

Patient and Family Resource Guide to ALS

Section 5 Caring for Persons with ALS

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Caring for Persons with ALS

Often ALS progresses to the point at which a person can no longer be independent in the activities of daily living (ADLs). It may even progress to the point at which the family can no longer provide the needed care. In these circumstances, the options are to hire a caregiver to supplement the family's care of the patient or to consider a nursing home. This section addresses both in-home care and nursing home care, how to choose between them, and the financial aspects of each. It also covers health insurance and additional resources that may be used to care for the patient.

Caring for Persons with ALS at Home

The term *home health* can be very confusing when discussing caring for a person with ALS (PALS) at home. A person can receive services in the home from various health care professionals from a home health organization, such as a nurse, a nurse's aide and a physical therapist. The organization is usually affiliated with an area hospital. A doctor's order is necessary to initiate the process of identifying a need for health care professionals and to bill the services to the health insurance company or to Medicare. In addition, these services can only be provided for a limited time. If family members cannot provide all the care needed, hiring an in-home caregiver could be considered if family finances allow for such an expense. Long-term assistance with the activities of daily living, which may be called maintenance, custodial or unskilled care is rarely covered by health insurance policies. It may, however, be covered by a long-term care policy. Some PALS may also be eligible for a state-funded assistance program that helps to provide care in the home.

Home Health Benefits

The five ADLs that are used as a measure of need are: dressing, bathing, feeding, toileting and transferring. Typically, the need for assistance with three of the five activities will satisfy the requirements for benefits. The following programs may provide assistance in obtaining and paying for in-home care.

Department on Aging: Eligibility for benefits checklist provides an evaluation of the services you may be entitled to at a low or no-fee rate.

Illinois Department on Aging (www.illinois.gov/aging) 312-814-2630

Chicago Department of Aging (www.illinois.gov) 312-744-0784

National Council on Aging: This website helps disabled people, as well as seniors, to identify programs that may improve the quality of their lives. www.benefitscheck.org

Community Care Program: This program is administered through the Department on Aging. It provides in-home personal care at sliding-scale rates. The patient must be at least 60 years old. There are savings limits for individuals and couples, not including one's home and car. Application must be made through Public Aid. www.cityofchicago.org

Respite Care: This program provides 5 to 7 days per calendar year in a nursing home in addition to an allotted weekly maximum number of hours of in-home care. Check with the Community Care Program case manager regarding contracted nursing homes. The Les Turner ALS Foundation has a grant program to assist families with the cost of respite care. Certain restrictions apply.

For more information, please contact the Les Turner ALS Foundation's Director of Patient services at 847 679 3311.

Illinois Department of Human Services is also called DHS (formerly the DORS/Department of Rehabilitative Services) program. This program is similar to the Community Care Program; however, the person with ALS must be less than 60 years old. The Personal Assistant program provides in-home personal care at sliding-scale rates. The agency also may provide an electronic emergency response system, home delivered meals, assistive equipment or environmental modifications.

Call for an evaluation to be made in your home.

Website: www.dhs.state.il.us

General inquiries 800 843 6154

Client information services 800 641 3929

Long-Term Care Insurance: A privately-held long-term care insurance plan may cover all or part of the cost of in-home and/or nursing home care with contracted agencies or facilities. Call the insurance company and ask for a case manager to review benefits and requirements.

Veterans Administration: The Department of Veterans Affairs offers many services to veterans with ALS. ALS veterans with an honorable or general discharge from the military should contact the VA as well as a National Service Officer for the Paralyzed Veterans of America (PVA) to receive information concerning benefit options.

Veterans Affairs 877 222 VETS www.VA.gov

312 663 5510

708 865 6580

Paralyzed Veterans of America pva.org

800 424 8200 ext.12

Chicago Area Representative 708 202 5623

Hiring a Caregiver Privately: The cost for an in-home caregiver can range from \$18 to \$25 or more per hour; the differences in price may vary with the level of experience. Many agencies

provide excellent caregivers for a fee and the staff at the Les Turner ALS Foundation can provide names of agencies that have ALS care experience. Please call the Les Turner ALS Foundation Director of Patient Services, 847 679 3311 for a list of recommended agencies. A home-health care agency provides background checks and coverage for days off, as well as caregivers to interview and choose among. It also acts as a liaison between you and a caregiver you have employed. A caregiver can also be hired through word of mouth, referral from a friend or newspaper, or from a registry, which provides the names and phone numbers of caregivers.

Questions to Ask when Hiring a Caregiver

- Do you smoke?
- Do you mind pets in the home (if applicable)?
- How many days out of the week would you be available?
- What hours are you available; or if hiring a live-in caregiver, what days of the week would you want off?
- Would you be available 24 hours each day, or would you expect to have an 8, 12, or 16 hour block of time during which you are not responsible or available to help? If so, what block of time?
- How do you feel about being awakened during the night to assist the patient?
- Would you be willing to do the following?
 - Cooking, meal preparation, feeding the patient?
 - Shopping, laundry, housework?
 - Patient's hygiene: dressing, bathing, toileting, etc.?
 - Assisting patient with ambulation that may include lifting?
- Would you be willing to learn to prepare tube feedings?
- How would you expect to be paid, by the hour, day, or week?
- Do you know anything about ALS, and have you worked with any other people with ALS ?
- Have you worked with anybody who is disabled?
- Do you have references that I can contact?
- When you are off duty, would you be staying here?
- Are you able to do lifting? Do you have any physical limitations or restrictions on your activities?

- What kind of sleeping arrangements do you require? Would you share a room or do you want your own room and bathroom?

Questions to Ask of an Agency

- Do you have male and female caregivers from which to choose?
- How long has the agency been in business?
- Is the agency licensed and accredited by appropriate governmental agencies?
- What kind of background checks does the agency run on employees?
- Are these professionals bonded?
- Does the agency supply references for its professionals?
- What language(s) do the caregivers speak?
- Exactly what services can we expect from a caregiver?
- What are the hourly fees or daily rates?
- How is the billing and payment of services handled?
- Who is responsible for the caregiver's taxes and social security contributions?
- Does the agency cover the caregiver for worker's compensation?
- Will the services be provided by the same person each day (if you are not hiring a live-in caregiver)?
- What kind of backup system does the agency have for emergencies, holidays, or sick days?
- Is someone at the agency available to handle questions or problems 24 hours a day?
- Does the agency supervise the caregivers?

For a listing of care agencies, contact the Les Turner ALS Foundation's Director of Patient Services, 847 679 3311

Nursing Home Care

Deciding if a Person with ALS Needs Nursing Home Care

Determining whether a loved one needs nursing home care is a difficult and often painful decision. Considering the following questions may help in making the decision.

- How much physical assistance does the patient need?
- How many times each day does the patient need to be transferred?

- Is the caregiver physically able to do the transfers without being in physical danger?
- How many times each night is the caregiver awakened to help the patient?
- Can the caregiver rest during the day if necessary?
- Is anyone available to help the patient and the caregiver with hands-on care?
- Is anyone available to help the patient and the caregiver with other household tasks?
- Are there other people to call on for help?
- What are the financial resources?

Nursing Home Care

Nursing homes provide two kinds of care:

Skilled Care: A registered nurse is on duty 24/7. Services of specially trained professionals, such as physical, occupational, and respiratory therapists, may also be included.

Maintenance care: Services are provided that assists a PALS with activities of daily living. This includes personal care and hygiene, as well as ambulation (movement) and transfers from one place to another, e.g. from the bed to the wheelchair. Assisted living services are sometimes covered by Long Term Care Insurance. Check your policy.

Ways to Pay for Nursing Home Care

Medicaid: If you cannot afford to pay for a nursing home, you may be eligible to have Medicaid pay the costs. Application is through Public Aid, and there are financial restrictions. An individual may have no more than \$2,000 in assets, not including a home and car. A patient's well spouse may keep almost \$109,000 in assets, but the patient's name must be legally transferred off of the assets.

Private long-term care insurance: A private long-term care insurance policy is separate from Medicare or other types of health insurance. If there is a long-term care policy, read the policy carefully to determine its restrictions and benefits. Many policies require a statement of medical need from a doctor and a waiting period before benefits are paid.

Medicare: Nursing home benefits available through Medicare are very specific. Medicare pays only for skilled care in a facility with a Medicare license. Although we may feel that the PALS's needs require great skill, Medicare has specific guidelines that define "skilled" care and determine when it is needed. Under Medicare's definition, most ALS patients are considered to be in need of "maintenance care," and so are not eligible for nursing home benefits from Medicare.

Private pay: If none of the previous options are applicable, and the financial resources are available, you may choose almost any nursing home and pay privately.

What to Ask and Observe When Choosing a Nursing Home

- Who is the doctor who will provide regular checkups, write orders, and prescribe medication and devices
- Is the residence clean and odor-free and is the temperature appropriate?
- Can the room and bathrooms accommodate the necessary durable medical equipment, such as a wheelchair?
- Are the residents clean?
- Who will be the liaison for questions or concerns?
- Is a 24-hour emergency response system accessible for the patient? What kind of meals are served, and who will help the patient eat, if necessary?
- Have you ever had an person with ALS as a resident?
- Are private and semi-private rooms and baths available?

Hospice and Palliative Care

The World Health Organization (WHO) defines *palliative care* as the active total care of patients whose disease does not respond to curative treatment. The goal of palliative care is to achieve the best possible quality of life for patients and their families. Palliative care includes control of pain and other symptoms. It also addresses psychological, social, and spiritual issues. Until there is a cure for ALS, palliative care should be considered beginning at the time of diagnosis.

For the person with advanced ALS, palliative care in the home or in a nursing home can be provided by a hospice program with an interdisciplinary team of professionals. In order to obtain care from a hospice, a patient must have a doctor's referral indicating that the patient has a life expectancy of six months or less if the disease runs its "normal" course. The hospice may also require a signed statement from the patient and doctor which includes a DNR/DNV, i.e. Do Not Resuscitate/Do Not Ventilate order. This order means that the patient does not wish to be placed on a ventilator in case of an emergency, and that he or she does not want any heroic measures performed to maintain life. For example, this document would instruct medical personnel not to use cardiopulmonary resuscitation (CPR) if the patient's heart stops beating.

Hospice is covered by most private medical insurance policies and is part of the Medicare Part A and Medicaid plans. Some hospices are located in a hospital as a special unit, others may be located in a free-standing facility. However, all hospice services can be provided in the home. The hospice team includes a doctor, nurses, certified nurse's aides (CNAs), a social worker, and a chaplain. The team may also include a music therapist, a physical therapist, and volunteers who provide brief periods of respite for the caregiver. A nurse is on call to help answer questions 24 hours a day, 7 days a week. One of the goals of hospice care is to keep the patient comfortable and as pain-free as possible. The staff arranges for all the necessary medications and equipment pertaining to the terminal illness to be delivered to the home. The hospice team of professionals provides the patient and family with expertise in managing physical and emotional end of life issues.

The doctors at the Lois Insolia ALS Clinic at the Les Turner ALS Research and Patient Center at Northwestern Medicine will help determine when it is appropriate to involve hospice in the care of the ALS patient. The primary doctor remains involved in the case along with the hospice staff. In addition, the ALS Clinic staff and members of the Les Turner ALS Foundation's Home and Community team remain available for consultation and assistance while hospice is involved.

Resources

Medicare hotline for hospice benefits 800 MEDICARE

National Hospice and Palliative Care Organization for information on local hospices:

800 658 8898

nho.org

Illinois State Hospice Organization 888 844 7706

isho.org

EMERGENCIES

PALS may have or may develop other medical problems or conditions unrelated to ALS. The types of problems that could occur cannot be predicted by the ALS Clinic staff and many can be difficult to separate from end-stage ALS issues.

Emergency Response Systems

This small, waterproof call button can be worn around the neck or around the wrist. If a problem occurs, the person with ALS or caregiver simply presses the button and an electronic signal activates a special speaker that is wired through the phone line. The line is monitored 24 hours a day, seven days a week, and someone will immediately ask what kind of help is needed. The help could just be someone to help the individual up, such as a neighbor, or it could be the paramedics for a more urgent situation. Some systems will automatically send help for people with ALS who cannot speak.

Philips Lifeline www.lifeline.philips.com

1- 800- LIFELINE

5 Star Urgent Response www.greatcall.com

1-800-463-5412

Direct Link 708 755 8440

directlink1.net

When to Call and Who to Call

Conditions or symptoms that should be handled by calling 911 may include, but are not limited to, the following:

- Chest pain with or without shortness of breath, sweating or nausea may indicate a heart attack or other heart problem.
- Pain in the jaw or in the upper arm, with or without shortness of breath, sweating, or nausea may indicate a heart attack.
- Back pain between the shoulder blades or in the lower back that may be sudden and/or intense, with or without shortness of breath, sweating, or nausea may indicate a heart attack or other heart problems.
- Sudden changes in breathing may indicate a heart problem or a lung problem, such as a blood clot.
- Sudden changes in level of consciousness may indicate a stroke.
- Sudden changes in function, such as sudden inability to speak or to move an extremity may indicate a stroke.
- Sudden change in color or swelling or feeling in a leg or an arm may indicate a blood clot.

If the patient is in extreme distress and you are not certain what to do, **do not hesitate to call 911**. Do not spend valuable time attempting to reach the ALS Clinic doctor or nurse. **If the patient is in hospice care, call the hospice 24-hour number immediately**. The on-call nurse will suggest how to help the patient, and may also visit the home to evaluate and/or treat the patient's symptoms.

Resuscitation or DNR

Activating the local emergency response system by calling 911 requires certain actions by the Paramedics or Emergency Medical Technicians (EMTs) who respond. They are required by the State of Illinois to attempt resuscitation unless there is a valid Do Not Resuscitate (DNR) order or POLST on the premises. This means they must begin cardiopulmonary resuscitation (CPR) unless you can show them a DNR or POLST order signed by the patient. Paramedics may be required to defibrillate (shock) certain heart rhythms and to give various medications. State of Illinois guidelines also require them to transport the patient to the closest hospital, unless the designated hospital acting as medical control for that particular system gives them permission to transport to another location. These guidelines are mandatory and cannot be altered or changed by the paramedic or EMT once they are on the scene.

If the patient does not wish to be placed on a ventilator or to have heroic measures performed to maintain life, the family must have available a signed statement from the patient which includes a valid Do Not Resuscitate (DNR/POLST) order. For example, this document would instruct medical personnel not to use cardiopulmonary resuscitation (CPR) if the patient's heart stops beating. Everyone involved in the patient's care should know where the DNR/POLST order is located. Other advance directives, or legal forms can ensure that the patient's wishes to have or not have heroic measures performed to maintain life are followed. These forms include the 5 Wishes document or a Living Will, which spells out the patient's wishes and a power of attorney for health care which appoints another person to make health care decisions if the patient is unable to speak for her/himself. Consult with your physician, clinical nurse coordinator or Les Turner ALS Foundation Patient and Family Advocate or Social Worker.

Disclaimer: All care has been taken in preparing this document. This information is of a general nature and should be used as a guide only. Always consult your health care team before starting any treatments.