

# Patient and Family Resource Guide to ALS

## Section 11 Useful Resources

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# Useful Resources

## Personal Computers

*“The fact is that my computer has been as vital to my well-being as my wheelchair or any medicine.”* —Ben, a Chicago-area ALS patient

Most people with ALS have found that personal computers add significantly to their ability to cope with the disease. As the disease affects each person in different ways, so, too, the personal computer can help each one in different ways. The personal computer can be thought of as an extension of yourself. It can help do many things you can no longer easily do. The computer can provide information about ALS, support from other patients, and techniques for dealing with limitations imposed by the disease. It can provide a way to communicate with relatives and friends, or serve as the “voice” for a person who can no longer speak. It can help you shop online when your ability to physically shop is limited or help you read a book if you can no longer turn pages. There is a good reason for calling it a “personal” computer—it can be adapted to your personal needs. All you need is an open mind, some patience, and a positive outlook.

A recently diagnosed person with ALS (PALS) will probably be able to use a computer, tablet or smart phone in a conventional manner. The many adaptive devices available allow each patient to continue to use and enjoy the computer regardless of the progression of their ALS. If using a standard keyboard becomes difficult, an on-screen keyboard can be used. This keyboard can be controlled by many different devices ranging from a thumb switch, such as the one used by English physicist Dr. Stephen Hawking, to a device activated by blinking an eye.

## Some Uses for Personal Computers (with appropriate software)

**Environmental control:** A computer can be adapted to help control the world around you. For example, it can turn lights on and off, turn the TV on and off, change TV channels, or signal for help to someone in another room or to a neighbor. With devices like Google Home or Amazon Echo, you can play music, ask about the weather, sports scores or the stock market or even order your groceries.

**Household administrative chores:** Classical uses for a PC include budgeting, taxes, tracking investments, and tracking income and expenses. Banking and investing can be done online. Even if your handwriting is illegible, you can still pay bills or perform other personal business transactions. Managing medical expenses is especially useful for PALS. On a simple spreadsheet you can record physician, laboratory, hospital, equipment, and prescription charges; insurance payments; and out of pocket costs. The spreadsheet can be very useful at tax time and for negotiating with insurers.

**Recording disease progress:** A computer can help to track your medical condition. You can record symptoms as they appear or change, the effects of therapies (such as vitamin and mineral supplements, medications, activities, exercises, and alternative medicine techniques), and the results of medical tests. Keeping a record of data provides a picture of the disease progression. It can act as a base for discussions with your physician and may even help the physician make recommendations for therapies. There are apps being developed to track ALS disease progression that will be more widely available in the near future.

**Communication assistance:** For many PALS, losing speech is the most frustrating aspect of the disease. If this happens to you, a computer can help restore your ability to communicate. It can take a phrase you have keyed, convert it to speech and play it through a speaker. Commonly used phrases can be stored in the computer and played when they are needed. With a speakerphone, you can even make telephone calls. Refer to [Section 7, Speech, for information on communication devices.](#)

**Correspondence:** At some point you may find that your handwriting is illegible and that it may be easier to type and communicate online.

**Games:** The computer makes a superb game platform. A number of games are included as part of the computer's basic programming support or can be easily purchased online.

### **How Is the Internet Useful to PALS?**

Many websites offer information about ALS, such as current and contemplated therapies, advocacy efforts and equipment designed to assist PALS in their daily lives. Information about legislation passing through Congress that relates to ALS can also be found at [www.lesturnerals.org](http://www.lesturnerals.org) or other medical advocacy groups. You can follow its progress and express your opinions to your Senators and your Representatives. As with any collection of information, care needs to be taken to realize that some “quacks” also frequent the internet. Chat rooms and bulletin boards are helpful in exposing dubious products and therapies. Of course, you can always contact a member of the Foundation's Home and Community Team or our physician to confirm the truthfulness and appropriateness of information that you read online.

**Support groups:** ALS support groups are available online. PALS and caregivers share ideas and experiences, offer help and emotional support. The interchange is not immediate in an online support group, but PALS and caregivers are involved from next door to literally around the world. “Chat rooms” are a way of communicating with others in a conversational dialog. Chat rooms occur on a scheduled basis. The Les Turner ALS Foundation also offers virtual, real-time support groups, allowing those who cannot attend in person to join a support group. Check the Foundation's website at [www.lesturnerals.org](http://www.lesturnerals.org) to learn more.

**Shopping:** Online shopping can replace nearly all physical shopping and can save time and energy for persons with ALS.

**Reading:** If you have difficulty holding a book, newspaper, or magazine and turning pages, you can easily find the information online. Books, including access to your local library, many of which are free, can be downloaded and read on a computer. Most newspapers and many magazines have online versions and you can have access to publications of every locality as well as national, international, and specialty publications.

**Electronic Books:** For many people with ALS, the pleasure of reading books becomes a casualty of the disease. Books become too heavy to hold. Pages are too hard to turn. The struggle outweighs the pleasure of reading. Electronic books, commonly referred to as e-books, are readily available.

There is no dearth of formats for e-books or of devices for reading them. A little bit of research is needed to decide on the environment best for you.

The basic formats for electronic books are Microsoft Reader and Adobe Acrobat e-Reader. All have the capability of setting multiple bookmarks, a search function, selection of text size for clarity, highlighting, and annotating. You can read an e-book on a computer, either desktop or laptop, Windows PC or Macintosh; a mobile phone, tablet/iPad.

**Microsoft Reader** is free computer software for electronic books. It is available for computers running Windows, but not for Macintosh computers. The books are downloaded to and read on the computer, tablet or smart phone.

**Adobe Acrobat eReader** is also free computer software. Books in this format are read on a computer, either a desktop or laptop, Windows or Macintosh.

Acquiring an e-book is done on the Internet. Some suppliers of e-books include:

Amazon.com	<a href="http://amazon.com">amazon.com</a>
Barnes and Noble	<a href="http://bn.com">bn.com</a>
Book Bub	<a href="http://www.bookbub.com">www.bookbub.com</a>

Purchasing a separate device, as is the case with an iPad, Kindle, etc, adds to the cost, but significantly enhances the convenience and the prices are reasonable.

## Hobbies

Hobbies that can no longer be actively pursued due to physical limitations can still be followed “virtually” through the myriad of internet sites devoted to almost any endeavor.

## Transportation and Travel

*The Foundation is not affiliated with any of the transportation companies listed below. You will need to contact the company for rates, service areas, etc.*

**Open Taxis** – Fully accessible vehicles equipped for manual or power wheelchairs. For additional information and/or scheduling call 773-657-3006

**Special Needs Chicago:** Fully accessible vans and service cars available with disability trained and experienced drivers. Transportation provided on a same-day basis with a 2-3 hour advance call. For additional information contact Michelle Dacy, General Manager, at 630-668-9999.

**Pace:** Special bus service is available for wheelchair-bound patients in various suburbs and the city.

**RTA ADA Paratransit program** – program available to those whose disability and/or health condition prevents them from using CTA and/or standard PACE service. These vehicles are equipped to transport patients on a ventilator. Patients must apply and be approved to use this service. Call 312-663- 4357 for an application.

**First Transit, Inc.**– program through the Illinois Department of Healthcare and Family Services to assist patients on Medicaid with non-emergent transportation needs. 877-725-0569

**Handicapped Parking Privileges:** For information about cards or license plates: 217 782 2434 or 312-793-1010.

**Travel Information:** Smarter Travel; <https://www.smartertravel.com>

## Van Conversion

When you are considering using a manual or power wheelchair, you must consider how you will transport it in your present car or vehicle. You may need to consider a mini-van or full-size van, depending on the person's ability to transfer from the car to the wheelchair, the strength and ability of the caregiver, and your lifestyle and resources. Get good advice before purchasing the wheelchair or van. Consider that your garage may need a ramp or other modification. If you do not use a garage and you park on the street, you may need a special parking zone sign from your city or town for your parking area.

### Accessible Van-Rental and/or Sales

- **Mobility Works**, 888 378 9166 or [mobilityworks.com](http://mobilityworks.com) is a nationwide supplier of wheelchair accessible vans and driving aids. They stock new and pre-owned mobility vans, rental vans and a variety of adaptive driving equipment. Locations in Illinois include Niles, Villa Park and Plainfield.

- **Sherman Dodge**, Skokie, IL 855 828 5268, [www.shermanmobility.com](http://www.shermanmobility.com)
- **New Ability Inc.**, Melrose Park, IL, 708 345 3939. Provides adaptive vehicle equipment ie: hand controls, ramps, etc. [www.newabilityinc.com](http://www.newabilityinc.com)
- **Wheelchair Getaways** – van rentals, [www.wheelchairgetaways.com](http://www.wheelchairgetaways.com) 800 637 2597 or 847 967 2083.

## Regional Transportation Authority (RTA)

The RTA offers a Reduced Fare Permit for senior citizens and qualified persons with disabilities to ride **ALL RTA** services at a reduced rate. These services include:

- CTA Buses
- Rapid Transit
- Pace Buses
- Metra Trains in Cook, DuPage, Lake, Kane McHenry and Will counties

Benefits of using the reduced permit are fares that are approximately half the full fare and you save on gas.

### Who is eligible for the permits?

- All seniors 65 years or older
- Persons with disabilities who have been prequalified by Social Security, the Veterans Administration or their doctor.

### How do persons with disabilities apply?

- You will need the following pieces of identification: Driver's License, State ID card or Passport and a Veterans Validation of 100% disability or valid Medicare card as proof of disability. This can be obtained by calling the Social Security Administration at 800 772 1213, visiting any Social Security Office or going online at [www.ssa.gov](http://www.ssa.gov)

### How long does it take to receive my permit?

- It takes approximately three to four weeks to receive your permit. If you have questions call 312 913 3110

## Alternative Treatments

PALS have always been interested in alternative treatments. With the rise in the use of social media and the ease of mass communications, the promotion and marketing of such treatments has never been easier. As a result, the International Alliance of ALS/MND Associations, of

which the Les Turner ALS Foundation is a founding member, has developed a “Statement on Alternative Treatments, which follows:

## **International Alliance of ALS/MND Associations**

### **Statement on Alternative Treatments**

The International Alliance of ALS/MND Associations recognizes the interest that people affected with ALS/MND can have in seeking alternative forms of treatments.

The International Alliance supports the individual’s right to choose what treatment they wish to undertake but would strongly encourage anyone considering any treatment to fully discuss the issues around such treatment with their doctor, health care professional and family before making a final decision.

The International Alliance believes that treatments for and research into ALS/MND should be legal, have a sound scientific rationale and have the potential to bring us closer to the cause, treatment or cure for the condition.

The International Alliance only recommends treatments that have been proven through thorough scientific testing and clinical trials to be safe and effective.

An excellent resource in identifying tested alternative treatments is ALS Untangled, through the Duke University ALS Clinic, at [www.alsuntangled.com](http://www.alsuntangled.com)

The International Alliance recommends all providers of non-proven and/or alternative treatments for those affected by ALS/MND to conduct scientific research and submit papers to the appropriately recognized journals so that peer review can be undertaken and the information can be shared amongst the whole ALS/MND community.

### **Guiding Principles**

When looking at alternative treatments, the International Alliance would recommend that you give careful consideration to the following questions to help you think through the issues and to make an informed decision:

#### **What claims are being made for the treatment?**

Often there will be claims of stopping the progression of the disease or a reversal/improvement in symptoms. Check who is making these claims and what evidence there is to back them up. If the claims are genuine then they will have been published in recognized scientific journals and there will be published results of clinical trials. Often there will be testimonials from people with ALS/MND of the improvements they have experienced. It is important to find out how

long the improvements lasted for as there is a recognized phenomenon called the “placebo” effect which occurs when individuals experience beneficial effects only because they believe that they’re receiving beneficial treatment. Does their doctor agree that there has been a benefit in undergoing the treatment?

### **How are people finding out about the treatment?**

Is it mainly being promoted through the mass media, i.e., newspapers, magazines, the Internet, etc.? Any genuinely safe and effective treatment will be promoted and recommended by your doctor and the ALS/MND associations.

### **Who is offering the treatment?**

Is the treatment being offered by an appropriately recognized institution? Is it being offered by a number of different institutions or just one? If it’s just one then why are others not following and doing the same? Do you have to travel to another country to receive the treatment and if so why is it not available in your country?

### **What are the risks involved?**

Is it clearly stated what risks are involved in undergoing the treatment? Are there any side effects and how long may they last? Has the treatment been proved to be safe and effective and if so how was this done? Don’t forget that there can be financial risks associated with treatment particularly if it is expensive and involves overseas travel.

### **What follow-up monitoring is carried out after the treatment?**

Follow-up monitoring is extremely important not just for you but for all those with ALS/MND. For you it is important to know that you will be monitored so that many adverse effects can be picked up as soon as they occur. For all those with ALS/MND they need to know if the treatment is successful and that they can rely on the claims being made.

### **Web Sites Related to ALS**

There are numerous web sites related to ALS. We recommend the following:

The Les Turner ALS Foundation [www.lesturnerals.org](http://www.lesturnerals.org)

ALS Untangled [www.ALSuntangled.com](http://www.ALSuntangled.com)

Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS)  
[www.alsconsortium.org](http://www.alsconsortium.org)

Centers for Disease Control (CDC) [www.cdc.gov/als](http://www.cdc.gov/als)



ALS Association

[www.alsa.org](http://www.alsa.org)

Muscular Dystrophy Association

[www.mdaua.org](http://www.mdaua.org)

International Alliance for ALS/MND Associations

[www.alsmndalliance.org](http://www.alsmndalliance.org)

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