

# Patient Bill of Rights For People Living with ALS

## Introduction

The Amyotrophic Lateral Sclerosis Association (ALSA) prepared this Patient Bill of Rights to inform people living with ALS about their rights related to health care and health plan insurance coverage.\* ALSA encourages people living with ALS to participate in the process of managing their health care because patients who are informed and empowered gain the greatest benefit from the health care system.

In order to navigate the health care system, patients need to understand their rights and obtain current, understandable information about ALS, the treatment and prognosis. In today's health care climate, cost control measures in most health plans present challenges to patients and their family members. The patient or his/her advocate should be proactive by appealing for and interceding to reach a solution if a person's health or safety is jeopardized by health plan policies, coverage limits, exclusions or restrictions.

Eight of the eleven rights are protected by law or federal or professional regulation. The three rights that are not protected are identified in this brochure with a parenthetical "not protected" reference.

While issues of cost and access in our society and health care system present barriers to achieving these rights, these barriers should not prevent the clear expression of the rights of people with ALS and the values these rights represent. ALSA's Patient Bill of Rights creates a vision of what the ALS community is striving to achieve for each person living with ALS.

\*The term health plan is used throughout this document and refers broadly to indemnity insurers, managed care organizations, self funded employer-sponsored plans, Taft-Hartley trusts, church plans, association plans, State and local government employee programs, and public insurance programs such as Medicare and Medicaid.

Footnotes (1,2,3, etc.) within the text of this document refer to resources listed on the bottom of page 4.

## Patient Bill of Rights

**As a person living with ALS, you have the right to:**

**1.** *You have the right to receive comprehensive information about ALS, including options and resources for your health care needs. This includes the right to communicate with your government representatives regarding policies and practices of the FDA, NIH, DHHS and other agencies that impact ALS. 1,2,4*

People living with ALS have the right to obtain current, understandable information about:

- the disease, its progression and prognosis,
- how to manage symptoms effectively,
- the full range of current treatment options including the known costs, benefits and risks,
- the availability of and individual eligibility for clinical drug trials,
- research advances into cause, treatment and cure, and
- policies and practices of federal agencies such as NIH, FDA and DHHS that affect ALS research and clinical care.

People living with ALS have the right to comprehensive information about specific interventions and resources for:

- psychological or psychiatric counseling,
- spiritual counseling,
- employment issues and work-place support,
- products and techniques to:
  - ✓ provide maximum mobility and range of motion,
  - ✓ support nutritional needs,
  - ✓ assist with activities of daily living,

- ✓ continue communication, and
- ✓ maintain ventilation and prevent respiratory complications.

People living with ALS have the right to information about the following resources:

- ALSA certified Centers providing specialized, comprehensive care for people living with ALS,
- ALS clinics working in partnership with local ALSA chapters,
- ALSA support groups, chapters and National Office,
- local community sources for assistance and social services,
- government sources for information and services,
- national referral sources for information and assistance
- web sites and Internet sources of support and information, and
- other people with ALS who offer to speak with patients and their family members about living with ALS.

**2. You have a right to participate in decisions about your health care including the right to accept, discontinue or refuse treatments and therapy. 1,2,3,4,7**

People living with ALS have the right to participate fully in all decisions related to their health care. This includes the right to receive medical treatments for which you have the resources to pay -- either through insurance or privately, or you qualify for a government or other health benefit program. It is acknowledged that some decisions are not in the sole purview of the patient, but all decisions should include an opportunity for active participation by the patient.

Patients have the right to make informed decisions to institute, discontinue or decline treatments and therapies, as well as the right to change a decision at any time. Informed treatment decisions should be based on current, accurate and understandable information regarding the prognosis, treatment, cost and management of ALS. People with ALS have the right to make treatment decisions in advance of an urgent or emergency situation. Patient choices about treatments should be respected and supported by their health care professionals.

Examples of treatment decisions a person with ALS may need to make include:

- participation in a drug trial,
- medication therapy,
- alternatives to eating for nutritional support (P.E.G.),
- ventilation (breathing) support (non-invasive and tracheostomy),
- assistive, augmentative communication devices,
- advance directives,
- end-of-life care -- hospice, emergency interventions, palliative care, comfort care.

**3. You have the right to access ALS specialty care in a timely manner. 4 (Not protected)**

People with ALS have the right to receive specialty care from health care providers credentialed, experienced and knowledgeable in treating patients with ALS. Patients have a right to ask for information about the credentials, experience and knowledge of their health care providers.

The range of disciplines best equipped to provide experienced, knowledgeable ALS care and services include the following:

- neurologist specializing in ALS,
- gastroenterologists experienced in inserting percutaneous endoscopic
- gastrostomy (P.E.G.)
- mental health counselor
- occupational therapist
- orthotist
- physiatrist

- physical therapist
- psychologist (Ph.D.) or psychiatrist (M.D.)
- pulmonologist experienced with noninvasive and tracheostomy ventilation
- registered dietitian
- registered nurse
- respiratory therapist
- social worker (MSW or CSW)
- speech and language pathologist

People with ALS have the right to information and services that are helpful in the management of ALS including psychological and social services, special equipment to support activities of daily living, communication and basic physiologic functions.

Patients and their family members have a right to a reasonable choice of providers to ensure access to appropriate high-quality ALS health care. Access to specialty ALS providers should be timely to make the diagnosis and initiate treatment and supportive care as quickly as possible. A second opinion from a qualified ALS physician should be available in a timely manner.

**4. *You have the right to receive health care that is coordinated and individualized for you across the spectrum of home, hospice, hospital, nursing home, outpatient, and work-place. 2,5*** (Not protected)

Patients have the right to receive the level of care appropriate to their needs in the setting that best meets their physical, financial, social and psychological situation. Continuity of care is important to persons with ALS and requires that health care providers and health plan personnel communicate with the patient on an ongoing basis regarding anticipated changes in the level and site of care -- for example, home care, nursing home, hospice or hospital. Patients are encouraged to discuss necessary workplace accommodations openly with employers in order to be able to continue to work as long as possible. If you can perform the essential functions of your job, even if you require reasonable accommodations, your employer cannot discriminate against you with respect to your wages, hours, terms and conditions of employment.

**5. *You have the right to access health care benefit coverage without discrimination based on your ALS diagnosis or physical disability. 5***

People with ALS who are eligible for health plan coverage under the plan's terms and conditions, must not be discriminated against in enrollment practices or in the delivery of health care services based on disability.

**6. *You have the right to obtain clear, timely information regarding your health plan including benefits, exclusions and appeal procedures. 4,6***

People living with ALS have a right to timely, understandable information on a range of issues related to their health plan including:

- types and choices of health plans and cost of premiums,
- out-of-pocket expenses, catastrophic cost limits, and lifetime maximums,
- covered benefits and required authorizations, service restrictions and limitations on
- services or choice of health care provider,
- how coverage decisions (including drug formularies) are made and by whom,
- procedure for appeals and arbitration,
- cost of medications, services and equipment not covered by health plan,
- clear indication as to whether home care (skilled and unskilled), hospice and
- nursing home care are covered benefits.

Patients have a right to a full and fair review of their benefit claims.

**7.** *You have the right to access your medical records and have the information in your records explained to you.*  
(Not protected)

People with ALS have the right to request and receive a copy of their medical records and to have the information in their records explained or interpreted in lay language.

**8.** *You have the right to prepare an advance directive to tell health care providers your wishes regarding emergency and end-of-life treatment choices.* **1,2,4,7**

An advance directive is a document allowing a person to give directions about future medical care or to designate another person to make medical decisions if the individual loses decision-making capacity. Advance directives may include living wills, durable powers of attorney, right to die, or similar documents expressing the individual's preferences as specified in the 1990 Patient Self-Determination Act.

People living with ALS have the right to make advance directives concerning treatment with the expectation that the directives will be honored by health care providers. Advance directives refer to legal documents outlining a patient's preferences regarding treatment choices such as tracheostomy and ventilation support. Terminology and interpretation related to the laws governing advance directives differ by state, but the overall purpose is to assure that individuals are treated with dignity and that treatment decisions are respected by their family and health care providers. Patients are encouraged to seek out information, laws and procedures in their state of residence.

**9.** *You have the right to receive care that is considerate and respects your dignity, your cultural, psycho-social and spiritual values and your privacy. You have this right no matter what choices you make about treatments and therapy, what your disabilities related to ALS might be or what your financial situation is.* **1,2**

People with ALS have a right to receive considerate, respectful care and treatment without discrimination based on the ALS diagnosis, the related disabilities and limitations or financial considerations.

**10.** *You have the right to know that the information about you and your medical condition will be held confidential by your health care providers.* **1,2,3,4**

Maintaining patient confidentiality is a basic responsibility and ethical obligation of all health care professionals and organizations. Patients have a right to have their medical records maintained confidentially by the professionals and organizations providing health care, unless the patient has agreed to waive confidentiality protection as when required for some research purposes. People with ALS have a right to communicate in confidence with their health care providers.

**11.** *You have the right to receive support to enhance or maintain your quality of life and have your family involved in all aspects of your health care.* **2**

This includes: support to continue employment, social support to increase access to public spaces for maximum mobility -- convenient parking, etc., psychological support so that you will be able to continue to express your feelings, thoughts and ideas, and care and services provided in an atmosphere of hope.

## **Footnotes**

Footnotes within the text of this document refer to the following "References and Resources" noted below:

1. AHA = American Hospital Association
2. JCAHO = Joint Commission on Accreditation of Health Organizations
3. MEDICARE = condition of health care providers' participation in program
4. NHC = National Health Council's "Putting Patients First"
5. ADA = Americans with Disabilities Act
6. ERISA = Employee Retirement Income Security Act

## Resources for Patients and Families

ALS patients and families can call or write to the following organizations and agencies for assistance if they encounter a problem obtaining one or more rights that are protected by law or regulation. It may be best initially to contact the local chapter or support group of The ALS Association and the ALS physician or hospital. Patients and their families are encouraged to try to resolve problems first with the person or organization involved in the issue.

1. Your ALS physician, clinic and/or hospital. In most cases, clinics and hospitals have offices of patient relations/representatives or risk management that can provide information and assistance.
2. The local chapter or support group of The ALS Association.
3. The National Office of The ALS Association (800) 782-4747.
4. Ombudsman. Your state's Department of Health Facilities. This is generally the state's licensing and regulatory agency for all health facilities and for consumer complaints.
5. Your state's Department of Corporations (consumer complaints division) if your problem relates to a health insurance company.
6. Your state's Department of Mental Health (consumer complaints division) if your problem relates to mental health issues.
7. Americans with Disabilities Act, Information Line at the Department of Justice (800) 514-0301 or (800) 514-0383 TDD for problem with disability rights. Web site address [www.usdoj.gov](http://www.usdoj.gov)
8. The Joint Commission on the Accreditation of Healthcare Organizations (800) 994-6610 for problems covered by the regulations of this accrediting organization. Web site address [www.jcaho.org](http://www.jcaho.org)
9. Paralyzed Veterans of America for veterans with advocacy or benefits issues (800) 424-8200. Web site address [www.pva.org](http://www.pva.org)
10. Medicare for information and questions. Web site address [www.medicare.gov](http://www.medicare.gov)
11. National Association of Area Agencies on Aging for problems experienced by the elderly. Elder Care Locator (800) 677-1116. Web site address [www.n4a.org](http://www.n4a.org)

The Amyotrophic Lateral Sclerosis Association  
National Office  
27001 Agoura Road, Suite 150  
Calabasas Hills, CA 91301-5104

Telephone: 818-880-9007  
FAX: 818-880-9006  
Information & Referral Service: 800-782-4747  
e-mail: [info@alsa.org](mailto:info@alsa.org)  
<http://www.alsa.org>

Member National Health Council

The ALS Association is the only national not-for-profit voluntary health organization whose sole mission is to find a cure for amyotrophic lateral sclerosis (Lou Gehrig's disease) and improve living with ALS.