

Section I

INSURANCE, FINANCIAL, AND LEGAL ISSUES

HEALTH INSURANCE

It is very important for the ALS patient to maintain his or her health insurance. ALS typically requires a variety of medical treatments, and equipment. Many of these items can quickly diminish a family's assets if insurance is not available to fund a significant portion of the costs. Even medications can present an overwhelming expense. The drug Rilutek, which is currently the only FDA-approved drug for ALS, can cost \$700–\$850 per month, depending upon where it is purchased.

Group Health Insurance Policies

Most people obtain health coverage through their employer or their spouse's employer at group rates. While some patients are fortunate enough to have their employer keep them on the payroll and thus continue benefits, most lose their group health insurance when their employment ceases. If a patient has a short-term disability plan through the employer, then the patient is on the payroll until that short-term disability plan ends. At that time, the patient is no longer considered to be actively working. Under a federal law, the Consolidated Omnibus Budget Reconciliation Act of 1985, or COBRA, an employee who worked for a business with 20 or more employees is entitled to continue her/his existing health insurance coverage for 18 months after leaving work. COBRA policies can be extended to 29 months after leaving work if the coverage is being taken due to disability. Under a law that went into effect as of July, 2001, patients with a confirmed diagnosis of ALS can receive coverage within six months of the date of disability. For information on obtaining COBRA coverage, contact the human resources department at your place of employment.

COBRA for an ALS patient is usually necessary because of the extreme difficulty in obtaining "new" coverage after diagnosis. However, since the employer is not required to fund COBRA coverage, a patient whose coverage was subsidized by the employer may experience a great jump in the rates being charged for the health insurance as compared to when the patient was working. Family members covered under a patient's group coverage

may choose to select separate health insurance at the time the patient exercises her/his COBRA rights.

Medicare

If you are 65 or older, you are automatically eligible for Medicare. However, patients who are 64 and younger, and have a confirmed diagnosis of ALS, may also receive Medicare health insurance. In order to obtain this, the patient must apply for long-term disability through Social Security. As soon as the first disability check is received, five to six months from the official last date of active work, the patient is also covered by Medicare.

Medicare Part A covers 80 percent of most inpatient charges.

Medicare Part B covers 80 percent of most outpatient charges, as well as lab work and X rays. However, as of 2001, a \$50 charge for Part B coverage, will be automatically deducted from the Social Security or disability check each month.

For information call Medicare at 312-938-6266 if you are 65 or over; call Social Security at 800-772-1213 if you are less than 65 years of age.

Private Health Insurance

Some private health insurance companies supply Medicare supplement policies, often called Medigap policies. These provide payment for the 20% of medical charges not covered by Medicare, as well as the Part A hospitalization deductible. In Illinois, these companies are required to accept any resident over 65 who has Medicare Parts A and B, regardless of the present state of health. However, companies are not required to accept those who are under age 65 and disabled.

Medicaid

You may obtain Medicaid at any age, but there are financial restrictions. An individual may have no more than \$2,000 in assets not including the home or car. A patient's well spouse may keep almost \$90,000 in assets, but the patient's name must be legally transferred off of those assets.

In Illinois, for information call 800-252-8635 or 312-793-2608.

Veteran's Administration

For medical care in VA facilities, highest priority is given to veterans with service-connected disabilities. Other veterans may be entitled to receive health care benefits from the VA, including medical and respite care, as well as equipment such as wheelchairs, walkers, canes, etc. Other possible benefits include prescriptions and medical supplies, and a home improvement and structural alteration grant (HISA). Eligibility will depend upon the patient's period of service, type of discharge, and income level.

For information call 800-827-1000 (0466) or 312-663-5510 or on the internet go to www.va.gov.

The Paralyzed Veterans of America (PVA) is a congressionally chartered veteran's organization that has been serving veterans with spinal cord injury and disease since 1946. You may call the PVA to receive information regarding how to obtain your maximum VA benefits at 1-800-424-8200, ext. 12, or on the internet go to www.pva.org.

The *Study of ALS among Gulf War Veterans* will continue to screen and count new patients—both Gulf deployed and non-Gulf deployed. Although new cases cannot be added to the study data that have already been analyzed, they will be counted and reflected in a revised rate of incidence (as appropriate). Veterans with ALS or families of these veterans who served in the military between August 2, 1990 and July 31, 1991 are encouraged to consider self-referral to this study. Note that veterans need not have been deployed to the Gulf War region to self-refer to the study.

To be included in a revised count, veterans or family members should call 1-877-342-5257. This telephone number should not be used for benefits questions.

Illinois Comprehensive Health Insurance Plan (ICHIP)

This is a state-administered program that provides medical insurance to persons whose medical conditions make them otherwise uninsurable by conventional standards. It is funded and supervised by the State of Illinois, but operated through a private insurance carrier.

For information contact the Illinois Dept. of Insurance at 312-814-2427.

KidCare

This is an insurance program for Illinois children from birth through age eighteen. The household income may be larger than allowed by the financial restrictions for Public Aid. For information call 1-800-226-0768.

HANDLING HEALTH INSURANCE CLAIMS

The terms and benefit levels of commercial health insurance plans vary widely, and few generalizations can be made. All policies and plans have definitions of what constitutes covered medical treatments. None of these definitions were written with ALS and its medical ramifications in mind, and the policy language will not specifically address many treatments, devices, and equipment. As a result, there may be no immediate answer for coverage on a particular claim item, and dealing with insurance claims handlers is an art.

What Do You Need to Know about the Policy?

Gathering information on a policy will reveal at least some of the benefits provided as well as information on:

- Policy limits: No health insurance policy is limitless, and maximum lifetime benefit amounts can become significant issues.
- Deductibles and co-payments: These are the amounts the patient will pay on covered claims.
- Claim requirements: These include what permission or notice is required before certain medical treatment is deemed “covered.”
- Provision for large case management: This provision recognizes that certain catastrophic illnesses do not fit the mold of the policy and allows for expanded coverage based on an agreement by the doctor and the insurer to an overall treatment plan. ALS should qualify if the plan has large case management.

Dealing with Claims Personnel

ALS treatments are varied and extensive and may not be specifically addressed in a policy. A typical claims examiner probably has never heard of ALS, let alone handled an ALS claim. Dealing effectively with claims personnel can go a long way toward maximizing benefits and speeding up the payment of claims.

Establish a single person as a case manager. Having a single person on the insurer's staff as the contact point avoids needing to explain ALS every time a claim is submitted. It also allows personal relationships to develop that will help as "gray area" claims arise. The contact person should be at least at a supervisory level, with some medical knowledge and the authority to exercise some discretion. Many insurers employ such ideal contacts as nurses and other medically trained individuals.

Establish a single family representative. To aid in communication, one person should become the insurance contact representing the family.

Establish a contact at the neurologist's office. Personnel at the neurologist's office may be skilled at dealing with insurance claims and can run interference or otherwise expedite the process.

Educate the insurance contact. Most claims personnel have no experience with ALS; inform them of the nature of the disease, and outline what might be expected in the future.

Keep the contact advised. For policy provisions that require notice before expenditure, inform the contact early about an upcoming purchase or service. This gives the insurer time to fully consider the claim before it is a "rush" decision, and allows for input. For example, many plans have cost containment provisions, and obtaining some items at a discounted price or purchasing a cheaper but comparable item may turn a questionable claim into a covered claim.

Ask the contact's advice. While perhaps not knowledgeable about ALS, claims personnel often know a great deal about medical needs such as wheelchair models, equipment costs, and the best suppliers. This kind of advice, in addition to the advice of Center personnel, can be invaluable whether or not the claim is covered. Insurers also often can get some drugs and medical equipment at a lower cost. Even though a claim may be denied, a friendly claims supervisor might allow the patient to buy at the insurer's discounted price.

Get a physician's prescription. Regardless of the nature of a purchase, from a shower stool to a communication system, a physician's prescription

or letter of medical necessity for the item always helps support a claim of “medical benefit.”

Remember that *no* does not always mean *no*. Many ALS-related claims are in a “gray area” of coverage, requiring discretion on the part of the insurer. A “no” may be simply a knee-jerk reaction that the square peg of the claim did not fit into the round hole of the coverage. Further discussion regarding medical benefit may result in either a reversal, or more likely, an offer by the insurer to pay some amount toward the claim. If the claims personnel persist in denying a claim the patient feels is clearly covered, avenues of recourse exist short of filing a lawsuit. The patient may enlist the support of the former employer’s employee benefits manager to help plead the case. Clearly, a large employer may have more leverage in getting claims paid due to their payment of many premium dollars to the insurer.

Built-in grievance procedures may also allow for an appeal of a claims denial. This option can be particularly helpful in employer self-insured plans where the appeals board may include former work associates of the patient. Finally, a complaint to a state insurance department may be helpful. State insurance departments control the licenses of health insurers, and if a state insurance department raises the issue, it will be at least addressed promptly and thoroughly.

Choose claims battles carefully. Insurance will not pay for everything the patient wants covered. Some claims will be denied. It makes little sense to battle over reimbursement for a \$45 shower stool if that war may affect the insurer’s prompt decision to pay for a \$20,000 electric wheelchair.

FINANCIAL ASSISTANCE

Social Security Disability Payments

ALS may prevent a patient from working, at whatever his or her age. Social Security Disability payments can relieve at least part of the financial burden. The following paragraphs are extracted from the Social Security Administration Office of Disability web site, <http://www.ssa.gov/dibplan>.

How to qualify: “To qualify for benefits, you must have worked in jobs covered by Social Security. Then you must have a medical condition that

meets Social Security's definition of disability. . . 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. . . .”

“We consider you disabled if you cannot do the work you did before and we decide that you cannot adjust to other work because of your medical condition(s). . . . Your disability must last or be expected to last for a year or more. . . .”

How to apply: “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. To apply by phone, call our toll-free number, 1-800-772-1213, and we will set up a time for your local Social Security office to contact you.”

Information needed: “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 get any other medical evidence needed to show that you are disabled. Here is what you should bring us:

- Your Social Security number and proof of your age;
- 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;
- Medical records from your doctors, therapists, hospitals, clinics and caseworkers
- Laboratory and test results;
- 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.

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

When benefits start: “If your application is approved, your first Social Security benefits will be paid for the sixth full month after the date we find that your disability began. For example, if we find that your disability began on June 15, 2000 your first benefit would be paid for the month of December, 2000, the sixth full month of disability. Social Security benefits are paid in the month following the month for which they’re due. This means that the benefits due for December would be paid to you in January, 2001, and so on.”

Note: Congress enacted legislation that waives the 24 month waiting period for Medicare for ALS patients who are on Social Security Disability.

Disability Insurance

In addition to Social Security benefits, a patient with ALS may be entitled to disability insurance benefits as a result of the termination of the patient’s employment. While a few states have state-operated worker disability funds, most patients will probably be covered by private employer or union disability insurance policies and plans. For these coverages, the patient must be able to show that he or she is permanently disabled. Each policy will specifically define the term “permanently disabled,” but most require that the patient be unable to perform any type of work for which he or she has any skills or can be trained. The definition and criteria generally parallel the criteria of Social Security. A patient with a confirmed diagnosis of ALS will qualify for disability payments when his progression no longer allows her/him to work.

Disability benefits usually are not payable until some stated time period has expired. This time period is usually six months of disability, or inability to work—the same waiting period as for Social Security Disability benefits. During this “qualifying period,” the patient may be entitled to some form of wage continuation or short-term benefit from his employer. Benefit amounts for short- or long-term disability depend on the specific coverage or plan in effect with the patient’s employer or with his or her private policy.

Long-Term Disability Benefits

Long-term disability payments are typically a stated percentage of the patient’s salary, up to a maximum dollar amount. Almost all plans will deduct Social Security and similar payments received by the patient from the benefit amount. Payments are often made monthly, and if the payment is made under

a plan paid for by the patient (either through direct premiums or employee contributions), it should not be taxable. Payments under employer-funded plans are taxable as income. However, there is no withholding requirement.

Like Social Security, long-term (also known as “permanent”) disability insurers will require detailed applications and medical documentation. Most neurologists should know how to complete these forms, and most disability insurers recognize ALS as likely to be qualifying. However, it is important that physicians list in detail the specific symptoms that prevent the patient from working. A complete application and a thoughtfully prepared physician certification should result in a prompt adjudication of disability and avoid insurer-requested “second opinions.”

Patients and families should find out well before the patient has to leave work what the exact terms and conditions of the short-term and long-term disability plans are. There may be added requirements or benefits, such as payment by the insurer of health and life insurance premiums. Plans may also allow the patient to work part-time. If so, find out whether the wages will offset plan benefits. Find out how and when the patient can formally apply for benefits. The plan may not allow benefits until a six-month waiting period expires. However the insurer may recognize ALS as a permanently disabling illness. This may allow for early filing, early acceptance, and prompt check receipt when the waiting period concludes.

ADDITIONAL RESOURCES

Illinois Grievance Hotline 312-814-1700. They will investigate health insurance companies when they are made aware of problems in how insured persons are managed.

Treasurer’s Office for Low Cost Loans 312-814-1700. Eligibility for loans: Gross annual income per household up to \$75,150, with combined household net worth up to \$500,000.

Athena Pharmacy 800-5-Athena. Athena is a pharmacy in California, which specializes in neurological drugs and can offer one of the best prices on Rilutek. Athena can also help you find out whether or not you would be eligible for financial assistance through NORD (National Organization for Rare Diseases) to obtain Rilutek.

NORD National Organization for Rare Diseases 800-459-7599. Provides financial assistance to eligible patients for receiving Rilutek.

Circuit Breaker 800-624-2459 or **www.revenue.state.il.us**. As of 2002, this is a state-funded program for seniors and the disabled that provides up to \$2,000 worth of medication annually for diabetes, arthritis, cardio-vascular disease, Alzheimer's disease, cancer, glaucoma and Parkinson's disease. After the \$2,000, Circuit Breaker pays 80% of the costs of those prescriptions and the participant pays 20%. To be eligible, a one-person annual income can be up to \$21,218; a two-person household income limit is \$28,480 and the limit is \$35,740 for a household of three people or more. For those above the poverty level, there is a \$3 co-payment for each prescription.

QMB: Qualified Medicare Beneficiary 800-272-1213. This little-known benefit pays the monthly Medicare premium, plus hospital deductibles and whatever doctor's costs Medicare doesn't pay. Eligibility is determined by Social Security and based upon an income of less than \$947 a month and assets of less than \$4,000.

The Medicine Program 573-996-7300, www.Themedicineprogram.com. This program seeks to aid those who have exhausted all other sources for help with medication. It helps people apply for enrollment in one or more of the many patient assistant programs now available through drug manufacturers. These programs provide free medicine to qualified individuals who cannot afford to purchase expensive prescriptions. For each prescription needed, there is a \$5 processing fee. Decisions concerning which medications are provided free of charge and which individuals are accepted into the program are made solely by the various pharmaceutical sponsors. Each manufacturer has established specific criteria to determine an applicant's eligibility.

LEGAL CONSIDERATIONS

ALS patients and their families will face numerous legal issues as the disease progresses. Because ALS is a terminal illness, the issue of living wills and medical powers of attorney must be addressed. Items such as preparing various powers of attorney and protecting rights under private and public disability and health insurance plans should be addressed before the disease affects the patient's ability to act and communicate. Many of these actions can be handled by the patient and the patient's family, but some will require

consultation with a lawyer. The key, however, is advance planning on the part of both patient and family to avoid unnecessary legal problems in the future.

Powers of Attorney and Other Documents

Since ALS also will eventually affect a patient's ability to write, the patient and the family should decide whether or not to use one or more "powers of attorney." A power of attorney is a document that grants another person the authority to act on an individual's behalf and to execute documents on behalf of the individual. This may range from endorsing checks to signing titles and deeds. An attorney should prepare any power of attorney to guarantee that it will be legally enforceable and recognized, particularly if real estate transactions are involved.

The person to whom the power of attorney is granted may be anyone who is at least eighteen years old and is legally competent. Obviously, a patient should grant this power only to someone he or she completely trusts. The person holding the power of attorney has the authority to act fully on an individual's behalf until the power of attorney is revoked in writing. This authority is subject only to the restrictions, if any, contained in the power of attorney. The need for a power of attorney may seem diminished with banking transactions, one of the major uses for a power of attorney, now increasingly done electronically and not requiring signatures. Having such a document, however, may prove to be essential if the patient needs to execute unforeseen legal documents and cannot sign his name or otherwise act.

Medical Powers of Attorney Persons with ALS will face a number of significant life or death decisions regarding their care. These decisions include whether to use a ventilator or to refuse "heroic" measures such as resuscitation. Although ALS does not usually affect an individual's intelligence or judgment, the potential change in the patient's ability to communicate strongly suggests that these decisions be made early in the disease process. This allows for full discussion with the patient's loved ones, provides assurance that the patient's desires are clearly known, and permits such desire to be recorded in one or more effective documents.

Health care professionals will require effective and clear documents before they will refrain from taking all medically available means to prolong life. These documents may be called durable powers of attorney, living wills, or

some other name, and the form of such documents depends on state law. Patients and families may need an attorney's assistance to guarantee that the patient's wishes will be carried out. Hospitals may also require specific "Do Not Resuscitate" (DNR) forms. If a patient decides to forego any form of treatment or assistance, inform the patient's attorney and physician to ensure that all needed documentation is in place.

An in-depth discussion with the neurologist will help the patient to better understand all the possibilities that may occur, and to address each in the written document. The more specific the written document is, the more likely the patient's desires will be carried out when situations arise. Like wills and other powers of attorney, documents dealing with heroic medical action and invasive life-extending surgery are not irrevocable. Should a prior decision be reconsidered, the patient should retrieve and destroy any documents previously given to health care providers or family. Another way to facilitate changes of decisions is to have the documents prepared and executed but retained by a trusted family member or friend for delivery "when needed."

The goal is to communicate, as specifically as possible, the patient's desires. Communication is just as important for the patient who wants all of medical science's resources used to prolong life as it is for the patient who wants less than "full" medical treatment. The patient's family will feel much more comfortable knowing that actions are truly determined by the patient's wishes, best evidenced by a signed and unambiguous document.

Wills and Estate Planning

Since ALS is a fatal disease, patients and families should consider preparing a will for the patient and beginning estate planning. The "plan" may range from utilizing existing life insurance and making specific tangible bequests to handling the custody of minor children. Whether a person needs a will, which is a written directive on how the person wants his or her affairs handled after death, is as personal a matter as are the contents of a will itself. It should be considered carefully in consultation with the family's attorney and any financial advisors. If someone dies without a will, that is dies "intestate," state laws set forth who will receive what from the estate. These laws often provide for specified shares of the estate to a surviving spouse and to the children. However, such a simplistic formula may not be appropriate in the light of divorces, extended families, and other special situations.

A will allows the individual to set out the property division that is appropriate to the circumstances and wishes. A will should be considered soon after diagnosis. If circumstances change as the disease progresses, the will can be changed or a new will drawn. A will is not irrevocable until death. However, an ALS patient should not wait until the last minute. Since ALS often affects a person's ability to communicate, a patient who waits too long may not be able to clearly express his or her wishes. In addition, even though ALS does not usually affect the soundness of mind, a fully debilitated and noncommunicative patient may be perceived as not being of "sound mind" to execute a will.

The cost of a will varies, based on the complexity of the estate. A "simple" will should cost no more than a few hundred dollars. Will "kits" exist that allow for "do-it-yourself" wills. However, there is no substitute for the specialized skills of attorneys and accountants.

Life Insurance

Life insurance proceeds are often the major asset of an estate. A will is not necessary to specify "who gets what" from life insurance. The patient should specify a beneficiary in the policy itself. Shortly after diagnosis, a patient should gather up all life insurance policies—individual, group, mortgage, and credit—to make certain the beneficiary designations are correct. Be sure premium payments are made promptly. **DO NOT LET A POLICY LAPSE.** ALS is a condition that makes obtaining further life insurance virtually impossible. A lapse in payment may result in cancellation of the policy with no right of reinstatement. Group policies, purchased through an employer, should be continued. Even when the patient can no longer work, conversion rights exist. Check with the patient's employee benefits manager to be sure that all conversion rights are exercised. Some companies have disability plans (discussed in detail under Disability Insurance) that make premium payments on the patient's behalf while the patient is disabled.

Life insurance can also be a benefit before death. In addition to traditional policy provisions that allow for borrowing against the policy, "living" benefits may also exist. Recently, some insurers and others have developed plans which allow a terminally ill individual to receive the policy proceeds prior to death, with the actual payment amount discounted by some percentage. Although this results in a reduced payment, the funds can be used for current and future needs. This is called a viatical settlement.

Family and Medical Leave Act

The Family and Medical Leave Act, or FMLA, is a federal law that requires employers to allow an employee up to 12 weeks leave per year for certain family and medical-related situations. As a serious health condition, ALS is an eligible illness under FMLA, provided the employee demonstrates that he or she is needed to care for a spouse, parent, or child who has ALS. FMLA time off is unpaid after the employee's vacation and sick time is used; however, two important rights are granted. The employee is entitled to continued employee benefits during the period of the leave, as well as to job security. This means that the employer must allow the employee to return to his or her job or a comparable position at the end of the leave period.

The FMLA does not apply to workers in small operations (as defined under FMLA) where worker absence would present an undue burden on the employer, or if the employee's position is within a 10 percent "key personnel" category, as specified by the employer. In addition, some seniority requirements exist.

FMLA is a relatively recent law, and the regulations under it are still evolving. An employee who is considering leave under FMLA should contact the personnel manager to ensure that all substantive and procedural requirements are met. Some states have enacted additional laws that offer greater leave than FMLA provides, and a personnel manager should also be aware of any additional benefits such state laws provide.