

February 2007

MS Quality of Life Project

Relationships:

- with Self
- with Family
- with Caregiver
- with Physician
- with Support Group

501 (c)(3) Non Profit Public Benefit Corporation

RELATIONSHIPS

**By Donna Krasnow, MSQLP
Executive Director, Volunteer
Coordinator**

It's not hard to come up with a theme for a February newsletter. Look around – hearts are everywhere: decorating store windows; on cards clutched in children's hands; in the shape of red silky boxes of chocolates; and, stamped on paper surrounding bouquets of roses. The marketing industry assures us that these are what people give to those they love. Maybe. But think how often love is shown in a glance, a pat on the hand, a gift of time or attending someone's needs. Love, indeed, comes in many forms. In this edition we focus on *Relationships* and how they may nurture us.

Lotte Marcus, PhD and our first President, begins the analysis by describing the role conversations with ourselves play in our lives. She calls it "Self-Talk". She summarizes thoughts she expressed last July at our educational symposium held at the Hyatt in Monterey. Marilyn Howell, a board member and Marriage and Family Therapist, writes a follow-up to her November article in which she described how persons with MS can positively relate with their spouses. In this article she focuses on relationships

with family members other than partners. Terri Nash, an active local community member with MS, shares thoughts about successful relationships with caregivers. Andrea Dowdall, our Case Manager, analyzes ways to make your communication with your physicians more effective. And, finally, Marie Swank and Ruth Forsberg, peer support group leaders in Seaside and Salinas, identify how participation in support groups can positively impact our lives.

We hope you find these articles relevant and useful for nourishing your own relationships. As always, let us know what you think. We appreciate those who took the time to comment on November's newsletter. We were pleased with your responses.

Special thanks to Marie Swank and Kim King for guiding us through the renovation of our newsletter. We hope the columns make it easier to read – especially for those with vision challenges. If not, let us know. We all agree that it is a work in progress – just like relationships!

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*Nancy Deliantoni at
MSQLP's Holiday
Social at
Oldemeyer Center
December 9, 2006.*

"Self Talk" Relationship with Yourself

By Dr. Lotte Marcus, Psychologist

No one gave you a manual for dealing with MS. No one can foresee who will maintain or for how long, or who will suffer a progression of MS symptoms, or who will stoically balance the external with the internal factors. Or that, in the course of years, you may be bombarded with the new rules of the bureaucracy of social security employees, human resource folks, receptionists, bookkeepers, telephone answering machines, the authoritative language of bosses, the advertising language of equipment salesmen, medical language and a regimen of physicians: internists, neurologists, urologists, psychiatrists, social workers, pain centers, emergency rooms, and sometimes lawyers. Phew! What a job!

Self-talk is a way of fighting off uncertainty, your own Shadow Psyche.

It's 3 am, in bed, when time is scrambled, when day time stimulus has shut down, when your past struggles with a sense of loss which you thought you had overcome, and mind chatter begins: "I can't believe that I went kayaking three years ago, and now I can't move my left leg". Or "Who will help me with my telephone bill?" Or "My husband/wife looked so exhausted today, I can't imagine how long s/he will put up with me."

Or it's 7 am: You are getting ready for a new day. It's check-in time for symptoms. "Is this a good MS day or not? Has my body told me what I can do with it, or it with me?" Or, as Andrea Dowdall, our Case

Manager has said, "What's up with the Energy Pie?" Or you struggle with yourself over changes in plans. For weeks you have been meaning to see a friend. The date has been postponed several times. On this particular day, you're out of medication; or it's too cold; or your husband wants you to run an errand and you feel obligated because you know he does not ask too much of you.

You may or may not yet have a systematic way of analyzing trade-offs in the choices you face: you may choose to stay at home and disappoint someone (including yourself) or push through the fatigue and end up having a good time; or you may spend all your energy, have a good time but the increasingly speeded up hurly-burly of our daily world makes your body feel, oh so, slow and you will wish that you had conserved your energy. Become a spendthrift or conserve?

If you can't quiet or crystallize your mind's chatter, it may weigh on you; and all the health care provider at your bi-weekly or monthly appointment will hear is "How do I feel? Well, I can't quite explain it..."

So this is how it can work: self-talk softens when caregivers, friends, and healthcare providers move from sympathy to empathy. I have seen the most compassionately aware gestures between our MS clients and their loved ones. Also, self-talk doesn't necessarily get worse because the disease progresses. It essentially ends when, as one client told me "I no longer think that I have MS: I think of myself as disabled."

Self-talk, when it becomes self-aware, precedes self-acceptance.

**For reprints of
her complete talk on
MS & Communication,
write to:*

*Lotte Marcus, Ph.D.
PO Box 223537
Carmel, CA 93922*

Relationship with Family

By Marilyn Howell, MFT, MSQLP Board Member

We all have fears we don't necessarily voice because, if we said them out loud, it might make them real. Our family members have similar fears about our MS and how it may impact them. Education dispels fear regardless of age. Younger children do not need in-depth information. They just want to know how your MS will impact their relationship with you. "Last year she chaperoned field trips, can she still do that?" For elementary age children, having a parent help at school makes a child feel special. If MS is getting in the way, plan with your children how you can still be involved in their activities. Focus on ways to stay involved that don't include physical exertion. Help with reading in your child's classroom instead of chaperoning a field trip. And not everybody has to be the Den Mother. Teach a first aid lesson. Do art projects for the teacher or Cub Scout leader. Be creative. There are other things you can do that will keep you involved in your children's lives.

Children should not be given responsibilities beyond what is appropriate for their age. A 9-year should not be expected to cook dinner but he can help you with preparations. A 12 year-old boy should not be expected to become the man of the house because his father is disabled. Dad's role as head of the house is more intellectual than physical – his disabilities shouldn't diminish this. The 12 year old can be his helper - and will flourish with the one-on-one attention from his father – but Dad is still DAD.

Let me make this personal. My two daughters are 36 and 38, grown and out of the house. Even though they don't live with me, they are still concerned about my well-being and how it may affect them. They have the same fears that I do. As with younger children, education and communication remains the answer – but the conversation is at a much

more sophisticated level. I can share with them what is happening to me and what might happen in the future. We can make plans for how to deal with changes. For example, we have discussed what I think I will do if I can't walk. If I bring it up it is easier to begin the conversation.

What about other adult family members and friends? For example, I don't know if I will be walking next summer so I am hesitant to take on a responsibility related to the upcoming family reunion. But I don't want to be patronized and sat in a corner – I still have a good brain, lesions notwithstanding! I recognize that I am experiencing small cognitive problems, poor short-term memory, not able to switch gears quickly. For example if I am getting dinner ready, I am thinking about several things at once. Is the salad ready? Is the main course going to be done on time? Did I forget an ingredient? Is the table set? If someone comes in and interrupts me, I feel a little lost and a bit angry because I have lost track of what I was doing. I need to share this frustration with friends and family. "This is one way MS is affecting my life. I hope you will understand why I can't multi-task as easily as I could in the past." Again, when I bring it up, the conversation starts - a conversation that family and friends may have been hesitant to begin.

So how am I making adjustments? Well, I'll admit, I'm a Martha Stewart-type and Christmas is my time to decorate the house from top to bottom. Now I tell my daughters where to place the decorations and supervise while they do the work. It's not all bad! I now recognize that I will never learn to water ski. I might still go on a cruise, but I won't be scaling the climbing wall. Marathon shopping trips with my daughters, a wonderful bonding experience, are no longer possible. I don't have the stamina, but I do have a scooter. We plan more carefully and limit distance and time

when shopping. My husband has been wonderful, but he has had to shoulder more of my chores. We have talked about how we hate MS. It is not about me, but how our lives have changed. We focus on how to accommodate MS, and still have rewarding and fun lives. Next year Christmas will be at my daughter's house. We are moving from a large 2 story house to an accessible condo. Soon I will see you at Support Group meetings in the Monterey area.

Relationship with Caregiver

By Terri Nash

Communication is vital to a successful relationship with a caregiver, whether it is a family member, paid, or friend. You need to establish a care giving routine that is based on your needs and abilities. The caregiver must understand your expectations.

#1 Carefully consider what you want your caregiver to do.

What are your needs? What can and can't you do for yourself? Make a list. Think about a typical day. Start with tasks related to getting up and work through the entire day. Think about meals, getting dressed, bathing, housekeeping needs, and activities outside of the house. What routines have you already established? What would you specifically want a caregiver to do? Now re-read your list. Which of these areas of assistance are most important to you? Which are less? When your list is finished, you should have a complete picture of what you want a caregiver to do. The value of such a list is that your expectations are clearly stated. Clear expectations lessen the chance of misunderstandings.

#2 Describe exactly how you want things done.

A caregiver may not always understand why you want something done a specific way. It may not

make sense to them. Tell them why. Your explanation will help them better understand the reason for your request and help them remember to do it the way you want. But what if your description isn't clear to them? For example, after telling them how you want your legs positioned on the wheel chair, they do it incorrectly. Chances are that repeating the same instructions in the same way won't help. Although your explanation was clear to you, it wasn't clear to them. Be prepared to explain in more than one way.

#3 Remain flexible while also being realistic.

Your goal is to have an effective working relationship with your caregiver. If ever a disease required flexibility, MS is the one! As we all know, some days are better than others. Some days we need more assistance; other days we are better able to help ourselves. We also need to remember that our caregiver has good and bad days. We both need to remain flexible in our expectations. At the same time, we also need to be realistic. Sometimes it doesn't work out. If, after trying to establish a routine, you sense that a caregiver is not right for your needs, it is time to look for someone else. Learn from the experience, however, so that you are better prepared to work with the next caregiver.



Terri Nash

Relationship with Physician

By Andrea Dowdall, MSQLP Case Manager and Program Supervisor

The relationship with your doctor(s) is important. Doctors have more textbook knowledge of disease, but they cannot feel how you feel; they cannot experience your disease and how it affects you each day. It is in the patient's best interest to be ready to briefly and clearly state what brings them to a healthcare provider. With that information, the doctor can apply textbook knowledge, compare patient experiences, and learn which applications seem effective. Patients should realize that a good doctor needs patient input and needs to listen to the patient in order to apply his/her knowledge and experience. It is important to be honest about even the most embarrassing symptoms.

Based on their review of our data: "The Chart of Many Colors", two local neurologists have agreed to work with me and the MSQLP clients we have in common to improve doctor/client communication. I meet with a client before an upcoming doctor visit and review their treatment plan, medication sheet, and sociogram. Goals are set for the doctor visit, stressing why the client has an appointment at this particular time in the course of their MS. The client also shares with me what his/her "MS story" is at present. The story is distilled into 2-3 sentences which illustrate to the physician how MS is impacting the

patient's quality of life – giving insight beyond the medical into the biopsychosocial. For example: one client's story came down to "I just can't plan due to the daily changes in my MS. My roommate and boyfriend get so frustrated." Another client was ready to tell the doctor how her "life seemed to be about rushing here and rushing there. Everything is taking so much longer as my MS progresses. This is adding stress to my life." Then copies are given to the client for their records and to share with the doctor. Several clients have participated in this project and the initial response from the doctors has been very positive. MSQLP hopes to expand this project to include more clients and physicians.

Relationships

by Victoria Scaccia

Really important to have a good one
Everyone benefits
Let others express themselves
Always remain calm
Take a deep breath
If you listen you may hear what is
being said
Other's feelings matter
Never interrupt
Share your feelings
Have compassion
Is it so important you have to be
right?
Please treat others as you would like
to be treated
So now you have the guidelines

Relationships in a Support Group

***By Ruth Forsberg and Marie Swank,
Peer Support Group Leaders***

A support group (SG) provides a forum for people to gather and share around a common interest. Our MS Support Groups strive to provide a safe and empowering space for people to bring questions, feelings, new coping discoveries, triumphs and set backs. It's a place to learn from each other. Often someone in the group has been there and can listen with an informed heart. The SG functions as a resource for people to learn about medical updates and services.

The SG is also a social gathering that gets you out of the house and out of a rut; it can be a place to make new friends and share some laughs. Close friendships may develop as experiences are shared. It's a time to get together with other people with some similar concerns.

SGs can activate your sense of humor. Sharing our situations with others who can personally relate to what might seem tragic, occasionally morphs the situation into something you can laugh at.

People with all varieties of MS are welcome. MS is unique to each individual and the disease is unpredictable in its course. However, we can all learn together in the support group and enjoy the company along the way.

If you are interested in coming to a meeting, check the list on the following page. Caregivers and family members are welcome to attend and participate. If you don't want to come alone, or getting to a meeting is a problem, perhaps the office can help with car-pooling.



MSQLP Holiday Social, Oldemeyer Center



MS Support Groups

MS Support Groups

Anyone dealing with MS on their life journey is welcome to join, whether as one with MS, a family member, caregiver or friend.

MSQLP sponsored groups:

Oldemeyer Center: 986 Hilby Ave. Seaside
Second Saturday of each month
11:00 am to 1:00 pm

Salinas Valley Memorial Hospital
Downing Resource Center Third Friday of each
Month, 11:00 am to 1:00 pm

Pleasant Care

2990 Soquel Avenue, Santa Cruz
Second Thursday of each month
1:30 pm to 3:00 pm

Upcoming topics include:

- Dr. Centurion talks at Oldemeyer
- Rehab Specialists: New regulations and equipment
- Kathleen Villarreal, CHOMP's ER Case Manager: MS and the ER
- Disaster Preparedness for the Disabled
- Symptom Management

Times are subject to change, call the MSQLP Office at 333-9091 for current information.

National MS Society sponsored groups:

Monterey

Community Hospital (CHOMP)
Last Wednesday of each month
7:00 to 8:30 pm
Call Susan Jones at 659-1354

Santa Cruz

United Way, 1220 41st Ave. Capitola
3rd Saturday of each month
10:30 am to 12:30 pm
Call Ada Shannon at 440-1211

MS Foundation Cruise for a Cause

This year MSF's Annual "Cruise for a Cause" is going to
Alaska's Inside Passage!
June 8th-15th 2007

Join other MSers aboard the Royal Caribbean's "Vision of the Seas".

Ports of call include:

Seattle
Juneau
Skagway
Tracy Arm Fjord
Prince Rupert, B.C.

To reserve your stateroom call:
Fun Cruise and Travel at
888-826-9660

Starting at \$620.00 per person
based on double occupancy,
additional charges apply, subject to
change based upon availability at
time of booking

Water Aerobics

Please Note Time Change:

Beginning MARCH 9, the Water Aerobics Class will meet from 12:00 Noon to 1:00 pm.

The Water Aerobics class meets every Friday at the Monterey Sports Center. Classes are FREE for people with MS and their caregivers.

This year we will meet throughout the summer too!

Calendar

Call the Office to Join
"The Human Race"
Date TBA
Come walk and roll with
MSQLP!
Lover's Point in May

February

- 11 Support Group, Pleasant Care
- 16 Water Aerobics, Monterey
- 17 Support Group, NMSS, SCruz
- 23 Water Aerobics, Monterey
- 23 Support Group, SVMH, Salinas
- 28 Support Group NMSS, CHOMP

March

March is National MS Education and Awareness Month

- 2 Water Aerobics, Monterey
- 8 Support Group, Pleasant Care
- 9 Water Aerobics, Monterey
*New Time, 12-1 pm
- 10 Support Group, Oldemeyer
- 16 Water Aerobics, Monterey
- 16 Support Group, SVMH, Salinas
- 17 Support Group, NMSS, SCruz
- 23 Water Aerobics, Monterey
- 28 Support Group NMSS, CHOMP
- 30 Water Aerobics, Monterey

April

April is time to Join MSQLP and the Human Race!

- 6 Water Aerobics, Monterey
- 12 Support Group, Pleasant Care
- 13 Water Aerobics, Monterey
- 14 Support Group, Oldemeyer
- 20 Water Aerobics, Monterey
- 20 Support Group, SVMH, Salinas
- 21 Support Group, NMSS, SCruz
- 25 Support Group NMSS, CHOMP
- 27 Water Aerobics, Monterey

May

The Human Race

- 4 Water Aerobics, Monterey
- 10 Support Group, Pleasant Care
- 11 Water Aerobics, Monterey
- 18 Support Group, SVMH, Salinas
- 19 Support Group, Oldemeyer
- 19 Support Group, NMSS, SCruz
- 30 Support Group NMSS, CHOMP

Development

Thank you to all our MSQLP Angels!

Our fundraising or "development" plan includes a variety of ways you can support us.

MSQLP will join "**The Human Race**" in **May** of this year. The Human Race is the largest local collaborative fundraising event in Monterey County. MSQLP receives 75% of all funds we collect. We invite you to walk or "virtually walk" with us and collect sponsors and

donations. Look for details soon or call our office for more information!

We had a very successful **Angel Campaign** last fall. Our **Angels** are the people and institutions whose donations allow us to offer free services. Since our campaign began in November, we have received the following donations:

Marilyn Addington
American Karate

Jayne Brown
The California
Endowment
Charles and Franna Byers
Lucy Campen
Peter Coniglio
Phil and Carla Coniglio
Julie and Alexei Da Silva
Patricia De Pree
Donation Line
Granite Construction
George and Joyce Hahn
The Donald and Diane
Hansen Family
The Harden Foundation
Carrianna Hess
Richard Hess
Bob and Linda Holub
Marilyn and Dick Howell
Daniel Kelly



Susie King
Gina and Brent Kolhede
Donna Krasnow
Stephanie Krasnow
Janice Maroot
Raciel and Rosa Mena
Monterey Bay Oncology

MSQLP

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We're on the Web!

See us at:
www.msqlp.org

More Angels!

*MS Foundation
Leona Palmer
Rev. Jeri Murphy
Mary Sue Murray
Pebble Beach Garden Club
Mary Lou Schaeffer
Dr. Jerry Solomon
Howard and Joan Sitton
Sandra Spalding
Dr. David Spilker*

*Therese Suzuki
Dorothy Swank
Larry and Marie Swank
Ron and Linda Stoney
TEVA Neuroscience, Inc.
Betty Haywood Watt
Robert and Joan Wellington
Katherine Wiggins*

*Be an MSQLP Angel,
It's never too late to donate!*

About MSQLP.....

The Multiple Sclerosis Quality of Life Project (MSQLP) is an organization committed to improving the quality of life of persons living with Multiple Sclerosis in the areas of Monterey, San Benito and Santa Cruz counties. We

assist clients in attaining the greatest degree of independence they desire through creation of cohesive and comprehensive care plans on an on-going basis. Confidentiality is honored. Our services are free.

**MS QUALITY OF LIFE PROJECT
519B HARTNELL STREET
MONTEREY, CA 93940**



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