ALS of Michigan is pleased to be able to provide you with our ALS Patient and Caregiver Resource Manual. We have done our very best to provide you with the most comprehensive set of local and national resources available in the ALS community.

Our mission is to help our pALS (person with ALS) and their families live life as fully as possible. To that end, we believe that this resource manual is an instrumental document for you to keep as a reference, and just one of the many ways that we strive to make living with ALS easier.

ALS of Michigan wants you to know that you are not alone in your fight against ALS, and that we are here to provide assistance to you, your loved ones, and your healthcare professionals. If you have any questions about the manual, local or national resources, or our programs or services please feel free to call or email us. We are here to help you and to provide support.

With warmest regards,

Sue Burstein-Kahn

Executive Director
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Workshops & Seminars

ALS of Michigan offers workshops and seminars for PALS (persons with ALS), caregivers and health professionals. These seminars focus on living with ALS, research, and medical advances, and are offered at various times and locations. We offer seminars presented by neurologists and health care professionals who specialize in the field of ALS. Our research conference is held annually to discuss local, national and international research. In addition, many workshops are held on a variety of additional topics such as augmentative communication, children who have a loved one with ALS, newly diagnosed, respiratory symptom management and many other topics that are of interest to PALS and their loved ones.

Augmentative Communication

ALS of Michigan offers speech evaluations to PALS by a speech pathologist that specializes in communication issues for PALS. Speech evaluations are recommended as soon as a person is aware of changes in their speech. An evaluation is completed at ALS of Michigan or at home. Recommendations are made on what form of augmentative communication would be most appropriate. An augmentative communication loan closet is also available to PALS.

Equipment Loan Closet

A loan closet of durable medical equipment is available free of charge to PALS. Most items in the closet have been donated by patients and families and include wheelchairs, lifts, walkers, and communication devices to name a few. If you need an item, please contact our office with your request, and we will do our best to fill it from the items available. We can also help individuals obtain equipment that is not available through our loan closet by working with other local agencies that have loan closets.

Licensed Social Workers

ALS of Michigan has two Licensed Social Workers on staff. Their role is to support pALS and their families who are living with ALS. Our social workers also provide supportive counseling, act as social worker at the Henry Ford ALS Clinic, assist with locating community resources, and performing home visits at the request of a pALS. Please call the ALS of Michigan office at 800-882-5764 to speak with a social worker.
Support Groups

pALS and their caregivers (CALS) often have a multitude of questions about living with ALS. Support groups offer an opportunity to discuss topics such as health care providers, community resources, respite care, family issues, durable medical equipment, and to talk with other families living with ALS. For a list of our current support groups, please visit our website or contact our office.

Information, Referrals, & Resource Guides

ALS of Michigan has licensed social workers available to help you find community and national resources. Our trained staff is available to answer your questions or refer you to an appropriate source.

Respite Care Services

Caregivers have the overwhelming job of caring for a loved one 24-hours-a-day/seven-days-a-week. Our respite care program enables caregivers to take some time away for themselves. Respite care services are provided by home healthcare agencies which pALS and their families choose. For program information please contact our office.

Home Visits

Our professional staff is available to meet with you at your home to discuss living with ALS, your needs, and to coordinate services. We recommend meeting with a patient services staff person soon after diagnosis. To schedule an appointment to meet with one of our professionals, please contact us to schedule a home visit.

Research

ALS of Michigan supports both local and national research efforts focused on the cause and the cure for ALS.

ALS Neurologists

Michigan has a number of neurologists and clinics that specialize in ALS. Many ALS clinics provide a multidisciplinary approach to caring for pALS and are up-to-date on the latest advancements in the treatment of ALS. ALS of Michigan works with area neurologists and clinic to enhance education, support and programming to the ALS community.
Financial Donations

ALS of Michigan, Inc. receives no government or insurance funding and relies totally on the generosity of individuals, corporations, trusts and foundations for its support. ALS of Michigan, Inc. is a registered nonprofit organization. As a qualified 501(c)(3) tax exempt organization, all contributions to ALS of Michigan, Inc. are tax deductible.

Memorial Tributes

A donation as a Memorial Tribute allows you to support the programs and services provided by ALS of Michigan while, at the same time, remember a special family member, friend, colleague, or special occasion. When you contribute through the ALS of Michigan, Inc. in a Memorial Tribute, a letter is sent to the family of the deceased, acknowledging your gift. A contribution through a Memorial Tribute allows you to make a gift in recognition of important occasions such as weddings, anniversaries, birthdays and graduations. A letter is sent to the person(s) you wish to honor acknowledging the occasion and your gift. Under all circumstances, the amount of the gift remains confidential.

When making a Memorial Tribute, we need to know your name and address, the name of the person being memorialized or honored, and the name and address of the family to whom the card will be sent.

Call us to make a Memorial Tribute.

(800) 882-5764

ALS of Michigan, Inc.

24359 Northwestern Hwy. Suite 100

Southfield, MI  48075

To donate online visit:   http://www.alsofmichigan.org/

Medical and Assistive Technology Equipment Donations

ALS of Michigan gratefully accepts clean, usable medical and assistive technology equipment to share through our loan closet. If you have something that you no longer need please contact ALS of Michigan, Inc. to arrange a donation. We accept items that are in clean and working condition.
An acknowledgment letter will be provided confirming your gift. Your donation will not only provide you with a tax deduction but will help provide needed equipment to someone who may be able to use it. Examples of equipment which is needed are as follows:

- Bath Benches
- Shower Wheelchairs
- Hoyer Lifts
- Manual Wheelchairs
- Power Wheelchairs
- Recliner Lift Chairs
- Walkers
- Nutritional Supplements
- Augmentative equipment
- Scooters
- Bed Tables
- Raised Toilet Seats
- Transport Chairs
- Voice Amplifiers
- Wheelchair Cushions
- Transfer Boards
- Portable Ramps

**Employer Programs**

**Employer Matching Gift Programs**

If your employer has a Matching Gifts Program for charitable organizations, your contributions to ALS of Michigan, Inc. can grow! By simply checking with your Personnel or Employee Benefits department, ALS of Michigan, Inc. may be an eligible organization under your company's policy. Several donors have utilized their employer's Matching Gifts Program, allowing their personal gift to double.

**Charitable Employee Campaign Programs**

Support ALS of Michigan, Inc. the easy way…through workplace giving campaigns. Check with your employers Personnel or Employee Benefits department to see if your company has a Charitable Employee Campaigns program. These programs give donors an ongoing opportunity to give all year long in a no hassle process that allows you to automatically have a donation deducted from your paycheck. All the paperwork is done by the campaign; no checks to write...no envelopes to address. All you have to do is fill out a campaign pledge card with a designated amount of money to be deducted per pay period and name a specific charity you want to donate to.
Volunteers

The general public is one of the greatest allies in the fight against ALS. Through our public awareness and education activities, we reach out to our community to join in our battle.

ALS of Michigan relies heavily on volunteers to successfully execute our fundraising events. Any amount of time that you can give in the following areas will make such a difference in the life of an ALS patient!

Administrative Support

Help with mailings, answering the phones, talking with volunteers, families, and patients. Provide much-needed support to the on-going operations of ALS of Michigan, Inc. If you are skillful in talking to people, recording information, and have good attention to detail, then this volunteer work is for you!

Event Planning

Join the fun with others to create awareness and raise funds for ALS through events such as the ALS Walk and Roll, Lou Gehrig Day at Comerica Park, awards dinners, and much more!

Create Your Own Event!

Whether it is a “jean day at work”, “spaghetti dinner”, or bowling or golf outings, our pALS families and friends have put on their own great events to support the efforts of ALS of Michigan. These events help support their walk teams and/or some go directly to supporting programs and services for our ALS families. For assistance in creating your event call 800.882.5764.

Advocacy

We need our PALS and caregivers to tell their story. We need our legislators to be educated about ALS and how it impacts an individual and their family. It’s so very important for us to get the word out about ALS and how many people in Michigan are living with ALS. Please contact ALS of Michigan if you would like to help with advocating for our PALS and their caregivers.
ALS Information and Research

Common Questions about ALS

What is ALS?

ALS is the abbreviation for "Amyotrophic Lateral Sclerosis." "A" means no or negative. "Myo" refers to muscle, and "Trophic" means nutrition or stimulation. When a muscle has no stimulation, it "atrophies" or wastes away. "Lateral" identifies the area of the spinal cord where the pathways for motor nerves, those that innervate the muscles, are located. As this area degenerates it leads to scarring or hardening, "sclerosis," in the region.

Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's disease, and Motor Neuron Disease, is a progressive neuromuscular disease. ALS was first identified by French neurologist Jean-Martin Charcot in 1869. This disease affects the brain's motor neuron pathways causing progressive muscle weakness and can cause loss of function for speech, swallowing, and movement.

What are the symptoms of ALS?

Initial symptoms may include tripping, stumbling and falling, or loss of strength or muscle control in hands and arms, called limb-onset ALS. For some it may show up as difficulty speaking, swallowing or breathing, called bulbar-onset ALS. Symptoms may include: muscle stiffness (spasticity), twitching (fasciculation’s), muscle cramps, chronic fatigue or exaggerated reflexes. The voluntary muscles or skeletal muscles are affected by ALS, eventually leading to paralysis.

Involuntary movement, such as eye movement, bladder and bowel control, and sexual function are not “usually” affected, nor are the senses: touch, vision and hearing.

Pain is not specifically a symptom of ALS but can occur as a result of muscle cramps, loss of muscle strength and loss of mobility. Common pains as a result of ALS include pressure sores, muscle cramps, joint contractures, constipation, burning eyes, swelling feet, and muscle aches.

Some pALS may experience other cognitive and behavioral changes. Recent studies do show that 50% of ALS patients will show some mild symptoms of Frontotemporal Dementia (FTD), but only a small portion of pALS meet the criteria for an FTD diagnosis. FTD is a type of dementia that affects the frontal and temporal lobes of the brain. Symptoms of FTD include atypical behaviors, poor judgement, irritability lack of insight, and anger. Brain scans, such as CT and MRI scans, can assist a doctor in diagnosing FTD. A doctor may also interview a pALS family and friends about
changes they have noticed in their loved one. Speak with your loved one’s doctor if you notice any changes in their behavior.


Pseudobulbar Affect (PBA) is a symptom of ALS that involves uncontrolled or exaggerated crying or laughing in situations that do not warrant such strong expressions of emotions. PBA tends to occur in pALS as the disease progresses. If you are experiencing these symptoms, speak with a doctor about medications to control PBA.


Who gets ALS?

ALS occurs around the world with no obvious racial, ethnic, or socioeconomic boundaries. It is not contagious. Approximately 2 in 100,000 people get ALS.

In the United States, approximately 30,000 people are living with ALS. In Michigan, an estimated 1,000 people are living with ALS and 200 are newly diagnosed each year. Both men and women get ALS but statistics show that men are 20% more likely to get ALS. ALS can affect people at any age, and cases have been found in persons as young as 12 and as old as 98. Approximately 80% of ALS cases begin between the ages of 40 and 75 with the average age of onset being after age 60. There appears to be a trend of younger patients in their 20's and 30's being diagnosed with ALS.

ALS is classified as either “sporadic” ALS, meaning it occurs randomly, or “familial”, which means other family members have had ALS. Approximately 5-10 percent of the ALS population has familial ALS. In familial ALS there is a 50% chance each offspring will inherit the gene and could develop ALS.

What causes ALS?

The cause of ALS is unknown, and researchers have been unable to identify why this disease strikes some and not others. In searching for a cause, researchers have investigated several environmental factors such as exposure to toxic or infectious agents. Other research has examined the possible role of an individual’s diet and or traumas they may have sustained at an earlier age. However, they have been unable to link these factors in causing ALS.
In 1993 scientists supported by the National Institute of Neurological Disorders and Stroke (NINDS) discovered that mutations in the gene that produces the SOD1 enzyme (superoxide dismutase) were associated with some cases of familial ALS. This enzyme is an antioxidant that protects the body from damage caused by free radicals. If not neutralized, free radicals can accumulate and cause damage to the DNA and proteins within cells. It is not yet clear how the SOD1 gene mutation leads to motor neuron degeneration, researchers have theorized that an accumulation of free radicals may result from the faulty functioning of this gene.

In 2011, two research teams from the National Institutes of Health and the Mayo Clinic in Jacksonville, Florida, discovered chromosome 9 open reading frame 72 (C9ORF72) as a gene that when mutated, can cause ALS. About 40% of all familial ALS cases and 7-10% of sporadic ALS cases are caused by the C9ORF72 mutated gene. There is genetic testing available for the C9ORF72 gene, but it is best to speak with your doctor first before proceeding with the genetic test.


How is ALS diagnosed?

An experienced physician, usually a neurologist will complete a neurological exam. They will complete a medical history (including family history). The diagnosis is made by ruling out other diseases and by meeting specific criteria for ALS. There is no one test for ALS. Some of the diagnostics procedures might also include the following tests.

- Laboratory tests
- Muscle and/or nerve biopsy
- Magnetic resonance imaging (MRI)
- Electromyography also known as EMG. This procedure is used to evaluate and diagnose disorders of the muscles and motor neurons. Electrodes are inserted into the muscle, or placed on the skin overlying a muscle. Electrical activity and muscle response is then evaluated.
- Spinal Tap
- Blood and Urine Studies
**What is the treatment for ALS?**

There is no cure for ALS but the physician or Neurologist; preferably one experienced with ALS will work with the patient and family to manage ALS symptoms. The US Food and Drug Administration (FDA) approved the drug Rilutek®, the first drug that has shown to prolong the life expectancy of persons with ALS by approximately three months.

There are medications to relieve muscle cramping, excessive saliva, depression, and anxiety. Physical Therapy and Range of Motion exercises can be done (see treatment section of this manual for these exercises) to ease any stiffness or cramps.

Dieticians are able to show ways to promote good eating habits and what to do if swallowing becomes an issue. Meeting with a speech pathologist about techniques will allow pALS to continue to speak or use devices to communicate are available. Durable medical equipment (DME) such as bath equipment, eating utensils, walkers, and wheelchairs are forms of DME and can be used when mobility becomes an issue.

Emotional support and counseling can be provided by social workers and psychologists to help deal with the many changes.

**What is the future of a person with ALS?**

ALS progresses at different rates in each individual. Statistics show the average survival for someone affected by ALS is three to five years. A small percentage of people have a very slow progression and live 10-20 years. Again, each patient is different and it is hard to predict how the disease will impact each person. Each patient chooses different treatment plans and this could impact their future. Improved treatment is allowing ALS patients to live longer than ever before. Patients who stay involved in their treatment and treat their symptoms seem to do better than those who choose to not follow up with regular medical appointments. Patients with a positive attitude and good emotional health tend to do better than patients who are severely depressed. Being educated about the latest treatments and being open to what is available to ALS patients will benefit both the patient and family and will have a significant outcome on how one progresses.
Recommended Steps after Diagnosis

• If you suspect you have ALS but are not diagnosed yet, look into the possibility of getting additional life insurance and/or long-term disability insurance.

• ALS is difficult to diagnose. If you were not diagnosed by a neurologist who specializes in neuromuscular diseases, request a referral to one who specializes in ALS for a confirmation of the diagnosis.

*Consider attending an ALS Clinic at hospitals such as Henry Ford Hospital or University of Michigan to be seen by a neurologist that specializes in ALS and other disciplines including, nursing, occupational therapy, physical therapy, social work, dietician, and speech pathologist.

• Register with ALS of Michigan, Inc. (800) 882-5764. Request information about available services.

• If you served in the military, contact the Department of Veteran Affairs (800-827-1000) and PVA (313-471-3996) about extensive benefits available to those who have served.

• Contact an attorney who specializes in elder care law and make an appointment to discuss legal and financial planning recommendations. Complete a Durable Power of Attorney or living will that lists your medical wishes.

• Consider attending a support group or if you are a family member attend a caregiver conference. Contact ALS of Michigan an 800-882-5764 for a support group in your area.

• If you are employed, contact Michigan Rehabilitation Services at (800) 605-6722 or www.michigan.gov/mdcd and request information about available services.

Also consider a timeline for when you feel you will stop working and follow up with applying for Social Security Disability (ssa.gov). Your doctor and/or social worker can also help answer questions.

• When the time comes, be open to the medical equipment and treatment plans that are offered. These options will protect you and may give you a better quality of life.

*This is a good time to take inventory of your home’s accessibility and resources you have available for adaptations/modifications if/when needed.

• Don’t be afraid to ask for help. There are many services as well as individuals who do want to help you, allow them to.
The Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS)

The ALS Functional Rating Scale is a commonly accepted standard for monitoring disease progression and is used in clinical trials and in the treatment of patients. It is a dysfunction scale used in assessing the activities of daily living of patients with ALS. The ALS Functional Rating Scale assesses the following functions: Speech, Salivation, Swallowing, Handwriting, Cutting Food and Handling Utensils, Dressing and Hygiene, Turning in Bed and Adjusting Bed Clothes, Walking, Climbing Stairs, Dyspnea, Orthopnea, Respiratory Insufficiency. Each task is rated on a five-point scale from 0 = can't do, to 4 = normal ability.

Clinical Trials

What is a clinical trial?

A clinical trial is an experiment to determine if a drug or other intervention that has previously shown a benefit in animals is safe and effective for humans.

By participating in clinical trials each individual is not only actively trying to help themselves but, are helping others who are diagnosed with ALS. Many research projects and clinical trials are being conducted both at the local and national levels. PALS and caregivers should speak to their neurologists or call ALS of Michigan to find out what clinical trials are being done in Michigan or visit http://www.clinicaltrials.gov for more information. The information below is from the website and also gathered from alsal.org – Ask the Doc- Edward Kasarskis, M.D., Ph.D.

Who can participate in a clinical trial?

All clinical trials have guidelines about who can participate. Some research studies seek participants with illnesses or conditions to be studied in the clinical trial, while others need healthy participants. It is important to note that inclusion and exclusion criteria are not used to reject people personally. Instead, the criteria are used to identify appropriate participants and keep them safe. The criteria help ensure that researchers will be able to answer the questions they plan to study. Inclusion criteria might include age, sex, other medical conditions you may or may not have, how long you have had ALS, or muscle strength and breathing capacity.

What happens during a clinical trial?

There are three types of trials involved in testing a potential new drug: phase 1 (tests safety), phase 2 (testing on target population), phase 3 (tests the determined dose on a larger number of people and is compared to a placebo to prove a drug is effective)
To best determine a drug is effective, a randomized double-blind clinical trial is preferred. A randomized study means that once you meet the criteria for being included in the clinical trial, you are placed in either a placebo group or the group getting the test drug. The decision of whether you will receive a placebo or the actual test drug is solely by chance (random). Being double-blind means that neither the patient nor the research team knows which treatment (placebo or actual test drug) the participant is taking. This ensures that all the people involved in the trial will be unbiased and results will be objective.

Some clinical trials involve more tests and doctor visits than the participant would normally have for an illness or condition. For all types of trials, the participant works with a research team. Clinical trial participation is most successful when the protocol is carefully followed and there is frequent contact with the research staff.

**What is a placebo?**

A placebo is an inactive pill, liquid, or powder that has no treatment value. In clinical trials, experimental treatments are often compared with placebos to assess the experimental treatment's effectiveness. In some studies, the participants in the control group will receive a placebo instead of an active drug or experimental treatment.

**What is informed consent?**

Informed consent is the process of learning the key facts about a clinical trial before deciding whether or not to participate. It is also a continuing process throughout the study to provide information for participants. To help someone decide whether or not to participate, the doctors and nurses involved in the trial explain the details of the study. If the participant's native language is not English, translation assistance can be provided. Then the research team provides an informed consent document that includes details about the study, such as its purpose, duration, required procedures, and key contacts. Risks and potential benefits are explained in the informed consent document. The participant then decides whether or not to sign the document. Informed consent is not a contract, and the participant may withdraw from the trial at any time.
What are the benefits and risks of participating in a clinical trial?

Benefits

Clinical trials that are well-designed and well-executed are the best approach for eligible participants to:

• Play an active role in one’s own health care.

• Gain access to new research treatments before they are widely available.

• Obtain expert medical care at leading health care facilities during the trial.

• Help others by contributing to medical research.

Risks

There are risks to clinical trials.

• There may be unpleasant, serious or even life-threatening side effects to experimental treatment.

• The experimental treatment may not be effective for the participant.

• The protocol may require more of their time and attention than would a non-protocol treatment, including trips to the study site, more treatments, hospital stays or complex dosage requirements.

How is the safety of the participant protected?

The ethical and legal codes that govern medical practice also apply to clinical trials. In addition, most clinical research is federally regulated with built in safeguards to protect the participants. The trial follows a carefully controlled protocol, a study plan which details what researchers will do in the study. As a clinical trial progresses, researchers report the results of the trial at scientific meetings, to medical journals, and to various government agencies. Individual participants' names will remain secret and will not be mentioned in these reports.

What should people consider before participating in a trial?

People should know as much as possible about the clinical trial and feel comfortable asking the members of the health care team questions about it, the care expected while in a trial, and the cost of
the trial. The following questions might be helpful for the participant to discuss with the health care team. Some of the answers to these questions are found in the informed consent document.

• What is the purpose of the study?

• Who is going to be in the study?

• Why do researchers believe the experimental treatment being tested may be effective? Has it been tested before?

• What kinds of tests and experimental treatments are involved?

• How do the possible risks, side effects, and benefits in the study compare with my current treatment?

• How might this trial affect my daily life?

• How long will the trial last?

• Will hospitalization be required?

• Who will pay for the experimental treatment?

• Will I be reimbursed for other expenses?

• What type of long-term follow up care is part of this study?

• How will I know that the experimental treatment is working? Will results of the trials be provided to me?

• Who will be in charge of my care?

Can a participant leave a clinical trial after it has begun?

Yes. A participant can leave a clinical trial, at any time. When withdrawing from the trial, the participant should let the research team know about it, and the reasons for leaving the study.
What are the different types of clinical trials?

Treatment trials test experimental treatments, new combinations of drugs, or new approaches to surgery or radiation therapy.

Prevention trials look for better ways to prevent disease in people who have never had the disease or to prevent a disease from returning. These approaches may include medicines, vaccines, vitamins, minerals, or lifestyle changes.

Diagnostic trials are conducted to find better tests or procedures for diagnosing a particular disease or condition.

Screening trials test the best way to detect certain diseases or health conditions.

Quality of Life trials (or Supportive Care trials) explore ways to improve comfort and the quality of life for individuals with a chronic illness.

For more information on Clinical Trials and Research, please check these websites:

* National Institute of Health (NIH)  http://www.clinicaltrials.gov
* NEALS (Northeast Amyotrophic Lateral Sclerosis Consortium)  http://www.nealsconsortium.org/
* The Robert Packard Center for ALS at Johns Hopkins  http://wwwalscenter.org/
* National ALS Association  http://www.alsa.org
* Les Turner ALS Foundation  http://lesturnerals.org
* ALS Therapy Development Institute  http://www.als.net
* Muscular Dystrophy Association  http://www.als-mda.org
* MyClinicalTrialLocator.com
ALS Symptom Management/Treatment

Treatment begins with being followed by your neurologist. If you have access to an ALS clinic, you may additionally be seen by an interdisciplinary medical team.

The ALS Medical Team

It is very important to meet with health care professionals who specialize in the field of ALS, to help manage symptoms and help living with ALS easier. The team is made up of physicians and allied health professionals who work together to meet the needs of patients and families living with ALS. They regularly assess changes, so recommendations about strategies and the best treatment options to cope with symptoms can be made. They can help communicate and work with primary care physicians, case managers, and insurance companies to ensure comprehensive care; research treatments and procedures. The following are the disciplines that participate at the ALS clinic along with the neurologist.

• Physical therapy
• Occupational therapy
• Nursing
• Registered dietitian services
• Ph.D. psychology or psychiatry
• Speech and language pathology
• MSW social work services

Description of ALS Medical Team Specialties

Neurologist - The initial role of the neurologist is the medical evaluation of the patient and diagnosis or confirmation of diagnosis. Subsequently the neurologist becomes the key ALS team contact and monitors clinical function, initiates treatment programs as needed, and provides overall support to the patient and family. Information is provided regarding the latest developments in ALS
research and the patient is offered the opportunity to participate in clinical research trials if specific entry criteria are met.

**Nurse** - A nurse coordinator is the main contact between the different ALS team members and the patients and their families. The nurse also provides a multitude of services, including monitoring of vital signs and weight, maintaining the medical records for each clinic visit, assessing general health problems and providing practical solutions, and testing functional changes in the patient's clinical status. In addition, research nurses coordinate the different clinical drug studies for patients attending the clinic.

**Physical Therapist** - The role of the physical therapist is to assist the patient in the areas of exercise, equipment, and safety. This includes patient and caregiver instruction in stretching and range of motion exercises to help maintain flexibility and reduce cramping. The physical therapist may also recommend devices and equipment such as an ankle-foot-orthosis, a cane, a wheelchair, a neck brace to help in maintaining mobility and independence. Instruction in proper methods for moving, transferring and lifting patients and recommendations for safety equipment including aids for transfers, lifts, grab bars and shower chairs are also provided. The goal is to promote the highest level of possible function, for as long as possible while avoiding fatigue.

**Occupational Therapist** - The role of the occupational therapist is to provide the ALS patient with options, resources, and information for maintaining independence in activities of daily living. The occupational therapist assesses the patient's functional abilities (range of motion, muscle strength, daily activity levels, and mobility) and performance in activity areas such as dressing, feeding, hygiene, and in the work environment. Adaptive devices such as rocker knives, button hooks, handwriting aids, book holders, zipper pulls, key holders, reachers and grab bars may be recommended to assist weakened muscles, reduce fatigue, promote safety, and enhance life quality.

**Speech Pathologist** - The role of the speech pathologist is to assess the ALS patient’s speech and communication skills, implement strategies to enhance communication, provide patient/family and assure that ALS patients can express their feelings, thoughts, and needs. If there is muscle weakness in the lips, tongue, or palate, the patient may not be able to move their mouth precisely or fast enough, which results in slurred speech. Instruction in the use of compensatory strategies (such as slowing the rate of speech, separating the syllables, and over-enunciating the speech sounds) can be helpful. These strategies can also be augmented by communication devices such as magic writing slates, alphabet boards, picture boards, eye scanning boards, electronic devices with voice output, and even high-tech computerized devices.
Social Worker - The role of the social worker is to assess the impact of recent physical, emotional, and financial changes in the patient with ALS and how the patient and family are coping. Current and future needs are addressed, as well as the personal and community resources that may be available to help meet those needs.

Psychologist - The role of the psychologist is to assess and address coping strategies, signs of depression, maladaptive means of coping, communication style, quality of relationships, and the nature of family dynamics. A diagnosis of ALS changes everything not only for the patient, but for family and friends. The goal of the psychologist is not to change people, but to meet them where they are in the adaptation process, provide a supportive relationship and assist them in finding internal resources to help in coping with ALS. Successful coping strategies include the ability to articulate needs and wants, the willingness to share feelings with others, the ability to be a good listener, and the openness to look at new ways of communicating with loved ones and health professionals.

Dietitian - The role of the dietitian is to devise an individual program to provide adequate nutrients in the context of the patient's swallowing ability. ALS may cause weakness of the muscles involved in chewing and swallowing, which can result in coughing and choking episodes. The objective is to provide adequate nutrients while preventing aspiration of food or liquids into the lungs, which could lead to infection and pneumonia. This is typically accomplished by modifying the consistency and texture of foods and liquids or by recommending the use of alternative feeding methods.

Medication

Treatment of ALS is primarily a process of managing symptoms. As PALS get weaker, their symptoms change, their needs change, and consequently their treatments are always being modified. Treatment involves managing ALS symptoms through drugs, therapies, nutrition, dietary supplements, and adaptive equipment. Before taking medication, vitamins, or supplements patients should always speak with their neurologist.

FDA approved drugs to slow ALS progression

Rilutek (available by prescription) is the only drug approved by the Food and Drug Administration for treatment of ALS patients. Two randomized and placebo-controlled trials performed in both
Europe and North America found a difference of about 2 to 3 months in the time to tracheostomy or death in favor of patients treated with Rilutek as compared to those receiving placebo. However, there was no statistical significant difference in mortality at the end of the trial. Measures of muscle strength and neurological function did not show improvement. Potential side-effects include fatigue, nausea, dizziness, diarrhea, anorexia, vertigo, and somnolence. While the effect of Rilutek is modest, it is a significant development in that it is the first ALS drug proven to be effective in over 130 years of research. Because the effect is modest, one must weigh the financial cost versus the benefit when electing to use Rilutek. Rilutek is covered under most health insurance policies.

The National Organization for Rare Disorders (NORD) may be able to assist you with purchasing Rilutek if you do not have insurance (800) 459-7599.

Managing Neck Muscle Weakness

*Based in large part on an article written by Pamela A. Cazzolli, R.N.

Some people with ALS develop significant muscle weakness of the neck. This may cause limited mobility of the head. Turning the head from side to side or holding the head upright may be difficult, as the neck supports the head that weighs about 20 pounds. Limited head movement can contribute to a stiff neck, a poor head posture, and severe pain if these problems are not managed, causing more pain with emotional distress. Emotional stress can also compound muscle tightness and cause pain.

People with neck muscle weakness are vulnerable to injury. If the head suddenly flops backward, forward, or sideways, this can cause muscles and ligaments in the neck to tear. Injuries to the neck can be very painful, especially when turning the head, raising and lowering into bed and rolling over when in a lying position. Besides causing pain and injury to the neck, poor head posture can aggravate breathing, swallowing and communication.

Through effective management of neck muscle weakness, complications of pain and injury can be prevented or treated. Finding the best methods for supporting the head in an upright position to protect against injury is essential.

Strategies for improving the head posture and promoting head/neck mobility, comfort and safety
1. Achieve and maintain a good body alignment when sitting to promote an upright head position. Use of a cushion, pillow, or rolled towel behind the lumbar region of the low back not only helps to align a slumped posture, but will help keep the head and shoulders from slouching forward. Placing a pillow under each arm or on top of each armrest of the chair helps promote an upright head position, and provides maximum comfort when sitting for a long time. Proper alignment of the head, neck, and body allows the lungs to expand for better breathing.

2. Wearing a soft collar or a neck brace, called a cervical collar, is an effective method of holding up the head if this is difficult. A collar supports the head when the person is walking or being transferred from one sitting position to another. To protect against injury from sudden motion, people with advanced neck weakness should wear a collar when they are moving or being transferred from one seat to another, when walking, or riding in the car. Use of a collar to hold up the head when walking permits a better sight line and may reduce the risk of falling.

3. Identify and use the appropriate cervical collar(s) that will best meet your needs. Most people with neck weakness are unable to tolerate wearing a collar all the time, especially one that can lead to skin breakdown and discomfort. A variety of comfortable collars are available. Cervical collars can be obtained at most medical suppliers, and the cost is usually covered by health insurance if ordered by the physician.

4. To promote comfortable use of head support, alternating the use among several collars may be a solution to reducing pressure points on the skin of long-term collar wearers. The therapist or physician will need to test the strength of the neck and upper body muscles to determine the degree and type of support required.

5. Leaning back in a reclining chair is another method to support the head and to help keep the head from falling forward. This may include a reclining wheelchair with a high back or one on which a headrest can be attached. Power lift chairs also recline, and with a push of a button they can recline back exactly to the desired angle. People with excessive oral secretions might have difficulty reclining backward. To help prevent choking on oral secretions, the head can be positioned to the side and propped with a pillow.

6. Using a wheelchair head support system can position the head in an upright position by a band across the forehead that attaches to an adjustable headrest that mounts to a chair. Some head support systems include the use of an elastic band. Head support systems usually can be obtained from a medical supplier who specializes in wheelchair accessories. People who need maximum support in holding up the head and who cannot tolerate long term use of a cervical collar might benefit from intermittent use of a head support system.
7. When in bed, avoid sleeping on a pillow that is too high. This will not only strain the neck, but may cause wakefulness at night. A rolled towel placed underneath the back of the neck with the head resting on a low pillow can provide support and comfort of the neck and head when sleeping. In addition, people who have trouble keeping their head upright might try lying in bed a few times during the day to relieve the neck muscles.

8. Stretching exercises of the neck muscles can help promote mobility of the head, alleviate stiffness of the neck, and help prevent and treat neck pain. To avoid injury, evaluation and training of other exercises by a physical therapist or a visiting nurse may be warranted.

9. Consult with your physician who may prescribe physical therapy for treating neck problems. A physical therapist is specially trained to evaluate the neck, help relieve neck pain, make recommendations for supporting the neck and head, and provide education on reducing the risk of neck injuries.

Choosing a Neck Support for Patients with ALS

It may be difficult to find a collar that will meet all the needs of an individual patient and the type of support needed will change if weakness progresses. The patient should take an active role, with the help and advice from the medical team, in choosing the neck support that best meets their individual needs.

Range of Motion Exercises

Range of Motion (ROM) exercises are done to preserve flexibility and mobility of the joints on which they are performed. These exercises reduce stiffness and will prevent or at least slow down the freezing of your joints as the disease progresses and you move less often. Range of motion is the term that is used to describe the amount of movement you have at each joint. Every joint in the body has a "normal" range of motion. Joints maintain their normal range of motion by being moved. It is therefore very important to move all your joints every day. Stiff joints can cause pain and can make it hard for you to do your normal daily activities. Each person with ALS needs a program of exercise tailored to his or her individual needs and abilities. With a prescription, your doctor can either send you to an outpatient clinic to see a Physical Therapist or have one come to your home to help you design a personalized exercise program. The therapist will see you until you or your
caregiver are independent with a home exercise program that you can follow through with daily. It is important to remember that as the disease progresses, the type of ROM exercises you will need will change. It is important to be proactive when this occurs and ask your doctor to write you another prescription to see a therapist so your home exercise program can be modified.

There are different kinds of ROM exercises. There are stretching exercises you can do yourself when you still have the muscle strength to move your joints through their complete ranges. These are called Active ROM exercises. There are Self-ROM exercises, which involve using a stronger arm to assist a weaker arm to perform the exercises, eliminating the need for caregiver assistance. Then there are Passive ROM exercises, which are done for a weaker PALS by a caregiver. Often a combination of the types of ROM exercises above will be used. For instance, if a PALS has strong arms but very weak legs, he would use an active ROM program for the arms independently and a passive ROM program for the legs. Even within a limb the type of exercise used can vary depending on the strength of the different muscle groups. PALS with increased muscle tone (spasticity) will also need to learn techniques to decrease the tone before exercising. What type of ROM exercises are most effective for an individual is best determined by a therapist who can evaluate your own muscle strength and tone.

If your joints are very painful and swollen, move them gently through their range of motion. These exercises should be done slowly and steadily. It is important with ROM exercises not to force movements and to stop a movement if it causes you pain. Damage to the joint space can occur if too much force is applied. Joint range of motion is done on one joint at a time. Stabilize with one hand just above the joint and place your other hand below the joint to move the part through its full range of motion. Your physical therapist will tell you how many times to do each one.

**Lower Extremity Passive ROM Exercises**

Lower extremity passive exercises are for someone else to stretch your hips, legs, and knees if you are unable to do this yourself. These exercises should be done slowly and gently while you are lying on your back. Each exercise should be done ten times on each leg each day.

**Hip and Knee Flexion**
Cradle the leg by placing one hand under the bent knee. With the other hand, grasp the heel for stabilization. Lift the knee and bend it toward the chest, with the kneecap pointed toward the ceiling. Do not allow the hip to twist during this movement. The foot should stay in a straight line with the hip and not swing in or out.

**Hip Rotation**

Place one hand on the thigh and other hand just below the knee. Bend the knee halfway to the chest so that there is a 90-degree angle at the hip and knee. Pull the foot toward you and then push it away. Remember, do not go beyond the point of resistance or pain. Lower leg to starting position.

**Hip Abduction**

Cradle the leg by placing your hand under the knee and holding it. Place the other hand under the heel to stabilize the hip joint. Keeping the knee straight, move the leg along the surface of the bed, toward you and away from the other leg, to approximately 45 degrees. Then bring the leg back to the other leg.

**Ankle Rotation**

With the knee straight and one hand holding the ankle steady, place the other hand around the foot and turn foot inward, then outward.

**Toe Flexion and Extension**

With one hand, stabilize the foot just below the toes. With the other hand, gently move each or all of the toes forward and backward.

**Heel-Cord Stretching**

Cups or cradle the heel with your hand and place your forearm against the ball of the foot. Push the ball of the foot forward, bending the foot toward the knee and stretching the muscles in the back of the leg. Cup the heel of the foot into the palm of your hand. Gently push the foot down to “point the toes.” Do this with knee bent, then repeat with knee straight.

**Lumbar Rotation**
Bend knees up and keeping them together, lower than to one side as far as they comfortably go. Repeat to the other side.

**Hamstring Stretch**

With the knee and heel supported slowly raise the leg up, keeping the knee straight. Return to starting position.

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**Upper Extremity Passive ROM Exercises**

Upper extremity, passive ROM exercises teach someone else how to stretch your arms if you are unable to move your arms by yourself. These exercises should be done slowly and gently, and can be done with the person sitting in a chair or lying down. Do each exercise three to five times.

**Elbow Flexion and Extension**

Hold the upper arm with one hand and forearm with the other hand. Bend the arm at the elbow so that the hand touches the shoulder. Then straighten the arm all the way out.

**Shoulder Flexion and Extension**

Hold the wrist with one hand. With the other hand, grasp the elbow joint to stabilize it. Turn the palm inward, facing the body, and keep the elbow relatively straight. Move the arm from the side of the body over the head.

**Shoulder Internal and External Rotation**

Place one hand under the elbow. With your other hand, hold the forearm. Bring arm out to the side to shoulder level. Turn arm so that the hand points to the ceiling. Then turn arm back down so that hand points to floor and the upper arm is twisting in the shoulder joint.

**Horizontal Shoulder Abduction**

Place hands behind or above head. Gently touch elbows to bed and hold as tolerated. Stretch felt in chest. Pull arm across chest. Stretch is felt in back of arm and shoulder.

**Neck Rotation**

Turn head slowly to look over left shoulder then turn to look over right shoulder, touching the chin to the shoulder if possible.
Neck Flexion

Tilt head slowly toward left shoulder and then toward the right shoulder, touching the ear to the shoulder if possible.

Thumb Flexion and Extension

Move thumb to little finger. Then bend and straighten the thumb out to the side to stretch the "web space"

Finger and Wrist

Flexion and Extension

Hold the forearm above the wrist with one hand and grasp the fingers with your other hand. Holding the hand in this way, bend the wrist back, about 90 degrees, while straightening the fingers out. Then bend the wrist the opposite direction, about 90 degrees, while curling the fingers into a fist.

EXERCISE

It is important to realize that these exercises will not strengthen muscles that have been weakened by ALS. Once the supply of motor neurons that control a particular muscle has degenerated, it cannot be regenerated by exercise. It is important that all exercise be performed in moderation. Fatigue will only increase your weakness and rob you of energy that you need for your daily routines and the activities you enjoy. If you find that your prescribed set of exercises tires you, talk to your therapist. Changes can be made that will eliminate the risk of fatigue. Similarly, none of your exercises should cause you pain. If you do experience pain when exercising, stop that exercise and talk to your therapist. It may be that you are not doing the exercise correctly, or perhaps some modification to your exercise program must be made.

Managing Saliva and Phlegm in ALS

The build-up of saliva is a common problem among people with ALS who have tongue and throat muscles that are weak and not able to swallow the saliva. Some people have a lot of drooling, also called sialorrhea. Others complain more of phlegm sitting in the throat.
This build-up of saliva can cause choking and disrupt sleep. Relief may come from home remedies, over-the-counter products, prescription drugs and, in extreme cases, even surgical procedures. Speak with your doctor if you are experiencing excess saliva.

Saliva is needed to moisten the mouth cavity and to help with swallowing and digesting food. Saliva comes in two parts — thin, watery secretions and thick, mucus-containing secretions.

**Managing Saliva**

The first step in treating sialorrhea is typically to prescribe medications to reduce the production of saliva. For example, many antidepressants have the side effect of dryness of the mouth. In some cases, doctors use a scopolamine patch (brand name Scopoderm), which is usually used for motion sickness. Other medications that are often prescribed include atropine sulfate (brand name Sal-Tropine), clonidine (brand name Catapres) and propantheline (brand name Pro-Banthine). These agents block the action of acetylcholine, which comes from the nervous system and normally gives a "kick" to the salivary glands to produce saliva.

If these medications are not effective, a more potent drug like glycopyrrolate (brand name Robinul) may be used. Some drugs have more side effects than others. Some people don't tolerate certain medicines because of side effects, and in some people they're just not effective.

If medications like Robinul are not effective, the next option may be is the injection of botulinum toxin (brand name Botox or Myobloc). It works in the same way as the medications, by blocking acetylcholine release from nerve endings, but only at or near where it's injected. Typically the botulinum toxin is injected into each parotid gland. The parotids are the major glands for the thin, watery part of the saliva. It takes a week to 10 days for the maximum effect to be seen. Ask your physician about risks associated with this option.

In a few patients, radiation of the salivary glands has been used as a last option. The idea is to damage the gland and to induce scarring which takes several weeks or months, in order to reduce saliva.

**Dealing with Thick Phlegm**

At some point many ALS patients may experience problems with the thick mucus or phlegm that accumulates in the back of the throat. This is often exacerbated during or after meals or liquid
intake. Coughing it up can be a tiring and arduous process, and take its toll on the patient and the caregiver. It also has a tendency to block airways or make food stick in the throat, so coughing it up is essential.

Adequate fluid intake is the first essential step in prevention. Home remedies such as cold carbonated drinks, hot tea with lemon, Rose’s Lime Juice, and apple, pineapple or papaya juice may help thin mucus. These may be kept in the fridge and used on a swab for the mouth if the patient is unable to swallow. Meat tenderizer mixed with a little water can also be used to coat the tongue or can be placed under the tongue. Some patients have found that 12-hour allergy medications such as Zyrtec, Claritin or Allegra significantly reduce the amount of mucus produced.

For PALS who face unresolved problems with phlegm, contacting your physician and requesting an order for a suction pump and a visiting nurse to educate and demonstrate safe and effective airway secretion clearance is a good idea. Often times, suction machines are for use with trach patients, so it's important for you to tell your doctor this is something you feel you need. Also, request two types of suction catheters if you have feelings of phlegm stuck in the throat. While physicians may order only Yankauer suction tubes (often referred as Tonsil Tips), those tubes cannot reach secretions or phlegm effectively down in the throat. Therefore, a French suction catheter (such as a size 14) is always good to have on hand. This is a long narrow, soft and flexible plastic tube. Because training on suction techniques is a skilled nursing procedure, expenses for home visits by a registered nurse are covered by Medicare, Medicaid and most health insurance companies. However, be sure to request that ONLY a registered nurse with respiratory care experience be sent out to demonstrate how to use it safely and effectively to suction the mouth and the throat.

The Cough Assist machine (also known as a Coffalator or In-Exsufflator) may be effective for selected individuals (check to be sure of your insurance coverage for it). Those with advanced bulbar impairment may experience some difficulty adapting to its use. The Cough Assist Machine helps to clear secretions from the lungs by helping you with your breathing. When you breathe in, the machine gives you air to help expand your lungs. When you blow out, the machine creates a sucking force that pulls the air out of your lungs. This rapid change in pressure during the different phases of breathing helps make your cough stronger and more effective.

PALS who do use the device may also need a suction pump with appropriate suction catheters to clear phlegm and secretions from the throat and mouth. A portable suction pump provides a means for quick secretion clearance, and thus, helps to serve as a safety precaution. However, all suction machines need to be checked regularly to be sure they are working properly. Be sure to always keep portable units charged and ready to use. Some portable units have a tendency to lose their power after a period of time. Therefore, ask your respiratory equipment supplier about your unit and how to check and see if the pressure settings are adequate.
It's best to order and start using a suction machine (and Cough Assist) early on, while the ALS patient still has the ability to cough. This way he/she can help force the phlegm to the top of their esophagus and where the "yankheur" tool can easily reach to suction it away. It is helpful to suction the roof of the mouth, back of the throat (being careful to avoid the uvula) to reduce the stream of mucous. Make sure to ask that your physician prescribes a portable suction machine rather than a table top unit. A portable suction machine is lightweight and maneuverable. The portable machines generally have a battery backup, as well as a removable AC cord and many come with a carrying case and a DC converter, which allows you to plug it into a cigarette lighter. A portable unit allows the caregiver to bring the relief to the patient rather than vice versa. It also allows you the luxury of bringing it with you when going out. Suction machines are considered durable equipment, so your Medicare or insurance should provide for its purchase.

Managing Swallowing Problems (Dysphagia)

Adults swallow about 2400 times a day to clear saliva from our mouths. We do it so automatically that most people never think about how it happens. It is, in fact, a complex series of movements. Five or six major central nervous system nerves and about 23 muscles are involved in swallowing. This is why people with medical conditions like ALS, which affect the nerves or muscles of the face and neck, have swallowing problems. Muscle movements may become slow or uncoordinated; the swallow reflex can become delayed or incomplete, resulting in difficulty in swallowing known as dysphagia (dis-FA-je-uh).

Many ALS patients suffer from dysphagia or difficulty in chewing or swallowing. Signs of dysphagia include choking on foods or liquids, drooling, trouble swallowing medications, increased length of mealtimes, a wet gurgling sound to the voice, coughing and frequent clearing of the throat, weight loss, need for the Heimlich maneuver, or pneumonia. Complications can be severe and include aspiration pneumonia, dehydration, malnutrition, weight loss and increased muscle wasting due to decreased calorie and protein intake. If you are experiencing any of these symptoms it is important that you discuss these with your physician. A referral can be made for an evaluation by a speech pathologist and dietician. The dietician and speech pathologist can work with you to learn techniques to make swallowing easier, safer and keep you eating by mouth longer.

Before swallowing, food is chewed and held in the mouth. There is nothing in the throat, the windpipe is open and breathing occurs. When you swallow, the food is pushed into the throat, and
the windpipe closes off. Food then slips down the tube at the back leading to the stomach. Because
the windpipe is closed, you momentarily stop breathing. Once the food has passed through the
throat, the windpipe opens up again and breathing can resume.

If you have any food or drink in your throat when your windpipe is open and you are breathing,
there is a chance it could fall into the windpipe. This is experienced as 'going down the wrong way'
and coughing usually ensues. Aspiration is when liquids or food do go down the wrong way and are
not removed by coughing. A cough is the body's response to 'foreign bodies' entering the airway or
windpipe. It is our way of protecting our lungs from getting clogged up and interfering with
breathing. Unfortunately, in addition to swallowing problems, ALS symptoms also often include
weak respiratory function resulting in an inadequate 'protective' cough.

**Diagnosis of Swallowing Problems**

First, an initial assessment and screening process is conducted by a physician. It is often beneficial
to maintain a diary of the swallowing difficulties observed, including the setting in which the
symptoms occurred, and with which foods or liquids. This will help make recommendations more
specific to your needs. Then if the physician feels it is needed, a speech pathologist does a thorough
evaluation.

In this evaluation the speech pathologist goes through the patient's medical history, interviews the
patient and family, and performs a swallowing assessment to see if there is a disorder. During the
swallowing assessment a speech pathologist gives a patient a variety of items including liquids,
pureed foods (an eatable substance between solid and liquid), and solid foods in different
consistencies to swallow. The speech pathologist observes the patients swallowing and determines
if there is a problem.

If the speech pathologist feels the patient requires further evaluation, the patient will undergo a
swallow study. The objective is to show exactly what is happening when a patient swallows a
variety of different consistencies and amounts. The speech pathologist takes the information from
the swallowing study and determines the nature of the problem and what needs to be done.

**Strategies for Safer Swallowing**

Below are listed some common strategies and tips used to facilitate safe swallowing. It is
recommended that the advice of a speech language pathologist who specializes in swallowing
disorders be sought, as recommended strategies will vary according to the stages of the
swallow affected and the client. Other professionals, such as a dietician or occupational therapist
may also need to be involved. Ways to promote safe eating that may be suggested include:
Swallowing Tips:

• Sit upright, preferably in a chair, during meals.

• Eliminate distractions such as television or conversation during meals.

• Concentrate on maintaining a slow, steady rate of feeding.

• Make sure the mouth and throat is clear of excessive secretions/saliva prior to eating or drinking.

• Avoid taking too large a bite, drinking too rapidly or placing more than one bite in your mouth before swallowing.

• Maintain the head in a slightly chin tucked position when eating or drinking. If you put your head back to drink you are opening up the airway more making it is easier for food and drink to go down the wrong way.

• Swallow two to three times to make sure all food has cleared your throat.

• Alternate swallowing food and liquids to assist with clearance of drier or more textured foods.

• Moisten food with sauces and gravy.

• Take small mouthfuls of food and small sips of drinks.

• Use a straw to drink liquids to enable you to keep your chin down.

Changes in Diet

It is important to consult with a speech therapist and dietitian about changes in your diet to promote safer eating.

Special diets (soft or puree), merely avoiding certain foods, or preparing them differently can make a big difference. There are also cookbooks (available through ALS of Michigan) for those who have difficulty swallowing.

Foods that may present difficulty for someone with a swallowing problem include:

• Items of mixed consistencies or textures such as cold cereal and milk, chicken noodle or vegetable soups and fruit cocktail. These items should be blended into one consistency.
• Highly textured foods such as red meats and raw vegetables.

• Dry foods such as rice, pretzels, potato chips, crackers and cookies.

• Stringy textures such as bacon, celery and string beans.

• Floppy textures such as lettuce and cabbage.

• Sticky foods such as mashed potatoes and peanut butter.

• Small, hard textures such as peanuts and corn.

• Dairy products, which often have a tendency to make secretions thicker.

Changes in Food Preparation

• Consider changing to soft, moist foods such as canned fruits or cooked vegetables, fish and chicken, complemented with gravies and sauces.

• Cooking food longer so it becomes softer. Mashing it with the back of a fork or liquefying it in a blender can help.

• Thickening fluids to yogurt consistency may help as they are easier to control. Thicken liquids with a commercial thickener (such as Thick-It, Thicken-Up, etc.), potato or banana flakes, or fruit purees.

• The use of nutritional supplements such as Ensure, Slim Fast and Carnation Instant Breakfast if necessary.

• Crushing medications or using a liquid form may be easier for someone with a swallowing problem but seek advice from your doctor or pharmacist as some tablets need to be taken whole.

General Suggestions

• A portable suction machine may be of value to assist with clearance of secretions.

• It is important that the caregiver be educated in the use of the Heimlich maneuver.

• Monitor the patient for dehydration and for weight loss.

• Be alert to the signs of pneumonia, including increased chest congestion, chronic low grade fevers and increased cough.
Supervision during all meals is always a good idea.

Alternate Feeding Methods

Sometimes the strategies noted above may be insufficient to ensure an adequate dietary intake. If you find your intake of food and supplements is inadequate to maintain your weight or nutritional status or is just too risky because of choking, then it may be the time to consider alternative methods of eating. After discussion with your physician, speech pathologist and dietician it may be decided that feeding via a tube directly into the stomach is the best and safest option. This is called a feeding or PEG tube, and it can be used in conjunction with eating small amounts orally, or can be used alone. This is a very personal decision and should be discussed at length with family members and physicians. A feeding tube will provide adequate nutrition; however, it will not entirely eliminate the risk of aspiration. It is important that you consider this option early to prevent unnecessary complications. Studies suggest that early placement of the feeding tube can be utilized to supplement oral intake and allow you to eat more for pleasure.

About Feeding Tubes

Advantages of having a feeding tube:

* Feeding times are simpler and take less time.
* Adequate nutrition helps to maintain weight, prevent deficiencies, improves general health and resistance to infection.
* Fluids and medications can be given without choking.
* Energy can be used for other activities instead of expending it eating.

Disadvantages of a feeding tube may include:

* You or a caregiver must learn and be able to do the feedings
* Some nutrition formulas can cause diarrhea
* Potential infections or discomfort with the opening of the tube.
* Cost of special liquid nutrition. Insurance may or may not pay for these products.
As ALS progresses, throat/muscle control over swallowing commonly become impaired. As it becomes increasingly difficult to swallow, meal times become longer and longer and choking episodes become more common. This can result in food or liquids entering into the lungs instead of the stomach (aspiration), thereby increasing the risk of pneumonia, and in inadequate intake of liquids and/or calories resulting in dehydration and weight loss. Additionally, although the patient’s appetite typically remains good, the effort involved with eating can consume a tremendous amount of energy from the patient and caregiver.

For patients who tire from the efforts to chew and swallow food and/or caregivers who spend an excessive amount of time feeding the patient, tube feeding can result in a significantly improved quality of life. Not only does it give you more free time for enjoyable activities or to just relax with one another, it enables the patient to get the proper nutrition/fluids they could not otherwise consume.

When appropriate, a feeding tube is generally suggested by the physician after swallowing tests have determined the patient can no longer safely eat sufficiently to maintain their body. If a feeding tube is recommended, it is then the patient/caregiver's responsibility to make the determination whether or not they want to have this procedure done in order to maintain life.

The decision to get a feeding tube is a personal decision. It should be made by the patient (or their caregiver based on their knowledge of the patient's wishes) in concert with their physician, and should be heavily influenced by the patient's quality of life. Like any decision though, deciding whether or not to get a feeding tube should be an informed decision. The ALS patient, their family and their caregivers should understand what is involved so they know all the pros and cons of deciding whether or not to proceed with getting a feeding tube.

**Tube Types and Placement**

There are various different types. The two main ones are a PEG (Percutaneous Endoscopic Gastrostomy) and button. The PEG is a length of tubing with a valve at the end, which protrudes several inches from the incision area. Sometimes this is put in first until the stoma site has healed well. It can then be replaced with a button. A button looks very much like the small valve that is used to inflate a child's beach-ball. It is made of clear, soft plastic and sits right next to the skin and is flush to the body. A length of tubing is connected at feeding times.

The medical team will help decide the best feeding tube option. The placement of a feeding tube is a relatively simple procedure. As with any surgery, patients are more likely to experience complications if they are smokers, obese, use alcohol heavily, or use illicit drugs. In addition, some prescription medications may increase risks associated with anesthesia.
Depending on their level of health prior to having the PEG installed, their stay could be 1 to 2 days for observation of acceptance of the feedings. The stomach and abdomen will usually heal in 5 to 7 days.

**Will it hurt?**

There may be some discomfort from gas/air or adjusting to the liquid foods. There will be slight discomfort at the incision site after the operation but this can be dealt with using ordinary painkillers. Once it has healed you will hardly feel it is in there.

**Will people know that I have feeding tube?**

The tube is very small and is hidden by clothing, so nobody will notice it unless you show them.

**Will it leak?**

Occasionally the tube may pull away from the abdominal wall resulting in leakage around the insertion site. Most G-tubes leak a small amount but this is easily taken care of with a little damp cotton. The fluid that leaks out from the stomach can irritate the skin around the tube so it is important to clean any leaks. If skin irritation is noticed apply a little protective cream or a prescription skin barrier for protection. Normally, the degree of leakage is very small. A tube that leaks more than a little, it probably needs replacing.

**What other complications might there be?**

Occasionally, the skin around the stoma can become sore or infected, or it can get a bit hardened. It is therefore important to look at the stoma when cleaning it and let your nurse/doctor look at it if you are concerned. Stomach ache, bloating or diarrhea can also occur if too much food is put into the stomach too quickly. This may happen if the stomach is not used to large volumes. A feeding regime should be discussed with your doctor or a dietician so that tolerance can be gradually built up.

**Does the feeding tube ever need to be replaced?**

The feeding tube does not last a lifetime. They typically last about 6-12 months at a time, so it is important to understand they may have to have it pulled out and a new one inserted. If there is
substantial drainage but flushing can be easily done, there is a good possibility a replacement tube is needed.

**What happens if the tube comes out?**

This is unlikely as the tube is secured either by a little water filled balloon or a small plastic disc. As the hole is only a fraction of this size, the tube cannot pull out until the balloon is deflated. If the tube ever does come out - don't panic. Place a clean dry towel over the stoma to absorb drainage and call the doctor or a visit to the hospital emergency room is in order.

**What if the tube becomes plugged?**

This is most often caused by the build-up of formula residual in the lumen (internal space or opening that exists within the gastrostomy tube). Tube blockage may be prevented with the routine practice of flushing the tube after each use. The tube should be flushed at least once daily.

**What about oral hygiene?**

Good mouth care is imperative in preventing problems, especially with patients who are provided with total nutritional support through the PEG tube. Daily brushing of the patient's teeth, gums and tongue should be done. Mouthwash may be used with patients who retain a gag reflex. The patient's lips should be moistened with water and, if necessary, lubricated with petroleum jelly to prevent cracking.

*Below are illustrations and pictures of feeding tube placement*
A **G-tube** is placed in the stomach. The G stands for **gastrostomy** (an opening in the stomach). The tube may also be called a **PEG tube**.

A **J-tube** is placed in the small intestine. The J stands for **jejunum** (a section of the small intestine). The tube may also be called a **PEJ tube**.

In certain situations, the tube may be placed in the stomach and passed through to the jejunum.
Food and Medications

What kind of food is fed through the g-tube?

Commercial food: It is usually recommended that a commercially available prepared (canned) formula and water for hydration be fed through the tube. This will provide a balanced diet including all the essential vitamins and minerals needed. Some of these formulas contain fiber so that regular bowel movement can be maintained even if you are unable to eat fruit, vegetables and other high fiber foods. It is important to understand that nutrition is a very critical to the continued well-being of the ALS patient. Because of the need to make commercial brands of food supplements taste good to the public, they are high in fat and sugar content. Over a prolonged period of time excessive fat and sugar are not good for the human body.

If the patient is getting the bulk or all of their nutrition from supplements, it is suggested that you work with a dietitian to find a high content formula. The best formula is likely one that is not commercially available through retail outlets. The formula comes commercially prepared or in powder form which requires dilution with water. Common brands, typically with or without fibers, include Ensure, Jevity, NuBasics, Boost, and Isocal among others. Most come in 8 oz. cans and contain 250 calories.

Table Food: Table foods may be blenderized according to instructions from the physician. Many people use homemade formulas prepared from cooked, blenderized foods but caution should be used to prevent clogging the tube in the stoma itself. Most tubes are roughly the size of a straw in diameter. Therefore food would have to be liquidized to prevent clogging the tube. Old foods left in tubing and other apparatus can lead to infection, therefore adequate cleaning is necessary. Specific advice with respect to the type of food and the quantity required should be provided by your doctor or a dietician.
How much formula should be given?

This is determined by your medical advisors and is dependent on many factors. The physician will advise the patient/family on the type of food, methods of feeding, frequency and rates.

How do you take medications?

It is recommended that a physician or pharmacist be consulted for questions regarding medications and/or the administration of medications, as certain medications should NOT be crushed or dissolved. Some medications may be administered through the tube utilizing the bolus feeding method.

Feeding

Will I use the g-tube at normal mealtimes?

The g-tube can be used at any time that suits the individual. Some people choose to stick to regular mealtimes, while others use a pump and continuous feed to allow feeding to be done mainly at night. Some families find that it is nice to sit down for meals together.

Can I eat some normal food or drink by mouth?

It depends on why the tube was inserted. If it was because of slow mealtimes or poor weight gain only, it may be OK to continue eating and drinking as usual. Some people use the g-tube mainly as "insurance" so that the person can always be sure of getting food and drink even if they don't feel like eating by mouth. You should consult with your doctor and speech therapist to be sure, however, because if the reason for having the tube is due to swallowing problems and aspiration on food or drinks, it is important to have advice on what is safe to take by mouth. The team may recommend that only certain amounts or types of food or drink are safe by mouth. Sometimes it is the safest option to stop taking food by mouth altogether.

What will it feel like while I'm being fed?

Most people don't notice anything at all. If an attempt is made to feed a person too quickly they will soon complain of feeling sick, just as they would if they ate too much, too quickly. If this happens, then the rate of feeding is easily reduced or stopped temporarily.

What is Bolous Feeding?

Bolous feeding is where the food is poured into the tube slowly by hand. Bolous feeding allows you more freedom in that you can give feedings anywhere, which is nice when you leave the house. Bolous feeding allows for rapid feeding of formula over a relatively short period of time. Pouring
the formula slowly and carefully helps to prevent abdominal cramping, nausea and vomiting, gastric distension (inflated stomach) or diarrhea. If the formula is not infused (poured) slowly, the patient is placed at a high risk for aspiration (fluid into the lungs) and the complications of pneumonia.

**What is Continuous Feeding?**

This method is preferable for many patients because it allows for better regulation of the amount and rate of food. The feeding pump (a machine) is set up and the tubing connected to the PEG tube. The formula is infused over the prescribed period of time into the patient. Using a feeding pump to control the rate is normally better for digestion and causes fewer problems. Typically the slower the rate of intake, the better the tolerance. The risk for aspiration is also decreased because less formula is given during the prolonged period of infusion.

**What can be done about abdominal gas?**

Trapping of gas in the stomach is sometimes a side effect of tube feeding. Massaging of the abdomen can sometimes help, as can bending the knees up to the chest. Also try rolling onto one side or other to allow the gas to be dispersed. Should the patient experience bloating prior to or following any feeding, the patient's stomach and intestinal tract should be decompressed. Decompression is easily accomplished by removing the feeding adapter cap from the tube and allowing the PEG tube to be open to air. Encouraging the patient to cough will expedite the removal of excessive air. It is a good idea to put the bolous tube into the PEG before the patient cough's or burps to prevent the contents from splattering out all over.

**Summary**

The care of the tube and the feeding sound like a lot of work, but it really isn't. At first you swear you will never remember all of the steps necessary for each procedure!! It is a good idea to take notes and develop a checklist to use for the first week or so but you will find that you will quickly be able to do it from memory.
Many ALS patients will experience difficulty breathing at some point during the disease process. The problem ALS patient’s face is the inability to move a sufficient amount of air in and out of the lungs due to muscle weakness in their diaphragm and muscles between the ribs. This can result in low blood oxygen levels and can also lead to a dangerous build-up of carbon dioxide.

The solution to respiratory problems in ALS patients is the use of a bipap unit or ventilator to help move an adequate volume of air in and out of the lungs. It is generally believed that early use of this type of equipment, typically at night, helps slow the loss of respiratory function.

When an ALS patient has bulbar impairment there is a triple threat: weak respiratory muscles, a poor cough (which can lead to development of infection and pneumonia), and the risk of food aspiration.

**Bipap**

BiPap stands for bi-level positive air pressure. It is a machine with two levels of air pressure--higher when you breathe in--lower when you breathe out. A mask fits over your nose, or alternately nasal pillows fit in your nostrils. The machine senses when you are breathing in and pumps additional air into your lungs. Most ALS patients initially use bipap only while sleeping when breathing is more difficult.

**Nasal Masks**

There are three common styles of masks used for nasal ventilation: the nasal mask, the full-face mask and nasal pillows. The nasal mask covers the entire nose and is held in place by straps connected to headgear. There are a large variety of manufacturers, models and sizes available and comfort varies depending on the individual. Some patients use several masks, rotating between them to avoid repeated pressure on the same area of the skin. Some patients who have trouble keeping their mouth closed may need to use a chinstrap to hold the mouth closed. Full-face masks are also available to alleviate problems due to air leaks from the mouth or congested nasal passages. These masks cover both the nose and the mouth. These are not used frequently because they impair the ability to talk. Nasal pillows are cushioned inserts that fit comfortably inside the nostrils. Nasal pillows, while not as secure as a nasal mask, have the advantage of being more comfortable for many patients. They also have the advantage of easily permitting the patient to wear eyeglasses. Some patients use nasal pillows during the day and a nasal mask while sleeping.

**Ventilator**
The ventilator is similar to the BiPap machine but differs in one important aspect: it is designed and approved for life support. Primarily this means that these units have a variety of sensors and alarms to monitor proper operation expense, include an internal battery to allow them to work if there is a power failure and are designed to attach easily to an external battery. Ventilators also have more sophisticated controls and adjustments and support both non-invasive ventilation (via masks) and invasive ventilation (via tracheostomy).

**In-Exsufflator (cough assist machine)**

One problem ALS patient’s face as respiratory weakness progresses is the inability to cough. The In-Exsufflator manufactured by J.H. Emerson is designed to address this problem and as been successfully used in the treatment of numerous ALS patients. The In-Exsufflator (Cough Machine) assists patients in clearing secretions by gradually applying a positive pressure to the airway, then rapidly shifting to a negative pressure.

This rapid shift in pressure, via a facemask, mouthpiece or tracheostomy tube, produces a high expiratory flow rate from the lungs, simulating a cough. Use of the In-Exsufflator is particularly important for patients on non-invasive ventilation, since suctioning is difficult without a tracheostomy tube.

Pulmonary health is a significant issue. It is important for ALS patients to learn about mechanical ventilation by getting good information and talking to peers. Then, when the situation presents itself, a person can make an informed decision.

During forced or labored breathing, other muscles in the neck, chest wall, and abdomen also participate.

**Symptoms of Breathing Insufficiency**

Breathing problems can sneak up on ALS patients because they may not be easily identified. Is your answer “Yes” to any of these questions?

- Are you experiencing increased fatigue?
- Do you frequently awaken with a headache?
- Are you having problems sleeping?
- Do you need to use additional pillows when sleeping?
- Do you sleep better in a recliner or chair than in your bed?
• Do you have a poor cough or difficulty clearing secretions?

If your answer was “Yes” to any of these questions, then it is probably time for a breathing evaluation. If your answer to all of the questions was “No”, it is still important to educate yourself about possible breathing difficulties in ALS patients so that you will be able to recognize a problem if it does occur.

Sleep Study

Sleep aggravates weak breathing muscles and developing respiratory failure. Thus more breathing problems occur at night. If daytime breathing tests are within normal range, a simple over-night oximetry study can be done at home (this continuously records pulse and oxygen saturation). Sometimes a more expensive and elaborate over-night sleep study is needed. During this procedure a patient is connected to many measuring devices and when indicated, assistive breathing equipment may also be used to decide its effectiveness and to determine the proper settings. During REM sleep (deep “rapid eye movement” sleep) accessory breathing muscles and other voluntary muscles become so relaxed they are sometimes referred to as paralyzed. That is why breathing problems are first noticed during REM sleep because at that time breathing becomes completely dependent upon the patient's diaphragm, which may be weak due to ALS.

When to Start BiPAP

By Edward Anthony Oppenheimer, MD

The question of when to start BiPAP is important. There are clinical research studies going on now to get more information, and to determine if starting earlier has definite advantages (from my experience, I believe that it is better to start earlier).

If there are respiratory symptoms due to ALS respiratory muscle weakness, and an abnormal result of any one of the following tests, then starting noninvasive ventilation (such as BiPAP of VPAP) is justified and advised. There are many possible respiratory-related symptoms, such as: fatigue, shortness of breath, difficulty breathing lying down, poor cough, morning headache, etc…. The usual practice is to measure:

• Vital Capacity (VC)
• Maximal Inspiratory Force (MIF)

• Over-Night Oximetry. - This is the test most likely to be abnormal early, before other tests are abnormal.

• Arterial Blood Gas (ABG) - This is the test most likely to only be abnormal very late. (possibly too late)

If any one of these tests is sufficiently abnormal, then starting bi-level ventilation is justified and will be reimbursed by Medicare and/or most health plans/insurance programs (if there are any respiratory symptoms present):

• VC of 50% or less

• MIF of 60 cm water or less

• Arterial CO2 of 45 mm Hg or greater

• Nighttime oximetry that demonstrates oxygen saturation less than 88% for at least five continuous minutes, done while breathing room air (or breathing the patient's usual added oxygen level).

Starting even earlier may be an advantage as it often takes time to learn to use the equipment and develop comfort with it. If there is an unexpected respiratory infection (even just the "common cold") a person skilled using this equipment can often manage to get through it safely without hospitalization.

Dr. John Bach suggests using both the peak cough flow (PCF) and an oximeter for home monitoring. If the PCF drops below 300 lpm (using a simple peak flow meter to measure PCF), then training in assisted cough methods should be started. If a person is using a bi-level ventilator (such as BiPAP or VPAP), Dr. Bach advised adjusting the setting for both comfort and to maintain the oximetry oxygen saturation at 95% or better (without using added oxygen). You need to have a good home equipment company with respiratory therapists experienced in this equipment and assisted cough techniques. They need to be able to take plenty of time to set-up the equipment properly, follow-up carefully, and stay in close contact with your doctor.
Please discuss any medical care issues with your own physicians. An email can give general information; only your physician can give you reliable personal medical advice based on examining you and knowing your full medical record.

**Tracheostomy?**

A tracheostomy should be considered if NPPV fails, if the person has a problem with secretions and/or prefers a trach, or when long-term survival is important. Safety may be better with a tracheostomy when daily 18 to 24-hour ventilator life support is needed. Does a trach ventilator provide the most effective ventilation? The BiPAP also provides effective ventilation, but neither is perfect. Dr. Oppenheimer advises that if a trach works for you keep it, no matter what any physician tells you. Doctors' opinions will vary on this matter. If you have a trach you should also have a good suction machine. More suctioning may be required during the first year while the trach heals and matures. (Medicare may cover the monthly rental charge of about $30.00 until the machine is paid off in a year or two.)

**Conclusion:**

There are many benefits from Nasal Positive Pressure Ventilation:

- It provides muscle rest and recovery at night.
- It helps reset the CO2 sensitivity in the respiratory control system.
- It probably improves respiratory mechanics.
- It helps with periods of low oxygen and helps prevent acidosis.
- It improves the quality of sleep.
- It can improve cough and swallowing.
- It improves long-term survival.

**Not Choosing Ventilation**

*By Edward Anthony Oppenheimer, MD, FCCP*
If respiratory muscle weakness is not effectively assisted with mechanical ventilation, then the under-ventilation results in increasing CO2 levels and decreasing oxygen levels. This acts as a sedative and has been referred to a carbon dioxide narcosis: one essentially goes into a deep undisturbed sleep as the end of life occurs. This can occur when:

1. no equipment (such as BiPAP or VPAP) is used;
2. when noninvasive equipment (such as BiPAP or VPAP) is no longer providing effective ventilation;
3. when a person decides to stop using assisted ventilation;
4. when using a bilevel ventilator (such as BiPAP or VPAP) but the IPAP setting is too low, so that under-ventilation occurs - people should monitor themselves by checking to be sure oximeter readings are 95% oxygen saturation or better (without using oxygen) at night and during the day.

When there is a decision that end-of-life is desired (situations such as 1-3 above), then palliative care assistance provides additional help with medications that can be used, when needed, to be sure there is no discomfort from apprehension, respiratory distress, gagging, difficulty with secretions, etc...

There are PALS who develop more severe bulbar impairment and weak ability to cough. When bilevel noninvasive ventilation is used (such as BiPAP or VPAP), there may come a time when inability to clear airway secretions makes this type of assisted ventilation fail. Assisted cough techniques (manual or using the CoughAssist device) help considerably for quite some time. However, at some point, bulbar and cough impairment become too severe to allow successful noninvasive ventilation. This is the point when one either switches to tracheostomy ventilation or elects palliative care (plan this well in advance of trouble, of course). At this point people can experience respiratory and gagging distress as they try to use their bilevel noninvasive ventilation (such as BiPAP or VPAP).

Therefore I strongly advocate preparing in advance, and if tracheostomy is not desired, have medications and assistance available so that comfort is assured; so that distress is avoided. Do not wait to react at the last minute, be prepared. You should have support from your physician, a palliative care doctor, or hospice. Some people who say for a long time that they do not want to use tracheostomy ventilation, change their mind later. And, most PALS who do use tracheostomy ventilation (who can arrange the needed resources) say they are satisfied and would do it again, if they had a choice to do it again.
In general, at good medical centers in the USA, about 20-30% of PALS use bilevel noninvasive ventilation (such as BiPAP or VPAP). There is a wide range from almost zero to 40-50%; in great part this reflects the differences in the attitude and experience of the healthcare professionals. Only 4-5% of PALS in the USA use tracheostomy ventilation; again there is a wide variation. However most PALS decide that when BiPAP is no longer effective, that is the time to stop. These numbers are approximate and are changing with time (more PALS use assisted ventilation today than in the past).

This summary was reprinted with permission from Edward Anthony Oppenheimer, MD, FCCP. It is based on a report written by Mary Clarke Atwood with editorial assistance from R. Daggett, V. Duboucheron, and E. A. Oppenheimer, MD, FCCP. Minor modifications were made to the article so that it applies particularly to PALS, since it was originally developed for polio survivors. The original report was based upon a presentation by Dr. Edward A. Oppenheimer, MD, FCCP, to the Rancho Los Amigos Post-Polio Support Group on March 24, 2001. He had just returned from the Eighth International Conference on Home Mechanical Ventilation held in Lyon, France. Dr. Oppenheimer is Associate Clinical Professor of Medicine, University of California, Los Angeles (UCLA). He retired after 31 years with Kaiser Permanente Medical Group where he organized and coordinated the Kaiser home ventilator program.

**How can I make my wishes known about using a ventilator?**

It is important to speak with your family and your doctors about your medical wishes, including using a ventilator. Ask your doctor to go over advanced directives with you and then choose a patient advocate. A patient advocate will be your voice, if you can no longer communicate or make decisions about your medical wishes. Having your wishes in writing will guide your family to make the decisions you wanted, if you are unable to make them yourself. You can obtain advanced directives from your doctor, social worker, or organizations such as Aging with Dignity ([www.agingwithdignity.com](http://www.agingwithdignity.com)).
Adaptive Equipment

Adaptive Equipment Overview

Adaptive equipment or assistive technology can greatly improve the quality of life of an ALS patient if he or she chooses to take advantage of available technology.

**Important:** One thing to always remember is to investigate and try to obtain adaptive equipment before you really need it. There is no way to know how quickly your body is going to change, and you don't want to have to endure the frustration and aggravation of not having the equipment there when you absolutely have to have it. Keep in mind that it is not uncommon for insurance approval and supplier lead time to result in a delay of weeks and even months in getting equipment. Typically the more specialized or expensive the equipment is, the longer it will take to get. This is not to say that you should rush out and get every piece of adaptive equipment you can think of as soon as you are diagnosed. Rather, keep a close eye on your ALS "progression" and think ahead to your future needs.

Most health insurance, including Medicare and Medicaid, will cover most of the cost of adaptive equipment as durable medical equipment (DME). Coverage at 80% with an annual out of pocket limit is common. Other options for funding the cost of adaptive equipment include Michigan Rehab Services at (800) 605-6722 for those still employed.

Programs that loan equipment include ALS of Michigan, Inc. Please call ALS of Michigan at 800-882-5764 to speak with a patient services coordinator about our equipment loan closet. Other programs to check with are the Rotary, Kiwanis, Elks, Lions Clubs, and Michigan Loan Closets at [www.michiganloanclosets.us](http://www.michiganloanclosets.us). Local suppliers, support groups, hospitals, and churches are good places to ask about local programs. Another alternative is purchasing used equipment either from a local supplier or through the classified ads in local newspapers.

There are suppliers that offer extensive catalogs of adaptive equipment. It is a good idea to look into them and learn what is available. Most offer these catalogs at no charge. Some popular suppliers are:

- **Best Buy Healthcare** (800) 603-7366  [www.BestBuyhealthcare.com](http://www.BestBuyhealthcare.com)
- **Sammons Preston** (800) 323-5547  [www.sammonspreston.com](http://www.sammonspreston.com)

[www.activeforever.com](http://www.activeforever.com)
Many people with ALS experience arm and hand weakness that affects their ability to perform everyday living activities.

Below is a list of simple solutions that will assist you in maintaining the ability to perform daily activities.

**Self-Feeding with decreased grip strength:**

- Use built up foam tubing/cylindrical tubing.
- Universal cuff: Elbow and wrist strength is used versus hand strength.
- Economy wrist support: supports wrist and utensil is maintained in place for feeding.
- Light-weight cup with handles on both sides or T-handled cup.
- Built up utensils.

**For Decreased Shoulder Strength**

- Use extension utensils or prop arms on an elevated surface (such as a phone book or bed tray) to assist with decreasing the demand on the upper arms.
- Mobile arm supports help achieve controlled motion while eating.
- Extra-long drinking straws.

**One Handed Technique**

- Place non-slip mat under scooped plate/dish to prevent slipping.
• Use rocker knife/pizza slicer to cut food.

• Use plate guard.

**Dressing with arm and hand weakness**

• Adapt clothing for easier dressing and undressing.

• Use a button hook if difficulty with buttoning.

• Use Velcro instead of buttons if using button hook is too fatiguing.

• Elastic waist bands are easier to manage than zipping and buttoning.

• For difficulties with zipping, place fishing line hook in each zip and use one finder to pull up and down versus using a “pinching motion.”

• Use elastic show laces/Velcro straps/lace lock.

**Dressing with leg weakness**

• Sit to dress lower body.

• Use a sock aid for putting on socks if unable to do “crossed legged method.”

• Use a reacher for holding pants/underwear if unable to dress using a crossed leg method or unable to reach down to feet.

• Slip on shoes versus shoes with shoe laces are easier to put on.

**Grooming and Hygiene**

• Long handled brushes/combs assist with limited arm movements.

• Universal cuff can be used to hold toothbrush, razor, and hairbrush.

• Cylindrical tubing can be used to increase grip strength on personal care items.

• Electric toothbrushes and electric razors decrease the energy used on the hand and arm muscles.

**Toileting**

• Raising the height of the toilet may assist with the ability to get on and off. Use a commode and/or raised toilet seat.
• Extended toilet aids can assist with reaching personal areas.

• Bidet hygiene system.

• Toileting at bed level: use female/male urinal.

Mobility

Many ALS patients will experience difficulty walking. Loss of balance due to foot-drop, muscle atrophy, and spasticity can make walking extremely difficult and dangerous.

While most ALS patients will understandably resist the use of a mobility aid for as long as possible, it is important that they accept that they are going to get weaker and that mobility equipment can help them maintain independence, conserve energy and most importantly, avoid the perils of a serious fall and related injury. This last point cannot be over emphasized. Catfish Hunter, the famous baseball player who was stricken with ALS, died relatively soon after diagnosis as a result of a head injury sustained as a result of a serious fall. Living with ALS is challenging enough without the added burden and pain of injury.

Ankle Foot Orthosis (AFO)

One common mobility symptom resulting from ALS is the inability to hold the toe of one or both feet up while walking. This is commonly referred to as foot-drop and results in the patient having to lift the foot more than normal while walking to avoid tripping. Correcting foot-drop with a lightweight ankle-foot orthosis can be helpful to minimize falls and maintain endurance.

AFO’s are made of lightweight plastic and are available in a variety of types, styles and cost ranges. Insurance may pay for this, so check with your doctor and physical therapist.

Canes
There are basically two styles of cane available, the standard cane and the quad cane. The standard cane has a single tip while the quad cane has a rectangular four tip base for improved stability. The quad cane is typically considerably heavier and can actually be more awkward making it less stable depending on patient balance and strength. Newer model quad canes are designed using lightweight plastic making them lighter and allowing slight flex which provides some self-leveling. Which style works best for an individual patient will vary depending on condition and can only be adequately determined by having the patient try each style.

Walkers

When a cane does not provide enough support and the risk of falling becomes more frequent, it may be time to upgrade to a walker. There many styles and designs of walkers. The standard walker has wheels in front, grippers for hard surfaces or glides for carpets in the back and typically folds up for travel. More elaborate walkers are available with features such as larger wheels, three or four wheel designs, hand brakes, baskets for carrying items and fold down seats. Most tend to be slightly larger and heavier than the standard walker but typically fold up easily for transport. Walkers with seats provide a place to sit and rest when out and about.

Manual Wheelchairs/ Transport wheelchairs

If walking becomes more precarious and exhausting, it is a good idea to obtain a manual or transport wheelchair to use for longer outings. A manual wheelchair has large wheels on each side, typically used for self-propelling. It is usually heavier than a transport wheel chair and therefore a bit more difficult to fold for transport. Transport wheelchairs have 4 smaller wheels, therefore making them lighter and easier to fold for transport. Factors such as cost, availability, and how much the wheelchair will be used, may determine if it will be best to purchase or borrow a used wheelchair. ALS of Michigan, Inc. operates a loan closet of medical equipment including wheelchairs available for free to ALS patients.

Scooters

While scooters are an option for the ALS patient, they are typically only useful for a relatively short period of time and for some, power wheelchairs may be more appropriate. For this reason, it is advisable to talk with your physical therapist and neurologist to determine what is best for you to use. It is very important to know what you insurance covers before purchasing any equipment such as a scooter.
Power Wheelchairs

As the disease progresses many ALS patients will eventually need a power wheelchair. There are a large variety of power wheelchair designs and options available for people with ALS. Options you will want to consider should be those that will accommodate your needs as your disease progresses.

Insurance will pay for most or all of a power wheelchair, depending on the type of insurance you have. You will likely be required to justify the medical necessity for the wheelchair and options and features you need. For this reason, it is important to have your wheelchair prescription prepared by a physical therapist who understands ALS and can specify and justify your requirements in detail. Options and features the ALS patient should consider are as follows:

1. Measurement. The ALS patient should be measured carefully to ensure proper construction of the wheelchair to fit the patient. Remember, the wheelchair will be custom made for you and you have one chance to get it right. Once manufactured, critical dimensions can’t typically be changed.

2. Drive options. Power wheelchairs are available in rear wheel, front wheel and mid wheel drive. All three methods have their advantages and disadvantages, so evaluating your home environment and where you will be using the power wheelchair will help determine this.

3. Controls. Most power wheelchairs come with a joystick control, which can be mounted on either side. It is important to specify which hand you will be able to operate the power wheelchair with. Joystick controls are adequate initially but you should make sure the knob can be removed and replaced with other options when the knob becomes difficult to hold. You should also make sure the wheelchair can accommodate future control modification such as sip and puff or head controls. If controlling by hand is not possible, then a head array can be included to control with chin or head movements.

An attendant control (a second joystick mounted on the back of the wheelchair) is also useful in allowing a caregiver to maneuver the wheelchair.

4. Tilt. This feature allows the entire seat assembly to tip backwards. This feature allows the wheelchair to be tilted all the way forward to sit at tables and transfer. Otherwise it can be tilted back slightly to elevate the footrests so they clear ramps, thresholds, van lockdowns, etc. and because it is a more comfortable riding position. You can also tilt back more to go down steep slopes so you don't feel like you’re going to slide out. Lastly, tilting allows you to shift your weight helping to prevent pressure sores and elevate your feet and legs, which helps to prevent edema (swelling).
5. Recline. This feature allows the seat back to tip backwards allowing you to bend at the waist. Reclining allows you to relax and/or sleep while in your wheelchair.

6. Foot Pegs (Foot Rests). Power elevating foot pegs allow the feet to be elevated which helps to prevent edema (swelling). This feature also allows the feet to be pulled back from the normal position to enable you to move closer to tables which have legs that interfere with your feet.

7. Lift. This feature enables the entire seat assembly to go up and down, typically from 12 to 16 inches. This is a critical feature that you will likely use often. This feature is invaluable in helping the ALS patient stand up when this becomes difficult. By elevating the seat you will be able to slide off the front or side of the seat into essentially a standing position. The lift feature will also be utilized regularly when transferring since it allows you to adjust the height of the seat either slightly higher or lower than the surface to which you are transferring. It also enables you to sit at tall tables or counters and to reach up to grab or see things. This feature will likely be an out of pocket expense, and not covered by insurance.

8. Leg/Trunk Support. It is important that the wheelchair accommodate a variety of leg and trunk support methods. As ALS progresses it is common for the patient to begin having difficulty keeping their legs from flopping apart and falling off the sides the seat. This is typically addressed by installing support pads either on the foot pegs to support the calves or more commonly on the seat to support the thighs. As the upper body becomes weaker the wheelchair should accommodate support pads on the sides of the chest in addition to a second seat belt to go around the chest. Finally, it is important that all support pads be easily removable or easy to flip out of the way.

9. Arm Rests. The armrests need to flip up out of the way to enable transfers. As arms become weaker the standard armrests are typically replaced by armrests with troughs and padded palm rests.

10. Headrest. A cushioned, adjustable headrest, which is easily removable, is essential.

11. Charger. A built in battery charger is very convenient but not essential.

12. Vent Tray. The wheelchair should be able to accommodate a vent tray and an additional battery. If these options can be added later, it is not necessary that they be included upon initial delivery unless they will be required in the near future.

13. Seating. Good seating is extremely important not only for patient comfort but to protect against pressure sores. While the standard seat which comes with most wheelchairs is adequate if the patient is not using the chair continuously, as the disease progresses and the patient spends long periods of time in the wheelchair, a better quality seat cushion will be required. There are a
multitude of seating options available including foam, air and gel with the Roho and Jay2 being the most popular. Because of the variety available and the individual nature of decision, it is a good idea to consult a physical therapist and demo several options before buying. Some cushions are not readily covered by insurance.

Vans

The use of a power wheelchair outside of the home will likely require the purchase of a handicap accessible van or modifications to an existing van. The two common options are a minivan with a ramp or a full size van with a lift. There are a number of companies that modify minivans by lowering the floor and adding a ramp that either folds down or slides in under the floor. The ramp is much more convenient, though more costly option than the lifts typically installed in full size vans. However, the cost of a minivan is typically less than that of a full size van and they are smaller and therefore easier to drive and less costly to operate due to better fuel economy. Most vans have a power lockdown installed to secure the wheelchair. These are much less hassle and much faster to use than manual tie down straps.

These vans are usually sold through companies that specialize in handicap vans rather than through regular dealerships. Prices for new vans include handicap discounts/reimbursements offered by major auto manufacturers such as Chrysler, Ford and GM. Unfortunately, health insurance does not cover the cost of these vans or any of the handicap modifications, as they do not consider it a medical necessity.

The cost of any handicap van conversions is tax deductible, but the deduction is only for the modifications, not the van itself.

For ALS patients who are interested in sustaining employment and transportation is needed, assistance with vehicle modifications, or repair to existing modifications is available through the Michigan Rehab Services 1-(800) 605-6722 or www.michigan.gov/mdcd.

For veterans, funding may be available through the Department of Veterans Affairs.

Other modifications may enable the ALS patient to continue driving for as long as possible. These modifications facilitate driving from the standard driver’s seat after transferring from the wheelchair or driving directly from the wheelchair in the driver’s position. Other common vehicle modifications include low effort or zero effort steering, hand controls for operating the gas and brake, and touch pad controls for starting, shifting and operating accessories.
Transfers

Transfer Boards

When an ALS patient has difficulty standing, but can still maintain balance while sitting, a transfer board is recommended. A transfer board enables the person to slide smoothly from bed to wheelchair, wheelchair to shower chair, etc. Transfer boards come in several styles from simple wood or plastic boards to more elaborate options like the BeasyTrans "S" shaped plastic unit with sliding disk. The most common is the plain polished wooden board. While simple, these transfer boards have the advantage of being inexpensive enabling the purchase of several boards for use in different locations.

Gait Belts

A gait belt is a specialized belt with hand straps for the caregiver to grasp while assisting an individual during transfers or walking. This belt fits snugly around the moving individual's waist.

Personal Lifts

When a person with ALS can no longer stand or support himself in a sitting position, a patient lift becomes necessary for transfers. The most common type is usually referred to as a Hoyer lift, although Hoyer is actually a brand name. This type of lift typically consists of a horizontal arm attached to a vertical post that is mounted on a “U” shaped base with heavy-duty casters. A sling, which is placed under the patient, is attached to the end of the horizontal bar and the caregiver manually pumps a hydraulic lift on the unit (or some have electric controls) causing the patient to be lifted upward in the sitting position. The patient can then be easily transferred to wheelchair, shower, reclining chair, etc. To use this type of lift you need a bed that has at least 4-6" clearance from the ground so that the base of the lift can fit under it.

Hoyer’s are not good for bathtub transfers because they cannot get that close to the tub and they are too large to fit into most bathrooms. Wall mount versions, which can be mounted on the wall next to the tub, are available.

Insurance will generally pay only for a manual Hoyer lift. They are also commonly available on the used equipment market, from ALS of Michigan and from local MDA loaner closets.
Another lift option is the ceiling mounted lift system. This is an electric powered lift system, which operates from a track that is installed on ceiling and uses the same type of sling as the Hoyer lift. Ceiling track can be relatively short or can be elaborate extending throughout several rooms. These tend to make moving the patient much easier and safer, especially when compared to trying to roll a Hoyer lift on carpeted floors. While convenient and easy to use, ceiling mounted lifts are also considerably more expensive than Hoyer lifts and insurance rarely authorizes coverage for this type of system.

An option for assistance in obtaining a ceiling lift is through Project Freedom. The Knights Templar of Detroit Commandery No. 1, a Masonic organization, sponsors a private, nonprofit foundation that provides funding through Project Freedom to install and maintain the equipment until it is no longer needed, at which time it is refurbished and loaned to another patient who wishes to be cared for at home. For more information, go to: http://projectfreedommi.org/

As mentioned, both Hoyer and ceiling mounted lift systems utilize a sling for lifting the patient. It is important to make sure the type of sling selected provides adequate head and neck support. The newer 4-point style of sling features an open bottom, which makes it easy to put on when you are sitting in a bed or wheelchair without having to pick you up. The sling isn’t stuck under the patient, can be easily removed and the open bottom enables toileting.

Environment

As ALS progresses and hands, arms and legs become weaker, environmental access and control become more of a challenge. Opening doors, negotiating stairs and operating stereo and television equipment are examples of common problems that adaptive equipment can help address. Insurance typically will not cover environmental access modifications and control equipment. For ALS patients who are still working, assistance for environmental access may be available through Michigan Rehab Services. For veterans, funding for environmental access may be available through the Department of Veterans Affairs.

Ramps

Getting into the house can become a challenge especially once the ALS patient begins having trouble climbing steps or is using a wheelchair. Even a single step can prevent access. The most common solution to negotiating entry steps is the construction of a ramp. While ADA requirements
specify that a ramp can’t have more than a 1:12 slope (1 foot up for every 12 of length) ramps of twice that slope and are commonly built and work fine. Ramps should be a minimum of 36 inches wide and should have a wheel stop along both edges. Depending on the height and whether the patient is walking or using a wheelchair, a handrail on one or both sides may be appropriate. Intermediate landings should be built wherever the ramp makes a turn and a top landing should be built to allow a flat place to stop while opening the door. Most ramps are constructed of wood using post and beam construction similar to that typically used for outdoor decks. The ramp surface is typically 2x6 lumber laid perpendicular to the direction of travel. The Metropolitan Center for Independent Living (MCIL) in St. Paul, Minnesota has excellent ramp construction manuals and videos available for purchase. The manual is also available for free online. Contact information is as follows:

Metropolitan Center for Independent Living, (651) 603-2029
1600 University Ave., St. Paul, MN 55104-3825
Website: http://www.wheelchairramp.org/, Email: MCIL2@aol.com

Portable Ramps

Another type of ramp that many ALS patients find handy is the folding portable aluminum ramp. These ramps are typically 30 inches wide and can start from 2 feet long. The ALS of Michigan loan closet offers portable ramps that are up to 10 ft. long. They can also be purchased online through a variety of distributors, including www.discountramps.com/

Outdoor Lifts

Platform lifts can provide access when ramps are not feasible. These lifts are available in vertical and inclined versions, can be installed inside or outside and can provide vertical lifts of up to 12 feet.

Doors

As hands and arms become weaker, opening doors can become a problem. Door width may also present problems for wheelchairs. One of the simplest ways to make doors easier to open is to
install lever style handles. Many medical suppliers also sell doorknob turners which convert round knobs to lever handles. Another option is the installation of an automatic door opener. These are extremely useful for those in wheelchairs and are readily available for both standard doors and sliding glass patio doors. For doors that are too narrow to provide adequate wheelchair clearance, some relief can be obtained by installing offset hinges which typically increase clearance by about two inches.

**Hygiene**

**Bathing**

Since showers and tubs are wet slippery places, safety is extremely important to avoid the serious injury that can result from even a minor fall. Grab bars should be installed to provide support both inside and outside the tub or shower. Look for grab bars in 16, 32 and 48-inch lengths to facilitate mounting on standard stud spacing. Grab bars that clamp onto the edge of the tub are also available. You should also make sure your tub, shower and bathroom floor have a non-slip surface applied and it is a good idea to replace glass doors with a shower curtain. It is helpful to install a hand held shower unit and many patients find soap on a rope and a shower mitten easier to use than soap and a washcloth.

A shower chair is a good idea as leg strength and balance start to become problematic. Shower chairs are available in a variety of styles. The simplest fits completely inside a tub and is available with or without a back. Bench style units are available which extend outside the tub allowing you to avoid stepping over the edge of the tub. As transfers become more difficult, most ALS patients end up using a combination shower/commode wheelchair. This is simply a wheelchair with a padded seat, which has a hole in the middle it, allowing the patient to be rolled over the toilet and then into a shower, requiring that the shower area be accessible to roll in. Roll-in showers require bathroom modifications and can be expensive. Unfortunately, health insurance does not cover the cost of home modifications although the cost is tax deductible. For ALS patients who are still working, the state government may offer funding assistance through Michigan Rehab Services. For veterans, funding may be available through the Department of Veterans Affairs.

Another option to consider is foregoing a shower for a sponge bath and either shampooing your hair using a sink or using no-rinse shampoo and conditioners available from beauty supply dealers and pharmacies.
Toileting

Using the toilet can become a frustrating and dangerous activity if proper modifications are not made. One of the first recommended adaptations is a raised toilet seat. Raised toilet seats with arms to help you stand and push off the toilet, can be installed on standard toilets. Grab bars that can be installed on standard or handicap toilets giving you something on either side of the toilet to help you maintain balance while lowering or pushing yourself up off the toilet are also available. The use of a portable commode or combination commode/shower chair will typically become necessary once using/transferring to the toilet becomes too difficult. While most rely on a caregiver for help, one alternate solution to assistance with wiping is the use of a bidet. These units, which provide a cleansing warm water wash and air dry, replace the existing toilet seat and can be installed on any toilet, and can be found at places like Home Depot.

An inexpensive portable plastic urinal can make life a lot easier because you don't have to leave your wheelchair to use it. Urinals are available in both male and female varieties. Male patients commonly use external condom catheters and leg bags once they reach the point of using a wheelchair full time.

Dental Care

The action of brushing teeth can become difficult as weakness continues. A lightweight cordless electric toothbrush such as the Braun Oral B can make the chore much easier. Even if you have very limited arm strength, you can usually prop your elbows up either on your wheelchair or on the counter. Then put the toothbrush in your mouth and move your head from side to side as the brush does its work. As swallowing and choking become a problem, one option that is available is a manual toothbrush made to be installed on a suction machine. The handle has a hole in it like a typical suction wand, which when uncovered allows saliva and toothpaste to be suctioned from the mouth. It is also important to maintain regular dental checkups and cleaning appointments and to discuss optimal care with your dentist. Depending on your condition, your dentist may recommend other preventive care such as the use of an antibacterial mouthwash or fluoride rinse.

Sleeping
As ALS progresses, sleeping can become more of an issue. As the patient becomes unable to turn or move, sleeping comfortably in one position for extended periods becomes more challenging and the possibility of pressure sores becomes more likely. As respiratory weakness progresses, proper positioning to make breathing easier also becomes more important. Luckily, adaptive equipment is available which should enable the patient to comfortably sleep even in the advanced stages of ALS.

**Hospital Beds**

A hospital bed can make a big difference in comfort for ALS patients. These beds have adjustments for raising and lowering both the head and the foot sections. Sleeping with the head raised 10-40 degrees allows for easier breathing. Sleeping with the legs raised slightly will help reduce the common problem of swollen feet. There are three types of hospital beds: manual, semi-automatic, and fully automatic. A semi-automatic model with electrical controls to raise and lower the head and the foot sections is the most appropriate type for an ALS patient. A fully automatic bed, which will also raise and lower the entire bed to facilitate transfers and aid caregivers, is nice but not necessary. Hospital beds should be ordered with half linked side rails that can be raised or lowered as desired. These give the patient something to grab when transferring and turning or repositioning.

Insurance companies will usually cover the cost of a semi-automatic hospital bed. In most cases, the beds are provided on a rental basis.

**Mattresses**

As PALS become weaker and unable to turn in bed by themselves, a low air loss mattress or alternating pressure mattress becomes essential. Lying in the same position all night long on a conventional mattress is not only very uncomfortable, but can also lead to painful pressure sores. The only way to minimize this discomfort is to have someone reposition the PALS several times a night or use one of these special mattresses. The alternating pressure mattress is a special air mattress, which has many cells, which alternately inflate and deflate slightly. This prevents too much pressure building up in any area of the body. An even better option is the low air loss mattress. This is a high-tech air mattress made of a material that allows air to seep out slowly. An electric pump keeps the mattress inflated. The constant slow air loss keeps the skin from sweating and prevents pressure points. Both the alternating pressure mattress and especially the low air loss mattress are expensive but insurance companies will often provide them for ALS patients. This is because the cost of treating skin breakdown as a result of pressure sores is even more expensive for insurances.
Swelling (Edema)

Swollen feet and legs, due to the lack of muscle action in the legs is a common problem for ALS patients. The feet often get progressively more sensitive, painful and discolored during the day. Although it is probably impossible to prevent swelling entirely, it is very important to minimize it to prevent further complications such as persistent pain, blood clots and ulcers. The simplest methods to reduce swelling are massage and elevating the feet. Compression stockings and compression boots as described below are also helpful.

Compression Stockings

The use of compression stockings is by far the most common first treatment step beyond simply elevating the feet. These elastic stockings help keep the veins from getting distended by simply squeezing the legs and feet a little. Compression stockings vary from over the counter styles, which provide mild compression to high compression styles requiring a doctor’s prescription. Compression stockings can be difficult to put on and unless you have strong hands and arms, you will probably need help getting them on. One useful tip to make it easier to put them on is to wear Playtex style rubber gloves.

Compression Boots

Hospitals use what are called compression boots to help minimize edema. These are simply plastic or nylon boots that inflate and deflate to help pump the blood along. One study apparently showed that simple alternating pressure on the soles of the feet greatly improves flow, so some brands of boots simply apply waves of pressure to the bottom of the foot. These boots over sequential compression by dividing the calf boots into four separate sections: toe, ankle, lower calf and upper calf. By inflating these sections sequentially the boots provide a gentle and effective milking style compression motion. With help from your doctor you may be able to get your insurance to cover the cost of this equipment.

Communication

As ALS progresses, many experience difficulty with or loss of ability to communicate verbally. The good news is there is an explosion of new technology in the augmentative communication field. New, more sophisticated hardware and software systems are coming out to allow PALS to continue to communicate. High tech solutions are not the only answer. Low tech solutions such as alphabet boards, and communication charts are just a couple of convenient and effective ways to
communicate. Augmentative communication is an area where consulting a Speech Language Pathologist trained in assessing a patient’s ability and recommending assistive equipment is typically worthwhile.

Insurance coverage for augmentative communication is normally covered. Insurance coverage will also typically require an evaluation and recommendation from both a speech language pathologist and physician before considering equipment for coverage.

**Communication Charts and Alphabet Boards**

Communication charts are simply charts with lists of commonly used phrases that the patient simply points to to communicate. An alphabet or letter board is a grid of letters and symbols that one points to in order to communicate. Both can also be partner assisted, when pointing is no longer an option.

**Speech Synthesis**

In the case of bulbar onset, the voice is often one of the first losses experienced by the ALS patient. Many bulbar patients continue to communicate well either by writing, using a keypad device laptop computer. Speech synthesis programs are available for laptop computers to give a voice to what is typed. E-triloquist is a free Windows based computer program which provides an electronic voice for those who cannot speak. It can record, save and play words or phrases as well as performing free-form text to speech synthesis.

**Voice Recognition Software**

Limb onset ALS patients often lose the ability to use their hands while their voice remains strong resulting in difficulty being able to use the computer. An excellent option to solve problems using a computer keyboard is the use voice recognition programs.

**Onscreen Keyboards**

Once a patient loses both the ability to speak and to use a keyboard, the use of an onscreen keyboard allows the continued use of the computer for communication. These keyboards can operate by clicking on letters with a mouse or input device that provides mouse emulation. Many onscreen keyboards also have a scanning feature to enable operation via a single switch. When
using the scanning feature, each time you click the switch, the cursor "scans" through the "keyboard" row-by-row, then column-by-column until your desired selection is reached. Many onscreen keyboards also have word prediction to eliminate the need to type entire words. With word prediction, as you enter letters, the program predicts words that begin with the letters you have entered. When you see your word on the list of predicted words, you select it and the word plus a space is placed in your text.

Mouse Emulation

There are two common alternatives that provide mouse emulation: the head controlled mouse and the eye-controlled mouse. Head controlled mouse systems operate by placing an infrared camera on top of the computer display. This camera tracks a small reflective dot worn on the forehead and moves the computer mouse relative to movement of the users head. Eye controlled mouse systems work in a similar manner to head controlled mouse systems but track the movement of the eye rather than the head. The tracking cameras are either mounted on the computer display or built into a lightweight assembly attached to glasses.

Switches

There are a number of innovative switches on the market, which can help patients communicate even when most muscle function is gone. Switches are which can be operated by virtually any body part. As long as the patient has one muscle he or she can move, an infrared switch can be hooked up to the muscle allowing access to scanning communication software. Very often the eye muscles remain intact even though the rest of an ALS patient’s body may be paralyzed. Several systems are available which respond to eye blinks or eye movement.

Environmental Control

Controlling stereo and television equipment, turning lights on and off, adjusting the heat and opening blinds are just a few of the things around the house that become difficult as hands and arms become weaker. Environmental control will be able to help in these situations.

Financing the EADL

RESNA Technical Assistance Project
(703) 524-6686
http://resna.org/resnaresources/at-act-programs
RESNA offers low-interest loans for assistive technology.

Be sure to check with the Veterans' Administration if you qualify.

Some insurance companies assist with the cost of an EADL, as do various private nonprofit organizations.

**EADL Resources**

Products from these companies can be found at home improvement stores or online.

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<tr>
<th>Company</th>
<th>Contact Information</th>
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<td><strong>Cepia</strong></td>
<td>(800) 225-9319</td>
<td><a href="http://www.cepialc.com">www.cepialc.com</a></td>
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<td><strong>Lamson Home Products</strong></td>
<td>(800) 3-CARLON</td>
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<td>wireless remote wall switches, light sockets and dimmers, and more</td>
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<td><strong>Lord Henry Enterprises</strong></td>
<td>(800) 366-7235</td>
<td><a href="http://www.security2010.com">www.security2010.com</a></td>
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<td><strong>Pro Bed</strong></td>
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<td>an automated patient rotation bed with SAJE’s voice-command operation feature</td>
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<td><strong>Quartet Technology</strong></td>
<td>(978) 649-4328</td>
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<td><strong>Shop From Your Home</strong></td>
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<td>Click “Security and Automation,” then “wireless remote home automation.”</td>
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<td><strong>SmartHome1</strong></td>
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<td><strong>TASH</strong></td>
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<td><a href="http://www.tashinc.com">www.tashinc.com</a></td>
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<td><strong>VOS Systems</strong></td>
<td>(858) 679-8027</td>
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<td><strong>Words+</strong></td>
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<td>wireless remote control for TV, lights, and other appliances using a speech-generating device</td>
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Legal and Financial

Health Insurance Questions You Should Know the Answers To:

• What type of insurance policy do you have?
  * Indemnity Plan: No restrictions on where you are seen.
  * PPO Plan: Pays a better rate for participating providers.
  * 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?

• Does my plan cover Durable Medical Equipment (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?

• 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 it cover Rilutek? At what cost to you?

• Does my plan offer a mail-order pharmacy option? Describe this benefit.

• Does my plan have home health coverage? Describe this benefit.

• 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? Describe this benefit.

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?

Elder Law: The Basics

What is Elder law?

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 explain 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?

You may not always need to hire a lawyer, or even an elder law attorney, 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. Asking a professional attorney some key questions may help you select one right for your individual needs.

Some questions you may want to ask when selecting an attorney:

Who will handle your case?
What particular area of elder law do they practice?
How long has the attorney been in practice?
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?
How and when do elder law attorneys charge for their services and how are fees computed?
What information should you bring with you to the initial consultation?

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. The National Academy of Elder Law Attorneys 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.

Phone: (520) 881-4005


### Advance Directives

If a patient is unable to make or communicate decisions regarding life sustaining medical care, who should 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 unable to yourself. 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, for how your personal care is arranged and how your medical decisions are made should you not be able to answer for yourself, 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 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?**

Again, this allows you to appoint a person you trust to make financial decisions for you should you become unable to do so for yourself. 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 wanted 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 should I have 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.

Do I need a lawyer to do an Advance Directive?

No, a lawyer is not needed, but can be a helpful resource. 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 voice each personal preference. It is, therefore, critical that your documents be as personal as possible.

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 advance directives, you can check https://www.nlm.nih.gov/medlineplus/advancedirectives.html

http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289

or you can 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 action of a "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 or you stop breathing.

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, or those under 65 years of age with disabilities such as ALS. The program helps with the cost of healthcare, but does not cover all medical expenses or the cost of long-term care. Medicare has four parts, including part A, B, C, and D.

*As soon as you become eligible for Social Security Disability (3-5 month waiting period), you will automatically be enrolled in Medicare Part A. In December, 2000 Congress voted to waive the 24-month long waiting period for Medicare coverage for people diagnosed with Lou Gehrig's disease (ALS).

Part A (sometimes called hospital insurance) helps cover hospital stays, inpatient skilled nursing facility care, home health care, durable medical equipment, and hospice care.

Part B (sometimes called supplemental medical insurance) helps pay for outpatient hospital services, emergency room visits, ambulance transportation, doctor services, diagnostic tests, laboratory services, outpatient therapy services, and some preventative care. Medicare Part B has a yearly deductible and requires a monthly fee or premium which is usually taken out of your Social Security payment. In addition, an individual is required to pay a copayment of 20% for most doctors’ services and durable medical equipment.

Part D helps pay for medications prescribed by a doctor. You choose the drug plan and pay a monthly premium and deductibles. 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.

It can be difficult to choose a prescription plan under Medicare part D because there are so many choices. To help find the best prescription plan to cover your needs, [www.medicare.gov/find-a-plan/questions/hom.aspx](http://www.medicare.gov/find-a-plan/questions/hom.aspx) is available. This website allows you to identify and compare prescription plans.

• 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.

**Make sure to obtain the Medicare and You book from Centers for Medicare and Medicaid to understand the benefits of this program.** [www.medicare.gov](http://www.medicare.gov)

### 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](http://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. Please contact Medicare about annual deductibles.

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

**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. 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 custodial care, such as help with activities of daily living like bathing, eating or dressing. Many patients have additional private health insurance or purchase Medigap policies. These plans may cover items and services Medicare does not.

### What Is Medigap?

Medigap policies are health insurance policies sold by private insurance companies to fill "gaps" in Original Medicare coverage.
*You get help paying for some of the health care costs that Original Medicare doesn’t cover.

*You get benefits not covered by Original Medicare, like emergency health care outside the United States.

*You pay a monthly premium to the private health insurance company. Medicare and Medigap policy both pay their shares of covered health care costs.

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-N so you can compare them easily. 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 Basics**

What is Medicaid? Medicaid is a type of health insurance for those who do not have the financial means to obtain other insurance. To be eligible, people must be within the program’s limits for income and resources.

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.

Medicaid covers these types of services:

- Doctor visits, ambulance, dental, family planning, health check-ups, hearing and speech, home health care, hospice care, immunizations, lab and x-ray, nursing home
care, medical supplies, mental health care, personal care services, physical therapy, prenatal care, and substance abuse treatment.

Eligibility for receiving Medicaid is based on:

- A single person may not have more than $2000 in assets
- Own only one home, regardless of value
- Personal property can be unlimited
- Own only one vehicle, regardless of value
- Life Insurance – up to $1500 face value
- Allowed prepaid funeral contract & burial service

In addition to being eligible for Medicaid, an individual may also qualify for the MI Choice Waiver Program – Medicaid Chore Program. This program is for eligible adults to receive covered services in their own home like those provided in Nursing homes. Each eligible participant can receive the basic Medicaid services and one or more of the following services:

- Homemaker services – cleaning, meal preparation, laundry
- Respite services
- Adult day care
- Environmental modifications
- Transportation
- Medical supplies and equipment not covered under Medicaid
- Chore services – lawn cutting or snow removal
- Personal emergency response systems
- Private duty nursing
- Counseling
- Home delivered meals
- Training in a variety of independent living skills
- Personal care supervision – bathing, toileting, transfers

**What if only one spouse is in need of Medicaid?**

There is protection for married couples. When one person in a couple applies for Medicaid, the resources/assets that belong to the married couple are counted together in the application process.
But, each spouse’s income is counted separately, so the income of one spouse does not determine the Medicaid eligibility for the spouse applying.

For more information and assistance contact:

Contact local Area Agency on Aging
- 800-852-7795
Michigan Department of Human Services (DHS)
- 1-855-275-6424
- www.michigan.gov/mdhhs - go to Assistance Programs

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.

Attorneys who are familiar with the Medicaid requirements (including elder law attorneys) use a variety of approaches to assist clients who are trying to avoid spousal impoverishment. 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.

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  http://www.mmapinc.org/
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

**MI Choice Waiver Program**

MI Choice is a home and community-based program. Eligible adults must meet financial and medical requirements to be a MI Choice participant. This program allows the individual to access services in the community along with receiving support in their own home or other residential setting. MI Choice services include: personal care and supervision, homemaker services, adult day care services, counseling services, home delivered meals, respite care, personal emergency response systems, environmentally accessibility adaptations, private duty nursing and other services that are required to keep a person from being institutionalized. Service needs are assessed and coordinated supports coordinator teams. MI Choice Waiver is a statewide program funded by the Michigan Department of Community Health (MDCH).

Eligibility Requirements:

- Frail adults 65 years of age or older
- Persons who are physically disabled age 18 or older
- To be financially eligible for MI Choice, participants must qualify for Medicaid using special income and asset rules.
- Medical status must meet the Michigan Medicaid nursing facility level of care determination criteria.

**P.A.C.E.**

The Program of All-inclusive Care for the Elderly is a managed care program that features comprehensive services and coordinated Medicare and Medicaid financing. The services offered permit participants to continue living at home while receiving services rather than be institutionalized. Participants must be at least 55 years old, be certified as eligible for nursing home care, and live in a PACE service area.
To apply for these programs contact your local Area Agency on Aging (located in local resource section of this manual)

**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:
Veterans

Effective January 19, 2012, the Department of Veterans affairs (VA) amended its scheduled disability rating by revising the criterion to provide an evaluation of 100% for any veteran with service-connected ALS. ALS has been listed as a disease entitled to presumptive services connection.

Benefits are available to those veterans with 90 days or more of continuously active service in the military and an honorable discharge.

Applying for benefits should be done as soon as possible, as benefits are retroactive to the date of application for new applicants.

An initial appointment with a VA doctor to confirm diagnosis will be required, but you will be allowed regular appointments with your own physician.

Benefits include:

- VA Compensation (monthly monetary benefit that varies with the degree of disability and number of veteran’s dependents)
- Special Monthly Compensation (SMC) for Serious Disabilities (additional compensation for loss of specific organs or extremities)
- Dependency and Indemnity Compensation (DIC) (monthly payment to survivors if eligible)
- Insurance benefits for veteran’s dependents
- Specially adapted housing grant (SAH) (meant for eligible veterans to allow for the purchase of a specially adapted house or home modifications to meet their disability needs)
- Automobile grant (financial assistance to purchase a new or used automobile to accommodate the veteran’s disabilities)
• Adaptive equipment (the purchase of adaptive equipment and for repair of, replacement, or reinstallation required because of disability or for the safe operation of a vehicle purchase with VA assistance)
• Aide and attendance allowance (eligible veterans may be entitled to additional compensation to help pay for a regular aid and attendance of another person)
  **A veteran evaluated at 30% or more disabled is entitled to receive additional compensation for a spouse who is in need of an aid and attendance of another person**
• Survivors’ Benefits
• Vocational Rehabilitation
• Other benefits (Prescriptions, medical supplies and equipment, prosthetic items, home improvement and structural alteration grant, respite care)

**Property tax relief for Michigan veterans (disabled or unemployable) for those whom can provide a letter from the VA that says veteran was 100% disabled or 100% unemployable. For more information go to:


For on-line application forms for veteran benefits:  https://www.1010ez.med.va.gov/sec/vha/1010ez

**Or you may call a PVA Service Officer for more help with the application process:**
Stephanie Strickland  313-471-3996  ext 3993
www.michiganpva.org

U. S. Department of Veterans Affairs (877) 222-8387  www.va.gov
Social Security Disability Benefits

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.

Social Security Disability Insurance (SSDI) 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.

Social Security Disability Insurance (SSDI) provides regular monthly cash benefits, funded through federal taxes, to those diagnosed with ALS. In order to be eligible for SSDI you need a definitive diagnosis of ALS from a neurologist and a set number of eligible work credits.

It is important to inquire or apply for social security disability benefits as soon as you become disabled/receive an ALS diagnosis.

In order to qualify for disability benefits, you must have worked 5 of the past 10 years.

*If you have questions or unsure about applying for social security disability, contacting a social security disability lawyer may be useful.

Processing of your SSDI may be faster if you have all of your information ready. Documents needed include:

- Your Social Security number
• Your birth or baptismal certificate
• Names, addresses, and phone numbers of doctors, caseworkers, hospital, and clinic that took care of you and the dates of your visits
• Names and dosage of all the medicine you take
• Medical records from doctors, therapist, hospitals, clinics, and caseworkers that you already have in your possession
• Laboratory and test results
• A summary of where you worked and kind of work you did
• A copy of your most recent W-2 Form (Wage and Tax Statement) or, if you are self-employed your federal tax return from the past year

When approved, you will receive a letter from social security stating the amount of your monthly benefit and the effective start date. Your monthly disability benefit will depend on your average lifetime earnings.

*Please note that it will take 5 months to begin receiving your social security disability benefits.

Certain members of your family may qualify for SSDI benefits based on your work. They include:

• Your spouse, if he/she is 62 or older
• Your spouse, at any age if he/she is caring for a child of yours who is younger than 16 or disabled

• Your unmarried child, including an adopted child, or in some cases, a stepchild or grandchild. The child must be younger than 18 or younger than 19 if in elementary or secondary school full time
• Your unmarried child, age 18 or older, if he/she has a disability that started before age 22. (The child’s disability also must meet the criteria of disability for adults.)

Benefits may also be given to widows or widowers whose spouse was disabled. If a person’s spouse has died within the past three months, he/she should contact Social Security Administration immediately. If someone’s spouse who died already filed an application for SSDI before their death, the widow/widower may be entitled to back benefits.
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. 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.

Web Site: best.ssa.gov

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**How Do You Apply for Social Security Disability Benefits?**

*For more information or to start the application process contact 1-800-772-1213 or www.ssa.gov/disability/.

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.

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.

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 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.
Maintaining 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?

You may 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 consider retiring sooner. Other considerations in deciding how long to work include: your job satisfaction, your level of energy, and how you want to spend your time knowing that in the near future, you may lack energy and mobility to fully enjoy traveling or other activities.

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.

Should I tell my employer about my disability?

Many individuals with serious illnesses face the same issue. 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. 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.

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 (800) 605-6722

**Support Services**

Receiving a diagnosis such as ALS can leave one feeling alone, overwhelmed, and unsure. There are a number of ways for pALS and caregivers to obtain support, information, equipment, and services to help living with ALS easier.

**Support Groups**

ALS affects the entire family with changes that can be challenging, stressful, and at times frightening. Support groups provide an opportunity to both share and learn about issues affecting pALS (persons with ALS), including: community resources, current research initiatives, emotional support, what to expect, and on managing symptoms. The support group is an essential tool in helping patients and their caregivers, families and friends live with ALS.

For more information on our support groups, or if you are interested in starting a support group in your area please contact ALS of Michigan at 800-882-5764.

Please see our current list of support groups below:
### SUPPORT GROUPS

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<tr>
<th>Location</th>
<th>Date</th>
<th>Time</th>
<th>Location Details</th>
<th>Additional Info</th>
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<td><strong>LANSING</strong></td>
<td>3rd Tuesday</td>
<td>6:30 PM - 8:00 PM</td>
<td>Holt United Methodist Church 2321 N. Aurelius Rd. Holt</td>
<td></td>
</tr>
<tr>
<td><strong>MIDLAND</strong></td>
<td>2nd Wednesday</td>
<td>6:00 PM - 7:30 PM</td>
<td>Mid Michigan Medical Center 4000 Wellness Dr. Midland — Room H1225</td>
<td>Support groups are free and open to all pALS (people with ALS), their families, friends and caregivers (unless otherwise indicated). Attend as many groups as you wish, in any location. All groups are drop-in; no pre-registration is required. For information or to be added to a support group reminder mailing list call (800) 882-5764.</td>
</tr>
<tr>
<td><strong>SOUTHFIELD</strong></td>
<td>1st Monday</td>
<td>6:30 PM - 8:00 PM</td>
<td>ALS of Michigan Office 24359 Northwestern Hwy., Ste. 100 Southfield</td>
<td></td>
</tr>
<tr>
<td><strong>ST. CLAIR</strong></td>
<td>3rd Monday</td>
<td>6:30 PM - 8:00 PM</td>
<td>Marine City Lions Club 545 Ward St. Marine City 48039</td>
<td></td>
</tr>
<tr>
<td><strong>STERLING HTS.</strong></td>
<td>2nd Thursday</td>
<td>6:30 PM - 8:00 PM</td>
<td>Utica United Methodist Church 8650 Canal Rd. Sterling Hts.</td>
<td></td>
</tr>
<tr>
<td><strong>NORTHVILLE</strong></td>
<td>1st Wednesday</td>
<td>6:30 PM — 8:00 PM</td>
<td>Ward Church 40000 Six Mile Rd. Northville</td>
<td></td>
</tr>
<tr>
<td><strong>KALAMAZOO</strong> NEW!</td>
<td>3rd Tuesday of the Month</td>
<td>6:30PM — 8:00PM</td>
<td>Kalamazoo Free Methodist Church 931 W. Maple Kalamazoo</td>
<td>Call 800-882-5764 For more Information</td>
</tr>
</tbody>
</table>
Online Support

Chat Rooms
ALS Alternative Medicine Yahoo! Club
http://clubs.yahoo.com/clubs/alsalternativemedicine

ALS Forums
http://www.alsforums.com/

Living-with-ALS Email Group
http://health.groups.yahoo.com/group/living-with-als/

Moms with ALS
http://www.cafemom.com/group/momswithALS

Muscular Dystrophy Association Chat Rooms
http://www.mdausa.org/chat/calendar.html

Patients Like Me
www.patientslikeme.com

Women with ALS
http://health.groups.yahoo.com/group/womenwithals/
Loaner and Used Equipment

ALS of Michigan, Inc. offers a variety of new and used medical and assistive technology equipment at no charge to ALS patients on a loaner basis. If you have a need, please contact us to see what equipment we have available for loan. If you have something that you no longer need please consider contacting us to make a donation. Your donation will not only provide you with a tax deduction but will help provide needed equipment to someone who may be able to use it. Examples of equipment, which is needed or may be available are as follows:

- Canes
- Communication Devices
- Wheelchair Ramps
- Manual Wheelchairs
- Power Wheelchairs
- Wheelchair Cushions
- Bedside Tables
- Transfer Boards
- Walkers
- Transfer Chairs
- Recliner Lift Chairs
- Hoyer Lifts

Local City Services, Center for Independent Living, Churches, Senior Centers, or Local Fire Departments may offer a small equipment loan closets to their citizens. To look for loan closets in your area, you can go online to:

http://www.michiganloanclosets.us/

Michigan Rehab Services assists those who continue to be employed and will help in obtaining needed equipment in order for a person to continue working. For more information, contact Michigan Rehab Services 1-(800) 605-6722 or www.michigan.gov/mdcd.

The Muscular Dystrophy Association operates medical equipment loaner closets in Michigan. This program offers medical equipment, as available, for loan at no charge to registered ALS patients for as long a period as is needed. To find an MDA location near you please call (800) 572-1717.

Veteran’s Affairs will be able to assist in helping ALS Veterans obtain needed medical equipment. To find a VA facility near you, please call (800) 827-1000.
World Medical Relief-Detroit, Michigan Durable Medical Equipment Program. Through the DME program, low-income clients can obtain canes, walkers, hospital beds, over-the-bed tables, commodes, and tub benches. A doctor's prescription is needed to receive durable medical equipment. All items must be picked up from WMR's warehouse. A small handling fee is assessed. Address: 11745 Rosa Parks Blvd., Detroit, Michigan 48206-1270 U.S.A. Phone: (313) 866-5333 Fax: (313) 866-5588 Email: info@worldmedicalrelief.org

Caregiver Support

Being a caregiver, though rewarding, can also be challenging. No one can quite understand what it’s like unless they, too, have had the opportunity to care for a loved one. Being a caregiver presents unique experiences, and connecting with others in sharing some of those experiences can help to feel less alone.

The more people participating in the care, the less alone a caregiver feels in their role as well. It may be valuable to have a family meeting to discuss what caregiving roles family members are willing and able to undertake. Enlisting the help of those friends who are asking how they can help, can alleviate the burden by asking them to help with shopping, doing laundry, or meal preparation.

There are a number or organizations dedicated to the support of caregivers. Some include:

The Center for Family Caregivers
P.O. Box 224 Park Ridge IL 60068, (773) 334-5794
Web site: http://www.caregiving.com

Empowering Caregivers
Website: http://www.care-givers.com/
Family Caregiver Alliance
180 Montgomery Suite 1100, San Francisco, CA 94104, (800) 445-8106
Web site: www.caregiver.org, Email: Info@caregiver.org

National Alliance for Caregiving
4720 Montgomery Lane, Suite 642, Bethesda, MD 20814, (301) 718-8444,
Web site: http://www.caregiving.org/

National Family Caregivers Association
10400 Connecticut Ave, Suite 500, Kensington, MD 20895-3944, (800) 896-3650
Web site: www.nfcacares.org, Email: thefamilycaregiving.org

Today's Caregiver Magazine & Caregiver.com Web Site
6365 Taft Street, Suite 3006, Hollywood, FL. 33024, (954) 893-0550
Web site: http://www.caregiver.com / Email: info@caregiver.com

Other Programs for Caregivers:

Programs for Families-Compassion Partners

Provides free admission to many theme parks in Central Florida for individuals with a life threatening illness. Contact (407) 396-1114 for application information.
Share the Care Groups

Learn how to set up groups made up of family, friends, and the community to take care of someone with a disability based on the book “Share the Care” [http://www.sharethecare.org/](http://www.sharethecare.org/)

**Family Caregiving – Why Respite?**

Being a family caregiver, while a fulfilling role can consume a great deal of physical, mental, and emotional energy. Consequently, respite care is very important because it gives family caregivers an opportunity to care for themselves; something a caregiver often overlooks.

Respite care simply means an interval of rest or relief. Respite care gives you, the family caregiver, an opportunity to take a much-needed break from the daily care that you provide for your loved one. A period of respite may be a few hours or a few days at a time, depending on what is decided between you and the care recipient and resources available to help care for your loved one, so you can take care of yourself. There are a number of ways you can spend your “time off” during your respite. Here are just a few examples:

- Go to the movies
- Read a book, watch TV, take a nap
- Go on a short vacation
- Get a massage/facial/manicure
- Attend a caregiving support group/ visit with friends
- Sit in the sun
- Take a walk
- Treat yourself to lunch at a restaurant

It is important for the caregiver to have a plan for your own self-care because doing so can enhance the quality of life for you and the quality of life of your loved one, enabling you to have the energy and stamina needed to provide the necessary care to your loved one. It is also possible that your loved one will appreciate a respite from the normal routine of care as well!

Without a conscious plan of self-care, the caregiver can experience caregiver burnout. How do you identify caregiver burnout? Check in with yourself to see if you are experiencing consistent or increased of the following:
• Social withdrawal  • Anxiety
• Exhaustion  • Irritability
• Inability to concentrate or relax  • Forgetfulness
• Depression/feelings of hopelessness  • Lack of appetite
• Inability to sleep

Caregiver burnout makes the task of caregiving very difficult, if not impossible. It can lead to resentment on the part of the caregiver, and even illness. It is your responsibility as a caregiver to care for yourself as well as the person you are caring for.

Respite care is one tool you can use to help yourself avoid caregiver burnout. To begin the process of utilizing respite care assistance, the following steps should be initiated:

Step 1 - first, it is important to acknowledge your needs as a family caregiver. Remember that family caregiving may feel like an obligation, but with it comes the responsibility of making sure that the most important mechanism that makes the household run smoothly is maintained – and that’s YOU.

Step 2 – Have you discussed your needs with your loved one?

It is important to communicate your needs and desires with your loved one, the person you are providing care for. If you believe that you might like to pursue respite care services, it is essential to discuss this with your loved one. In doing so, you may discover that your loved one is very supportive of the idea. You may also find that having such a conversation opens up doors for even more communication and intimacy.

Step 3 – How do you find out about respite services available to you?

Respite care can take different forms. In-home respite care usually involves a trained professional (often from a home health agency) who comes into the house to provide necessary care during a period of time when the caregiver is away. In some communities, there may be a church, volunteer agency or group that provides respite care by a volunteer. (The level of training the care provider should have will depend on the level of care needed by your loved one.)
Another way to partake in respite care services is through a facility or residence that employs trained health care staff on-site. This type of respite would allow your loved one to stay at such a residence on a short-term basis (as determined by you and your loved one) and entitle him or her to receive whatever care he or she needs. This kind of service may be available through a local long-term care residence, hospital or assisted living facility.

A less formal way of receiving respite care assistance is by utilizing family and friends who are eager to be helpful. The next time a friend or family member asks you how they can help, consider responding by telling them that giving you a break for the day or an evening, or even for a few hours might be the nicest gift they can give you.

For additional information and tips on how to select a respite care provider, please contact ALS of Michigan at (800) 882-5764.

ALS of Michigan’s Respite Care Assistance Program

ALS of Michigan recognizes that caregivers have an overwhelming job of caring for a loved one with ALS 24/7. The responsibility and strain of providing the care needed by PALS (persons with ALS) can result in emotional and physical deterioration of caregivers and PALS. Providing respite (limited, intermittent relief) to caregivers enables time away for themselves. Please contact ALS of Michigan, Inc. for information about our respite care services and availability. 800-882-5764

How Do I Find Home Care Services?

Before starting a search, determine the types of services you need. Do you need assistance around the home with meal preparation, light housekeeping, laundry, shopping? Do you need help with personal care, such as bathing, eating, dressing, toileting? Is there a need for skilled nursing care, such as tube feeding or ventilation care?

ALS of Michigan has a list of a number of home health agencies that can be contacted for respite services. ALS of Michigan always confirms Worker’s Compensation and Employer’s Liability coverage by agency prior to service being provided. In addition, The National Association for Home Care & Hospice (NAHC) web site offers a listing of home care providers at www.nahc.org. This locator service will identify agencies within your ZIP code boundaries, and it provides contact information.

Contact your state’s departments of health, aging, and social services to obtain a list of licensed agencies. In addition, most state home care and hospice associations maintain directories of
existing home care organizations and can identify an appropriate provider. You can locate home care and hospice state associations at www.nahc.org.

Medicare has a website (Home Health Compare) that provides information about the home health agencies, including areas they serve and their quality of care compared to others in the state. The information is available at: http://www.medicare.gov/hhcompare

In addition, home care providers are listed in the yellow pages under “home care,” “hospice,” or “nurses.” You can also check with your local Area Agency on Aging or United Way for more agencies. Your place of worship also may have information about local home care providers.

How Do I Select the Right Home Care Provider?

You may want to ask these questions:

• How long has this provider been serving the community?
• What kinds of services does the provider offer?
• What procedures does this provider have in place to handle emergencies?
• Does provider have an infection control policy in place?
• Are caregivers available 24 hours a day, 7 days a week?
• How does the provider select and supervise staff?
• Does the provider bill directly to third-party payers?
• Are references available?
• If this is a Medicare provider, how does its quality compare to others on the Medicare Home Health Compare web site?
• Will the same person be providing care each visit? ALS of Michigan recommends at least two caregivers become familiar with case. This insures that someone familiar with case will be sent to home if another caregiver is ill or has an emergency.
• How does agency handle employee no shows?
Hospice

What is Hospice?

Hospice care is a type of compassionate care that addresses all the needs of a person who faces a life-limiting illness – not just the immediate physical needs, but also the emotional, psychological, social and spiritual needs. In addition, hospice addresses the needs of the family and friends of the ill person to the greatest extent possible so that all concerned can maintain dignity and quality of life. An important part of hospice is that patients and families help decide what care is right for them.

Hospice is a choice, not a requirement. The patient may choose to withdraw from the hospice plan of care at any time to seek other medical treatments that may become available.

Hospice focuses on caring, not curing, and in most cases, care is provided in the patient’s home. Hospice care may also be provided in freestanding hospice centers, hospitals, and nursing homes.

Hospice services are available to patients of any age, religion, or race.

How Do You Get Hospice Care?

Most patients admitted to a hospice program are referred by their physicians. Others come themselves or are referred by the hospital, a community agency or by a friend or relative. Family members may request information from a hospice care program even if the patient does not wish to be admitted to the program. If you are interested in learning about or getting hospice care talk to your physician or contact a hospice provider in your area.

How Much Does Hospice Cost?

Hospice care is covered by Medicare and/or Medicaid and private insurance. Patients may be asked to meet co-pay or other uncovered costs. However, no one will ever be turned down for financial reasons.

What Services does Hospice Provide?

Hospice works in conjunction with the patient's physician, providing care under a plan of treatment designed by the hospice team and along with the patient and family. The hospice team is made up
of the patient’s own personal physician, the hospice physician, nurses, home health aides, social workers, clergy or other counselors, trained volunteers, speech, physical, and occupational therapists as needed.

Hospice services include:

- Pain management
- Nursing care
- Medical supplies, equipment, and drugs (designed to providing comfort to the patient)
- Assistance with the emotional, psychological, and spiritual aspects of dying
- Home health aide and homemaker services.
- Bereavement programs.
- Dietary and other counseling.
- Care of the body after death.

Hospice programs exist in every county in Michigan. Hospice workers and volunteers in all these locations are dedicated to providing care to the seriously ill in a manner that honors them and celebrates their lives.

To locate a hospice provider in your area, visit [http://www.mihospice.org](http://www.mihospice.org)

*For more information, please check the organizations below or contact ALS of Michigan (800) 882-5764.*
National Organization & Palliative Care Organization (NHPCO)

1700 Diagonal Road, Suite 625
Alexandria, Virginia 22314
703/837-1500 (phone)
703/837-1233 (fax)
800/658-8898
http://www.nhpco.org

The Michigan Hospice and Palliative Care Organization

(800) 536-6300 Fax (517) 886-6737
6015 West St. Joseph Highway, Suite 104 Lansing Michigan 48917
www.mihospice.org

Grief / Bereavement Groups

If you have lost a loved one, you may want to consider participating in one of the many free grief support groups offered. Groups are made up of caring people who know the pain and turmoil of the loss of a loved one. Most are led by a grief counselor. If you are in emotional pain because someone you love has died, please consider attending a meeting. The groups are generally ongoing and you are welcome to join them at any time and at any location. Dates and times can change without our knowledge; please use the contact phone number to confirm date and time before attending a group. Many hospice organizations offer support groups, below is a listing of a few that offer regular grief and loss support groups. You can also check your local church and synagogue for grief support groups.

To locate a hospice in your area go to http://mihospice.org or contact 1-800-536-6300
Angela Hospice
14100 Newburgh Rd, Livonia, MI  48154
(734) 464-7810
For more information, including dates and times, please call at (734) 464-7810 or visit
Website: www.angelahospice.org

Hospice of Michigan
400 Mack Avenue
Detroit, MI  48201
(313) 578-5000 or (888) 247-5181
Website: www.hom.org

SandCastles-Henry Ford Hospital
A division of Hospices of Henry Ford, provides service for children (ages 3 to 18) who have
experienced the death of someone close to them. By allowing children to express their grief in an
understanding and accepting environment.
(313) 874-6881.
Local and National Resources

Local Vendors

This referral list is an information tool for patients and families. It is intended to identify some of the agencies that provide services to ALS patients in Michigan. This list is not designed to be an exhaustive compendium of all ALS agencies or to convey any recommendation. Neither the specialists included on the referral list, nor those not included are endorsed or sanctioned. Patients and Families should always work with their ALS medical professional for suggestions and recommendations for equipment and agencies that would be able to meet their specific needs.

Categories included below are:

- Adaptive Equipment and Medical Supplies.
- Assistive Technology Services and Devices.
- Financial Planning and Legal and Estate Planning.
- Home Adaptations.
- Transportation.
- Used Medical Equipment-Buy/Sell.
- Vans, Modifications and Conversions.

Adaptive Equipment and Medical Supplies

Binson’s Home Health Care Center

Wheelchairs, wheelchair repair, orthotics, Daily living aids, respiratory, bath aids, lifts, lift chairs, walkers, hospital beds.
Stores in Center Line, Royal Oak, Southgate, Troy
(888) BINSONS (246-7667)
www.binsons.com

Professional Home Health Care

Wheelchairs, wheelchair repair, walkers,
24706 Michigan Ave. Dearborn, MI 48124
(800) 322-5034 or (313) 277-2160
Sheldon Medical Supply

DME, respiratory, and mobility products. Stores in Sandusky, Bad Axe, Mt. Pleasant, Marysville, Houghton Lake, Caro, Marlette, and Saginaw

(800) 922-5101

www.sheldonmedicalsupply.com

Wright and Filippis - wheelchairs, wheelchair repair,

orthotics, lifts/ramps, respiratory, bath aids, lift chairs, walkers

Servicing: Alpena, Ann Arbor, Battle Creek, Cass City, Clarkston, Dearborn, Detroit, Detroit Medical Center, Detroit Rehab Institute, Escanaba, Flint, Gaylord, Grand Rapids, Kalamazoo, Lansing, Lapeer, Lincoln Park, Livonia, Marquette, Owosso, Port Huron, Saginaw, Sault Ste. Marie, Southfield, Warren.

Contact (800) 843-0222 for provider in your area.

2845 Crooks Road Rochester Hills, MI 48309

www.firsttoserve.com

United Seating and Mobility/NuMotion

Wheelchairs, rehab and assistive technology needs in Michigan, Ohio, Illinois, Virginia, Missouri, Colorado, New Mexico, and Oregon.

www.unitedseating.com
Detroit

53115 Grand River 248.446.3040 office
New Hudson, MI 48165 248-446-3042 fax

Assistive Technology Services and Devices
Assistive Technology of Michigan

Assistive Technology of Michigan’s four-step solution for the computer access, ergonomics, environmental control, and work site accommodation allows adults and children with physical, sensory, cognitive or learning disabilities to lead independent, productive lives.

43000 West Nine Mile Rd. Suite 113
Novi, Michigan 48375

Tel: 248-348-7161 Fax:248-348-7131 Website http://www.atofmich.com
Email: info@atofmich.com www.atofmich.com

Visiting Physicians Association
(877)468-7322 - *please have date of birth and insurance information when calling

Dental Services
Portable Dental Services-Serving Southeastern Michigan

(586) 873-5567
www.portabledentalservices.com
Podiatry Services

Motor City Podiatry Associates

In home services

(313) 582-3820 Dearborn

(586) 755-0022 Warren

Financial Planning and Legal and Estate Planning

Christopher B. Kroll & Associates
Elder Law Solutions
5748 24 Mile Road
Shelby Township, MI 46316
(586) 323-4001 *Dearborn Office (313) 359-2481
www.elderlawsolution.com

The Elder and Disability Law Firm, PLLC
117 Cass Avenue, Suite 302
Mount Clemens, MI 48043
(586) 493-7652
www.mymedicaid.com

Estate Planning Services, P.C.

Livonia Office

(734) 432-3132
42000 Six Mile Road Suite 125
Livonia, MI 48168
www.formyplan.com

Brighton Office

(888)Plan-050
306 W. Main Street Suite 2
Brighton, MI 48116
Jim Schuester—Certified Elder Law Attorney  Don Rosenberg—Attorney (elder law)
(248)356-3500 1301 West Long Lake Rd. ste 340
24330 Lahser Rd. Troy, MI 48098
Southfield, MI 48034 (248)641-7070
http://www.jimschuster.com

Michigan State bar Referral Service  (800) 968-0738

The Law Center for Social Security Rights
Clifford Weisberg
25925 Telegraph Rd. Suite 100
Southfield, MI 48033
(248) 350-1000

Home Adaptation

Able-One Elevator
Chairlifts/elevators/ wheelchair lifts
(248) 889-0699
13780 Hearthstone LN. Hartland, MI 48353
Accessible Home

Full service construction, ramps (permanent and rental), widen doorways, chairlifts.

(248) 321-8951

26675 Dequindre

Madison Heights, MI 48071

www.accessiblehomes.net

Bath for All

Specialize in home modifications and improvements.

(734) 414-9525

www.adaforall.com

Binson’s Home Health Care Center

Stairlifts, ceiling lifts, ramps

(888)-BINSONS

www.binsons.com

Disability Made Easy, LLC

Noah Rothenberg (248) 379-5775

Home Modification, Financing, Consulting, Handicap Accessible Homes, Free Consultation

www.disabilitymadeeasyllc.com
E &L Construction
Home adaptations/ramps
(810)744-4300

Paulson’s Construction  (517) 545-8651
Home accessibility and remodel

Planet Mobility
Wheelchair and scooter lifts, ceiling lifts
(866) GO-LIFTS or (586) 247-8900
www.planetmobility.com

Rebuilding Together
Home repair and revitalization for low-income homeowners who are elderly, disabled, military veterans, and families with children
(248) 432-6551
http://rebuildingtogether-oaklandcounty.org/

Wright and Filippis
Stairway lifts, wheelchair lifts, custom elevators, wood-constructed aluminum ramps
Servicing several locations. Please contact (800) 482-0222 ext.8214 for more information
**Funding Assistance**


Allows people with disabilities and seniors (or their family members) to purchase assistive technology devices or services, including modification of vehicles and homes. Loans may also cover cost of training to use the purchased equipment, warranties, and service agreements.

**Ramps**

Before you build a ramp it is very important to work with your physical therapist/occupational therapist, neurologist, and the wheelchair company representative to make sure you build a ramp that is going to work with your specific wheelchair.


Below is a listing of Michigan organizations that have helped PALS build ramps.

**Amramp**

616-403-6600

Grand Rapids, Battle Creek, Kalamazoo, South Bend, Lansing

[http://www.amramp.com/Michigan](http://www.amramp.com/Michigan)
Disability Connections  
517-782-6054  
http://www.disabilityconnect.org/page-703602  
Jackson County

Habitat for Humanity

Contact 248-338-1843. Critical Home Repair Program  
https://www.habitatoakland.org/critical-home-repair.html

Paralyzed Veterans of America

Provides veterans with assistance with obtaining a ramp.  
(248) 321-8951  
www.Acessiblehomes.net

Saginaw County United Way – Project Independence

989-755-0505  
http://www.unitedwaysaginaw.org/project-independence

Superior Alliance for Independent Living  
(906) 228–5744  
http://www.upsail.com/index.php  
The SAIL, a member of the Disability Network will help patients find organization that will help them build ramps.  
Upper Peninsula
The Accessibility Ramp Program – Washtenaw County OCED
734-622-9036

The Disability Network of Michigan
Centers for Intendent Living Directory
http://www.dnmichigan.org/cil-directory/

The Disability Network
(810) 742-1800
http://www.disnetwork.org/index.php/whatwedo/ramps
Flint and Genesee County

United Way of St. Clair County
810-985-8169
http://www.uwstclair.org/ramp-program
Must be three year resident of St. Clair County

Vans, Modifications and Conversions New and Used

Clock Mobility
Wheelchair lifts, driving aids, assistive technology, van modifications, rentals, vehicles for sale
Grand Rapids (616) 698-9400; Lansing (517) 272-4488; Kalamazoo (269) 903-2813; Traverse City (213) 943-9890
www.clockmobility.com

Creative Mobility
Wheelchair van sales (new & used), wheelchair van service, wheelchair/scooter lifts, in-home mobility products
32217 Stephenson Hwy
Madison Heights, MI 48071
248-577-5430
mvranic@creativemobilitygroup.com
Gresham Driving Aids
Wheelchair van sales (new & used), wheelchair van service, wheelchair/scooter lifts, in-home mobility products
Wixom (248)624-1533; Kalamazoo (269) 341-9566; Saginaw (989) 249-0417
www.greshamdrivingaids.com

Mobility Works
Wheelchair vans (sale & rental), lifts, hand controls
Madison Heights (877) 275-4907, Saginaw (877) 275-4907
www.mobilityworks.com

Advantage Mobility Outfitters
Vans, wheelchair lifts, scooter lifts, driving aids. Services all of Michigan.
(800) 990-8267
3990 Second St. Wayne MI 48184
www.advantagemobility.net

Chrysler
The Chrysler Mobility Program will provide cash reimbursement to assist in covering the cost of installing adaptive driver or passenger equipment on a vehicle. Conversions to Chrysler, Jeep®, Dodge, Ram or FIAT vehicles qualify for a maximum reimbursement of $1,000. Running boards qualify for a maximum reimbursement of $400. Alerting devices qualify for a maximum reimbursement of $200. For more information, contact the Chrysler Mobility Program toll free at 800-255-9877 (TTY Users: 800-922-3826).
http://www.chryslerautomobility.com/

General Motors
Through the GM Mobility Reimbursement Program, GM customers can receive up to $1,000 of the cost of any eligible aftermarket equipment when installed on any eligible purchased or leased new vehicle. http://www.gmfleet.com/overview/mobility-vehicles.html
Ford

Adaptive Equipment Financial Assistance provides up to $1,000 toward the cost of adaptive equipment or up to $200 for an alert hearing device, lumbar support, or running boards with purchase of a new or leased vehicle. (800) 952-2248 www.fordmobilitymotoring.com

Clock Mobility

Van conversions and custom modifications

Lansing
Traverse City
Kalamazoo
www.clockconversions.com

Gresham Driving Aids
Van conversions and custom modifications
Wixom, MI (800) 521-8930
Saginaw, MI (800)608-8284
Kalamazoo (269)341-9566
www.greshamdrivingaids.com

Mobility Works
1965 E. Avis
Madison Heights, MI 48071
(866)711-5071
www.mobilityworks.com

Local Government and Nonprofit Organizations

Michigan Area Agencies on Aging
Offers planning, developing, coordinating, funding, and monitoring services for the elderly or disabled, including meals on wheels, respite care, in home chore service, MI choice Waiver programs.

Detroit Area Agency on Aging (1A)
Brewery Park
400
1333 Brewery Park Blvd., Suite 200
Detroit, MI 48207-2635

Area Agency on Aging 1-B
29100 Northwestern Hwy., Suite
Southfield, MI 48034
(248) 357-2255 / (800) 852-7795
(313) 446-4444
Fax: (313) 392-0058
Website: http://comnet.org/detroiteldernet

Fax: (248) 948-9691
Website: www.aaa1b.org


Region 2 Area Agency on Aging
8363 US 12 – P. O. Box 303
Onsted, MI 49265
(517) 592-1974 (800) 335-7881
Serves: Counties of Jackson, Hillsdale, Lenawee

Valley Area Agency on Aging (5)
225 E. Fifth Street, Suite 200
Flint, MI 48503
(810) 239-7671 / (800) 803-7174
Fax: (810) 239-8869
Serves: Counties of Genesee, Lapeer,

Region VII Area Agency on Aging
126 Washington Avenue
Bay City, MI 48708
(517) 893-4506 / (800) 858-1637
Website: www.region7aaa.org

Serves: Counties of Bay, Clare, Gladwin, Gratiot, Huron, Isabella, Midland, Saginaw, Sanilac, Tuscola

Northeast Michigan Community Service Agency, Inc. (9)
2375 Gordon Rd.
Alpena, MI 49707
(989) 356-3474 / (800) 219-2273
Website: www.nemcsa.org

Serves: Counties of Alcona, Alpena, Arenac, Cheboygan, Crawford, Iosca, Montmorency, Ogemaw, Oscoda, Otsego, Presque Isle, Roscommon
Area Agency on Aging of Northwest Michigan #10
1609 Park Drive
P.O. Box 5946
Traverse City, MI 49686
(231) 947-8920

The Senior Alliance (1-C)
3850 Second, Suite 201
Wayne, MI 48184
(734) 722-2830
Website www.aaa1c.org
Serves: 34 Communities of Western and Southern Wayne County.

Area Agency on Aging III-A
3299 Gull Road
Kalamazoo, MI 49001
(269) 373-5147
Serves: Kalamazoo County
Region3-B

200 W. Michigan Ave.
Battle Creek, MI 49017
(269) 966-2450
Website: www.seniorresoruces.us

Serves: Barry and Calhoun

Branch-St. Joseph Area Agency on Aging III-C

809 Marshall Road Suite A
Coldwater MI 49036
(517) 278-2538
Website: www.bhsj.org

Serves: Branch, St. Joseph

Region IV Area Agency on Aging

2900 Lakeview Ave.
St. Joseph, MI 49085
(269) 983-0177
Website: www.areaagencyonaging.org

Serves: Berrien, Cass, and Van Buren.
Tri-County Office on Aging (6)
5303 Cedar Street
Lansing, MI 48911-3800
(800)405-9141
Website www.tcoa.org
Serves: Clinton, Eaton, Ingham

Area Agency on Aging of Western Michigan, Inc.
1279 Cedar Street N.E
Grand Rapids, MI 49503-1378
(616)456-5664
Website www.aaawm.org
Serves: Allegan, Ionia, Kent, Lake, Mason, Mecosta, Montcalm, Newaygo, Osceola

Region XI Area Agency on Aging
UPCAP Services
2501 14th Avenue, South
Escanaba, MI 49829
(906) 786-4701
Website http://upcapservices.com/upaging.shtml
Senior Resources-Region 14 Area Agency on Aging

560 Seminole Road
Tanglewood Park
Muskegon, MI 49444
(231) 739-5858
Website www.seniorresources.us
Muskegon, Oceana, Ottawa.

Hospice Services
Provides expert and compassionate care for people who are experiencing life threatening illnesses

Michigan Hospice and Palliative Care Organization
Hospice programs statewide and palliative care resources
(800) 536-6300 / (517) 886-6667
Website: www.mihospice.org

Jewish Hospice and Chaplaincy Network
Does not provide hospice service. Will assist families with locating local hospice services. They provide spiritual care, volunteer programs, health care advice, support services
(248) 592-2687
www.jewishhospice.com
Transportation Services

For transportation to local Dr. appointments you should always contact your city services department to see if they provide free wheelchair accessible transportation.

If you need help accessing transportation services in your area please contact ALS of Michigan and ask to speak with a patient services staff member at (800)882-5764.

Transport Care Services-servicing Oakland and Macomb Counties
1-888-811-4655
http://www.transport-care.com

Michigan Department of Transportation (MDOT)
Provide transportation with small buses and lift vans for individuals who cannot use the fixed route bus service
Public Transit Agencies / Urbanized & Non-urbanized Public Transit Agencies
State Transportation Bldg.
425 W. Ottawa St.
P. O. Box 30050
Lansing, MI  48909
(517) 373-2090

SMART
Customer Service
(313) 640-8931

Friendly Family Transportation, Inc.
(services Macomb, Oakland & Wayne counties (313) 962-5515 / (800) 624-3455
Give-A-Lift
(248) 569-5010
Services Macomb, Oakland, St. Clair, Washtenaw & Wayne Counties)

Michigan Department of Transportation,
Driver & Motor Vehicle Services (DMV)
Offers disabled parking permits

Michigan Department of State
Lansing, MI  48918 Information phone number (517) 322-1460

Jewish Federation of Metro Detroit
Escorted rides for seniors and people with disabilities
248-592-2226

Veterans Hospital & Healthcare Facilities in Michigan

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. Veteran’s Affairs may assist with medical care, equipment needs, home care, and case management services. Contact your local facility to inquire about services.

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:

Local Centers

Detroit-VA Medical Center
Social Work Department
4646 John R
Detroit, MI  48201
(800) 827-1000

VA Hospital – Ann Arbor
2215 Fuller Court
Ann Arbor, MI  48105
(800) 361-8387
Battle Creek VA Medical Center
5500 Armstrong Road
Battle Creek, MI 49015
Phone: (269) 966-5600 or (888) 214-1247
Fax: (269) 966-5483

Iron Mountain-VA Medical Center
325 East H Street
Iron Mountain, MI 49801
Phone: (906) 774-3300 or (800) 215-8262
Fax: (906) 779-3114

Saginaw -VA Medical Center
1500 Weiss Street
Saginaw, MI 48602
Phone: (989) 497-2500 or (800) 406-5143
Fax: (989) 791-2217

Other Support Service Organizations

Paralyzed Veterans of America (Michigan Chapter)
Expertise, resources and benefits for veterans with spinal cord injury or dysfunction.
40550 Grand River Ave.
Novi, MI 48375
(248) 476-9000
(800) 638-MPVA (Michigan only)
Fax (248) 476-9545 Website: www.michiganpva.org
Citizens for Better Care  [http://www.cbcmi.org/](http://www.cbcmi.org/)
Information on nursing home care, assisted
and independent living and adult foster care
Southeastern, MI (800) 833-954

Grand Rapids, MI (800) 782-2918
Eastern, MI (800) 284-0046
Lansing, MI (800) 292-7852

Jewish Assistance Program

Financial assistance, food, health care, housing,

Employment services, mental health services,

Services for children and teens, transportation
(248) 592-2650

Department of Human Services

State agency offering assistance with medical

services, food and cash assistance, social workers

to aid in the application of Medicaid benefits

P. O. Box 30037
Lansing, MI 48909
(517) 373-2035

Fax (517) 335-6101 Website: http://www.michigan.gov/dhs
Easter Seals of Michigan – Multiple Locations-Provides services for people with disabilities and their families [www.mi-ws.easter-seals.org](http://www.mi-ws.easter-seals.org)

Southeastern Michigan
7100 Lindenmere, Bloomfield, MI 48301
(248) 538-7830

Grand Rapids, MI
4065 Saladin Drive, Grand Rapids, MI 48546
(616) 942-2081

North Oakland Family Mental Health Center
28 W. Lawrence, Pontiac, MI 48342
(248) 858-5326

East–Central Region
804 South Hamilton, Saginaw, MI 48602
(989) 797-0880

Muscular Dystrophy Association
Contact (800) 572-1717 for Local Affiliates

3300 E. Sunrise Drive, Tucson, AZ 85718

Website: [http://www.mdausa.org/](http://www.mdausa.org/), Email: mda@mdausa.org

Michigan Protection & Advocacy Service
Legal rights for individuals with disabilities
(517) 487-1755 / (800) 288-5923

Website: [www.mpas.org](http://www.mpas.org)

Michigan Service for the Blind and Physically Handicapped (SBPH)
Unabridged library of books on tape or printed in braille and shipped to your door, also, adaptive technology center.

Michigan Library & Historical Center (Main Office)
702 West Kalamazoo Street
Lansing, MI 48915
(800) 992-9012 / Local number (517) 373-5614
Website: [www.michigan.gov/hal](http://www.michigan.gov/hal)
Michigan Department of Community Health (MDCH)

Information on health care coverage including HIPAA, Medicaid, services for seniors and persons with disabilities. Mental health treatment.

Sixth Floor, Lewis Cass Bldg.
320 South Walnut Street
Lansing, MI 48913 (517) 373-3500
TDD (517) 373-3573
Website: www.Michigan.gov/mdch

Share a Smile

Goal is to allocate financial resources directly to those underserved populations who cannot find assistance through traditional channels. Provide assistance to people as they face the everyday challenges of their lives, we are able to direct our giving and allocate dollars where they can have the greatest impact

5151 Corporate Drive, Mail Stop S-355-4
Troy, Michigan 48098
248.312.5345 (phone)

www.shareasmile.org

Social Security Administration – Multiple Locations

(Federal Social Security program intended to replace part of your earnings lost because of retirement, death, or disability)

Toll Free Number – (800) 772-1213 / Mon. – Fri. 7am – 7pm

www.ssa.gov
Who Was Lou Gehrig?

Lou Gehrig, arguably one of baseball’s most famous first basemen played for the New York Yankees in the late 1920s through 1939. Gehrig while famous for his baseball achievements is perhaps most remembered for giving his name to the disease that would eventually claim his life – ALS or as it is more commonly known Lou Gehrig’s Disease.

Gehrig wore the number 4 and was nicknamed the “Iron Horse” due to the record setting number of consecutive games he played during his career. He had over 200 hits in eight seasons and a career average of .340. He is most noted for his playing streak, which stretched to 2,130 consecutive games, a Major League record which stood for 56 years. Lou Gehrig also set an American League record with 184 runs batted in 1931. He holds the record for most career grand slams (23) and won a Triple Crown in 1934. Gehrig led the American League in home runs three times, RBIs five times, and won the League MVP in 1936 when he hit 49 home runs, scored 167 runs, and batted .354.

On May 2, 1939 in a game against the Detroit Tigers at Briggs Stadium, Gehrig then Team Captain took himself out of the game. He never played again. On July 4th, 1939, with more than 62,000 fans present the Yankee organization held "Lou Gehrig Appreciation Day." On this day, Lou Gehrig gave his famous “Luckiest Man on the face of the Earth” speech.

Gehrig was the first player to have his number retired (No. 4). The following December, he was unanimously elected into the Hall of Fame when the Baseball Writers Association waived the existing rule which required a player to be retired one year before being elected.

On June 2nd, 1941, Lou Gehrig died in New York from ALS.