



QUALITY OF LIFE PROJECT

November 2006

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Contact Us:

MSQLP
519-B Hartnell Street
Monterey, CA 93940
(831) 333-9091
fax: (831) 333-9092
email:msqlp@sbcgloal.net
www.msqlp.org

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**FROM THE DESK OF – Donna Krasnow, Chairman of the Board,
Volunteer Coordinator**

Gratitude is not the first word that comes to mind when one thinks of Multiple Sclerosis. *Challenging, life changing, exhausting, unpredictable* – these are more likely candidates. So, why did we choose *Gratitude* as the theme of this newsletter? Are we supposed to be grateful for a disease that changed our lives? A health system that makes it difficult to get the care we need? The pressures MS puts on relationships with our family and friends? Of course not. We are coping with one of the most unpredictable of diseases. *Gratitude*? And yet, when we have to ask for so much from so many, it is easy to overlook the individual acts of kindness we receive from those around us - acts that make our challenging lives a little bit easier.

I use the word “our” very carefully. I do not have MS, but my husband did. MS changed my life as it changed Gary’s. It changed it in very different ways, but it changed it significantly. Gary died four years ago and I miss him very much. I am grateful for the years we had together although the last five were particularly challenging. I certainly had difficulty acknowledging ways that Gary made my life better when I felt so overwhelmed by the needs of his caregiving. I also know that Gary had difficulty expressing gratitude for the things I did for him. There were so many and he hated being dependent. *Gratitude* is challenging for all of us. Is it significant to express gratitude? The following articles explore this theme.

Andrea Dowdall, social worker and case manager of our HouseCalls program, explores the importance of gratitude in the daily lives of persons with MS. Marilyn Howell, a marriage and family therapist, as well as a Board Member of MSQLP, analyzes gratitude as it applies to couples who contend with MS. Finally, Marie Swank, a Board Member and editor of this newsletter, examines the challenges of a very specific aspect of gratitude – gift giving and receiving. The holidays will soon be upon us and gifts may be a difficult part of the season for those with MS. Marie’s insights may be helpful.

In addition to being the widow of a person with MS, I am the new Chairman of the Board of MSQLP. I have been involved with our organization for several years but just recently took over this leadership role. I have met many of you at support group meetings in Salinas, Seaside and at Community Hospital, at monthly lunches in the Monterey area, at our MS water aerobics program Friday afternoons at the Monterey Sports Center (I have quite a bit of fun in the water assisting our trainer), and on the phone. I look forward to meeting more of you.

One way to interact is to let me know what you think of this newsletter. We would like to start a new feature – a “Letters to the Editor” column. We know that picking up the phone or writing an email or letter may not be easy, but we want to know if the themes we have selected for this and future editions resonate with you. Was it helpful? Did it annoy you? Were we on track or off? Let’s start a discussion. Direct phone calls to (831) 333-9091, emails to msqlp@sbcglobal.net or letters to 519-B Hartnell Street, Monterey, CA 93940. We really want to hear from you. And, by the way, would you prefer to receive our newsletter electronically? If so, send us your email address and we will switch you from a paper to an electronic copy.

FROM THE DESK OF – Andrea Dowdall, MSW, MEd, Case Manager/Program Supervisor

In my career as a social worker and as Case Manager for the MS Quality of Life Project, I have observed different ways people deal with a chronic, progressive disease such as Multiple Sclerosis. Some folks move toward acceptance and their overall mood mellows over time. Some become increasingly angry, anxious and depressed as their illness progresses. Others fall somewhere between these two states of being.

As we have discussed previously, MS is an illness that can create isolation. I have heard clients proclaim that they are not their MS. Yet I have also observed that some have become overly introspective as his/her life becomes centered on the illness, creating much misery for the individual and for those who surround them. In surrendering to the illness, a person may lose sight of his/her many blessings. Expressing and being in a state of gratitude is one way to reclaim and improve one’s quality of life.

The holiday season is fast approaching. To some, this is a time of family togetherness and joy. To others, it is a time of overwhelm, striving to do too much and doing all things “perfectly.” Still others may find this time of year sad and depressing. Whether it is a time of joy, overwhelm or sadness, expressing gratitude is an important element of participation in the holidays.

I have been in workshops where one of the exercises is to spend a few moments at the beginning of each day writing down things for which I am grateful. When I have taken the time to engage in this activity, things have shifted for me, in a positive direction. I become aware of simple gifts – the water that flows through my home, a smile, my beating heart, a phone call, assistance and support offered from others, a meal. We rarely acknowledge these simple gifts. We focus more on what is not working than what is. When we notice how many things are running smoothly, we can begin to appreciate the many miracles which comprise our lives. And although we all have days when it is easier to be more appreciative of life than others, if we really take note, there is always something to be grateful for.

So my suggestion for dealing with the many challenges of living with MS (or any other condition), especially during this holiday season, is three-fold:

Write out - Reach out - Get out

- 1) Take time every day to list or say what you are grateful for.
- 2) Reach out to others. Request and/or offer support and assistance.
- 3) Get out. Take the time to appreciate the beauty which surrounds us. Engage with others.

Let me indulge for a moment to express my gratitude: to my husband, Wayne, for his love and for granting me autonomy; to my daughter for her beauty (inner and outer) and support; to my son and his family for bringing me joy, especially through the sharing of my granddaughter, Reagan; to the board and supporters of MSQLP for giving me the opportunity to do work that I love; and to our clients and their caregivers for letting me into your lives and sharing your triumphs and challenges while we work together to improve quality of life.

FROM THE DESK OF – Marilyn Howell, MFT, Board Member, Volunteer

When a family member becomes a caregiver, the relationship between the person with MS and the caregiver may change. Two people who had previously seen themselves as spouses or partners find themselves moving into a relationship that has overtones of parent-child. This may have a significant impact on the relationship. The caregiver may be both angry and sad over the change of the relationship and the greater amount of time that has to be devoted to caregiving. The person receiving care may be both angry and sad over becoming dependent on others and changing or losing roles he or she may have had prior to MS. If they are not able to talk about the changes that are occurring, frustration and anger can build up. Often the caregiver won't talk about these concerns because of not wanting to cause hurt feelings. The person with MS has similar problems – not wanting to be demanding or complaining. For them to operate in a way that they can remain honest with each other requires respectful, open communication.

Awareness of gratitude happens as we begin to look for it in our lives. When you become aware of the things that enhance your life - the beauty of nature, the kindness of friends, or a great cup of coffee shared - you are now open to gratitude. It comes from looking beyond our current circumstances. MS doesn't change the history you have together. For couples, the goal is to continue the journey, communicating and problem solving with each other in every way possible.

So how does the couple with MS focus on gratitude rather than the anger, fear, or sadness that often accompany MS? Here are some ideas that might be helpful:

- 1) Laughter is healing; shared laughter is better. Plan special time together. Make dates. Drive to the beach to watch the sunset or simply share a glass of wine in the back yard. Go out to a movie or rent your favorite video and share popcorn on the couch. Invite friends over. If preparing dinner is difficult, use the "Point and Pay Method." Go to the store, point to what you want, pay for it, bring it home, heat it in the microwave. The focus is not on gourmet food but on shared time with your spouse and friends.
- 2) Sex can be a challenge depending on how MS has impacted you physically. Get creative. We all need touching, physical contact, skin on skin. Cuddling and snuggling have great value. The goal is to relax and not focus on your problems.
- 3) Develop empathy for your partner. Put yourselves in the other's shoes and imagine the struggles and frustrations they are experiencing. Ask your partner to share worries and concerns. Open the channels of communication so that you can address these concerns and

problem-solve together.

All of these suggestions will strengthen communication and intimacy. Gratitude comes from these positive connections.

FROM THE DESK OF – Marie Swank, Board Member, Volunteer, Newsletter Editor

Gift-giving season is approaching. Some of us enjoy the season just as it is. Some of us are opting out as a response to over commercialization. But if you find giving and receiving gifts challenging, here are some common sentiments and some ideas that have people with MS in mind.

Dictionary.com says a gift is “*something given voluntarily without payment in return, as to show favor toward someone, honor an occasion, or make a gesture of assistance.*” This definition tells us that you do not have to give a gift, nor should you expect a gift after you’ve presented one. The bigger pleasure really is the giving.

If you don’t want something that you received as a gift, be gracious, and in the future (or before it is too late) tell those close to you what you do want. If you need or want a specific item, or prefer a service, say so. There are situations and people one cannot speak openly to about presents. But wherever and whenever you can, consider this idea. The giver may prefer your input to needlessly spending time and money on an ‘iffy’ item.

After you have given a gift, be prepared not to be thanked. Expressing gratitude is difficult for some people. But thanks should always be expressed verbally or in writing. Heartfelt appreciation is a present in its own right!

If you cannot shop for financial or physical reasons, try thinking beyond material things. Maybe you can make or receive telephone calls for someone, be with a dog or cat while a friend goes out, or maybe you have something that you can ‘hand down’.

Giving should be fun. If it is not fun for any reason, do not participate, expect nothing, and enjoy what you have. Here are some more gift ideas you might ask for, or give:

- Netflix trial (\$5.99 plus tax for a month, \$10.71 a month if you like the trial. Must have a DVD player and be able to order by computer)
- A ride a month (to a doctor, movie, grocer, or whatever is requested)
- A one-time only house project like un-sticking the door, pulling weeds
- Sugarfree cookies
- Mail order gifts can be quite reasonable and hassle-free
- People with MS may prefer slip-on clothes (no buttons and perhaps no zippers) Visit these websites: silverts.com, buckandbuck.com, professionalfit.com, and easyaccessclothing.com
- Books on tape available at any major book store. Books, magazines, and listening machines are available through the California State Library FREE for the disabled. Call 1-800-952-5666 or visit your local library for an application.
- Consider scents in lieu of sweets
- A person with MS might appreciate a manicure, a fan, an electric toothbrush, a gel cushion, putting garbage out, walking the dog, bringing in the mail/newspaper

- Excursion to Pt. Lobos (there's an accessible trail)
- Music

Speaking of service as a gift, give us a call if you'd like an MSQLP volunteer to do your gift wrapping or if you want to volunteer to gift wrap for others!

FROM THE DESK OF – Kim King, Office Manager/Outreach Assistant

Interns

We welcome two new interns to the MSQLP office. They are invaluable!

My name is Susie Salgado. I'm a transfer student from Cabrillo College, currently attending California State University Monterey Bay. It is my second semester as a junior and I feel honored to be doing my internship at MSQLP. While shadowing Andrea, who is my mentor, I have gained the ability to really understand Multiple Sclerosis from a variety of perspectives. I have learned that every person has an individual and unique story.

Once I graduate from CSUMB with a degree in Collaborative Health and Human Services, I hope to work with the Latino community and be part of an agency like MSQLP that is committed, caring, and promotes social justice to the fullest. I enjoy spending time with my family. We love to party and barbeque.

My name is Daniela Spiegel. I am a student at California State University Monterey Bay. I am a junior, a transfer student from City University of New York in Manhattan, majoring in Collaborative Health and Human Services with a minor in social work.

Interning at MSQLP has given me the opportunity to experience the duties of a social worker on a "hands-on" basis. I have shadowed my mentor, Andrea, on home visits and have met very strong and inspirational people who have MS. I have also attended numerous conferences and am currently attending CHOMP's workshop, "Sick and Tired No More." I have broadened my knowledge about MS and other chronic diseases. I am from Southern California. My mother, who is a social worker, sister and brother live in Los Angeles. My father lives in New York. I enjoy running for exercise and stress release and I also enjoy knitting.

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 Avenue
Seaside
Second Saturday of each month
11:00 am to 1:00 pm

Pleasant Care

2990 Soquel Avenue
Santa Cruz
Second Thursday of each Month
10:30 am to 12:00 Noon

Salinas Valley Memorial Hospital

Downing Resource Center
Third Friday of each Month
11:00 am to 1:00 pm

Coming Soon in 2007

Soquel/Aptos/Watsonville
Please call if interested

Call the MSQLP office at 333-9091 for more information.

National MS Society sponsored groups:

Monterey

Community Hospital
Last Wednesday of the Month
7:00 pm to 8:30 pm
MaryLee Johnson: 373-2450

Santa Cruz

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

MS Water Aerobic Class

An *Angel* (see article below) has donated funds to sponsor our water aerobics class for persons with MS. It meets Fridays at the Monterey Sports Center's large pool. The class starts at 1:30 pm in the pool, and lasts for one hour. There is no cost to participants if they bring their own towel. Just tell the receptionist you're there for the MS class. Please note there is no class on November 24. For more information please call Marie Swank at 649-1645.

MSQLP Holiday Social at Oldemeyer Center

Saturday, December 9
12:00 Noon to 2:00 pm
Seaside Room

We'll have munchies and beverages. Potluck contributions are welcome.

We hope everyone can come. MSers, caregivers, family members, doctors, physical therapists, volunteers, donors, interns, etc. are invited.

Development

Giving is joyful. MSQLP gives its services free to all of our clients (persons with MS, their caregivers and family members). We are proud of this fact. At the same time, each HouseCall our Case Manager makes, has related costs. Given that our theme is *Gratitude*, we want you to know about our *Angels* for whom we are so grateful.

Our *Angels* are the people and institutions whose donations allow us to offer free service to you. Over the past 6 years we have received donations from individuals and grants from foundations and corporations. Most funding has come from California, but some has come from out of state. Starting in 2007, we will be publishing our donor's names in this newsletter (unless they wish to remain anonymous).

A challenge we face is that many foundations want organizations such as ours to become less dependent on them and more reliant on a donor base of individuals. We are working on such a development plan but we need your help.

With any donation made between now and the end of the year, the donor will receive a beautiful angel holiday ornament pictured below. Could you be an *Angel* and ask your friends and neighbors to help support MSQLP? Here is how you can help us:

1. Call us at (831) 333-9091 and we'll send you the Angel ornaments and cards (see below).
2. Tell a friend or neighbor about MSQLP and show them the card that identifies costs related to our HouseCalls program.
3. Ask if they would sponsor one of the costs.
4. If they make a donation, hand them an *Angel* ornament!
5. Send us their donation and name/address. We will send them a thank you note.

Be an Angel

Help a neighbor with Multiple Sclerosis

The Multiple Sclerosis Quality of Life Project (MSQLP) provides FREE support to our neighbors with MS in Monterey, San Benito, and Santa Cruz counties. Our social worker makes house calls to people with MS. She helps them develop strategies and meet goals that improve the quality of their lives. But we can't do it alone. House calls are expensive.

Would you be an *Angel* and help sponsor a cost related to a visit?

- \$7 box of file folders
- \$10 box of large file envelopes
- \$11 multi-chambered pill box
- \$13 accordion file
- \$15 4 client binders
- \$25 one week of cell phone use
- \$30 case of copy paper
- \$35 one visit of social work time
- \$39 100 stamps
- \$40 100 blank CDs
- \$75 gas for one week
- \$100 donation
- \$250 donation
- \$500 donation



We thank you. *You ARE an Angel!*

A final word about gratitude

We at MSQLP are grateful and privileged to have met so many wonderful clients, family members and caregivers. We recognize that each of you has had to meet incredible challenges in your lives and we are impressed with how often you face these with dignity and grace. We are richer for knowing you. Our volunteers – how helpful you have been – driving clients to meetings, visiting those who look forward to seeing a friendly face, helping out in a myriad of ways. Without your support we could not do what we do. Our CSUMB interns – your positive attitudes and cheerful willingness to jump in and help where needed is gratefully appreciated. We look forward to witnessing your future contributions to the world of social services. Our board members – you work hard! You chair committees, research new solutions to challenges our organization faces, contribute financially to our programs, cheer us on. The end-of-the-year holidays will soon be here. We wish all of the members of our extended MSQLP family a joyous season and the time to reflect on the gift of family and friends. It is, indeed, a time to contemplate gratitude.

Calendar

November

- 15** MSQLP Holiday *Angels* available
- 16** Monterey County Caregiver's Conference
Hyatt, call 645-1000 to register
- 17** Support Group, Salinas, DRC Rm. A
- 17** Water Aerobics Class, Monterey
- 18** Support Group, NMSS, Santa Cruz
- 24** *No Water Aerobics Class*
- 29** Support Group NMSS, CHOMP

December

- 1** Water Aerobics Class Monterey
- 8** Support Group, Salinas, DRC Rm. A
- 8** Water Aerobics Class, Monterey
- 9** Holiday Social, Oldemeyer Center
- 14** Support Group, Pleasant Care
- 15** Water Aerobics Class, Monterey
- 16** Support Group, NMSS, Santa Cruz
- 22** Water Aerobics Class, Monterey
- 27** Support Group NMSS, CHOMP
- 29** Water Aerobics Class, Monterey

January

- 5** Water Aerobics Class, Monterey
- 11** Support Group, Pleasant Care
- 12** Water Aerobics Class, Monterey
- 13** Support Group, Oldemeyer Center
- 19** Support Group, SVMH, Salinas
- 19** Water Aerobics Class, Monterey
- 20** Support Group, NMSS, Santa Cruz
- 26** Water Aerobics Class, Monterey
- 31** Support Group NMSS, CHOMP

Looking Ahead:

March

MSF Cruise for a Cure, Alaska

April

MSQLP walks in The Human Race

MS Quality of Life Project
519-B Hartnell Street
Monterey, CA 93940

Return Service Requested