



KESSENICH FAMILY MDA  
**ALS Center**  
newsletter

Volume 5, Issue 3  
Fall, 2003

*Kessenich Corner*

*The Kessenich Family MDA ALS Center  
and  
The University of Miami*

*Cordially invite you to attend their*

*Annual ALS Symposium*

*Saturday December 13, 2003*

*Time: 11:00 a.m. - 4:00 p.m.*

*RSVP: (305) 243-7400*

*Location*

*Radisson Mart Plaza Hotel and Convention Center*

*Salon G & H*

*711 NW 72 Avenue • Miami, FL 33126*

*Sponsors*

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## SAFE TRANSFERS

By Jean Hill

To perform safe transfers there are numerous principles/techniques and tools available to you.

Some of these principles/techniques will be mentioned, but are not all inclusive. They will depend on variables such as: caregiver strength, patient strength & range of motion, person's ability to help with transfers, and available transfer tools, etc. For safe transfers proper body mechanics should be used. Body mechanics is the way you use your body when performing a task, such as transferring a person/object from one place or surface to another. The reasons for using good body mechanics are: to prevent injury to your neck or back; prevent injury to the person being transferred; promote the use of less energy.

### Basic principles of body mechanics are:

- A. Keep a wide base of support – spread feet apart about 9 to 12 inches.
- B. Stay close to the person/object you are lifting/moving.
- C. Lift with your legs NOT your back – bend knees and hips, keeping your back straight.
- D. Shift your weight from one leg to another in the direction you are moving the person, do not twist your trunk.
- E. Always get help when needed.
- F. Always plan ahead – set up necessary equipment (i.e. wheelchair, transfer board, Hoyer lift); determine if you need assistance to transfer the person.

### Principles of safe and appropriate transfers:

- A. Lock all wheels to prevent rolling prior to transferring person
- B. Prior to/upon completion of moving person, raise/lower bedrails, remove/replace wheelchair arm rests and leg rests.
- C. Use necessary equipment – gait/transfer belt, transfer board, Hoyer lift, etc.
- D. Adjust bed to a convenient height.
- E. Explain what you are doing to the person you are transferring.
- F. Note and protect any drainage tubes, catheter, I.V., etc.
- G. Give short, simple commands and encourage person to assist you if he/she is able.
- H. Person should be moved in the direction of his/her strongest side.
- I. Transfer across the shortest distance.
- J. Once the person is in the wheelchair, place his/her arms on arm rests, legs on leg rests and any other equipment needed onto wheelchair.

When transferring a person with special needs, there are some issues to be

considered, for example: physical limitations (i.e. spasticity, flaccidity, and muscle strength/weakness); necessary durable medical equipment and modifications. A gait belt, transfer board, Hoyer lift, and transfer sling are a few of the transfer tools available to you for safe transfers. These tools can be purchased from medical supply stores and catalog companies.

If you have a prescription from your doctor stating it is medically necessary, Medicare and most insurance companies will cover these (basic) items. Many are not mentioned in this article. To use many of these tools appropriately, skilled instructions are needed. (Trained persons from medical supply stores or Physical/Occupational Therapist, etc.)

Whenever you are transferring a person always use good body mechanics, appropriate equipment, principles of safe/correct transfers and consider the person's special needs/limitations.



BEasy Slider Board



Standard Transfer Board



Jean Hill

# JOB WELL DONE

**Almost everyone knows someone who is a caregiver, but they don't know what it's really like for caregivers behind closed doors. The role of the caregiver can take many forms - from hands - on physical assistance to providing emotional, financial, legal and spiritual support.**

**The ALS Association Features Alice Smith's Story During November National Family Caregivers Month**

"My name is Alice Smith, and I'm an advertising executive. One day, my husband, Tom was having trouble opening a jar of pickles. Tom had previously mentioned symptoms of weakness in his hand, so I suggested he see the doctor. Initially, the doctor suspected a pinching of the spinal cord, but later we discovered that Tom had ALS. Our lives dramatically changed from that moment on."

Alice's story depicts the impact a debilitating disease such as ALS, more commonly referred to as Lou Gehrig's disease, can have, not only on the person afflicted, but also on family members who provide care for a loved one.

In November, The ALS Association, along with numerous national organizations, major corporations and community-based groups around the country, will observe National Family Caregivers Month 2003. NFC Month honors the millions of Americans who care for a family member of friend with an injury, consequence of old age or chronic illness, such as ALS.

The ALS Association is taking an active role in promoting and honoring ALS patient caregivers, whose hard work, time and care often go unnoticed. The ALS Association chapters and support groups across the country will sponsor programs to raise public awareness about the role of the caregiver in improving the quality of life of a person affected by ALS.

"We recognize the monumental task and crucial role caregivers play in the lives of Americans," stated Mary Lyon of the ALS Association. "Supporting patients with ALS and their caregivers, along with the medical research community, is the mission of our organization. During November and all year long, we applaud the dedicated service caregivers provide."

In addition, the ALS Association will be recognizing contributions of caregivers through various recognition programs and activities. This year, caregivers are invited to share their personal stories in the form of a 150 - 250 - word essay. Selected stories will be featured in public events and publications. For information about submitting a story, visit The ALS Association's website at [www.alsa-national.org](http://www.alsa-national.org).

People living with ALS are continually faced with new challenges in the progression of this devastating disease. Caregiving is an important part of managing the symptoms associated with ALS and provides and enhance quality of life to those affected by the illness.

# WHY IS IT IMPORTANT TO TRANSFER YOUR MEDICAL RECORDS?

1. When changing Doctor's is your responsibility to obtain a copy of your medical records.
2. If you do have a history of an illness, the new Doctor will be able to continue with necessary treatment.
3. Transferring records also maintains better communication among providers and better care for you, the patient.
4. Always request that test results are sent to your primary care Physician if you are seen by other specialist.
5. For safety and effective treatment, all Physicians involved in your care should know all of the medications you are taking.
6. When transferring to a new Physician, make sure you sign a release form; this will ensure that the new Doctor is able to get your medical records from your previous Physician.



## My Book Of Recipes

### ORANGE DELIGHT

#### INGREDIENTS

- 2 cups fresh orange juice
- 1 scoop vanilla ice cream
- 1/2 teaspoon vanilla

#### PROCEDURE

1. Place all ingredients in blender and blend at low speed until smooth



### BROCCOLI CHOWDER

#### INGREDIENTS

- 1 10 OZ. PKG FROZEN BROCCOLI
- 2 TSPS. INSTANT MINCED ONION
- 1/2 CUP BOILING, SALTED WATER
- 2 CUPS MILK
- 1 CAP CONDENSED CREAM OF POTATO SOUP
- 1/2 CUP SHREDDED SWISS CHEESE (2 oz)

#### PROCEDURE

1. Cook broccoli and onion in the boiling salted water until tender
2. Do not drain
3. Stir in milk and soup, heat thoroughly
4. Add cheese, stirring until melted
5. Cool slightly.
6. Place half at a time in blender. Blend until smooth
7. Serve chilled or hot

# A Page in Ed White's Journal An E-mail Conversation Between Ed White & Dr. Walter Bradley

Part 2

**Ed White:** MIND AND BODY: Before ALS, I never gave a great deal of thought about the connection between the mind and the body. After being diagnosed over 10 years ago, I have spent a great deal of time thinking about this subject. I believe that trying to battle a disease like ALS without having your mind in gear, or in sync with your body, is analogous to having one arm tied behind your back. In other words, there must be both a physiological and a philosophical approach to any serious disease. My "philosophy" towards ALS can be summarized with 3 points. My underlying, or basic philosophy was laid down by Descartes over 3 centuries ago when he said, "I think, therefore I am". As long as I have my cognitive abilities, I will do everything in my power to survive ALS. Secondly, a heavy dose of stoicism is a must. One can learn to be stoic, and with ALS, we must accept those things we cannot change, and they are numerous. Finally, I have always been a little bull-headed, and it is finally paying off with ALS. I just won't let those things I cannot do interfere with those things I still can do. Although my body is out of order physically, I believe the activities I am still capable of doing and enjoying, outweigh those I can no longer do.

So in summary, give me one part Descartes, one part stoicism, and throw in some bull-headedness, and I'll live with ALS. Epicurus said that the unplanned life is not worth living. In that regard, I will continue to plan and manage my affairs with an orientation to the future. Finally, hope does spring eternal; there is always hope. And, then, there is stress. Excessive stress is extremely debilitating for the ALS patient. Everything about ALS is stressful. The patient and caregivers must find a way to minimize stress. Developing a philosophy for coping with ALS can help. Stress can never be completely eliminated even when we are healthy, but for the patient to successfully live with ALS, it must be

kept at a minimal level. High levels of stress with ALS adversely affect the way we breathe, speak, move, swallow and even think. In short, stress is a direct result of ALS, but it is incompatible in living with it.

**COURAGE:** Does it take more courage and personal fortitude to live with ALS or, conversely, to decide not to live with ALS? I thought about this question numerous times over roughly the first 5 years of my diagnosis. Fortunately, I don't ask myself these questions anymore. I have many ALS friends who have chosen to live with ALS. This takes courage, particularly when the patient is facing the prospect of a locked-in status. I also have had many friends over the years who have chosen not to live with ALS, either by refusing respiratory care or by directly taking their own life. In my opinion, any of the above actions takes courage, and I would never be judgmental concerning a particular patient's decision. Each patient is unique, including his or her circumstances; there is no template that fits all when it comes to decisions relating to ALS or any other life-threatening disease.

On numerous occasions, people without ALS have insinuated to me either directly or indirectly that they could not exist the way I am living. I've decided that I find these comments somewhat puzzling and irritating, and I've concluded that I would not indicate my feelings to a patient if the role were reversed. I never know whether the person is saying this because they are admiring my personal fortitude to survive, or whether it appears to them that I am very high

maintenance (which I certainly am), and am wasting the time of the people around me. In short, until they are in the patient's shoes, no one is qualified to make that statement.

In summary, both the decision to live with ALS or to die with ALS is one requiring courage and personal fortitude. I will say that ALS is not necessarily fatal, but to decide to live with ALS involves many factors and is very unique to the patient and his or her circumstances.

**Dr. Bradley:** ED, I CANNOT BETTER YOU IN HOW YOU DESCRIBE THE PHILOSOPHY OF LIVING WITH ALS. IT IS, AND HAS TO BE PERSONAL. IN JAPAN, AS YOU KNOW, THEY BELIEVE THAT RESPIRATORY FAILURE IS OF NO GREATER SIGNIFICANCE THAN A FOOT DROP; JUST SOMETHING THAT NEEDS TO BE TREATED. SO EVERY PATIENT ESSENTIALLY GOES ONTO A VENTILATOR. EVERYONE MAKES THEIR OWN PATH IN LIFE. YOU HAVE CERTAINLY MADE YOURS, AND YOU HAVE DONE SO VERY EFFECTIVELY. ALL POWER TO YOU, AND GOOD LUCK.

Printed with authorization  
of Ed White

## Research Corner

There are many opportunities to participate in experimental clinical trials for ALS and associated symptoms.

**Q Will my doctor just tell me or do I have to ask about research opportunities?**

**A** Your doctor may tell you and you should always ask about research. Not all doctors participate in research projects.

**Q Does my doctor know about all the research that is on going?**

**A** Not always, but most of the doctors that specialize in ALS will probably know about ALS research.

**Q What are the requirements for the study?**

**A** The rules are different for every requirements.

**Q How much will it cost?**

**A** Participation in a study should not cost anything, however clinical studies will usually not pay for testing to diagnose ALS.

If you are interested in information and/or participating in a research study here at the University of Miami,

please call  
305-243-7526.



University of Miami  
School of Medicine  
Neuromuscular Studies

by  
Julie Steele, LPN, CCRC  
Study Coordinator

We are introducing a new research study that is being conducted at the Kessenich Family MDA/ALS Center at the University of Miami School of Medicine. All eligible patients and family members are welcome to participate. The study is examining the association between psychological factors and physical health outcomes in ALS patients. We are interested in learning about our patients' thoughts and experiences through the disease process.

In order to participate in the study, patients must be newly diagnosed with ALS, having received an ALS diagnosis within the past six months. Most of the assessments taken for the

study are part of the routine medical examination. Participants will also be asked to fill out some questionnaires and have their forced vital capacity measured. Family members and other caregivers of newly diagnosed patients are also encouraged to participate. They will be asked to fill out questionnaires. Family members will not have any physical measurements taken.

If you are interested in participating in the study, or if you have any questions pertaining to the project, please contact Dr. Alison Grossman at (305) 243-8590



# NURSES STATION



"HIPAA set up patient privacy ...  
how about a little rear view privacy?"

## 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) 757-4357 or 877-970-9696
  - ALS Association ..... 1-800-782-4747
  - ALS Association in Florida ..... 1-888-257-1717  
..... 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 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 to assist patients and families at home. Please call 305-243-7400. This could be a health care professional or even a family member who has had experience with ALS patients and now has time to volunteer.**



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**MDA ALS Center**  
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Suite 701  
Miami, FL 33136

## Calendar

### Support Group Dates

- Saturday, November 8, 2003  
Thanksgiving Luncheon
- Saturday, December 13, 2003  
Annual Symposium

### Support Groups Year 2004

- Saturday, February 21, 2004
- Saturday, March 13, 2004

### Support Groups for Caregivers only

- Saturday, January 10, 2004

### 8th Annual Jose Perez ALS Golf Classic

- Saturday, January 31, 2004  
For more information about this event call 305-243-1005

### Memorial Day

- Saturday, April 18, 2004

Location: University of Miami  
Hospitals & Clinics Room 1301  
475 NW 12th Avenue, Miami

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