

What You Should Know About Health Insurance:

Guidelines

For Persons

With A Spinal Cord Injury

**Developed For
National Spinal Cord Injury Association
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**by
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National Spinal Cord Injury Association

Serving People With Spinal Cord Injuries, Their Families And The Entire SCI Community Since 1948

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Committed to majority representation by people with spinal cord injuries on
our board of directors and staff

Introduction

Knowledge is power; it enables you to become more effective in daily living! Become an educated consumer of health insurance and your own best advocate. This information is compiled for persons with spinal cord injuries/diseases (SCI/D) and other disabilities and their families. It gives a basic overview of information that an individual needs to know to become a more enlightened consumer of health insurance. For people with SCI/D, achieving and maintaining optimal health and preventing secondary conditions is vital.

Access to quality healthcare often requires an understanding of the following topics, all included on this website:

- Understanding your rights as a health consumer
- Guidelines for selecting an insurance policy *and understanding its provisions*
- Steps to negotiate the insurance maze
- Frequently asked questions
- General guidelines for the appeals process (if your claim is denied)
- Suggestions if you have been unable to obtain health insurance
- Appendices of Helpful Resources
 - a. Where to find your State Insurance Commissioner
 - b. Where to find information about changing Federal and State laws that affect health insurance coverage
 - c. Booklets, offices pertaining to health insurance

As with any information dealing with this subject, it is impossible to include and address all concerns one may have about health insurance. This website is not intended to cover every situation or every nuance of insurance law. Highly technical questions that you may have should be directed to your insurance agent, personnel specialist, or your own lawyer. Hopefully, you will gain the basic knowledge that you need to exercise your rights regarding health insurance and your own plan.

RIGHTS AS A HEALTH CONSUMER

As a person living with SCI, it is important that you exercise your rights to:

- Maintain and improve your own health and that of your own family and community
- Access information that enables you to make knowledgeable choices for your health practices including:
 - a. Choose your doctor
 - b. Choose suitable and appropriate health insurance
 - Understand types of health insurances
 - Know what services and conditions are included, excluded, limited
 - Know steps to assure your ability to have rights and needs met
 - c. Make selections to foster a healthy lifestyle that include:
 - Quality care choices that promote disease prevention and reduce risk of secondary conditions, provide interactive checkups, support your caregiver needs
 - How to recognize quack providers and scam practices [see appendices]
 - Mechanisms and processes for reporting product and provider complaints
- Achieve a relationship, as a *person with SCI/D*, of mutual understanding with your insurance company supported by:
 - a. Copy of your insurance company's booklet of a full and detailed explanation of benefits
 - b. Designated claims advisor, benefits provider, or case manager as your representative within the insurance company; this person should understand your particular needs, become an advocate for you and be the person with whom you will interact whenever you have an insurance issue.
 - c. Opportunity to educate your designated insurance representative about the health care needs of the person with a SCI/D. (*Teach this person the risk factors for the secondary complications of spinal cord injury, necessary measures to preserve the health and integrity of your paralyzed body and importance of immediate access to insurance and health care professionals*)

Educate your insurance representative to be an advocate for your health care needs

FORMS OF HEALTH INSURANCE

Since 1992, there has been a strong move to contain the spiraling costs of health care. Today, health insurance is offered in three major formats:

- Third Party Payors - Insurance companies or organizations that sell commercial insurance to employers, process claims, and pay providers. There are two categories:
 - a. “Fee for service” (traditional kind of health care policy) pays providers a fee for the services provided to the insured; offers consumers the most choices of doctors and hospitals. In most cases, the insurance covers 80% of the charge and the patient pays the remaining 20% coinsurance.
 - b. Managed Care Organization (MCO) – A payor organizes a group of providers, called a network, who have agreed to provide specified health services to persons who enroll in the MCO plan. The network providers are paid according to a predetermined, contracted rate. (Because of lower costs to employers, MCOs have almost entirely replaced the indemnity “fee for service” plans in the U.S.)
- Health Maintenance Organization (HMO) These are prepaid health plans for which there are several existing models; the major differences in the models exist in the relationship between the HMO and the participating physicians. You or the insured, the HMO member, pay(s) a monthly premium. In exchange, the HMO provides comprehensive care for you and your family, including doctors' visits, hospital stays, emergency care, surgery, lab tests, x-rays, and therapy. The HMO arranges for this care; usually, your choices of doctors and hospitals are limited. However, exceptions are made in emergencies or when medically necessary.
- Preferred Provider and Point of Service Organizations (PPO/POS) These are mixed model plans that blend a combination of MCO and HMO features. A PPO, similar to an HMO, has a limited number of doctors and hospitals from which to choose and requires that you choose a primary care doctor to monitor your health care. A POS offers a broader selection of providers; the insured selects the provider of choice when the medical services are needed. When you use PPO/POS providers (sometimes called "preferred" providers, other times called "network" providers), most of your medical bills are covered. Usually there is a small co-payment for each visit; for some services, you may have to pay a deductible and a co-payment. If you choose (a) provider(s) outside of the network, coverage payment may be less and you may pay a larger deductible or co-payment. Covered services most often included preventive care such as visits to the doctor, well-baby care, immunizations, and mammograms.

There are three *government-funded health insurance plans* that it is important for the person with a SCI/D to know and understand:

- [Medicare](http://www.cms.hhs.gov)¹ [www.cms.hhs.gov] a federal health insurance program for persons who are disabled and have received Social Security Disability Insurance (SSDI) for at least 24 months, and for persons 65 years of age or older. Medicare has two parts; these do not cover the same things:
 - a. **Part A** covers inpatient hospitalization, skilled nursing facility care, and hospice care. It will pay for some home health care services, however, you must need *skilled care* and be *homebound*. Most people don't have to pay premiums for Part A coverage, but you will have deductibles to pay.
 - b. **Part B** covers inpatient and outpatient physician services, as well as outpatient therapies, limited medical supplies and medical tests, and some durable medical equipment (DME). (DMEs require a Certificate of Medical Necessity (CMN) submitted by your physician) Part B is optional, requires a monthly premium, an annual deductible, a co-payment for each visit or service.
- [Medicaid](#) is a federal program that is administered by the states. It provides medical assistance for persons with low-income and limited assets. Medicaid covers inpatient and outpatient hospital care, physician services, home health care services, medications, and some supplies.

Inquire about your eligibility for Medicare/Medicaid as soon as possible following your injury. If you are still in acute rehabilitation, seek the assistance of your social worker or discharge planner. Begin the application process immediately. The approval process is lengthy; periodic inquiries to determine status of the application is appropriate and encouraged.

- [Social Security Disability Insurance \(SSDI\)](http://www.ssa.gov/applyforbenefits) [www.ssa.gov/applyforbenefits] is for one who is permanently disabled; eligibility is based on one's prior work history under Social Security and determined by the Social Security Administration.
 - a. If you are permanently disabled and have been receiving SSDI benefits for 24 months, you will then be automatically enrolled in Medicare

¹ [Understanding the Benefits](#), p. 24. Social Security Administration, Publication No. 05-10024, January 2000

- b. **Please note:** *SSI is not an insurance program.* [www.ssa.gov/index.cfm]
SSI disability payments are made on the basis of financial need. *SSI recipients are automatically enrolled in Medicaid, i.e. State Medical Assistance.* There are several differences in the eligibility rules for SSI and SSDI.²

² Disability Benefits, p. 1. Social Security Administration, Publication No. 05-10029, September 1999

GUIDELINES FOR SELECTING A HEALTH INSURANCE POLICY

Insurance companies are businesses; their goal is to make money. Your responsibility is to be an educated, informed consumer who is able to make appropriate selections for your health insurance coverage. The National Committee of Quality Assurance, a non-profit organization has developed a “Health Plan Report Card” that can assist you in your decision.³ You may obtain a [consumer guide](#) for your state [online resource only].

Insurance companies are regulated by each of the states in which they do business. Generally, a State Insurance Commission oversees these regulations [see Insurance issues on Resources page]. However, **self-insured plans** are not regulated by the state; the federal law known as ERISA or Employees Retirement and Income Security Act regulates them. The employer of the insured runs self-insured health plans. It is important to know if your employment-derived health insurance coverage is a ‘self-insured’ plan. This will be useful and important information when negotiating with your insurance company for disability-related coverage.

The following are important contributors to your **selection process**: (*Considering your own circumstances, use these sections to identify and prioritize your needs and health goals*)

I. List your personal considerations:

- What are your health practices that promote your health and well-being as a person with a SCI/D
- Do you have any existing chronic conditions in addition to your SCI/D
- What specialists provide your care, i.e. physiatrist, urologist, cardiologist (list your doctors, the hospital(s) at which they have admitting privileges and the plans in which they participate)
- How often is it necessary for you to be seen by each specialist
- What rehabilitation therapies do you need and how frequently, such as physical or occupational therapy
- Do you need personal assistant services; if so, how many hours daily or weekly
- What durable medical equipment, rehabilitative, assistive and adaptive devices do you require for accessibility and independent functioning
- Do you live near your needed health services (What is your hospital preference)
- How do you get to the doctor, urgent care center or hospital, when needed
- Is your health insurance only for yourself or do you have beneficiaries
- Are you employed or is seeking employment within your goals

³ [Health Plan Report Card](#). National Committee for Quality Assurance. www.healthchoices.org or 1-888-275-7585

II. Questions to ask *about a health insurance plan*:

- What kind of policy is this, i.e. read the description of the policy
- Can I choose or retain a specialist (e.g. physiatrist) as my primary care physician (PCP)
- Is there coverage for specialists including those with SCI expertise
- Does the plan provide out-of-network referrals or standing referrals to specialists or specialty care centers
- Are physicians' offices and related health facilities accessible
- What services are and are not covered (i.e. its inclusions, limitations and exclusions): inpatient and outpatient rehabilitation, home health assistance, mental health care, medical transportation (This information is often in obscure places within a policy such as within definitions)
- What are the policies regarding deductibles, co-payments, prescription and durable medical equipment coverage, long-term, community-based services
- Are there case management services for people with SCI/D
- Does the plan offer a help line or advice line for assistance; if so, who staffs this line
- What are the requirements for pre-certification or authorization for preventive, routine, elective, urgent and emergency care
- Does the plan have lifetime caps, i.e. a maximum amount of dollars that will be paid for a condition or for particular services such as rehabilitation, personal assistance or equipment needs
- Is there a clearly explained process for you to file a complaint; are you eligible to receive reimbursement when seeking a second opinion, if and when you believe you are not receiving necessary and/or appropriate services

III. Understanding Insurance Definitions before Selecting a Health Insurance Plan:

- Premium – a periodic payment (usually monthly) made to a payor (insurance company) to keep an insurance policy active; must be paid before, and whether or not, any services are actually received.
- Deductible - an annual, out-of-pocket amount, fixed by the individual insurance policy, that the insured must pay each year before the company will begin payment for covered benefits. (If there is a deductible, you should know how much it is, if it is for the entire family or does each member of the family have to satisfy the specified deductible before the plan pays individual benefits)
- Co-payment – a fixed amount that is required every time you use your health plan for service(s) and pharmacy prescriptions.

- Co-insurance – a percentage of a health care service fee that must be paid by the patient; a person’s second insurance program (secondary) may pay all or a portion of this amount.
- Basic medical services - well care visits
- Major medical plan – may include such services as dental, pharmacy, mental health, vision care
- Pre-existing condition – an illness, disability, or disease that the insured has incurred before coverage has commenced. The passage of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) has prohibited the exclusion of individuals from coverage in health insurance plans due to pre-existing conditions.
- Network - physicians, auxiliary services, and hospitals with which an HMO contracts to provide care to its clients.
- Out-of-network: physicians, auxiliary services, and hospitals that are not associated with a particular plan or organization. Depending on the plan, consumers who select out-of-network services may have to pay a higher cost or the entire cost of going out-of-network. Exceptions are usually made when members of the plan are traveling out of range of the service provider network.
- Lifetime cap (**Important knowledge for a person with a SCI/D**) – Maximum amount that a plan will pay for a given condition (usually \$1,000,000)
 - a. Inquire if a higher cap is available and the cost of this addition to the policy
 - b. In self-insured plans, the employer can set different lifetime caps for different medical conditions
- Medically necessary services - must comply with the terms of the insurance contract (policy); cannot be experimental, non-FDA approved, educational, or investigative in nature

Knowledge of lifetime caps on health insurance benefits is important information for persons living with SCI

STEPS TO NEGOTIATE THE INSURANCE MAZE

I. Recommended Steps:

- Obtain a copy of the full (not abbreviated or summarized) explanation of insurance benefits. Read your policy *carefully and thoroughly*, including fine print, definitions, exclusions, etc., to learn the extent of covered services [such as those specific topics and services noted in Section I & II, pp. 8-9]
- Find out if you have been assigned a case manager and contact that individual; if not, request that you be assigned to a case manager or benefits advisor. [see page 4] To be your own *best advocate*, you should educate this individual about your SCI/D and your particular needs to preserve the integrity of your body and health.
- Determine the rehabilitation benefits: inquire about the number of allowed days of coverage for inpatient acute and sub-acute rehabilitation, outpatient and home health rehabilitation; is there an annual maximum number of days; is there a lifetime maximum number of days (these need to be differentiated according to the above categories of service)
- Inquire about rehabilitation in a SCI/D-accredited rehabilitation facility; does this include both an in-state or out-of-state facility
- Know the benefits re: durable medical equipment (DME); is there a lifetime maximum amount of dollars for DME
- Select a doctor: Your choice will depend upon the type of insurance plan that you have. You will need a doctor with expertise in SCI/D; can this person be your primary care physician (PCP) or will your PCP consult with your SCI/D doctor in the management of your health care? The following will apply:
 - a. HMO: must use a physician who is part of the HMO
 - b. PPO or POS: Choose a doctor within the system; if your doctor is not on the given list, you may choose to go out of network; you will probably have to pay all or a larger portion of the fees
- Contact your insurance representative for issues and/or concerns that relate to your health insurance and whenever you have been denied a service that you believe to be covered
- **Remember to always document/record *all* conversations with your insurance company:** include date of the call, the reason for the call, the person with whom you spoke and the outcome of the call

- **Keep all correspondence that has anything to do with your health insurance coverage!** All written communications should include your Name, Insurance Identification (ID) and/or Group Number, Social Security Number and your date of birth; require that all actions regarding health benefits coverage be in writing

II. Frequently Asked Questions

- Can I go to a doctor with SCI/D expertise?
Consult the provisions of your insurance policy; if your PCP does not have this knowledge, ask him/her to consult with a SCI/D physician in the management of your health care
- Can I continue my health insurance that I had through my employment, even though I cannot return to that place of employment?
COBRA, the Consolidated Omnibus Budget Reconciliation Act of 1986, is a federal law that gives certain employees and dependents the right to "continuation coverage." This means that they can temporarily continue to keep the same coverage they had through a [group health plan](#), even after they are no longer entitled to stay in the group health plan. The benefits will be the same, but the [premiums](#) will probably be higher. COBRA continuation coverage is only available when coverage is lost due to certain qualifying events, such as losing a job, death, divorce, or other life events. Under certain circumstances for the person with SCI/D, this continuation may be extended an additional 11 months beyond the initial continuation.
- What is durable medical equipment (DME)?
Equipment such as wheelchairs, walkers, commode and shower chairs that must be ordered by your doctor, accompanied by a 'certificate of medical necessity' (CMN), for long term use, and for use in the home.
- Who is responsible for a 'certificate of medical necessity'?
Your physician must complete and sign, in his/her own handwriting, a CMN. This form should accompany any DME request to your insurance company or Medicare; it should specify that your diagnosis is permanent, that the requested item will be used over time and that it contributes to your health by preserving the integrity of your paralyzed muscles, well-being and/or functional independence.
- Will my insurance pay for experimental or research procedures?
*For possible consideration for access to and coverage for experimental medications or procedures: Ask the plan administrator for a "Compassionate Use Waiver" from the FDA. If the waiver is granted, the health insurance plan **may** permit access and coverage*

- What can I expect if I become acutely ill?
Prior to an acute illness, you should request a consultation appointment with your PCP during which you discuss your immediate needs regarding urinary tract infections (UTI's), spasticity, autonomic dysreflexia (AD), pressure sores and other possible urgent health care needs. Ask about "standing referrals" to a specialist such as an urologist, procedures and policies when you become ill after office hours and/or have an urgent care or emergency need.
- What should I do if I am too ill and weak to wait for care in an emergency waiting room?
Call your health insurance provider advice or hotline. Ask that they make arrangements for you to be seen, or at least placed, in an emergency patient room as soon as you arrive at the ER or arrange for your doctor's office nurse/staff to assist with such arrangements or contact your hospital trauma or SCI nurse specialist and ask for this assistance
- What should I do if I require urgent or emergency care?
*Call your PCP or insurance advice/hotline if your situation is non-life threatening. If your situation is life threatening, go immediately to the nearest ER; take your insurance card with you; take information about AD and any allergies, if these are risk(s) for you. Following your emergency, **immediately** contact your health insurance case manager.*

III. Guidelines When a Health Service or an Insurance Claim is Rejected or Denied

All health insurance plans have some form of appeals procedure. It is not unusual for medical procedures, medications, therapies, 'length of stay' days and durable medical equipment to be denied to individuals covered by healthcare plans. Over 70% of those persons, who have been denied coverage, do not attempt to appeal the decision. **It is strongly recommended that you should appeal all denied or rejected insurance decisions or claims. Decisions are reversed in 43% to 80% of cases that are appealed, according to recent reports.**

Recommended steps:

- Contact your insurance representative immediately; ask for an explanation of the action
 - a. If needed information was not provided with the original request, resubmit your request with the pertinent or necessary information.
 - b. If the action is a denial, request the reason(s) for each denial in writing
- **Read your policy carefully:**
 - a. To discover which type of dispute resolution mechanism (appeals process) is available to you
 - b. To determine if your insurance carrier has mistakenly denied coverage

- c. To determine if the service, that has been denied, is deemed “*medically necessary*”
- **Document/Record *all* conversations:**
 - a. Include name, date, time and actions, of anyone related to the problem/issue, with whom you have spoken
 - b. Keep copies of all correspondence that has anything to do with the initial denial of coverage, and anything that pertains to your appeal
 - c. Keep copies of all claim forms and bills
- Submitting an appeal: **Be your own best advocate!**
 - a. Be familiar with appeals procedures
 - b. Know deadlines to file claims and appeals
 - c. Inquire as to when a hearing will be scheduled. (Most plans have a maximum number of days in which to set a hearing date.) Make repeat phone calls until you get concrete answers to your questions. **Be insistent, consistent and persistent!**
 - d. Base the contents of your appeal in relation to the reason for the denial:
 - Learn and be informed about your own health impairment, level of injury, care required to preserve the integrity of your paralyzed body, risk of secondary complications.
 - Enlist the cooperation and collaboration of your doctor in providing supporting documentation as to the need for a reversal of action
 - Submit supporting statements from experts in the field with your appeal
 - Submit published articles that substantiate the necessity of the service or durable medical equipment that was denied with your appeal

Be your own best advocate - when uncertain or dissatisfied – Appeal!

- Should you feel that you have not been treated fairly by your plan provider or that the appeals process has become too lengthy, contact your state Insurance Commissioner. Each state has an agency whose sole responsibility is to regulate the insurance industry within that state. No two states have exactly the same insurance regulations; you must contact your state insurance agency to learn your rights about the appeals process. [see Insurance issues on Resources page]
- Health Insurance Ombudsman: Twenty states now have these government-paid intermediaries to help the consumer navigate the health care system and resolve health insurance problems. Contact your state insurance agency to find out if this is a service offered within your state. [see Insurance issues on Resources page]

Resources for the Uninsured SCI/D Person

The lack of health insurance has become a serious concern within the U.S. An analysis of the 2000 census reports revealed that 81% or 13 million Americans have incomes too high to qualify for State Medicaid. Studies reveal that the uninsured person accesses health care less frequently, has more untreated medical problems, are less likely to receive preventive care and more likely to be hospitalized for preventable medical conditions.⁴

Avoid secondary complications – Seek medical care

Access to appropriate health care is very important for the person with SCI. The above-identified problems can be direct contributors to intensifying the risk for secondary complications that are consistent with SCI. It will be particularly important that you become an advocate for yourself in a persistent effort to obtain the medical care that is vital to preserving the integrity of your paralyzed body and achieving a good quality of health.

There are charitable and patient assistance programs for which you may be eligible. Several of the prescription assistance programs include pharmaceutical companies that produce some of the medications commonly used for SCI persons. Each pharmaceutical company has its own application form that must be obtained, filled out and submitted by your physician. To be considered for all assistance programs, you should be prepared to:

- Show proof of no insurance coverage
- Show proof of no prescription coverage
- Provide detailed financial information
- Demonstrate being under the care of a licensed physician

The following resources may provide assistance:

- **Community Free Clinics:** [Volunteers in Health Care](http://www.volunteersinhealthcare.org/home.htm) www.volunteersinhealthcare.org/home.htm or Toll-free 1-877-844-8442 for list of network of clinics or call your local Department of Health and Social Services to locate a free clinic in your community
- **Charity Doctors:** Call local Department of Health and Social Services or County Medical Society for a list of names
- **Community Health Centers:** County or city health departments; State or local listing in telephone directory; may offer subsidized or free programs for residents of a particular geographic area

⁴ Fact Sheet re: Uninsured. Families. USA, May 2001

Millions of Low Income Left Uninsured. Health Care Safety Net, July 19, 2001

- Easter Seals : www.easter-seals.org or Ph: 1-800-221-6827 to locate your state office
- **Prescription Assistance Programs:**
 - **DisabilityResource.org: Prescription Drug Assistance Programs:**
<http://www.disabilityresources.org/RX.html>
 - **Needy Meds:** www.needy meds.com
 - **Pharmaceutical Research and Manufacturers of America:**
<http://www.phrma.org/pap/> Ph:1-202-835-3400
 - **RxHope:** www.rxhope.com
Email: customerservice@rxhope.com Ph:1-908-850-8004 will help with the application process for approval for medication assistance
 - **The Medicine Program:** www.themedicineprogram.com
Email: help@themedicineprogram.com Ph:1-573-996-7300 will help with the application process for approval for medication assistance, small fee is charged
 - **National Council on the Aging Benefits CheckupRX:**
<http://www.benefitscheckup.org/> Primarily for ages 55 and above, however, may link in to other programs for younger persons
- **Catholic Charities:** local listing in telephone directory
- **Shriners Hospitals for Children:** www.shrinershq.org Ph: 1-800-237-5055
* Contact any Shrine Club
- **University Medical Centers:** State or local listing in telephone directory; inquire about research protocols, ‘sliding fee’ programs
- **Rural Information Center Health Service (RICHS):**
www.nal.usda.gov/ric/richs
Email: ric@nal.usda.gov Ph: 1-800-633-7701 – has database of information, including funding resources and other needs for special populations
- **Vocational Rehabilitation:** Phone Numbers for **State Vocational Rehab Services** listed at www.spinalcord.uab.edu/show.asp?durki=30035 or go to State Government listing (Blue pages) in telephone directory – If your long range goals include returning to gainful employment, this can be an entry-way to resources for health care

RESOURCES:

Current legislation, policies and news re: health insurance:

- **Centers for Medicare and Medicaid Services:**
<http://cms.hhs.gov/media/>
- **Families USA:** www.familiesusa.org
Email: info@familiesusa.org Ph: 1-202-628-3030

Advocacy:

- **Families USA:** www.familiesusa.org
Email: info@familiesusa.org Ph: 1-202-628-3030
- **Patient Advocate Foundation:** www.patientadvocate.org
Email: help@patientadvocate.org Ph: 1-800-532-5274
- **American Association of People with Disabilities:** www.aapd-dc.org

Insurance issues:

- **State Insurance Commissioner:**
<http://www.naic.org/regulator/usamap.htm> see State Government listing (Blue pages) in telephone directory or contact National Insurance Consumer Hotline: 800-942-4242
- **Health Insurance Ombudsman Programs:** selected states have begun these programs; contact [State Insurance Commissioner](http://www.naic.org/regulator/usamap.htm)
<http://www.naic.org/regulator/usamap.htm>
- **National Association of Protection and Advocacy:** to locate State office: www.protectionandadvocacy.com
Email: napas@earthlink.net Ph: 1-202-408-9514
- **National Council on the Aging [Benefits Checkup](http://www.benefitscheckup.org/) :**
<http://www.benefitscheckup.org/> Primarily for ages 55 and above, however, may link in to other programs for younger persons

Insurance plans:

- **National Committee for Quality Assurance:** www.healthchoices.org
Ph:1-888-275-7585
- **Agency for Health Care Policy and Research:** *Checkup on Health Insurance Choices*. AHCPR Publication No. 93-0018, (December 1992) <http://www.ahrq.gov/consumer/insuranc.htm>
Ph: 301- 594-1364
- **Consumer Health Insurance Guide** (state specific, online only):
<http://www.healthinsuranceinfo.net/>
- **Getting the Most Out of Managed Care: A Guide for People with Disabilities** : EPVA publication, 2000.
http://www.epva.org/Videos_Publications/publication_database.asp
Email: publications@epva.org Ph: 1-800-444-0120

Insurance appeals:

- **Families USA:** www.familiesusa.org
Email: info@familiesusa.org Ph: 1-202-628-3030
- **Patient Advocate Foundation:**
www.patientadvocate.org/resources.php
Email: help@patientadvocate.org Ph: 1-800-532-5274
- **Finding Your Way through the HMO Grievance and Appeals Process: An NRH Field Guide for People with Disabilities**
<http://www.nrhdr.org/FindingYourWay.pdf> (June 2002) For additional copies call 1-866-380-4344

Medicare and Medicaid:

- **Center for Medicare and Medicaid Services:** www.cms.hhs.gov/
Ph: 1-410-786-3000
- **Medicare:** <http://www.medicare.gov> Ph: 1-800-633-4227
Locate your area Medicare office: <http://s00dace.ssa.gov/pro/fo/fo-home.html>
- **Medicaid:** <http://cms.hhs.gov/medicaid/tollfree.asp> For State Medicaid '800' phone number or State Government listing (Blue pages) in telephone directory: Department of Health and/or Human Services

Federal assistance, related resources:

- **Supplemental Security Income (SSI):**
<http://www.ssa.gov/pubs/11000.html> SSA Publication No. 05-11000 (2000) Ph:1-800-772-1213 Ph: 1-800-325-0778 (TTY)
- **Social Security Administration Office of Disability and Income Security Programs:** <http://www.ssa.gov/disability/>
Ph: 1-800-772-1213 Ph: 1-800-325-0778 (TTY)
- **Social Security Disability Income (SSDI)**
<http://www.ssa.gov/pubs/10029.html> SSA Publication No. 05-10029 (2002) Ph:1-800-772-1213 Ph: 1-800-325-0778 (TTY)
- **Benefits for Children with Disabilities:**
<http://www.ssa.gov/pubs/10026.html> SSA Publication No. 05-10026 (2001)
- **Ticket to Work Program (TWWIA):**
www.ssa.gov/work/Ticket/ticket_info.html
SSA Publication No. 05-10060 (2001) Ph: 410-965-8904
- **COBRA (Consolidated Omnibus Budget Reconciliation Act of 1986):**
<http://cms.hhs.gov/hipaa/onLine/120001.asp>
- **HIPAA (Health Insurance Portability and Accountability Act of 1996):** <http://cms.hhs.gov/hipaa/online/default.asp> Ph: 1-410-786-3000

Uninsured:

- **Kaiser Family Foundation:**
<http://www.kff.org/sections.cgi?section=kcmu>
- **Covering the Uninsured:** www.coveringtheuninsured.org
- **Families USA:** www.familiesusa.org
Email: info@familiesusa.org Ph: 1-202-628-3030
- **Volunteers in Health Care:** www.volunteersinhealthcare.org
Ph: 1-877-844-8442
- **1997 NHeLP Manual on State and Local Responsibility for Indigent Health Care:** <http://nhelp.org/pubs/19971101state.html>
National Health Law Program, 2639 S. La Cienega Blvd., Los Angeles, CA 90034 Ph: 310-204-6010

Booklets:

- **Understanding Your Benefits:** SSA Publication No. 05-10024
- **Benefits for Children with Disabilities:** SSA Publication No. 05-10026
- **Working While Disabled – How We Can Help:** Publication No. 05-10095

Free copies of these above books can be obtained: www.ssa.gov
Ph: 1-800-772-1213 Ph: 1-800-325-0778 (TTY)

- **Medicare and You 2003:** Publication No. 10050
- **Guide to Health Insurance for People with Medicare**
Publication No. 02110

Free copies of these above books can be obtained:
<http://www.cms.hhs.gov/publications/> or write to: Centers for Medicare and Medicaid Services, 7500 Security Blvd., Baltimore, MD 21244-1850

- **The Consumer's Guide to Medicare Supplement Insurance**
- **The Consumer's Guide to Disability Insurance**

Free copies of these above books can be obtained:
<http://www.hiaa.org/store/bookstore/> or write to: Health Insurance Association of America (HIAA), 555 13th St., N.W., Suite 600 East, Washington, D.C. 20004

- **On the Move: A Financial Guide for People with Spinal Cord Injury:** A collaborative effort of PVA, NSCIA and The National Endowment for Financial Education. Free plus cost for shipping and handling from PVA: Ph: 888-860-7244
- **The Medicaid Resource Book** (2003)
<http://www.kff.org/content/2003/2236/> by The Kaiser Commission on Medicaid and the Uninsured