **Poor report:** "I have a pain that bothers me sometimes; what do you think it is?"
- **Better report:** "I get a stabbing pain on the left side of my right knee when I walk fast. What do you think that means?"

Connecting your providers with one another is also important so they can easily communicate with one another when necessary. Good communication may help you get the best possible advice and treatment.

Maximize your 15 minutes

Seventy-five percent of all office visits last less than 15 minutes. How to get the most out of yours:

- Provide good information.
- Ask for an appointment when the provider is less likely to be rushed.
- Be clear about your priorities and what you want to discuss by creating a questions-and-concerns list, placing the most important topics first.
- Mail, fax or email a copy of the questions-and-concerns list to the provider before the visit or give a copy to the receptionist when you arrive.

Keep your own records

Get and read your medical records to help you become a more involved and informed health care consumer, more attentive to your health, and more in control of your own care.

Providers and facilities are permitted to and often charge you for copies of your records. The cost can be well worth it. If you have had long hospitalizations or are aware that your medical records could fill volumes, then consider asking only for summaries.

Keep complete and thorough records of your health history, the onset of conditions and/or disability, surgeries, etc. in your medical records file. Give copies to a new or potentially under-informed provider, or present summaries of the following information when visiting new providers:

- Information on medications, including nutritional supplements, vitamins, herbs and minerals. If you take medication that cannot be interrupted without serious consequences, make sure this is stated clearly and include: prescriptions, dosages, times taken when first prescribed and how long you have been on the drug.
- Surgeries, including dates
- Allergies and sensitivities
- Record of tests and shots *with results or reports*; include dates
- Your personal baseline for existing conditions, such as headaches, abdominal pain, patterns for bowel and bladder function and the like. Track changes.

Once you have organized your information, consider storing a copy with a trusted friend or in a safe deposit box.

By June Isaacson Kailes, Disability Policy Consultant. Material from this article was excerpted from her book, *Be a Savvy Health Care Consumer: Your Life May Depend On It*.



HOW TO COMMUNICATE BETTER WITH YOUR HEALTH CARE PROVIDER

As an individual with a disability, you may have a harder time accessing health care than your non-disabled peers. The following tips will help you build a positive partnership with your health care provider and promote your health.

Know your health Get regular check-ups when you are healthy because preventive health care greatly increases your chances of staying healthy. Monitor your own health and visit your provider when you know something is not normal for you.

Get referrals When choosing a health care provider, ask for referrals from friends, disability agencies, and family support groups to learn which providers adequately address the needs of individuals with certain disabilities.

Ask questions When choosing a new health care provider or when you have concerns regarding an upcoming exam, consider scheduling a pre-appointment or phone call to ask questions and help put yourself at ease. This appointment may not be covered by your health care insurance and you may have to pay for it yourself.

Check accessibility When you schedule your medical appointment, ask about physical accessibility. Ask about accessible parking and what you should do if all these parking spaces are filled. Ask if the examining room and bathroom are wheelchair accessible. You may want to ask if you can bring your own urine sample if one is needed.

Think through concerns Always think through what you want to discuss with your provider before you meet with him or her. Create a list of your concerns and take it with you to your appointment.

Take health records Be knowledgeable about your specific health conditions. Keep complete, thorough records of your medical history so that you can help educate your provider. Take these records with you to your appointments.

Know your health plan Be knowledgeable about your specific health care insurance plan and what it will and will not pay for.

Take a friend Consider bringing a friend or caregiver with you to the examining room. This person can listen, help take notes, ask questions, or just make you feel more comfortable. If necessary, remind your health care provider to speak to you rather than your friend. You may want to ask your companion to leave the room for a few minutes if you have something private to discuss with your health care provider.

Write down info Take notes during your health care visit, if this will help you to remember details. At the end of the visit, check and make sure you correctly understood your provider's information and recommendations.

By the NC Office on Disability and Health.

Tips on Improving Communication

One of the most common barriers for people with disabilities is not physical—it's communication. To help put people at ease and to facilitate inclusion of people with disabilities, the NC Office on Disability and Health has released *Tips and Strategies to Promote Accessible Communication*.

This 36-page book gives recommendations and guidelines for a number of issues, from communication aids and alternative formats to media relations. Disability-specific tips for personal interactions and interviews are also included.

For a free copy, contact NC Office on Disability and Health at 919-966-2932 voice or 919-966-0862 fax or send an email to bogues@mail.fpg.unc.edu. <www.fpg.unc.edu/~ncodh>

HELP FOR ADDICTION PROBLEMS

If you or a friend has problems with alcohol or drugs, please call the National Drug Information, Treatment, and Referral Line (free and confidential) at 800-662-HELP.

The web site is <www.drughelp.org>.

For additional information on substance use, check out the Center for Substance Abuse Prevention at <www.samhsa.gov/csap>

HEALTH INSURANCE RESOURCES

American Association of Retired People (AARP)

<www.aarp.org>

Go to the link, "9 Ways to Get the Most from Your Managed Health Care Plan" at <www.aarp.org/hcchoices/9ways/seven.html>

Independent Living Research Utilization

<www.ilru.org/mgdcare/index.html>

HCFA: The Medicare, Medicaid, and SCHIP Agency

<www.hcfa.gov>

NC Institute of Medicine

<www.nciom.org>

Go to the link, "Questions to Ask Your Plan: People with Special Health Needs" at <www.nciom.org/hmoconguide/GENDIS.html>