



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

Legal and Financial

Insurance Questions	111
Insurance Problems	113
Elder Law: The Basics	118
Advance Directives	122
Medicare Basics	125
Medicaid	129
Social Security Disability	132
Employment	138
MI Child.....	140



Health Insurance Questions **You Should Know the Answers To:**

General Questions:

- What type of insurance policy do you have?
 1. Indemnity Plan: No restrictions on where you are seen.
 2. PPO Plan: Pays a better rate for participating providers.
 3. HMO Plan: Must see a primary care physician and get a referral to see other providers.
- How do you get a case manager assigned to coordinate your care and benefits?
- Does your policy include a catastrophic medical benefit that offers more benefits?
- Is there an annual deductible?
- Is there an annual out-of-pocket expense limit or maximum?
- If I meet my limit, does my coverage increase and to what extent?
- Do I have a major medical plan? Is there an annual or lifetime maximum?
- Do I need to complete any claim forms?
- Am I subject to pre-existing condition regulations?

Durable Medical Equipment (DME) Questions:

- Does my plan cover DME? What about ventilator and BiPAP-S/T (noninvasive ventilator) coverage; are they under respiratory equipment or DME?
- What percentage does my policy cover?
- Is there a preferred provider I must see?
- Is pre-authorization or a medical review required?



Prescription Questions:

- Does my plan cover prescription drugs? What are the terms of this coverage, and is coverage different based on using brand-name versus generic drugs?
- Is there a specific pharmacy/supplier network I must use?
- Are injectable medications covered under my plan?
- Is there a limit on the amount of prescription drugs I can get through this plan?
- Is there coverage for all FDA-approved drugs, or is coverage provided only for those listed on your formulary (a list of drugs that an insurance policy covers)?
- Does my plan offer a mail-order pharmacy option? Describe this benefit.

Home Health Questions:

- Does my plan have home health coverage? Describe this benefit.
- Do I have coverage for a home health aide (for skilled or custodial care)?
- Is there a preferred home health care agency I must use?
- Is there private duty nursing coverage at home? Describe this benefit.
- Does my plan cover hospice care?

Questions for Health Maintenance Organization (HMO) and Preferred Provider Organization (PPO) Subscribers:

- Is my ALS neurologist (or other ALS specialist) a member of the network or a participating provider?
- Explain the referral process. Do I need a referral from my primary care physician every time I go to the neurologist or other specialist; is there a limit to the number and frequency of referrals?



Insurance Problems

The following are a few important guidelines to follow when you have a complaint with your medical insurance provider. Keep in mind, that every organization has its own set of complaint/appeals procedures which must be followed. It is important to remember that following the standard appeal process established by your insurance company, while necessary, is basically playing by their rules. Remember, denying "or" delaying your claim saves money and is therefore in the best interest of the insurance company. It is in your best interest to appeal to the insurance company in as many ways as possible in an effort to increase the likelihood of a successful and timely reconsideration and approval of your claim. In addition to approving your claim because it is a benefit you are entitled to, insurance companies may be encouraged to approve claims for business, legal, public relations, cost, or political reasons.

- **Phone your insurance company request an explanation.** Most insurance companies offer their participants an "800" customer service number which should be called immediately when you have a question, complaint, or grievance. These customer service numbers use forms of call tracking systems to record calls. By calling them, you begin a traceable record of concerns, complaints and grievances. When speaking with a representative from your insurance company, be direct and to the point in explaining your problem. Ask the company representative to point to the specific clause in the Plan which supports their denial. If the representative is not able to solve your problem immediately, request that he or she send you a detailed denial in writing based on the terms of your Plan. Additionally, you should ask them what response time you should expect with your situation. It should take no longer than 31 days.
- **Be polite.** In every insurance company, there is some knowledgeable employee waiting to be helpful. This person could be the claims supervisor or your case manager. Appeal to them. If you approach the case from a problem-solving rather than an adversarial perspective, you may gain good general advice and valuable insight into the workings of the overall bureaucracy. By making a valuable ally out of this person, you may ultimately gain a good advocate for you within the insurance company. It's often a good idea to ask them early on in the process whether they think it would be a good idea to contact your employer, file a complaint with the insurance commission, contact a lawyer, contact the press or if there is any other similar action they would suggest you take. By asking this question you not only get valuable feedback, but unofficially inform them you are not going to give up easily and this claim is likely to be a high profile problem if not resolved. This information usually finds its way quickly to key decision makers such as reviewers and medical directors. It also gives your representative or case manager the courtesy of an opportunity to resolve the problem before you take such action.
- **Read your Plan.** If you don't already have a copy of the Plan, you should obtain one by requesting a copy from your insurance company or employer. The plan document is the legal document which states all of your rights and obligations for benefits. It summarizes your rights and also specifies information concerning the administration of the plan. Specifically, it will describe the amount and duration of benefits, waiting periods, limitations on coverage, and the process for appeal benefit denials. Read your Plan thoroughly. Find the terms applicable to the denial. Determine whether or not the denial is justified



under the terms of the Plan. You should also review the appeal process defined in your Plan taking particular note of deadlines and response times. Remember that your Plan is a contract between you and your insurance company. The terms of the contract govern your relationship.

- **Send a written letter stating your complaint again.** Be sure your problem is stated in a clear, concise manner and include all appropriate documentation with the letter, including: your full name, the insurance company name, your policy number and policy ID, any test results, doctor's statements, etc. that back up your complaint. Most important, clearly state what action you want your insurance company to take to solve the problem.
- **Formally appeal the denial following the insurance companies defined appeal process.** If your problem is not solved by your initial call and letter, you should appeal your grievance to the next level within your insurance company's organization. Unfortunately, most medical insurance company grievance procedures have several levels of appeal. The process can take an excessive amount of time and when you or a family member is ill, time is of the essence. Therefore, do not hesitate to fight for your rights outside the company's appeals system as well.
- **Ask your physician to become involved.** Don't be afraid to ask your physician to contact the HMO on your behalf. More often than not, durable medical equipment is denied on the grounds that it is not "medically necessary" for an individual with ALS. Home health care is often denied on the grounds that it is in fact "maintenance" or "custodial" care, and therefore not covered under the terms of the Plan. You must prove to the insurance company that the equipment or care you require is "medically necessary" and is not simply maintenance or custodial in nature, but rather essential for your continued survival. Establish this point by asking for letters from your doctors detailing the medical necessity of the equipment or home health care benefits you need. Ask them to specifically detail the innumerable medical complications that can arise if you do not receive adequate home health care. Supplement these letters with similar letters from your neurologist, physical therapist, occupational therapist, skilled nurse.
- **Begin building a detailed chronological record.** Throughout this process, always keep accurate records. Keep a record of dates, times, names (first and last) of people you talk to and keep copies of all correspondence. You should keep copies of each letter you send and receive. Save the envelopes of all letters received from the insurance company. It is not uncommon that letters are often mailed days or weeks after the date of the letter. Many of these letters are mailed after the expiration of the statutory deadlines but purport to be sent within the deadline. Being able to demonstrate the violation of the deadline could be helpful in the future should litigation become necessary. All letters that you send should be sent certified mail, return receipt requested. It not uncommon that insurance companies deny that letters and forms were sent to them. All attachments should be described in your cover letter. If not, you have no proof that a particular attachment was sent to them. You should send a letter to the insurance company confirming the content of any telephone conversations that you have. It is often helpful to have a paper trail to quote from later. You should also ask your doctor to document any telephone conversations with the insurance company in writing to both you and the insurance company. It is not uncommon that insurance companies often misrepresent what your doctor told them.



- **Request a copy of your claims file from the insurance company.** You are entitled to a copy of this file under law. The file contains valuable information that can be used to prove that the insurance company's justifications for denying your claim lack merit. Such information includes the names of the reviewers and medical directors involved in your case and the background reasons for the denial. Use this information to your advantage. Ask your treating physicians to respond to the specific justifications by the medical reviewers for denying your claim. Don't stop there. Question the credentials of the reviewers. Do they have experience with treating and caring for individuals with ALS? Have they spoken to your treating physicians about the level of care you require? The answers to these questions provide the basis for challenging the insurance company's denial, and will save your lawyer a tremendous amount of work if you are faced with engaging legal representation.
- **Contact your state insurance commission, in writing, about your complaint.** Send them a letter detailing your complaint and include copies and records of any correspondence between you and your insurance company. Let your insurance company know that you are contacting the state insurance commission about your problem as well. Most state insurance commissions will require the insurance company to respond in writing to consumer complaints. This represents a major inconvenience which the insurance company would prefer to avoid. Many state insurance commissions also track consumer complaints and use them to compile statistical reports made available to the public. Contact information for Michigan is as follows:
- **Contact your employer and ask for assistance.** If you receive your insurance through your employer, inform the human resources department at your work of your dissatisfaction with the plan. If you are a federal employee contact the Federal Employee Health Benefit Program (FEHBP) at the Office of Personnel Management (OPM). Remember, you represent a benefit claim and therefore an expense to the insurance company. The insurance company, like any other business, wants to minimize expenses so they can maximize profits. Your employer however, represents a customer who the insurance company wants to keep satisfied so they can retain their business. Insurance companies will often make accommodations to your employer they will not make to you including authorizing claims for benefits not strictly covered by the plan.
- **Contact your state and federal elected officials.** Ask them to contact the insurance company. They may be able to assist you in the appeals process. Plus you are giving them a first-hand look at the problems patients commonly face within the managed care system.
- **Request a conversion of benefits.** If the insurance company claims that you do not have a benefit such as home health care under your Plan, check your Plan to see if it provides for placement in a skilled nursing facility or rehabilitation hospital. If so, ask your insurance company if it would consider converting that benefit to a home health care benefit.
- **Contact the press.** Do not be afraid of "going public" with your claim. In this current climate where the phrase "managed care" connotes restricted health care access, the shared sense of vulnerability that the general public feels can help to detonate an outpouring of anger at a payer who is exposed putting its pocketbook above its compassion. Remember, the insurance company is a business and no business likes bad publicity.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

- **Be Persistent.** Make your presence known. Let the insurance company know that you will not go away until you receive the benefits to which you are entitled. And, don't be afraid to ask anyone and everyone you can think of for ideas and help. This information is sometimes overwhelming. Don't be discouraged. Be tenacious. - Don't Give Up!

The Medicare Appeal Process

Sometimes you may disagree with a decision about whether a service is covered by Medicare or the amount the program will pay on a claim. You have a right to appeal such decisions. A brief overview of Medicare Part A and Part B coverage and the associated appeals process are as follows:

Medicare Part A Coverage:

- Inpatient Hospital Service
- Inpatient Skilled Nursing Facility Services
- Home Health Services
- Hospice Services

Medicare Part B Coverage:

- Physicians' Services
- Some Outpatient Services & Therapy
- Durable Medical Equipment
- Prosthetic Devices
- Ambulance Services
- Home Health Services Not Covered under Part A
- Some Pap Smear and Mammography Screens
- Flu Shots
- Some Therapeutic Shoes

If you are appealing a decision made by a service provider, the provider should send a notice about why it believes Medicare will not pay and also file the notice with Medicare. You will then receive an official determination from Medicare, called a Notice of Utilization. If you disagree with the Notice of Utilization, the notice itself includes instructions for appealing.

If you are appealing a decision made by an Intermediary on Medicare Part A claims, it must be within 60 days of receiving official notification from the Intermediary (the company which administers Medicare Part A in your state). To appeal, contact either the Intermediary or Social Security.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

If you disagree with a decision on a Part B claim, you have six months from the date of the decision to ask the company that administers Medicare Part B in your state to review the decision. If you still disagree, you can ask to have a hearing before a hearing officer.

Finally, Peer Review Organizations (PROs) decide whether care provided to Medicare patients is medically necessary and of good quality. If the patient is admitted to a Medicare-participating hospital, the patient or caregiver will be given a notice called "An Important Message from Medicare." This notice will contain the name, address and phone number of the Peer Review Organization (PRO) in your state and describe your appeal rights.



Elder Law: The Basics

What is Elder law?

Thousands of federal and state laws govern the many decisions an ALS patient or caregiver will be responsible for making. Whether you are navigating the Social Security or Medicare/Medicaid system, looking out for money and property, discussing powers of attorney and living wills or dealing with questions of long-term care, you will run into a tangle of legal rights and obligations. These various requirements can be confusing and sometimes conflicting.

Elder law is a legal specialty to help seniors, those with disabilities and their caregivers make the right decisions. For example, it takes only a few simple steps for an ALS patient to protect home and savings from being depleted to cover long-term care. An attorney specializing in elder law can improve your life and your family's life by explaining the best way to prepare for every eventuality. A strong legal safety net will reduce stress and save time and money at crucial points.

What areas does Elder law address?

Among the many questions elder law addresses are:

- What steps can legally be taken to preserve and/or transfer income and assets to avoid spousal impoverishment when a spouse requires expensive medical or custodial care or enters a nursing home
- Are you making the most of health insurance options, including private policies, Medicare, Medicaid, disability and prescription coverage? What is the proper procedure for making claims and appealing adverse decisions?
- What rights does a nursing home patient have? What should you do if a patient is being abused or defrauded?
- What is the best way to ensure that the appropriate people have the legal power to make prompt medical and financial decisions when you no longer can? How and when should you consider setting up a living will, a living trust and durable powers of attorney?
- Are you getting the full benefit from pensions, investments and Social Security? How can those benefits be passed along to survivors with a minimum of hassles and expense?
- If you will be handling a will, trusts or other means of transferring money and property, are the documents in order? Are they the right ones to accomplish the intended purpose and avoid unnecessary taxes or legal hang-ups?



Elder law also covers such issues as age discrimination, housing, probate, estate planning and mental health, among others.

Do you always need a lawyer?

The easy answer is no. But it depends upon how much work you can do on your own. A huge amount of information is available in self-help books, on the internet, from government agencies and from private organizations. But the terminology and legalese can be daunting, and many complex federal and state laws come into play. It's essential to know the law before you make your decisions and sometimes it pays to do your homework and then consult briefly with a lawyer. This keeps your legal costs down but assures that no costly or painful surprises will pop up later when it may be too late to make changes.

If you hire an attorney, does it have to be an elder law specialist?

No, many attorneys understand the legal issues related to trusts, investments, insurance, disability, discrimination and so on. But when it comes to many areas, including wills, long-term care and housing concerns, asset preservation, retirement planning, durable powers of attorney and taxation, you may make different decisions depending upon factors such as age and health. Elder law attorneys can be better attuned to an older or disabled person's needs, more aware of the subtleties involved and more knowledgeable about the intricacies of the law as it applies specifically to your situation.

How do I find an elder law attorney?

If you know any attorneys, ask them for a referral to an elder law attorney. An attorney is in a good position to know who handles such issues and whether that person is a good attorney. You can get referrals from your local bar association and organizations that deal with aging. Please contact ALS of Michigan at 1-800-882-5764 or The [National Academy of Elder Law Attorneys](http://www.naela.org) also has a nationwide directory of practitioners in all aspects of elder law. Contact info is as follows:

National Academy of Elder Law Attorneys, Inc.
1604 North Country Club Road. Tucson, Arizona 85716
Phone: (520) 881-4005 Web site <http://www.naela.org/>

How do I select an elder law attorney?

Ask any lawyers you contact about their areas of expertise and experience. Even within the area of elder law, some attorneys may specialize. You don't want a tax expert if what you really need is to set up a conservatorship or guardianship. You don't want to end up in the office of an attorney who can't help you. Start with the initial phone call. It is not unusual to speak only to a secretary, receptionist or office manager during an initial call or before actually meeting with the attorney. If so, ask this person your questions.

- How many attorneys are in the office?
- Who will handle your case?



- What percentage of his/her practice is devoted to elder law?
- Does his/her practice emphasize a particular area of elder law?
- How long has the attorney been in practice?
- How long has he/she been in this field?
- Has that attorney handled matters of this kind in the past?
- Is that attorney a member of the local bar association, its health advocacy committee, or trust and estates committee?
- Is that attorney a member of the National Academy of Elder Law Attorneys?
- If a trial may be involved, does he/she do trial work? If not, who does the trial work? If so, how many trials has he/she handled?
- How are fees computed?
- Is there a fee for the first consultation and if so, how much is it?
- What is the estimated cost to resolve your problem and how long will it take?
- What information should you bring with you to the initial consultation?

The answers to your questions will assist you in determining whether that particular attorney has those qualifications important to you for a successful attorney/client relationship. If you have a specific legal issue that requires immediate attention, be sure to inform the office of this during the initial telephone conversation.

How and when do elder law attorneys charge for their services?

There are many different ways of charging fees and each attorney will choose to work differently. Be aware of how the attorney charges. You will also want to know how often he/she bills. Some attorneys bill weekly, some bill monthly, some bill upon completion of work. Ask about these matters at the initial conference, so there will be no surprises! If you don't understand, ask again. If you need clarification, say so. It is very important that you feel comfortable in this area.

Some attorneys charge by the hour with different hourly rates for work performed by attorneys, paralegals and secretaries. If this is the case, find out what the rates are. Other attorneys charge a flat fee for all or part of the services. This is not unusual, for example, if you are having documents prepared. Your attorney might use a combination of these billing methods.

In addition to fees, most attorneys will charge you out-of-pocket expenses. Out-of-pocket expenses typically include charges for copies, postage, messenger fees, court fees, disposition fees, long distance telephone calls and other such costs. Find out if there will be any other incidental costs.

The attorney may ask for a retainer. This is money paid before the attorney starts working on your case. It is usually placed in a trust account and each time the attorney bills you, he/she pays himself or herself out of that account. Expenses may be paid directly from the trust account. The size of the retainer may range from a small percentage of the estimated cost to the full amount.

Once you decide to hire the attorney, ask that your arrangement be put in writing. The writing can be a letter or a formal contract. It should spell out what services the attorney will perform for you and what the fee and



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

expense arrangement will be. REMEMBER-- even if your agreement remains oral and is not put into writing, you have made a contract and are responsible for all charges for work done by the attorney and his/her staff.

How do I make using an elder law attorney a positive experience?

A positive and open relationship between attorney and client benefits everyone. The key to getting it is communication. The communication starts with asking the kinds of questions contained in this document. Use the answers to the questions as a guide not only to the attorney's qualification, but also as a way of determining whether you can comfortably work with this person. If your concerns are given short shrift, if you don't like the answers to these questions, if you don't like the attorney's reaction to being asked all those questions, or if you simply do not feel relaxed with this particular person, DO NOT HIRE THAT PERSON. If you take the time to make sure that you are happy right at the beginning you can make this a productive experience for both you and the attorney.



Advance Directives

Medical science has made it possible for people to survive illnesses or injuries that used to be fatal. Medicine is able to keep people alive who would otherwise die were it not for life sustaining machines or the artificial provision of nutrition and water through tubes or other techniques. If a patient is unable to make or communicate decisions regarding life sustaining medical care, who is able to make the decision to initiate such care or stop it and allow the patient to die?

Until recently, the decision often rested with the patient's family members acting in consultation with the patient's physicians. Because of questions of possible legal liability and because of changing relationships between doctor and patient, such informal arrangements are not usually possible anymore. Unfortunately, the courts are often asked to appoint a guardian to make health care decisions for a person unable to do so for himself. This can be expensive, time-consuming and can lead to decisions that might not reflect the personal wishes of the patient.

There are legal tools available to give someone authority to make and enforce decisions for you if you become disabled. These decisions arise not only with regard to life and death matters, but are involved any time there is a patient unable to make or express decisions about medical care, personal matters or possible institutional placement. If you are concerned about how your personal affairs are conducted, how your personal care is arranged for and how your medical decisions are made if you become disabled, advance directives allow you to make choices now to assure that your own preferences are honored.

What are Advance Directives?

Advance directives are written instructions stating how you want your future medical decisions made, in the event that you become unable to make or to communicate such decisions for yourself. Advance directive forms vary from state to state. The most common prepared advance directives are a Power of Attorney for Health Care, Power of Attorney for Finances, and a Living Will.

What is a Medical Power of Attorney?

A Power of Attorney for Health care is a type of advance directive that allows you to appoint a person you trust to make medical decisions for you should you become unable to do so for yourself. This type of advance directive may also be called a "Durable Power of Attorney", "Health Care Proxy" or "Appointment of a Health Care Agent." Depending on the laws in your state, the person you appoint may be called your agent, health care representative, surrogate, attorney-in-fact, or proxy. This document, now recognized everywhere in the United States, allows you to designate someone (as well as at least one alternate) to have legal authority to grant or refuse any consents needed to obtain or refuse any kind of medical or other health care treatment. The Power of Attorney can be very specific as to what the agent may approve or refuse or it can be very general, relying on the agent's discretion. Such a power of attorney is always revocable and amendable at any time. The agent will be able to review your medical records, consult



with your caregivers and sign any forms that may be needed to assure care according to your preferences. This document covers health care matters only. It goes into effect when and only when you do not have the capacity to make or to communicate decisions for yourself.

What is a Power of Attorney for Finances?

This can cover a whole host of situations, from handling real estate, to dealing with bank accounts, to paying taxes, to anything related to financial situations.

What is a Living Will?

A Living Will is a type of advance directive in which you indicate the kind of medical care you want (or do not want) in the event of a terminal illness. It is not a "medical order" but rather a description of the kind of treatment we want given up until the point of a code situation. It's a guideline, not a rule or a binding legal document. This document goes into effect when and only when you do not have the capacity to make or to communicate decisions for yourself. It describes how far you want your physicians to go in providing care when death would otherwise be imminent. It further provides for carrying out your wishes about relief from pain. Unlike the Medical Power of Attorney, the living will applies only in a terminal illness. The Power of Attorney for Healthcare is effective anytime you cannot express your own wishes. Most people will sign both a Power of Attorney for Healthcare and a Living Will. You should read each document carefully to be certain it reflects your actual desires.

Why do I need an advance directive?

Advance directives give you a voice in decisions about your medical care when you are unconscious or too ill to communicate. As long as you are able to express your own decisions, your advance directives will not be used and you can accept or refuse any medical treatment. But if you become seriously ill, you may lose the ability to participate in decisions about your own treatment.

What laws govern the use of advance directives?

Both federal and state laws govern the use of advance directives. The federal law, the Patient Self-Determination Act, requires health care facilities that receive Medicaid and Medicare funds to inform patients of their rights to execute advance directives. All 50 states and the District of Columbia have laws recognizing the use of advance directives.

Do I need a lawyer to do an Advance Directive?

No, a lawyer is not needed. Yes, a lawyer is a helpful resource, but not the only resource, nor necessarily the best resource for all persons. While there are many preprinted forms available, such forms are often general in nature and may not meet your personal needs. At the time that the documents may actually be needed, you will not be able to be heard. It is, therefore, critical that your documents be as personal as possible.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

An attorney will counsel you about the choices available to you, and will discuss the considerations involved in selecting your agent and alternate and will advise you about any special requirements or limitations on such documents within your particular state. Your attorney will also assure that all of the formalities involved with such legal documents are properly carried out and will instruct you about whom to give copies to and how to make your preferences known.

Advance directives are not difficult to complete, but they require a few steps to do well. To learn more about completing an advance directive, contact ALS of Michigan at 1-800-882-5764.

Ways Your Physician Can Help Communicate Your Wishes

Since Emergency Medical Service responders are required to take heroic measures unless otherwise directed by valid physician orders, advance directives will generally not stop the uncoiling spring of high-tech "rescue" if you stop breathing or should your heart stop beating. A DNR form provides the means for a patient to have their physician write orders that indicate what types of life-sustaining treatment (e.g. cardiopulmonary resuscitation, tube-feeding or focus on comfort) that you do or do not want

What is a DNR form?

A DNR order (Do Not Resuscitate, sometimes referred to as a No Code order) is a specific physician order that alerts medical staff to your wishes not to be resuscitated. A DNR is a physician's order which all doctors and nurses are legally required to follow. In the event that your heart stops beating or you stop breathing, a DNR order would let medical staff know that you do not want them to try to revive you. If you do not want to be resuscitated, you should discuss this with your doctor. Unless you specify otherwise, you will be considered a full code, meaning that medical staff will do everything medically possible to keep you alive if your heart stops.

A DNR order does not (or at least should not!) affect any care given up until the point of cardiac or respiratory arrest. A DNR order does NOT mean do not treat. A DNR only refers to resuscitation and says nothing about your wishes for other medical treatments. IV's, blood transfusions, antibiotics, should all be ordered just as they would be for any other patient. Also, a DNR order is not the same thing as an advance directive. While advance directives are completed by you and document your wishes regarding medical treatments other than resuscitation, DNR orders are completed by your physician and provide medical orders needed by emergency medical personnel.

Where Should I Keep the Documents?

Once completed, copies should be kept readily available to both the person and the designated health care representative. Safe-deposit boxes and lawyers offices are generally not the best places to keep these documents because in a medical emergency you may need to get them very quickly. You can keep them in your home, or a primary care physician can make these documents part of the permanent medical record.



Medicare Basics

What is Medicare?

Medicare is a Health Insurance Program for people 65 years of age and older, some people under 65 years of age with disabilities such as ALS. It offers two components: Part A (sometimes called hospital insurance) and Part B (sometimes called supplemental medical insurance). Most people do not have to pay for Part A. Most people pay monthly for Part B. You may be able to choose from the following types of plans depending on the area of the country in which you live. Also available is Medicare Part D, is the prescription program.

- **The Original Medicare Plan** - This plan is available everywhere in the United States. It is the way most people get their Medicare Part A and Part B benefits. You may go to any doctor, specialist, or hospital that accepts Medicare. Medicare pays its share and you pay your share.
- **Medicare + Choice Plans** – This program will provide you with more choices and sometimes extra benefits by letting private companies offer you your Medicare benefits through **Medicare Managed Plans, Medicare Private Fee-For-Service Plans, Medicare Preferred Provider Organization Plans, and Medicare Specialty Plans**. In most plans, *you can only go to doctors, specialists, or hospitals that are part of the plan*. You need to make sure that the ALS Clinic or neurologist is covered under the plan you choose. Plans must cover all Medicare Part A and B benefits. Some plans cover extras, like prescription drugs. Your out-of-pocket costs may be lower than in the Original Medicare Plan.

***Make sure to obtain the Medicare and You book from Centers for Medicare and Medicaid to understand the benefits of this program.**

Who Is Eligible for Medicare?

Generally, you are eligible for Medicare if you or your spouse worked for at least 10 years in Medicare-covered employment and you are 65 years old and a citizen or permanent resident of the United States. You might also qualify for coverage if you are a younger person with a disability or with chronic kidney disease. You can get Part A at age 65 without having to pay premiums if you are already receiving retirement benefits from Social Security, are eligible to receive Social Security but have not yet filed for them or you or your spouse had Medicare-covered government employment. If you are under 65, you can get Part A without having to pay premiums if you are a kidney dialysis or kidney transplant patient or have received Social Security disability benefits for 24 months.

In December, 2000 Congress voted to waive the 24-month waiting period for Medicare coverage for people diagnosed with Lou Gehrig's disease (ALS), as part of the fiscal year 2001 spending bill (H.R. 4577) for labor, health and human services, and education. While ALS patients who apply for Social Security Disability Insurance (SSDI) will still have a wait of about five months before benefits begin. A person must have contributed to Social Security taxes over a period of time to meet disability status and collect benefits.



How much does Medicare cost?

Most people do not have to pay a monthly payment (premium) for Part A because they (or a spouse) paid Medicare taxes while they were working. If you (or your spouse) did not pay Medicare taxes while you worked, you may still be able to get Part A. Those who do not qualify to receive Medicare Part A without paying premiums may still be able to purchase coverage. You can find out more by calling the Social Security Administration at (800) 772-1213 or visit www.medicare.gov. Even if you do not have to pay a premium for Part A, Part B is only available by paying a monthly premium. The Part B monthly premium for 2009 is \$96.40. There will be a higher premium for those listed below:

- You are single (file an individual tax return) and your yearly modified adjusted gross income is more than \$85,000
- You are married (file a joint tax return) and your yearly modified adjusted gross income is more than \$170,000

The cost of Part B may go up 10% for each 12-month period that you could have had Part B but did not take it. Enrolling in part B is your choice. If you choose to have Part B, the premium is usually taken out of your monthly Social Security, Railroad Retirement, or Civil Service Retirement payment.

Medicare sends you a bill for your part B premium every 3 months. There is a deductible that must be met before benefits start to pay its share. The 2009 rate is \$135.00

***There is support for those who need financial assistance and or have low income. Contact Medicare for more information about the programs available.**

What does Medicare Part A cover?

Part A helps pay for necessary medical care and services provided by Medicare-certified hospitals, skilled nursing facilities, home health agencies and hospices. It covers up to 90 days of inpatient hospital care in each benefit period. In some circumstances, additional coverage is available for up to 150 days. A benefit period begins on the first day the beneficiary receives services for a particular condition in a hospital or skilled nursing home and ends after the senior has been home from the facility and not received care in any other facility for 60 consecutive days. There is no limit to the number of benefit periods you can have. Under certain circumstances, Medicare Part A will cover some home health care services, such as intermittent skilled nursing care, physical therapy, speech-language therapy and home health aides and certain medical equipment, such as a wheelchair, hospital bed, oxygen or a walker. It also helps pay for hospice care for eligible terminally ill patients who select the hospice care benefit. The doctor and the hospice medical director must certify that the senior has a terminal illness. In addition, the senior must sign a statement choosing hospice care instead of routine Medicare-covered medical benefits, and a Medicare-approved hospice program must provide the care. Patient costs in each benefit period under the Original Medicare Plan for the year 2008 are as follows:

- **Hospital Stays**- The patient pays a total of \$1,068 for days 1-60 and \$267 per day for days 61-90 if additional coverage is available up to 150 days the patient pays \$534 per day for days 91-150.



- **Impatient Skilled Nursing Facility Care** - The patient pays nothing for the first 20 days, up to \$133.50 per day for days 21-100 and all costs beyond the 100th day in the benefit period
- **Home Health Care** -The services described in the Medicare-certified home health agency plan of care are generally free to people with Medicare, with the exception of small co-payments for some supplies and in home equipment.
- **Durable Medical Equipment** - The patient pays 20% of approved amounts for covered equipment after you meet the \$135.00 deductible.
- **Hospice Care** - The patient pays 5% of the Medicare payment amount for inpatient respite care and a co-payment of up to \$5 for outpatient prescription drugs. Medicare does not cover room and board should you choose to stay in a residential hospice facility.

What does Medicare Part B cover?

Medicare Part B helps pay for outpatient hospital services, emergency room visits, ambulance transportation, physicians' services, diagnostic tests, laboratory services, outpatient therapy services, some preventive care and a variety of other services. Under certain circumstances Part B also pays for some home health services and durable medical equipment not covered by Part A.

What services does Medicare not cover?

Medicare Part A will not pay for what are called convenience items, such as televisions or telephones provided by hospitals or skilled nursing homes, private rooms unless medically necessary or private duty nurses. Medicare Part B does not pay for routine physical examinations or services not related to treating an illness or injury. Part B also does not pay for hearing aids, eye examinations, glasses, dental care or dentures, or routine foot care. The only type of nursing home care Medicare will pay for is short-term rehabilitative treatment in a skilled nursing facility after a hospital stay or injury. Medicare does not pay if the patient needs help only with activities of daily living like bathing, eating or dressing. Many patients have additional private health insurance or purchase Medigap policies. These plans often cover items and services Medicare does not. Those with limited incomes may also be eligible for Medicaid.

How Does One Enroll in Medicare?

Keep in mind there are certain times of the year that you can enroll and change plans. If you miss the time frame you may be penalized or you may be unable to change plans. Enrollment in Medicare is handled in two ways: either you are enrolled automatically or you have to apply.

Automatic Enrollment - If you are not yet 65 and already getting Social Security or Railroad Retirement Board benefits, you do not have to apply for Medicare. You will be enrolled automatically in both Part A and Part B effective the month you are 65 and your Medicare card will be mailed to you about 3 months before your 65th birthday. If you do not want Part B, follow the instructions that come with the card.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • email alsofmi@alsofmi.org • website www.alsofmi.org

Apply for Social Security Disability – When an ALS patient applies for disability and is approved they are able to receive Medicare benefits. You can apply by contacting the Social Security Administration (or Railroad Retirement Board).

Medicare Prescription Coverage Part D

Medicare prescription drug coverage is now available to everyone with Medicare, regardless of income, health status, or how you pay for prescription drugs today. Private insurance companies provide the coverage. You choose the drug plan and pay a monthly premium and deductibles.

There are several different programs available in Michigan. Keep in mind that each plan must cover the individual until they are able to change plans to one that will cover their prescribed medication. An ALS patient should not have to go without a drug that is recommended by their physician. For more information visit www.medicare.gov or contact ALS of Michigan about applying for benefits.

Like other insurance companies you must choose and enroll in a plan to avoid a penalty. **If you have limited income and resources, you may get extra help to cover your prescription costs.** Everyone with Medicare needs to make a decision about prescription drug coverage. Even if you don't use a lot of prescription drugs now, you should still consider joining a plan.

If you are receiving prescription coverage through a former or current employer or union you should check to see what program is going to work best for you.

What Is Medigap?

Supplemental insurance policies are sometimes called Medigap plans. Medigap plans are private health insurance policies that cover some of the costs the Original Medicare Plan does not cover. The costs of plans from different companies can vary significantly. In Michigan call 1-800-803-7174. **There is an enrollment period for Medigap.**

What does Medigap cover?

Every Medigap policy must offer certain basic benefits. These include:

- Coinsurance for Medicare-covered hospital stays.
- Coinsurance on doctors' bills and on all other Medicare-covered outpatient services.
- The cost of the first three pints of blood the patient may need per year.

Medigap Plans are listed as A-L so you can compare them easily. None of the plans cover vision or dental care, hearing aids, private-duty nursing, unlimited prescription drugs or long-term custodial care. For more information about Medigap policies contact 1-800-Medicare for a copy of "Choosing a Medigap Policy: A Guide to Health Insurance For People With Medicare".



Medicaid

What is Medicaid. Medicaid helps people pay for medical care. This includes families with children, pregnant women, and persons under the age of 21. Medicaid is also available to the blind, the disabled, and people age 65 and over. Medicaid is funded by the State of Michigan and the federal government. It is possible to have both Medicare and Medicaid. **To be eligible, people must be within the program’s limits for income and resources.**

Medicaid covers these types of services:

Ambulance	Lab and x-ray
Dental	Nursing Home Care
Doctor Visits	Medical Supplies
Family Planning	Mental Health Care
Health Check-ups	Personal Care Services
Hearing and Speech	Physical Therapy
Home Health Care	Prenatal Care
Hospice Care	Substance Abuse
Hospital Care	Surgery Vision
Immunizations	

How Do I Apply. You can apply for Medicaid by contacting the **Michigan Department of Human Services** <http://www.michigan.gov/dhs>. The local health department may also assist you will applying for Medicaid. If you need help with unpaid medical bills please let them know when you apply as it is possible that Medicaid will pay if the services occurred within 3 months before you apply.

Income is compared to an income allowance based on family size. The allowance varies across the state.

Medicaid Asset Qualifications (these numbers do change, please contact ALS of Michigan for updated information)

- Cash - an individual can possess up to \$2000 dollars while a couple can possess up to \$89,280 dollars
- Homestead - only one, regardless of value
- Personal Property - unlimited
- Vehicle - only one, regardless of value
- Insurance - up to \$1,500 dollars face value
- Irrevocable Prepaid Funeral Contract & Burial Space
- Income Producing Property - if it generates rental income of 6% or more of the owner's equity after operating expenses.



Protections for Married Couples. For many years, married couples faced impoverishment when either the husband or the wife went into a nursing home. Now there are laws and rules that make it possible for the spouse who remains at home to keep a share of the resources and income that would otherwise have to be spent for care and other expenses.

- When a married person applies for Medicaid assistance, **the property and resources belonging to either spouse or to both spouses together are counted** and listed on a special resource assessment form. Again, certain assets (including the home and one vehicle) are generally exempt and are not counted. The non-exempt resources are valued as of the date on which the ill spouse began to receive long term care.
- The amount set by court order or administrative hearing.

Lawyers who are familiar with the Medicaid requirements use a variety of approaches to assist clients who are trying to avoid spousal impoverishment. The options include planning the spend-down; transferring exempt assets and non-exempt assets; using non-exempt assets to provide income for the spouse who remains at home; and petitioning the court for a support order or other domestic relations order awarding additional assets to the spouse who remains at home.

Although the resources that belong to a married couple are counted together in the Medicaid application process, each spouse's income is counted separately. Income is treated as belonging to the person whose name is on the check. If the income comes in both names, it will be divided equally. The spouse who remains at home (who is also called the "community spouse") can receive an allowance from the ill spouse's income after the ill spouse begins receiving Medicaid assistance.

It is also very important that you contact and Elder Law attorney for assistance with the Medicaid process, please contact ALS of Michigan for a referral to an experienced attorney who has worked with the ALS community.

Michigan Medicaid Assistance Program –MMAP

MMAP is a free service that will help you with health care decisions:

- *Help with Medicare and Medicaid
- *Compare plans
- *Explore long term health insurance
- *Review supplemental insurance needs

Contact MMAP at 1-800-803-7174



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • email alsofmi@alsofmi.org • website www.alsofmi.org

Other Government Programs

Michigan Department of Human Services (MDHS)- When filing a Medicaid application MDHS will also direct you to other programs that you may qualify for. 517-373-3740 or <http://www.michigan.gov>

Veterans

The Veteran's Administration (VA)

The VA will now award full benefits to veterans with ALS based on an Institute of Medicine report that found limited and suggestive evidence of a link between the disease and their military service.

All veterans with amyotrophic lateral sclerosis (ALS) who have served at least 90 days in the US military will be eligible for full medical and disability benefits from the Veterans Administration. To register for benefits you may contact:

Michigan Paralyzed Veterans at (313) 471-3996
www.michiganpva.org

U. S. Department of Veterans Affairs (877) 222-8387
Health Benefits Center
www.va.gov/healtheligibility

U. S Department of Veterans Affairs
Detroit Regional Office (800) 827 1000
www.va.gov



Social Security Disability Benefits

Social Security Disability (SSD) and Supplemental Security Income (SSI) disability programs are the largest of several Federal Programs that provide assistance to people with disabilities. While these two programs are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under the program.

Social Security Disability Insurance pays benefits to you if you have worked long enough and have paid Social Security taxes.

Supplemental Security Income is based on financial need.

To qualify for benefits, you must first have worked in jobs covered by Social Security. Then you must have a medical condition that meets Social Security's definition of disability. In general, Social Security pays monthly cash benefits to people who are unable to work for a year or more because of a disability. Benefits usually continue until you are able to work again on a regular basis. There are also a number of special rules, called "work incentives," that provide continued benefits and health care coverage to help you make the transition back to work. If you are receiving Social Security disability benefits when you reach age 65, your disability benefits automatically convert to retirement benefits, but the amount remains the same.

How Much Work Do You Need?

The rules for how much you work need to qualify for disability benefits are as follows:

Credits are used to find out whether you have the minimum amount of covered work to qualify for Social Security Disability. Benefits can not be paid if you do not have enough credits.

You earn up to a maximum of 4 credits for each year by working in jobs covered by Social Security or by operating your own business as a self-employed person.

Before 1978, when employers reported your wages every 3 months, social security called credits "quarters of coverage", or QCs. Back then, you got a QC or credit if you earned at least \$50 in a 3-month calendar quarter.

Starting with 1978, employers report earnings just once a year. Credits are now based on your total wages and self-employment income during the year, no matter when you do the actual work. You might work all year to earn your 4 credits, or you might earn enough for all 4 in a much shorter length of time. In 2009, you get one credit for each \$1090.00 in earnings. You have up to a maximum of four credits per year. This means you will



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • email alsofmi@alsofmi.org • website www.alsofmi.org

need 40 credits to be eligible for benefits (can take up to 10 years of working to complete). Each year the amount of earnings needed for credits goes up as average earnings levels increase. The credits you earn remain on your Social Security record even if you change jobs or have no earnings.

During your lifetime, you will probably earn more credits than the minimum number you need to be eligible for benefits. These extra credits don't increase your benefit amount, however; it is your average earnings over your working years that determine how much your monthly payment will be.

Important: Remember that whatever your age is, you must have earned the required number of work credits within a certain period ending with the time you became disabled.

For More Information:

Benefit Eligibility Screening Tool (B.E.S.T.)

A screening tool made available through the Social Security Administration that an individual can use to inquire about eligibility for any of the programs that Social Security Administers. (i.e. Social Security Disability, Supplemental Security Income, Retirement Benefits, Survivor Benefits.)

Service Area: UNITED STATES

Phone:

Fees: None

Web Site: best.ssa.gov

Social Security Rules for ALS Patients

In the fall of 2003, the Social Security Administration announced that the Office of Management and Budget (OMB) approved the inclusion of a “**Presumptive Eligibility**” ruling for persons with ALS. This is a monumental breakthrough for ALS patients, as they automatically gain disability status at the time of their diagnosis from their primary neurologist. This status will make receiving Social Security disability benefits far less tedious and frustrating for ALS patients. In fact, it can help an ALS patient receive disability benefits months, and even years before patients might have received benefits prior to this ruling. Upon gaining disability status, persons with ALS must still wait the 5-month period before they will receive their benefits. **You must have earned the required number of work credits within a certain period ending with the time you became disabled.**



How Do You Apply for Social Security Disability Benefits?

You should apply at any Social Security office as soon as you become disabled. You may file by phone, mail or by visiting the nearest office. You can find out the name and address of the closest Social Security office here. If you want to apply by phone call their toll-free number, 1-800-772-1213, and they will set up a time for your local Social Security office to contact you. If you are deaf or hard of hearing you can call them at TTY 1-800-325-0778.

Claims for disability benefits take more time to process than other types of Social Security claims--from 60 to 90 days. You can help shorten the process by bringing certain documents with you when you apply, and by helping Social Security get any other medical evidence you need to show that you are disabled. Here is what you should bring:

- Your Social Security number and proof of your age (birth certificate)
- Names, addresses and phone numbers of doctors, hospitals, clinics and institutions that treated you and the dates of treatment
- Names of all medications you are taking
- A summary of where you worked and the kind of work you did
- Your most recent W-2 form, or your tax return if you're self-employed
- Social Security numbers and proof of age for each family member applying for benefits
- Dates of prior marriages if your spouse is applying

IMPORTANT: You will need to submit original documents or copies certified by the issuing office. You can mail or bring them to Social Security. They will make photocopies and return your original documents. If you don't have all the documents you need, don't delay filing for benefits. Social Security will help you get the information you need.

When Do Benefits Start and How Much Will You Receive?

If your application is approved, your first Social Security disability benefits will be paid for the sixth full month after the date your disability began.

Here is an example: If the state agency decides your disability began on January 15, your first disability benefit will be paid for the month of July. Social Security benefits are paid in the month following the month for which they are due, so you will receive your July benefit in August.

You also will receive [*What You Need to Know When You Get Disability Benefits*](#) (Publication No. 05-10153), which gives you important information about your benefits and tells you what changes you must report to us.



How much will my benefits be?

The amount of your monthly disability benefit is based on your average lifetime earnings. The [Social Security Statement](#) that you receive each year displays your lifetime earnings and provides an estimate of your disability benefit. It also includes estimates of retirement and survivors benefits that you or your family may be eligible to receive in the future. If you do not have your [Social Security Statement](#) and would like an estimate of your disability benefit, you can request one from www.socialsecurity.gov or call our toll-free number, **1-800-772-1213**.

Social Security will also automatically enroll you in Medicare after you get disability. Medicare has three parts--hospital insurance, medical insurance, and prescription drug coverage. Hospital insurance helps pay for inpatient hospital bills and some follow-up care. The taxes you paid while you were working financed this coverage, so it is free. Medical insurance helps pay doctors' bills, outpatient hospital care and other medical services. You will need to pay a monthly premium for this coverage if you want it.

How Long Do Benefits Last?

In most cases, you will continue to receive benefits as long as you are disabled. However, there are certain circumstances that may change your continuing eligibility for disability benefits. Two things can cause Social Security to decide that you are no longer disabled and to stop your benefits.

1. Your benefits will stop if you work at a level Social Security considers "substantial". Social Security encourages you to go back to work and has special rules called "work incentives" that can help you make the transition back to work. These incentives include, but are not limited to, continued monthly benefits and Medicare coverage while you attempt to work on a full-time basis.
2. Your disability benefits will also stop if Social Security decides that your medical condition has improved to the point that you are no longer disabled.

Are Other Family Members Eligible for Benefits?

When you start receiving disability benefits, certain members of your family may also qualify for benefits on your record. Each family member may be eligible for a monthly benefit that is up to 50 percent of your disability rate. However, there's a limit to the total amount of money that can be paid to a family on your Social Security record. The limit varies, but is around 150 to 180 percent of your disability benefit. If the sum of the benefits payable on your account is greater than this family limit, the benefits to the family members will be reduced proportionately. Your benefit will not be affected.



Benefits for Your Spouse

Benefits are payable to your spouse age 62 or older, unless he or she collects a higher Social Security benefit based on his or her earnings record. The spouse benefit amount will be permanently reduced by a percentage based on the number of months up to his or her full retirement age.

Benefits are also payable to your spouse at any age if he or she is caring for your child who is under age 16 or disabled and receiving Social Security benefits. Your spouse would receive these benefits until the child reaches age 16. At that time, the child's benefits continue, but your spouse's benefits stop unless he or she is old enough to receive retirement benefits (age 62 or older) or survivor benefits as a widow or widower (age 60).

If your spouse is eligible for retirement benefits on his or her own record, Social Security will always pay that amount first. But if the spouse benefit that is payable on your record is a higher amount, he or she will get a combination of benefits that equals that higher amount. It doesn't matter if your spouse starts getting benefits before, after, or at the same time you do--Social Security will check both records to make sure that your spouse gets the higher amount whenever he or she becomes entitled to it.

Benefits for Your Children

When you qualify for Social Security disability benefits, your children may also qualify to receive benefits on your record. Your eligible child can be your biological child, adopted child or stepchild. A dependent grandchild may also qualify. To receive benefits, the child must be unmarried; and be under age 18; or be 18-19 years old and a full-time student (no higher than grade 12); or be 18 or older and have a disability that started before age 22. Normally, benefits stop when children reach age 18 unless they are disabled. However, if the child is still a full-time student at a secondary (or elementary) school at age 18, benefits will continue until the child graduates or until two months after the child becomes age 19, whichever is first.

Within your family, each qualified child may receive a monthly payment up to one-half of your full disability amount, but there is a limit to the amount that can be paid to the family as a whole. This total depends on the amount of your benefit and the number of family members who also qualify on your record. The total varies, but it is approximately 150 to 180 percent of your disability benefit.

Where Do You Get More Information or Get Assistance?

You can get more information 24 hours a day by calling Social Security's toll-free number, 1-800-772-1213. You can call for an appointment or to speak to a service representative between the hours of 7 a.m. and 7 p.m. on business days. The lines are busiest early in the week and early in the month so, if your business can wait, it's best to call at other times. Whenever you call, have your Social Security number handy. If you have a touch tone phone, recorded information and services are available 24 hours a day, including weekends and holidays. Information is also available on the Social Security website at www.ssa.gov/disability/.

There is a program called Access that will help you step by step when applying for Social Security. They answer all your questions and help you fill out forms. They will also file an appeal for you if you are turned



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

down. They are very nice and willing to help in any way that they can. This is an excellent organization and the services are 100% free. Their toll free phone number is 888-700-7010.



Employment

Employment issues are some of the first things that ALS patients must deal with when they have evidence of a neurological problem. Major decisions need to be made, and need to be made quickly because there is no way to know how quickly ALS will prevent a patient from working. Each ALS patient and their family have their own unique issues to address, but the following questions and answer may provide some helpful information.

How long should I work?

Work as long as you want, keeping in mind the type of work you perform, and the nature of your disability. If your job requires manual labor, or if you have bulbar symptoms and your job requires much speaking, you may have to retire more quickly. Keep in mind that you do not qualify for Medicare benefits for five months after Social Security declares you to be disabled. You cannot be declared disabled until you quit working. This leaves many employed PALS in a bind, because they need to work as long as possible in order to support themselves and their families, but they also want to be eligible for government help from Medicare in the expensive latter stages of the disease. There are no easy answers to this question, which is one reason many people are trying to get the laws changed. Other considerations on deciding how long to work include: your job satisfaction, your level of energy, and how you want to spend your remaining time in your new shortened life span. If you are one of those fortunate few who truly love their job, you may prefer to work as long as possible. If you have a less satisfying job, and you can manage it financially, it might make sense to retire quickly in order to spend time on activities you enjoy more.

Should I tell my employer about my disability?

Many individuals with serious illnesses face the same issue. Should I tell my employer about my illness? This is a very personal question with no right answer. There are, however, certain legal issues that should be considered before making this important decision. Most individuals are reluctant to tell their employers about a serious illness because they fear that this could jeopardize their future and will affect how others view them at the workplace. These are very real concerns. Many disabled individuals could attest to the fact that they have been discriminated against on the job once their employers found out that they had a serious illness or disability. However, by not telling your employer, you could jeopardize your future at your employer. The American with Disabilities Act (ADA) only provides legal protection if the employer knows that you have a disability. If your illness adversely affects your job performance, and your employer does not know that you are disabled, then you face the possibility of being fired with no legal recourse.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

What kind of accommodations must my employer provide?

All disabled Americans have specific rights under ADA, the Americans with Disabilities Act. By telling your employer about your disability, you are in a position to request that certain reasonable accommodations be made to your job. Under the ADA, your employer must provide accommodations which enable you to perform the essential functions of your job, unless to do so would cause an undue hardship on your employer. What is an undue hardship varies greatly given the size and financial resources of your company. Large corporations are expected to incur greater costs than mom and pop businesses. Reasonable accommodations are limited only to the needs of the disabled employee, and the imagination of the employer and the employee. Some of the accommodations that could be requested include modifying your work schedule, altering some of the nonessential duties of your job, changing your physical workspace, providing special equipment and providing an assistant. Please note that the ADA only applies to employers with 15 or more employees. However, individuals working for smaller companies may be entitled to similar protections under State and local laws.

The U.S. Department of Justice provides information about the Americans with Disabilities Act (ADA) through a toll-free ADA Information Line. This service permits businesses, State and local governments, or others to call and ask questions about general or specific ADA requirements including questions about the ADA Standards for Accessible Design. Spanish language service is also available. For general ADA information, answers to specific technical questions, free ADA materials, or information about filing a complaint, call: 1-800-514-0301. Information about the Americans with Disabilities Act is also available at the U.S. Department of Justice website: <http://www.usdoj.gov/crt/ada/adahom1.htm>.

Bureau of Vocational Rehabilitation

Every US state has a Bureau of Vocational Rehabilitation (BVR) which operates to serve the disabled by helping them maintain or find employment. BVR can help ALS patients who want to keep working obtain mobility equipment such as wheelchairs and scooters, assistive technology such computer equipment, lifts for vans, ramps for home, bathroom modifications, etc. Since BVR assistance is not income based, all ALS patients should be able to qualify. ALS patients who plan to continue working should contact their Bureau of Vocational Rehabilitation Services Office as soon as possible because the approval process is often lengthy. Contact information for Michigan is listed in the Resources section of this manual.



24359 Northwestern Hwy. • Suite 100 • Southfield, Michigan • 48075
phone 800.882.5764 • *email* alsofmi@alsofmi.org • *website* www.alsofmi.org

MI Child of Michigan

MiChild is a health insurance program. It is for uninsured children 18 and younger living in Michigan. MiChild services are provided by HMOs and other health care plans throughout Michigan. Many children of ALS patients are enrolled under this plan.

MiChild covers:

- *Regular checkups
- *Shots
- *Emergency care
- *Pharmacy
- *Hospital care
- *Vision and Hearing
- *Mental Health and substance abuse services

If you qualify, you would pay a monthly premium of \$10.00 for one or more children. There are no co-pays or deductibles. To qualify for the program you must meet the following criteria:

- *Be citizen of the US
- *Live in Michigan
- *Be under 19 years of age
- *Have no health insurance
- *Meet the income requirements

To apply contact:

MiChild/Healthy Kids at 1-888-988-6300
TTY 1-888-263-5897 for persons with hearing and speech disabilities

Or apply online at: www.michigan.gov/mdch

Beneficiary Helpline at 1-800-642-3195
TTY 1-866-501-5656 for persons with hearing and speech disabilities