

## Section 11

### 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 Gill, a Chicago area ALS patient

Many 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 shop in the traditional manner 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.

Personal computers have evolved over the years to nearly mind-boggling capability and complexity. However, just as an intimate knowledge of the internal combustion engine is not necessary for driving a car, you don’t need to understand how a computer works in order to use it. 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 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.

**Household administrative chores** Classical uses for a PC include budgeting, taxes, tracking investments, and tracking income and expenses. Banking and investing can be done on-line. 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.

**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 G, Speech, pages 5–9 for information on communication devices.

**Correspondence** At some point you may find that your handwriting is illegible. When connected to a printer, your computer becomes a very smart typewriter.

**Games** The computer makes a superb game platform. A number of games are included as part of the computer's basic programming support. A computer store has shelf after shelf of additional computer games.

## **The Internet**

A computer can be connected to the telephone line or to the television cable by a device called a modem. With the modem and a subscription to an Internet service provider, you can reach the Internet. Choosing among the thousands of Internet service providers can be a daunting task. A few of the big names are America On-line, CompuServe, Prodigy Internet, and Microsoft Network. The Yellow Pages will list Internet service providers in your area. Internet locations are often called web sites. Web is short for World Wide Web, the system for making sense out of the many thousands of sites that are available on the Internet.

## **What Is Electronic Mail?**

Lack of mobility and possible loss of speech may mean that you cannot easily communicate with friends and relatives. People of all ages have computers today and electronic mail, commonly known as e-mail, is an excellent way to reach them. The cost of sending a message to a friend in Australia is the same as sending one to your next door neighbor. The Lois Insolia ALS Center staff, as well as the Les Turner ALS Foundation staff, can be reached through electronic mail. Using e-mail to ask questions and receive answers can often be less frustrating than trying to communicate with someone directly. Electronic mail requires a connection to the Internet.

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

Many Internet sites 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 on the Internet. You can follow its progress and express your opinions to your Senators and your Representative. 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.

## **Support groups**

ALS support groups have been formed within Internet bulletin boards and message boards. PALS and caregivers share ideas and experiences, offer help and emotional support, just as in a support group sponsored by the Les Turner ALS Foundation. The interchange is not immediate in an on-line 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.

### **Shopping**

The many retailers and rapidly growing e-businesses on the Internet offer virtually every available product or service. When shopping trips to conventional stores become difficult, the Internet can provide an easy alternative.

### **Reading**

If you have difficulty holding a book, newspaper, or magazine and turning pages, the Internet can help. Dictionaries and encyclopedias (even Britannica!) are available for on-line reading and reference. Other books, many of them free, can be downloaded and read on a computer. Most newspapers and many magazines have Internet versions. Most newspaper and magazine material is free on the Internet, and you can have access to publications of every locality as well as national, international, and specialty publications. You can browse the on-line New York Times or Washington Post, the local newspaper, or the newspaper from a former home town.

### **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.

### **WEB SITES RELATED TO ALS**

There are hundreds of web sites related to ALS. They have been organized into categories under an ALS Web List, which may be found at <http://www.geocities.com/sweekes99/ALStitle.html>

The Les Turner ALS Foundation site is at <http://www.lesturnerals.org/>

Other noteworthy national sites are:

ALS Association (ALSA), [www.alsa.org](http://www.alsa.org)

Muscular Dystrophy Association (MDA), [www.mdaua.org](http://www.mdaua.org)

Instructions at each site explain how to get an e-mail summary of the new material for the site.

## **ELECTRONIC BOOKS**

For many ALS patients, 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. To the rescue comes an item of our digital age, electronic books, commonly referred to as ebooks.

You can select among the books available in electronic format, purchase them with a credit card, and download them to your computer or ebook device. No waiting for delivery and no shipping charge. The price and discounting are about the same as for print books.

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

There are three basic formats for electronic books: Microsoft Reader, Adobe Acrobat eReader, and Palm Reader. All have the capability of setting multiple bookmarks, a search function, selection of text size for clarity, highlighting, and annotating. Books and documents from the Internet, either in plain text or in the Internet's hypertext format, can be used as well.

You can read an ebook on a computer, either desktop or laptop, Windows PC or Macintosh; or on a handheld personal digital assistant (PDA), Pocket PC or Palm.

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**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. It is available for a Palm handheld device as well.

**Palm Reader** is free electronic book software for Palm devices as well as for Pocket PCs and for Macintosh and Windows computers.

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Barnes and Noble [www.bn.com](http://www.bn.com)  
Powell's          [www.powells.com/ebook/ebookeditions.html](http://www.powells.com/ebook/ebookeditions.html)

The Powell's web site has an interesting chart comparing the capabilities of the four formats and the devices each supports. It's a good spot to initiate research on the many alternatives.

A fourth option is one of Franklin Electronic Publishers three relatively inexpensive models of **eBookman**. The format is proprietary. The eBookman can handle audio books as well as electronic books. Many titles are available, many of the free. More information can be found at: <http://www.franklin.com/ebookman/>.

Classics and public domain books are available at a very minimal cost from the retailers mentioned above. Alternatively, they are available at no charge on the University of Virginia's web site. Free books can be downloaded using Microsoft Reader and Palm devices. You can find their offerings at <http://etext.lib.virginia.edu/ebooks/>

Purchasing a separate device, as is the case with a Palm or Pocket PC handheld, adds to the cost, but significantly enhances the convenience. It's hard to take a computer to bed with you or in the car during a road trip. And since electronic books are not specifically for the disabled, the prices are reasonable.

## **TRANSPORTATION AND TRAVEL**

**Chicago Disability Transit** 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. Passenger plus two companions can ride for the price of one. For additional information contact Michelle Dacy, General Manager, at 630-653-9815. To make a reservation call 312-335-1244.

**Pace** Special bus service is available for wheelchair-bound patients in the following suburbs: Evanston, Glencoe, Glenview, Golf, Kenilworth, Lincolnwood, Morton Grove, Niles, Northbrook, Northfield, Skokie, Wilmette, and Winnetka. 847-364-7223.

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

**Travel Information** Handicapped Travel Newsletter. P.O. Drawer 269, Athens, TX 75751; 903-677-1260.

**Frommer's A Guide for the Disabled Traveler**, by Frances Barish. Simon & Schuster, 1230 Avenue of the Americas, New York, NY 10020; 212-698-7000.

## **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 the city for your parking area.

## **Accessible Van-Rental and/or Sales**

- **Associated Rollx Vans**, Savage, MN, 800-956-6668 or [www.rollxvans.com](http://www.rollxvans.com); rents and sells vehicles.
- **Midwest Mobility, Inc.** 800-809-3738 or [www.midwestmobility.com](http://www.midwestmobility.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.

- **New Ability Inc.**, 708-345-3939. Sales only.
- **VMI Vans**, Phoenix, AZ, 800-348-VANS or [www.vantagemobility.com](http://www.vantagemobility.com).
- **Wheelchair Getaways** 800-637-2597 or 847-967-2083.

### **ALTERNATIVE TREATMENTS**

PALS have always been interested in alternative treatments. With the rise in the use of the internet 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 rational 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.

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 it is that 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.

**ALS Veterans Registry**

This study is currently recruiting patients. Sponsors and collaborators are the Department of Veterans Affairs and the ALS Association. The purpose of the national registry of living veterans with ALS is to identify as completely as possible all veterans with ALS and to collect data which will be available for approved studies examining the cause(s) of ALS. A secondary objective is to provide a mechanism for the VA to inform veterans with ALS about clinical trials and other studies for which they may be eligible.

Diagnosis of ALS will be verified by study neurologists via medical record review. Registry participation includes a bi-annual telephone interview to collect functional status data.