



**The Kessenich Family
MDA ALS Center**
1150 N.W. 14 Street (M-712)
Suite 700
Miami, FL 33136

Non Profit Org.
U.S. Postage
PAID
Miami, FL
Permit N° 438

*«If there is a lesson
you can learn from me
let it be: Stubbornness is
a virtue when you use
it to succeed; live as
if each day may be your
last; use the power of
your mind and believe
that you're going to get
well; fill yourself with
enthusiasm for life...
And perhaps we can all
grow old together»*

Alec P. Courtelis

CALENDAR

SUPPORT GROUP DATES

Saturday, June 09	Location: University of Miami Hospitals & Clinics, 1475 N.W. 12th Avenue at 12:00 -1:30 p.m. Room 1301
Saturday, August 11	
Saturday, September 8	
Saturday, November 10	
Saturday, December 8	

SUPPORT GROUP FOR CAREGIVERS ONLY

Saturday, July 14
Saturday, October 13



Kessenich Family MDA ALS Center Newsletter

Volume 3, Issue 2

Summer, 2001

KESSENICH CORNER

Dedicated to the Memory of MARK KESSENICH, JR.:



THE FOUNDER AND BENEFACTOR OF THE KESSENICH FAMILY MDA ALS CENTER AT THE UNIVERSITY OF MIAMI

By: Walter G. Bradley, DM, FRCP
*Medical Director, Kessenich Family
MDA ALS Center*
Professor and Chairman
Department of Neurology
University of Miami School of Medicine

Mark Kessenich was a wonderful man, and perhaps one of the most strong willed people that I have ever met. He hated suffering from ALS, and fought against the way that it interfered with his life every step of the way. He continued to trade on his computers until the last few weeks of his life. Until the last winter of his life he insisted on maintaining his regular schedule of wintering in Palm Beach and summering in West Hampton. This involved enormous expenditure of effort on the part of his many wonderful caregivers, and in particular I want to commend his main nurse, MarioTyson, who stayed with

Mark through thick and thin. Mark believed that his life was his own, and that it was he who decided his own fate. The development of ALS was a severe blow to this belief, and he never really accepted that he would not beat the disease. At one time he was taking thirty-six different medications and alternative medicine preparations, all of them aimed at arresting the disease.

Mark first came to see me when I was running the University of Miami MDA Clinic, seeing patients as an academic neurologist and Chairman of the Department of Neurology. I had a clinic secretary, and the ability to refer him to all the specialists that he needed, pulmonary, gastroenterology, physical therapy, respiratory therapy and so forth, but only with separate appointments in different offices around the very large University of Miami Medical School Campus. After a few visits he said: "You don't know how to look after ALS patients". This set me back on my heels, since I had been caring for ALS patients for thirty years. "You need a multidisciplinary clinic with nurses, physical therapists and so on, for the patient to see all in the same place at the same visit, and not to have to ask them to come back for multiple appointments". I pointed out that health insurance would not cover the cost of such a multidisciplinary team, to which he said: "I'll get you the money if you'll keep me alive". I said that if he got me the money,

we would keep him alive forever. Sadly, I was not able to keep my end of the bargain, though he did live for seven years, albeit the last three on a ventilator. On the other hand, he and his family and friends more than fulfilled their commitment. They have endowed the multidisciplinary center, the Kessenich Family MDA ALS Center. We are now able to provide multidisciplinary care in the "one-stop shopping" format that Mark envisioned. At the clinic, each patient sees the specialized ALS neurologists, the rehabilitation neurologist, the ALS nurses, the pulmonologist, gastroenterologist, respiratory therapist, physical therapist, occupational therapist, psychologist, social worker, dietician, speech language pathologist, and others as necessary. We see about 250 new ALS patients a year and care for about 250 ALS patients on an ongoing basis. We have an active clinical trials division studying new drugs for the treatment of ALS. We have a new Home Visit Program run by our nurses to allow the Kessenich Center to remain in contact with patients and their caregivers if they are not able to get to the center itself. We have a very active support group that meets monthly with sessions given to patients and to caregivers, education and support. We are part of a national database, the ALS Care Program, supported by a grant from Aventis Pharmaceuticals. I sit on the National Advisory Board of ALS C.A.R.E., which is working to enhance ALS patient care nationally and to bring the multidisciplinary clinic concept of Mark Kessenich to an every increasing proportion of ALS patients in the United States and Canada.

We are going to miss Mark for his vision, his unwillingness to accept anything other than the best, and for the question that he unfailingly asked whenever I saw him: "Why



DOCTOR CORNER

SIALORRHEA OR DROOLING IN ALS PATIENTS

By Oscar Farronay, MD



Excess saliva is a common feature in patients diagnosed with ALS and results in increased drooling, choking or coughing.

Drooling is an embarrassing and distressing symptom that is not believed to be due to overproduction of saliva but to decreased ability to swallowing. In patients with ALS who has swallowing difficulties, saliva is not swallowed automatically, and repetitive volitional swallowing is needed to compensate for this. Patients should be reminded to swallow before trying to open the mouth or speak, and to be aware of the need to swallow frequently to keep the mouth free of saliva.

Saliva is a sticky fluid produced in the mouth, mainly by several pairs of glands known as salivary glands. The main glands that produce saliva are the parotid glands, which produce almost 50% of the saliva in the mouth. The second main saliva producers are the submandibular glands. Saliva is also produced by numerous other glands. Including the sublingual glands and several other small glands in the mucous membrane of the mouth. The parotid glands are located just in front of the ears, the submandibular glands are located under the lower jaw, and the sublingual glands are located under the tongue.

Saliva moistens and softens all food that is taken into the mouth. It helps in the chewing and swallowing of food. It also keeps the mouth moist, which is important for comfort. Saliva is very important in digesting food. It contain an enzyme called ptyalin that breaks down all starches into maltose.

Saliva secretion is well controlled by the autonomic nervous system. The sympathetic nervous system decreases the salivary secretion and increases its «stickiness», and the parasympathetic nervous system increases the volume and wateriness of the saliva. Classically, when we are in a stressful situation or anxious, the secretion of saliva is decreased due to the sympathetic action. On the other hand many medications that contain anticholinergic components may block the parasympathetic action and decrease the secretion of saliva.

Based on the evidence that anticholinergic medications decrease the secretion of saliva, pharmacological interventions have been proposed. Anticholinergic therapy includes atropine (SalTropin 0.4 mg. 2-3 times daily), amitriptyline or Elavil (prescribed in low dose, initially 10 mgs at bed time, then incremental doses of 10 mg to 50 mgs weekly), glycopyrrolate or Robinul (1 mg daily, may be increased up to 2 mg 2-3 times daily), scopolamine transdermal patch applications, and sublingual hyoscine. It is also important to be aware that the side effects of the anticholinergic medications include drowsiness, sleepiness, constipation, blurred vision, urinary retention and cardiac arrhythmia. Confusion and hallucinations can occur especially in elderly patients. All anticholinergic drugs have to be given with caution in patients with glaucoma, prostatic or gastrointestinal obstruction.

If saliva or mucus from other sources such as the nose or lungs are disturbing swallowing because of thick secretions, N-acetylcysteine or a beta blocker (metoprolol) may be helpful.

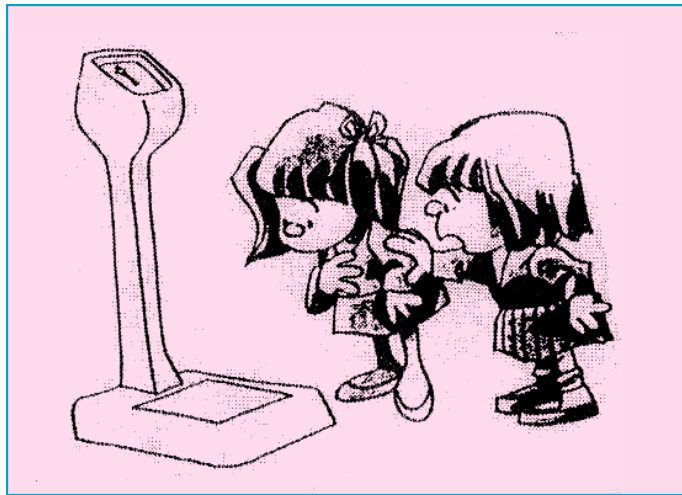
Gastro-esophageal reflux disease, is a condition that may aggravate swallowing difficulties. Therefore in ALS patients suffering from reflux, proton pump inhibitors such as omeprazole should be administered.

Other modalities of treatment for drooling have been developed recently. One of the most effective methods consists of injecting Botulinum toxin A into the salivary glands, mainly the parotid glands. The goal is to block acetylcholine release at the parasympathetic nerve endings in the salivary glands.

Currently, a few medical centers in the United States and Europe have been using this procedure and the results are satisfactory, effective in 60% - 75% of patients..

In our Kessenich Family MDA ALS Center we are doing a pilot study in patients with excessive drooling who have not been help by conventional anticholinergic medications. And our results will be published soon. Our protocol consists of injections of a minimal dose of Botulinum Toxin A of 7.5 units into each parotid gland. After an evaluation in 2 months, we may increase the dose of Botulinum toxin to 15 units into each parotid gland. The most important side effect is increased swallowing difficulty due to weakening effect on the nearby muscles. This effect is transitory, disappeared by itself in 3-5 days. Another side effect reported is pain at the site of injection.

Surgical measures include denervation of salivary gland by transtympanic neurectomy, salivary duct ligation, excision of the sublingual glands, and laser intraductal photocoagulation of bilateral parotid glands. Several complications have been reported when using surgical procedures, including glandular infections, swelling of the gland, and bleeding. Radiation therapy of the parotid glands is another alternative measure to control drooling. It is currently used in several centers. Its results so far show moderate control of drooling. The main risk is excessive dryness of the mouth and soreness of the tongue.



“Don’t step on it... it makes you cry”

IMPORTANT NUMBERS

- Kessenich Family MDA ALS Center **305-243-7400**
- **1-800-690-ALS1**
- www.miami-als.org
- Muscular Dystrophy Association (National Patient Information) 1-800-572-1717
- www.mdausa.org
- St. Petersburg 717-576-5202 or 1-800-393-8552
- Palm Beach Gardens 561-242-5084 or 1-800-289-0535
- Miami 305-717-9937 or 1-800-572-0085
- Broward (954) 970-9696 or 877-970-9696
- ALS Association 1-800-782-4747
- www.alsa.org
- National Caregiving Fdn 1-800-930-1357
- National Family Caregivers Assn 1-800-896-3650
- www.nfcacares.org
- Foundation for Hospice and Homecare 202-547-6586
- National Hospice Org. 1-800-658-8898
- A.D.E.L.A. Asociación Española de Esclerosis Lateral Amiotrófica
- www.advernet.es/adela/index.htm
- Social Security Online 1-800-772-1213
- www.ssa.gov
- The Feeding Gastrostomy Information: www.iinet.net.au/~scarffam/gtube.html
- ALS Digest (Bob Broedel): To subscribe, please e-mail to bro@huey.met.fsu.edu

If you need a referral to see one of our satellite centers, please call 305-243-7400 or 1-800-690-ALS1.

NOTES:

*** We are seeking volunteers to assist in running the ALS Center and in assisting patients and families at home. Please call 305-243-7400. This could be family members who have had experience with ALS patients and now have time to volunteer, or even health care professionals.**

QUESTION & ANSWER CORNER

Q My husband is bed-bound how can I prevent pressure ulcers in his back?

every two hours. This will prevent pressure to vulnerable areas as: back of head, shoulder blades, elbows, hips, tail bone and heels. Patients with ALS tend to loose weight and body mass and in some patients pressure sores develop easily. Placing a pillow between their thighs prevents knees from rubbing against each other and skin lesions to the area. Nutrition plays a very important role in skin texture while patient is confined to bed. A diet high in calories and proteins is essential for maintaining proper skin turgor. Swallowing and lack of appetite is one of the challenges that people with ALS face every day often meaning that they cannot get enough nutrients.

A It is very important for the bedbound patient to change position frequently, at least

Elsa Cusido, RN

Q Is there any physical pain in ALS?

important that you talk to your doctor, nurse or physical therapist about your pain in order to find the source and give proper medical management.

Muscle cramping is very common in ALS patients. Try to pace your activities so you do not overwork your muscles and participate in an exercise program. Quinine Sulfate is the medication of choice to control this problem.

When you lose your strength and it is not possible to move each joint through its complete range of motion, the muscles, tendons and ligaments stiffen, producing joint pain. Nonsteroidal anti-inflammatory medication can be useful, together with a range of motion exercise program. Shoulder joints can sublux (dislocate), when shoulder weakness appears and no support is provided.

The reduced movement leads to increasing skin pressure on bony areas like the hips, heels, etc., and this is perceived as pain. To treat this type of pain you should use an adequate mattress (air or gel), repositioning at least every 2 hours and foot positioners. Maintenance of posture throughout the disease has implications for control of pain. As muscles weaken, special positioning devices may be needed to maintain normal alignment of the body like neck support, splints, back support, lateral support in the wheelchairs, head rest, etc.

A full multidisciplinary assessment is necessary to prevent and treat the pain and improve quality of life.

GINNA P. GONZALEZ, RN, BSN, CGRN

ANNOUNCEMENTS

DOUBLING YOUR DONATION

Does your company have a matching gifts programs? If so, you could double your donation to Kessenich Family MDAALS Center. Many companies match the cash gifts given by their employees.

Check with your employer to see if the donation you make to us can go twice as far.



SI USTED NECESITA INFORMACION EN ESPAÑOL

cerca de la enfermedad, por favor contactenos y con mucho gusto se la daremos Llamenos al 305-243-7400

nuestro web-site tiene la posibilidad de traducir la información de ingles a español

www.miami-als.org



PATIENT CORNER

NEW PHONE SERVICE FOR PEOPLE WITH SPEECH DISABILITIES

Imagine that you have a speech disability and people can't understand what you say. How do you talk to a friend who lives in another part of the city, order a pizza, or tell the 911 operator what kind of help you need? Until now, many Americans with a speech disability have faced formidable obstacles to telephone use, but a new service called Speech to Speech is overturning this barrier.

Speech to Speech Relay (STS) is a service mandated by the Federal Communications Commission that enables people with a speech disability to use their own voice, voice prosthesis, or communication device to make a phone call. The service became available nationally March 1, 2001.

Commonly people who have a speech disability cannot communicate by telephone because the public, friends, or even family members cannot readily understand their speech. This is sometimes the case for people with cerebral palsy, ALS, MS, muscular dystrophy, Parkinson's disease, or others who are coping with limitations in the aftermath of stroke or traumatic brain injury. Those who stutter or had a laryngectomy may also have difficulty being understood. In general, STS can be used by anyone with a speech disability or anyone who wishes to call someone with a speech disability. STS calls can also be made by people, or to people, who use a TTY, or other TRS-communication modes such as VCO (voice carry over), HCO (hearing carry over), or to another person with a speech disability.



Some people who have a speech disability use a TTY (text telephone) to make calls, but many people are not able to employ that option. A TTY is a teletype-like device that is used by the deaf and hard-of-hearing, as well as hearing people who want to talk with another TTY user. The ability to type is a prerequisite of TTY use. People with a speech disability often have physical disabilities and therefore may not possess the required manual dexterity to type, or to type as fast as they wish. STS offers an alternative to a TTY, or to no phone communication at all.

STS is provided by TRS, or Telecommunications Relay Service, a little known service that has existed in all 50 states and District of Columbia since 1993, and is required by Title IV of the Americans with Disabilities Act (ADA). Originally created to accommodate telephone service for the deaf and hard-of-hearing, TRS permits those who communicate by a TTY and those who use a conventional telephone to communicate with each other. Because the technology of a TTY and conventional phones is not compatible, an interface is required. TRS is that interface. STS will be provided by each state's Telecommunications Relay Service. STS is available for English to English callers as well as Spanish to Spanish callers. However, it is important to note that STS does not provide a translation function, therefore it will not provide English to Spanish service. [Note: California and Texas offer English/Spanish translation Relay calls.] Use this link to view the STS dial-up number for your state. STS Relay, like TTY Relay, is available 24 hours per day, 365 days per year.

An STS phone call is a relayed call. That means the speech of one person is relayed to the other by a communication assistant in a three-way-call environment. The person who relays the call is known as the C.A., or Communication Assistant. C.A.'s are specially trained to be able to understand the speech of a wide variety of speakers whose speech disability may range from mild to severe. The C.A. facilitates the STS call by listening to the speaker with a speech disability and then restating what that caller has said word-for-word. The term for this verbatim restating of the speech is revoicing. The role of an STS C.A. is similar to that of the ASL (American Sign Language) interpreter who serves as the go between for someone who communicates using sign language and one who does not. The interpreter's role is to verbally state what is being signed by the individual using ASL, and to sign what is being spoken by the hearing individual. At no time does the interpreter participate in the conversation. Likewise, the STS C.A. only restates what has been said by the person with a speech disability.

Confidentiality of TRS calls is required by U.S. law. Communication Assistants (C.A.'s) are prohibited from disclosing the content of any Relay conversation regardless of content. They are also prohibited from keeping records of the content of any conversation beyond the duration of the call even if to do so would be inconsistent with state or local law. This code of confidentiality prohibits C.A.'s from intentionally altering a Relay conversation, and unless federal, state, or local law prohibits, C.A.'s must relay TRS calls verbatim, although a TRS caller may instruct a C.A. to summarize content of a TTY call. An exception to TRS-call confidentiality is Section 705 of

the Communications Act, 47 U.S.C. 605 which states that incidents that violate laws related to interstate or foreign communications are not protected by confidentiality. If such an illegal call were made through Relay, and if the person who made the call were brought to trial, the C.A. who relayed it could be called as a witness and forced to testify about its content. Since TRS calls are not documented nor are records kept of TRS calls, a C.A.'s testimony would be limited to his or her ability to remember the content of the call.

In United States, STS was founded by Bob Segalman, Ph.D. who has a cerebral palsy related speech disability. STS was first implemented in California by California Relay Service (CRS) and Sprint Telecommunications. Although exact data are difficult to locate, estimates are that 1.5 to 3.4 percent of the US population has a speech disability. STS is also offered in Australia and Sweden. Sweden offered STS prior to US or Australia. According to STS founder, Bob Segalman, New Zealand and South Africa are currently considering adopting STS.

Segalman conceived the concept of STS because he desired a faster, more convenient way to communicate by the phone than using a TTY. Typing is difficult for Segalman whose manual dexterity is limited. In order to establish STS in California, Segalman worked with California legislators, California's Public Utilities Commission (PUC), the California PUC's Deaf and Disabled Telecommunications Program, and California Relay Service. He argued that full telecommunications access should not be denied to people with speech disabilities. After a campaign that lasted several years, Segalman persuaded California PUC to offer STS on a trial basis. The trial was successful; California Relay Service adopted STS in June 1996. Sprint Telecommunications developed the technology employed in California's STS trial and startup.

Telecommunication providers compete on a state-by-state basis via a bidding process to win the state contract to provide TRS Services. A percentage of the TRS provider's gross revenues and a "contribution factor" determined by FCC are the means by which TRS costs are recovered. These contributions are administered in a TRS Fund by an association of local telephone companies known as NECA (National Exchange Carrier Association.) TRS providers are compensated for interstate TRS-use, per minute, based on a payment rate determined annually by FCC. Intrastate calls are paid by each state to its TRS provider based on a contractually determined rate or rates established through the aforementioned bidding process. The states usually recover costs for these intrastate calls through a very small surcharge applied to telephone bills of all telephone customers in the state.

Long distance calls made by TRS consumers are not paid for by NECA, by the state, or the federal government. Consumers who make a long distance or local toll charges (LATA) are billed for the toll call. However, making a Relay call, like an

ordinary local phone call, is free of charge unless a toll call is made. Relay calls are discounted because a TRS call takes longer than a non-TRS call. TRS callers should instruct the C.A. to bill to the caller's long distance carrier.

TRS is usually administered by a state's Public Service/Utility Commission, or by an agency within the state. In Texas, for example, the Public Service Commission oversees Texas Relay Service whereas the Department of Social & Health Services administers the Relay Service in the State of Washington.

A website dedicated to news and information about STS provides a list of each state's STS Relay toll free dial-up number. The site's URL is <http://www.stsnews.com>. This site also provides links to individual state Relay Service websites, and a monthly interview with Bob Segalman. Although not all states provide a website about their Relay Service, most do.

FCC also provides information about TRS/STS Services. Two useful URLs are <http://www.fcc.gov/cib/dro/dtffaq.html> that provides answers to frequently asked questions (FAQs) about TRS, and <http://www.fcc.gov/cib/consumerfacts.tr.html>, which provides information about TRS basics.

Phone numbers for TRS access and customer service are commonly printed in the first few pages of a phone book's white pages. The Public Service or Public Utility Commission, as well as Departments of Rehabilitation or Disability Services should be able to provide information about a state's Telecommunication Relay Service. Each state Relay Service has a customer service staff that educates citizens about TRS. Often the staff provides presentations to individuals, groups, businesses, and institutions. The customer service staff may also have information about state or other programs that assist individuals to obtain assistive technology that may be required to access TRS.

*This article preprinted with permission of author Katherine Keller. To learn more about STS visit <http://www.stsnews.com> ©2001 STSNews
More Information
Information about Title IV of Americans with Disabilities Act: <http://www.fcc.gov/cib/dro/title4.html>*



SAFETY CORNER

HURRICANE SEASON

South Florida's beautiful weather also brings with it tumultuous atmospheric conditions, better known as hurricane season. From June 1 through November 30, South Florida prepares for and anticipates the possibility of being affected by a hurricane. It will visit us every year, like an out-of state relative, and not bother us too much, hopefully. But if it does, you need to have a plan. Every year we give you information on what to do if a hurricane is headed your way and a disaster plan will be explained as follow: (Kessenich newsletter Volume I, Issue 1; Volume II, Issue 2)

- If you live in an evacuation zone, make plans to move inland to a friend or family member's house.
- If you live in a mobile home or are ELECTRICALLY DEPENDENT, you should evacuate to the closest hospital for any category of tropical storm or hurricane.
- Anyone needing assistance with their daily living including having electrically dependent medical equipment, should register for the EEAP (Emergency Evacuation Assistance Program) by calling the Office of Emergency Management at: **(305) 513-7700 TDD (305) 468-5402**

to receive an application. Applications are available in Creole, English, and Spanish and can be downloaded from the OEM Website. <http://www.co.miami-dade.fl.us/oem> When an application is turned into the office, the application should have all the information completed, including the doctor's signature. The key for this program is pre-registration, priority will be given to those who had the foresight to register ahead of time.

Special Needs Evacuation Centers are opened as places of safety for residents on the registry. Registrants are provided with transportation when eligible, additional medical personnel at the centers, and placement at safe facilities until the threat from the disaster is over.

Hurricane season is from June 1 to November 30. Information on what to do if a hurricane is headed your way and a disaster plan will be explain as follow

Before a hurricane comes knocking:

- Check your insurance.** If you live in an area that could be affected by a hurricane's storm surge, make sure you have flood insurance.
- Prepare and take** with you a box with your medical insurance papers, home owner insurance papers, valuable papers, etc.
- Plan a meeting place.** Make sure that everyone in your family knows where to meet, a relative's house, for example, to prevent family members from becoming separated.
- Pick an emergency contact.** Develop an emergency communication plan in case family members are separated one from one another.
- Ask an out of state relative** or friend to serve as the family contact. Make sure everyone in the family knows how to reach the contact person.
- Be ready to evacuate.** When an order comes to evacuate your area. Be ready for it. Have your car gassed up and your disaster kit ready to go.

Emergency Evacuation Assistance Program (EEAP)

Many of your neighbors may need assistance with their daily living, and a disaster occurring makes them even more vulnerable. OEM maintains a registry of Miami-Dade residents that will need assistance evacuating before or after a disaster. ITIS NOTJUSTFOR HURRICANES! Any sudden incident that may require evacuations could trigger the need to help some of these residents with special needs.

Special Needs Evacuation Centers (SNECS) are opened as places of safety for residents on the registry. Registrants are provided with transportation when eligible, additional medical personnel at the SNEC, and placement at safe facilities until the threat from the disaster over. Anyone who needs assistance, with their daily living, including having electrically dependent medical equipment should, register for the EEAP as soon as possible.

Contact us by e-mail or call directly at (305) 273-6790 • TDD: (305) 273-6711 to receive an application.

During a hurricane watch:

Stay aware. Listen to radio or television hurricane reports. Persons assigned to Special Needs Evacuation Centers should listen to the media and determine if they must evacuate and what time the centers will open.

Rumor Control Lines (IN DISASTER SITUATIONS ONLY):

Team Metro Hotline: 305 375-5656 • Haitian Support, Inc: 800-443-2951
State of Florida Emergency Information Line: 800-342-3557 • TTY: 800-226- 4329 • City of North Miami Beach: 305-919-0892
City of Miami: 305-579-1800 • City of Miami-Beach: 305-673-7222 • Broward County: 954-831-4000
Monroe County: 800-955-5504 • Palm Beach County: 407-233-3500

Check your emergencies emergency supplies, turn your refrigerator and freezer to the coldest setting and open them only if necessary. Store drinking water in clean bathtubs and bottles. You should lock and board up windows, stow away small objects that could cause damage in high winds, remove outside antennas, and if you are going to ride the storm out elsewhere, turn the utilities off.

During a hurricane warning:

Listen to your radio or television for official instructions. Stay inside the house away from windows and glass doors. Secure windows and shutters. If you've been ordered to evacuate, leave as soon as possible. Make sure you tell someone where you are going.

ABC's OF DME's

by Jean Hill, G.C.S., P.T.
Physical Therapist Kessenich Family MDAALS Center

What is one expecting when receiving DME (durable medical equipment)? Whether payments is from: medicare/medicaid, private ins, (supplemental/primary/secondary), out of pocket or other payment sources, there are some important issues to be considered upon receiving DME.

DME consists of equipment such as wheelchairs (w/c), canes, walkers, shower chairs, bedside commodes, splints, braces, etc... Some items can be acquired on either a rental or a purchase basis and others can only be purchased. Many DME suppliers differ in their return/exchange policies. Most policies range from 7 days to 30 days for returns & exchanges. Items like bedside commodes, shower chairs, eating and mouth products are non returnable for hygienic reasons. This means, once you sign a purchase slip or once the item container / box is opened it cannot be returned.

There are many reasons for using DME. To mention a few: 1) to increase safety, 2) to increase independence, 3) to increase mobility (i.c. transferring, walking, etc.), 4) to decrease the risk of skin breakdown &/or limited joint movement.

Some issues that need to be considered prior to your accepting a DME items(s) are:

- Does the supplier measure you for a w/c, splint or brace? If at all possible, request to be measured to ensure proper fitting. Upon receiving the splint/brace, try it on, remove it and check for any red pressure areas on the skin. If there are any pressure areas, the supplier should assist in correcting the problem.
- Check the w/c. Do you need elevating legs or removable armrests? Is the w/c too wide on too narrow?
- Check to make sure the shower chair or bedside commode fits in the shower or bathroom to suit one's needs.
- Always ask the supplier about their return/exchange policies on the items you plan to purchase. If there is a problem with an item, don't put it off. bring it to the supplier's attention as soon as possible. Before the date the item can no longer be returned, if you are not satisfied & the product does not meet your needs, you can return/exchange the item.

The physician prescribes specific DME because it is medically necessary in relation to one's condition. An item that is medically needed but is not properly fit will do more harm than good. A DME that is placed in the corner, closet or garage because it does not fit your special needs is no good to anyone. Also, accepting an inappropriate item can keep one from receiving the appropriate needed items at a later date and cost unnecessary added expense. If you are in doubt, discuss it with the doctor, therapist, nurse or social worker, they will direct you in the most suitable way to resolve the problem.

CRITERIA AND TIPS FOR COMPLETING THE SOCIAL SECURITY DISABILITY APPLICATION FOR BENEFITS

- A person is entitled to SSD when
 - he/she is no longer able to perform gainful activity due to any physical or mental impairment which is expected to last for 12 months or result in death,
 - and the severity of the impairment meets or equals the level of severity described in the Social Security regulations,
 - or the impairment or disability condition is of such severity that the person cannot do their previous work, nor any kind of substantial gainful work for someone of the same age, education and work experience.
- A person must have contributed to Social Security payroll taxes over a period of time to meet insured status requirements. The length of time a person must have paid into SSD varies by age. If a person stops working and paying Social Security taxes, the patient must be able to show that their disability was present during the period when no Social Security taxes were paid.
- Specific criteria for disability due to ALS are included in the Social Security Listing of Impairments. It is important that the patient's physician be familiar with these criteria when completing his/her portion of the application paperwork.
- Complete the SSD application without delay as soon as the disability criteria are met.
- It is important to provide a full and accurate list of all symptoms in the Social Security (SS) application for Disability. A30 to 60 day disability diary describing each aspect of how ALS affects the patients is a useful adjunct to the SSD application.
- It is not uncommon for a claim for SSD to be denied and for the timeframe of the initial and subsequent appeals to be lengthy. Many claims are denied because the patient's medical record lacks adequate documentation that fully establishes the severity of the ALS disability. It is important to fully explain the extent of the disability and symptoms to the physician including specific ways that ALS limits daily activities. Be sure the initial application is comprehensive to avoid a denial of benefits.
- For obvious reasons, many people with ALS focus on their abilities and what they can do and what they contribute to society. However, when applying for SSD, it is critical to honestly account for all limitations and symptoms in a specific and detailed manner.
- If the application for SSD is denied, reapply after determining the reasons the initial application was denied.
- In some states, Medicare eligibility entitles the person to purchase supplemental insurance - "Medi-gap" - policies, regardless of current health status. "Medi-gap" policies can provide coverage for items that Medicare does not cover such as prescription drugs.
- Other programs that may assist people with ALS to maintain access to health care insurance coverage, whether or not they are eligible for SSD and Medicare include:
 - Title X of the Consolidated Budget Reconciliation Act (COBRA)
 - Health Insurance Portability and Accountability Act (HIPAA)
 - Family Medical Leave Act (FMLA)

MY BOOK OF RECIPES

Instant mousse

- 3 1/2 ounce package chocolate instant pudding and pie filling
- 1 1/2 cups milk
- 1 cup thawed whipped topping.



Prepare pudding mix, using 1 1/2 cup milk. Fold in whipped topping and spoon into dessert dishes. Garnish with additional whipped topping. Makes 4 servings.

Calories 251.5

Isocal Strawberry Gelatin

- 8 ounces of isocal
- 1 small package (3 ounces) strawberry gelatin dessert powder
- 4 ounces boiling water
- 1/2 cup fresh strawberries



Dissolve gelatin in boiling water. Chill until slightly thickened. Pour into blender and isocal; blend at low speed. Pour into four individual serving dishes. Stir in 1/2 of strawberries, garnish with remainder. Chill and serve. Yield 4 servings.

Calories 148

CAREGIVER'S CORNER

TAKE CARE OF YOURSELF TOO

By Alison B. Grossman
Psychologist, Kessenich Family MDAALS Center

When an individual is diagnosed with a chronic, progressive illness the impact is felt by each family member. The initial experience of shock and disbelief at hearing the diagnosis is quickly replaced by the realization that their loved one faces a tremendous challenge. It also becomes clear that they will be intricately involved in the process. Family members may feel overwhelmed and somewhat helpless. However, it is their role that will be crucial in the management of the patient's disease course. Caregivers' strong support in the face of ALS will help determine the patient's quality of life.

The caregiving role entails many new responsibilities. Keeping track of doctor's appointments, as well as medication prescriptions and regimens are only part of the tasks involved. The emotional adjustment that accompanies ALS is a difficult and trying process. Many patients do not know, at first, how to accept their prognosis and how to incorporate it into their lives. The level of acceptance and amount of time it takes for patients to achieve a balance varies from

person to person. After all, each of us has a different personality, temperament, life experience, and expectations for the future. A caregiver can facilitate this process of adjustment by providing emotional support. Anyone who is unsure about how to do this needs only to ask the patient, "How can I best help you?" Providing educational information about ALS to patients is also valuable, particularly in the beginning stages of the illness. This is usually handled by the medical team, however, family support groups are very helpful for disseminating information and for allowing individuals to share personal experiences.

What caregivers tend to have the most difficulty adjusting to is the resulting changes in family roles. The wife whose husband has ALS may feel frightened by her inability to depend on him to take care of business-related and financial matters. The husband of an ALS patient may have difficulty getting used to preparing meals or helping children with homework. The added burdens, constant worrying about their spouses, and concerns for the future often result in feelings of resentment,

isolation, and loneliness. This can be counterbalanced by turning to social support systems outside the nuclear family. Relying on a close friend for support may be critically important at this time.

The family's challenge is to minimize the disruption ALS has on the everyday functioning of the household, especially when children are involved. A loved one's illness should not preclude the rest of the family members from getting enjoyment out of life. In fact, many patients report that facing ALS actually brought their families closer together. It is important to take some time off to relax so that "burnout" can be prevented. Taking care of oneself is just as important as the patient's care. This may require family members to rely on each other and/or on a home health care worker to pitch in and help with caregiving responsibilities whenever possible. The goal is to achieve a healthy balance between patient caregiving and maintaining the quality of life of all of the family members.

PATIENT TALK

IT COULD HAPPEN TO ANYONE, AND IT DID TO ME

Back in August of 1999, we came back from a cruise. I was tired and short of breath, but I thought it could be the jet lag. That was the beginning. Ever been told there is nothing wrong by your doctor? Don't believe him.

Over one year I was going to doctors. Internist, Gastroenterologist, Ear, Nose and throat, Pain Management, Orthopedic, Swallowing Pathologist, Pulmonary, Cardiologist, Neurologist, Psychiatrist, Oral Surgeon and Rheumatologist, they all said there was nothing wrong. In fact one doctor told me he wished all his patients were as healthy as I was. Needless to say, I no longer go to him. I persisted and went from one to the other about fourteen of them always hoping for something.

Finally my Neurologist sent me to the University of Miami, where I was diagnosed by Dr. Walter Bradley with ALS, Amyotrophic Lateral Sclerosis. (Lou Gehrig's Disease). This was one year later in August of 2000. When the doctor first told me what it was, I thought okay, now what. Then I was given literature, and more literature.

After reading and reading about what was going to happen to me, I thought, well everyone has to die sometime. I'm not going to let this get me. I'll do what I can, ask for help when I need it and live with it. No sense crying, because that does no good. No sense feeling sorry for yourself because that does no good. Take one day at a time.

Go with me to my support group and see all the young people in various stages of the disease, then you can feel sorry for them. Young men with families, young women in their prime with their teenage daughters. Feel sorry for them. At my age I've lived my life seen my grandchildren and great grandchildren. So I won't get to the weddings, but I went to all the graduations.

Why am I telling you all this? Keep persisting with your doctors. Go to support groups for cancer, Alzheimer's, or whatever. They are the best things, because you learn how to cope, and have your Care Givers, (spouse, children, relatives) go with you. They learn too.

Be sure you get Home Care Insurance while you have the chance. Lucky for me, we took it out about two years ago.

I know I am going down hill. I can no longer eat solid food, so I have a feeding tube. I need a cane to walk for balance. For any distance that we must go, I use a wheel chair. At night I am hooked up to a pump that gives me my Ensure. My speech is going, and people find it difficult to understand me at times. Eventually I will not be able to speak. My breathing is bad, and I am on a «BIPAP» machine part of the day. This helps inflate my lungs.



Miriam Turbow • 05-18-01

I'm telling you all this because ALS is not your everyday sickness. It is something that I would like everyone to become aware of Muscular Dystrophy works with the ALS people and funds are given for research. So far there is only one medication that slows this down.

What do I do to keep busy and my mind off myself. I play cards as often as I can. I have friends who are truly friends and help me whenever they can. I never refuse their help, because I need it. The women in Greenleaf and Park Shore with whom I play bridge, canasta and Pan are one in a million. I love them all. I had to resign from the Greenleaf Entertainment Group, but they are continuing with new leadership. They are the best. And my family, always calling, along with all my friends up north.

But the top of the list is the main care giver, my husband Sheldon. He now does all the cooking, makes sure I get all my medications everyday. He has the brunt of it. He is the one that must go through each day with me. Thank you Sheldon.

If anyone would like to talk with me about family or friends with ALS, I would love to hear from you.
Tel.: (561) 483-4870

EVENT CORNER

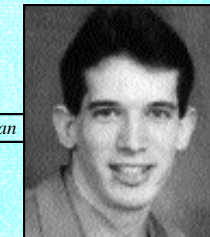


The Kessenich Family MDA ALS Center held its 3rd Annual Education Day on April 7, 2001. Thanks to several companies and organizations, seniors and persons with disabilities received a lot of information regarding communication devices, equipment, services, disability advocates, nutritional products and much more. We would like to give a great big thank you to all of the volunteers and to the companies who made this possible.



2001

HEALTH CARE Heroes® AWARDS



Kevin Packman

Kevin Packman nominated to win the HEALTH CARE HEROES AWARD for Volunteers

Kevin Packman, chairman and founder of the ALS Recovery Foundation, recently was nominated to receive a Health Care Heroes Award from the Greater Miami Chamber of Commerce in recognition of his work as a volunteer in our community. The awards are given each year to individuals, institutions, student, volunteer or your next door neighbor who, through their actions have made an impact in the South Florida health care community. Through their commitment to their profession and community, they serve as an inspiration to others in an effort to improve the quality of health care and discover new ways to assist those in need.

Mr. Packman has probably done more single handedly to advance public awareness about ALS, than anyone. As a college student he did an internship in Washington with Senator Graham, and during that short time arranged for Senator Graham to sponsor a bill passed by Congress to make May every year ALS awareness month. This has now become the central time on the national calendar for programs related to ALS, and in the middle of May Congress holds an ALS Advocacy Day. He is an attorney, specializing in litigation related to the Americans with Disabilities Act. He is rapidly developing the ALS Recovery Foundation, a Miami-based foundation to advance public awareness about ALS and to promote ALS research. Kevin's father is a long time sufferer with ALS, having been on a ventilator at home for eight years. He is receiving an enormous amount of help from his wife Cila, two kids and all the family.