



Monthly Update

ALS Association
Fighting Lou Gehrig's Disease

Serving Greater New York and Northern and Central New Jersey
42 Broadway, Suite 1724, New York, NY 10004, 212-619-1400 f: 212-619-7409 www.als-ny.org

October Support Groups

NASSAU COUNTY, NY

October 4, 2009 2:00-4:00 PM

(1st Sunday of every month)

North Shore's Central General Hospital

888 Old Country Road, Plainview

Downstairs Meeting Room; (516) 719-3000

Topic: Communication Devices

Facilitators: Theresa Imperato, RN - (631) 444-4623

Jody Wiesel, PhD - (917) 699-9751

SUFFOLK COUNTY, NY

October 6, 2009 6:00-8:00 PM

(1st Tuesday of every month)

Stony Brook University, Dept. of Neurology

179 Belle Meade Rd, E. Setauket

(631) 444-1970

Topic: Communication Devices

Facilitator: Theresa Imperato, RN - (631) 444-4623

NEW BRUNSWICK, NJ

October 17, 2009 11:00-12:30 PM

Topic: Open Discussion

October 17, 2009 1:00-3:00 PM

Topic: Support Group for the newly diagnosed.

(Please Note: Time change.)

Robert Wood Johnson University Hospital

Medical Education Building, Rm 108A

180 Somerset Street, Follow signs to meeting.

Facilitators: Debbie Schlossberg, LMSW

(732) 710-8832

Mary Ann Mertz, RN

MANHATTAN, NY

October 20, 2009 6:00-8:00 PM

(3rd Tuesday of every month)

Phillips Ambulatory Care Center (Beth Israel)

10 Union Square East (Bet. 14th & 15th St.)

2nd Floor, Conference Room #1

Topic: Open Meeting

Facilitator: Jody Wiesel, PhD - (917) 699-9751

For more information about our Support Groups go to the Patient Services section at: www.als-ny.org or call 212-619-1400.

Special Support Group Meeting for Newly Diagnosed PALS at Robert Wood Johnson.

October's support group meeting at Robert Wood Johnson University Hospital will be designed especially for PALS and families who have been diagnosed within the past 10 months. The goal of the special meeting will be to provide basic information and share resources which are of particular relevance to individuals at the beginning of the ALS journey. Information will be available on The ALS Association and its services as well as facts about ALS, basic home care, information of interest to Veterans, caregiving, and advocacy. If you have questions about clinical trials, the multi-disciplinary approach of ALS clinics, commonly used equipment and devices, and coping, this will be a safe place to get your questions answered by others who share your experiences and the professionals who partner with them. For more information, contact Debbie Schlossberg, Patient Services coordinator at schlossberg@als-ny.org.

What is a Charitable Gift Annuity?

A gift annuity is a simple contract between you and The ALS Association Greater New York Chapter. In exchange for your gift of cash or stock, The ALS Association Greater New York Chapter makes regular payments to you, you and your spouse or someone you name for life. The remaining principal goes to The ALS Association Greater New York Chapter when the contract ends. For information please call Beth Mohsinger at (212) 720-3060 or email: mohsinger@als-ny.org

CALENDAR of EVENTS

10/5/09, Monday. Fourth Annual Arch Enemies of ALS Golf Outing in memory of Archie Darragh. Bellport Country Club on Long Island. Please email us at als@als-ny.org or call Vinnie Darragh at 631-244-1599 for more info.

November 2009, National Family Caregiver Month Educational Series. In honor of National Family Caregivers' Month in November 2009, a set of presentations has been designed specifically for caregivers providing attention and care to people living with ALS. Please join us for informative and practical discussions, sharing of experiences, tips and support. Caregivers, family, people living with ALS and friends are invited to attend these web-based presentations. For more information please go to the Patient Services section at www.als-ny.org or call 212-619-1400.



The NY Chapter has a Lending Library available to all PALS. We have DVDs of movies & TV shows and books on CD or audio tape to lend. Please contact Christine Dunn at the Chapter office or e/mail dunn@als-ny.org.





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VOLUNTEER NIGHT October 22, 2009 5-7 PM. Contact Christine @ 212-720-3044

Focus On: Overcoming Communication Breakdown

By Debbie Schlossberg, LMSW

So the other day, in the course of a busy clinic schedule, a Caregiver of an ALS patient (CALS) shared with me her concern that her husband of 24 years, a normally gregarious man who was diagnosed with ALS nine months ago, seems to have “shut down.” She said she felt as if there were a wall, building brick by brick every day, in their communication. She expressed feelings of isolation and hurt as well as growing concern. Luckily, we had some time to talk and we continued our conversation the next day on the phone.

I understood her feelings. After all, communication breakdowns are always frustrating in a relationship. They are downright harmful when the need to communicate is, ironically, greatest. She understood this. What was new to her was the realization that this happens frequently when dealing with frightening topics such as ALS. I suggested that she come to support group where she would hear others going through the very same thing.

We spoke about the fact that there are many reasons for people to become withdrawn and that often it is a temporary phase as individuals work through their own feelings and figure out their own coping styles. In my experience, I think there are several common reasons for her husband's particular communication difficulties.

One of these reasons which I see regularly is that there is a strong protective impulse. This impulse can be directed at others, at oneself, or both. At times, loved ones will go to great lengths to protect their family and dear ones

from their own fears. They fear that sharing their own vulnerabilities will add to their partner's emotional burden. Although communicating one's deepest fears is an extraordinarily difficult thing to do, one must be reminded that the alternative, where one keeps things to him/herself in an effort to “shield” others from pain, usually results in, well, in just what this particular CALS was sharing with me; feelings of being shut out, great hurt and worry that they don't know



what their loved one is really thinking.

When one is reluctant to talk out of a need to protect oneself, the mechanism is one of denial. We've probably all been in situations where we erect walls around ourselves because the incoming information is too much for us. This is fine and even healthy. The trick is in being able to view these defenses as temporary measures and to be able to deconstruct the fortresses of will that keep feelings from flooding in. Slowly. This can take time with a diagnosis of ALS.

I often see the process over the course of

weeks or maybe months. When newly diagnosed and/or when changes are happening quickly it is a lot to expect of ourselves to be open and clear all the time. A conversation I often have with families is the idea of visiting denial, like a respite, but coming back to reality when it is time for planning, decision-making, and when those around us need our presence most.

Something else to keep in mind is that many of us aren't great communicators to begin with. It is a matter of personality and it is inordinately difficult to expect someone to change their style of coping now, when the going gets rough and the tendency is to seek comfort in what is familiar and well-worn. Of course I have observed breathtaking change among the families I've worked with over the years. Sometimes it is precisely this sort of adversity which shakes us to our core and something new and evolved comes out of it. But it's hard and sometimes, the lesson is not that we should expect dramatic change, but subtle, gentle metamorphoses.

Sometimes sharing articles or films, dealing with a task or talking about dreams and goals is all that is needed to break through the wall.

In any case, it is important to remember, even if subconsciously, that people will take cues from the PALS. If he/she is not talking, those in the inner circle may also tend to tiptoe around the difficult subjects. Holding in or suppressing these fears and worries leads to a very heavy load. The liberation lies in letting go, a little bit at a time perhaps, sharing the burden rather than attempting to bear it alone.