



Multiple Sclerosis Quality of Life Project

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SUMMER 2011 COMMUNICATION

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- Preparing for the visit: from the patient's perspective
- From the neurologist's perspective
- MSer Interview
- A doctor faces MS
- Support Groups
- Doctor Schapiro's talk
- Upcoming Ed event
- MSQLP Calendar
- In Memoriam

TOPICS of PAST ISSUES

- Exercise: August 2006
- Nourishment: November 2007
- Caregiving: February 2008
- Anxiety: May 2008
- Advocacy: August 2008
- Mobility: November 2008
- Housing: February 2009
- Bowel Management: May 2009
- Wellness: August 2009
- Celebrate 10 Years: June 2010
- Changes at MSQLP Autumn 2010
- Finances Winter 2011


To read previous issues, go to www.msqlip.org/learn/newsletter.html

Letter from the Editor

—*Donna Krasnow*

How would you assess the communication between you and your physician? Do you believe he or she understands how MS impacts your life? That he or she listens to you? Do you get home from an appointment and then mentally slap your forehead in frustration when you realize you forgot to ask your doctor an important question? Effective communication is important in all parts of our lives, and especially when thinking about our health. This is true for all of us whether we have MS or are a caregiver, partner, family member, or friend of someone with MS. The ramifications of ineffective communication may be profound: not understanding treatments you are supposed to follow, not taking medications in the prescribed manner, or losing confidence in your ability to handle the many challenges of MS. The opposite is true if you and your physician understand each other and communicate well. You will feel more confident as you walk the path of MS.

To help you evaluate your own communication patterns with your physician we have included several interviews that look at doctor-physician communication from different perspectives. Our own Andrea Dowdall, a social worker, talks about preparing for your appointment, while Dr. Liz Crabtree, a neurologist at UCSF, tells how she evaluates the success of appointments. Amy Lamb, the third member of our editorial staff, has interviewed several MSers about their thoughts on effective communication. The final interview is with Paula Reif Headbloom, an OB-GYN physician who had to give up her practice after her MS diagnosis. Yes, even physicians experience communication difficulties. In another article, Amy summarizes what we all learned from Dr. Schapiro at his presentation on May 10 in Monterey.

Finally, this is my last issue as editor of the MSQLP newsletter. I have decided to move to Portland, Oregon to be with family—my daughter, her husband and my most precious almost-2-year-old grandson. Although it is difficult to leave this area, I look forward to living in an urban environment (never have before) and spending more time with my grandson. I thank you for your support of our newsletter. I am very proud of what we have achieved: it has become an important tool for educating our clients, and I thank the many, many people who have contributed their time, articles, and editing skills. 

continued page 2

- Aug-Dec 2004: 21
- 2005: 59
- 2006: 119
- 2007: 173
- 2008: 201
- 2009: 226
- 2010: 248

Effective Doctor-Patient Communication... from the Patient's Perspective

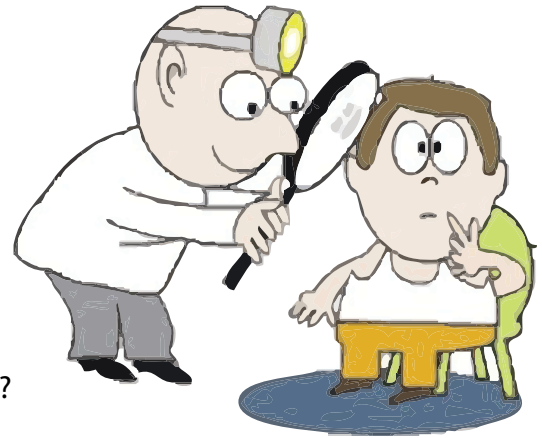
—*Andrea Dowdall, MSW, MEd, MSQLP social worker*

Over the years I have accompanied clients on visits they have made to their doctors. In the process I have learned much about effective doctor-patient communication. Here's what I'd like to share with you!

1 Prepare for the visit

Write down the goal of your visit.

Do you want to tell your doctor about a new symptom? Your reactions to a new medicine? How changes in cognition or mobility affect your employment? How fatigue affects your family? Or is this a 6 or 12-month check-in and you just want to touch bases about your overall health? Keep your goal in mind and make sure your doctor addresses it.



Another way to approach the visit is to identify what most affects your quality of life at this moment in time. Does urinary urgency, for example, mean you plan your life around proximity to bathrooms? This greatly limits what you can do and how much you can enjoy your life and should be addressed with your doctor. He or she may offer solutions you hadn't considered.

Bring an updated list of your medicines that identifies dosages and when you take each. Include vitamins and supplements on your list. Bring any lab work or MRIs that are new since your last visit.

Bring a list of questions about medicines, symptoms, and treatments. Your doctor can't read your mind so identify what you want to know. Be prepared to write down what your doctor says. Consider bringing a family member or friend with you. He or she can serve as a second pair of ears, take notes during the visit and jog your memory to make sure your goals are addressed.

2 Be honest with your doctor

Honesty is the best policy. Let your doctor know how you are following your prescribed treatment plan. For example, if you are not taking a medicine as prescribed or have stopped taking it altogether, tell the doctor and explain

TOTAL NUMBER OF CAREGIVER CLIENTS

- Aug-Dec 2004: 1
- 2005: 21
- 2006: 47
- 2007: 75
- 2008: 92
- 2009: 107


why. If you stopped because of the medicine's side effects, a smaller dosage might work or there may be a different medicine that could be used in its place. Your doctor cannot do the best for you if he or she is not aware of how you are following the directions you were given. Also be aware that there is no guarantee that your doctor will go along with a request you may have. For example, if you wish to try a different medicine, a medicine you have read about, your doctor may not believe it will help as much as the one he or she has already prescribed or may believe you do not match the profile of a patient who is appropriate for the medicine that interests you. So while you are being honest, expect your doctor to be equally honest with you.

3 Be proactive, not passive

You should be your best advocate. When discussing symptoms, you need to identify how much they affect your quality of life and how much you can tolerate its treatment or lack of treatment. Let's use urinary urgency example again. Are you content to address it with a non-medical solution – to wear pads? Or are the negatives associated with pads more than you can tolerate? Would you prefer a medication? To fully address this question, however, you need to discuss possible side effects, risks and benefits of the new medicine. Will the addition of this new medicine interact with other medicines you are currently taking? It is crucial to be up front about your level of tolerance of both the symptom and possible solutions. The goal is to have a treatment plan that addresses your quality of life in a way that works for you.

4 Some final thoughts . . .

Keep in mind that your local neurologist knows a lot about MS but is not an MS specialist. If you are newly diagnosed or in transition (experiencing a bad exacerbation or you believe your MS might be becoming progressive), you may want a referral to the MS centers at UCSF or Stanford. And remember, not all symptoms are MS-related. The pain in your arm may be associated with your MS, but it could also be bursitis or something else altogether. You may need a referral to a physiatrist (a rehab doctor—not a psychiatrist!) or occupational, physical or speech therapist (OT, PT, ST).

And finally, remember that there is a relationship between you and your doctor. Not only do you need to speak honestly, you also need to listen. Effective communication can result in better comprehension and more effective implementation of your treatment plan. 

Congratulations go to our former interns!

Miryam Mejia for passing her licensure test (LMFT - Licensed Marriage and Family Therapist) on the first try.

Grant Helm for graduating from CSUMB. Grant is now our Assistant Clinical Manager.

Margot Frey for graduating from CSUMB.

Ian Fagan for graduating from CSUMB. Ian is off to graduate school in the fall to begin his MSW studies.

All had awesome capstone presentations as witnessed by Andrea Dowdall, MSW.



We thank our volunteers!

- **Carieanna Hess**
- **Marie Swank**
- **Larry Swank**
- **Jane Brown**
- **Tammy Jennings**
- **Terry Bennett**

Tips for Making the Most of Your Appointments

—Amy Lamb Heckel, RDH

For this article, Amy interviewed a number of MSers. You may already adhere to the following five common sense suggestions. If so, good for you!

Arrive on Time

So many practitioners have limited time for each appointment — why cut yours short? If you are dependent on another for a ride and discover that you are going to be late, call the office and let them know. They might be worried about you.

Be Honest

Remember that your doctor cannot help you solve a problem if they are unaware of it. Being honest about side effects or other drawbacks will help you and your doctor form a more effective team. This will lead to better treatment planning and management of your symptoms.

Bring a Friend

As the saying goes, “two heads are better than one.” Your friend may catch something that you did not. They also may remember something afterwards that you did not.

Bring a List of Current Medications

Your doctor may have no idea what other medications have been prescribed for you by other health care professionals. Be sure to include any over-the-counter (OTC) medications and/or any supplements that you are taking. There may be potential interactions that both you and your doctor should be aware of.

Bring a Prioritized List of Discussion Topics

If you occasionally experience difficulties speaking, write the list out (with the priorities clearly marked) and hand it to your doctor first thing. By prioritizing in advance you can be sure that whatever is most important to YOU will be addressed, even if time runs short. 🏠



Challenging at times

Open up to one another

Might help if you can be objective

Mindless chatter is a waste of breath

Understand there is more than your point of view

Now you must realize this takes patience

It may be uncomfortable at times

Conquer the fear if someone disagrees with you

A amazing opportunities will be presented to you

Take time to think, before you speak

If you repress feelings, nothing will be solved

Oh we should have learned all this in kindergarten

Negative energy does not attract positive energy

— Victoria Scaccia

Successful Physician-Patient Appointments



Dr. Liz Crabtree

Dr. Liz Crabtree is an MS Clinic Neurologist at the UC San Francisco (Clinical Director, UCSF MS Center; Director Patient Education and Support; Assistant Clinical Professor of Neurology).

Now that two medical professionals who interact mainly with patients have given you their advice about effective patient-physician communication, in this interview with Donna Krasnow,

Dr. Crabtree will tell you from a doctor's point of view how she decides whether or not an appointment was productive for both doctor and patient.

One way I evaluate the success of an appointment is to note patient attitude when we walk out to the waiting room at the end of our clinic appointment. What I want to sense is a lessening of any anxiety the patient brought to the appointment. My hope is that their questions have been answered, they understand what has been said, and this information has adequately addressed what they really wanted to know.

One challenge when following the traditional step-wise approach that physicians use during an appointment — collect patient history, conduct a physical exam, review diagnostics, and make an assessment and plan — is that concerns a patient brings to an appointment may get lost in the process. Their issues may not fit neatly into one of these steps, or may be eclipsed by other competing information. For example, a patient may be concerned about bladder issues, but during the appointment, the latest MRI discloses new lesions. Appointment time might then be spent discussing/explaining new therapies that address the lesions (representing breakthrough disease activity) but in the process, the bladder issue is never raised. If the patient does not identify the concern and if the doctor is time-pressed, clients may walk out with important information about new therapies but have no answers to what really concerned them initially.

I believe that there is a dynamic relationship between doctors and patients, but appointments must be patient-centered. If I could give one piece of advice to your MSQLP clients it would be to bring a list of concerns to your appointment. It can be handwritten or listed on your phone but don't trust your memory. When you are anxious, it is easy to forget. Think about the issues before the appointment so you have time to add things over time. Do you have concerns about medications or supplements: "Should I take vitamin D?" "What are possible side effects of medications I am taking?" or questions about new symptoms that

TOTAL NUMBER OF
HOUSE VISITS

- Aug-Dec 2004: 57
- 2005: 286
- 2006: 346
- 2007: 715
- 2008: 993
- 2010: 1,292

may have appeared: "I now have to go to the bathroom 3 times each night" or "Why am I experiencing more muscle spasms than in the past?" Bring the list with you and then, with it in your hands, you will not forget to ask the doctor about each question or concern. It may not be possible to address all the items if your list is long, but you and your doctor can then make an action plan to address the 'top 3', and plan for a phone or in-person appointment shortly thereafter to address the remaining items.

I wish I could say that all of my appointments are 'successful'. What is frustrating for me is not having answers to client concerns. It may be that a concern addresses issues for which there is not yet an answer. It may be that I have to wait for results of tests that a patient must first take. In either case I am sorry when it happens because I know that, even if an answer may not be what patients want to hear, at least they have an explanation of what is happening and anxiety can be reduced.

One always hopes that appointments will result in successful communication between a doctor and a patient. Don't forget- your role in this successful communication is as great if not greater than the physicians' component.

Take care—Dr. C 🚩

Is communication different for a physician with MS?



*Paula Reif Headbloom with
her two grandchildren*

Funny how threads in your consciousness find each other and quietly weave something useful. In this case, it was something useful for persons with MS.

On a recent trip to Michigan, I remembered that my dear friend Sarah told me about her wonderful OB-GYN who had been forced to leave her practice after her MS diagnosis.

I didn't know Paula Reif Headbloom, but wondered how she, an accomplished medical practitioner, felt when she was faced with leaving the specialty that she loved... and if her medical knowledge made it easier to communicate with physicians in another field.

I mentioned my interest in talking with Paula to another friend. "Oh, sure," she replied, "I know her. I'll call her." Little did I know she was calling Paula in Hawaii! Paula was warm and helpful, and when I told her about MSQLP and our newsletter, she quickly agreed to tell me about her experience. Here's what she said in her email as an answer to my question, "Is communication different for a physician with MS?" — Mary (Mimi) Wessling

PHONE CALLS WITH
OR FOR CLIENTS

- Aug-Dec 2004: 480
- 2005: 5,246
- 2006: 11,414
- 2007: 15,823
- 2008: 19,493
- 2009: 22,373
- 2010: 26397

Aloha Mimi,

Perhaps a brief history will help frame the answers to your questions. Following a viral illness in late 1991, I was left with disabling vertigo. I was a wall-walker, couldn't drive, had trouble reading, had difficulty with short-term memory, and was nauseated unless I was flat on my back much of the time. My OB-GYN practice came to an abrupt stop. I spent several years seeing ENT's and neurologists, trying different medications, trying vestibular rehabilitation, and trying patience. But it was trying MY patience!

One day during a particularly challenging time with vertigo and nausea, I called my neurologist and he said, "I have nothing more to offer you." I was devastated. The icing on the cake was when he called me back later that same day to see if I would be willing to talk with a patient who was also experiencing vertigo. Ordinarily I am happy to talk with people who are having similar symptoms, but on that day, I was the patient and I needed help.

It was time to take a new approach, so I went to see a nationally recognized neurologist who specialized in MS. I thought he would be the best person to know what it was *other* than MS because he had to make that distinction every day. However, he found other neurologic deficits on my exam and explained that while my MRI was negative for MS, clinically I still presented with MS. There was nothing else to call it. Now I had a name for it - and ironically, though I wasn't reassured, I could focus on learning to live with it rather than feel like a failure because I wasn't getting better.

I had asked, how did your experience with your patients, who were facing an uncertain course of events and outcome, prepare you to ask questions of your neurologist after your MS diagnosis?

To be honest, I didn't do very well at first primarily because I was too miserably ill to think very well or to be an advocate for myself. I just wanted them to diagnose the problem and fix it; I had no idea at the beginning that this was going to be a long term problem - I didn't know the outcome was uncertain.

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With my own patients, if there was an uncertain diagnosis, I strove to provide the best medical care I knew, and if I reached the end of what I knew and they still had the problem, I would say, "You need to see someone smarter than me" and make the appropriate referral for new eyes to look at the problem. And if there still was no answer to their problem, I would provide comfort and promise to keep my eyes and ears open for new developments that might help them. *Short of a terminal illness, there is always hope. And with a terminal illness, there is still comfort and care to be provided.*

The afternoon that my neurologist said, "I have nothing more to offer you", my own words came back to me and I realized that he wasn't saying "There is nothing more to offer you" - he was saying, "I have nothing more to offer you." Unfortunately, he didn't take the next step, but at that point, I knew to take the next step, and that is when I moved on to someone who was "smarter."

In that moment, I had to find my own hope and my own referral. It is possible to find doctors who are not only excellent clinicians, but who are also good listeners, who are able to speak to your listening, who provide hope and not a dead-end, and who provide comfort. It is worth seeking them out.

Other ways that my being a doctor helped inform me to be able to ask questions of my neurologist were:

1. To make the most of an office visit, I would try to shorten my history of new events or problems to the most clinically succinct and pertinent form possible. I left out extraneous details (avoiding things like "It happened on the Saturday before Father's Day I remember because we were driving to the mall and it was hot and the radio was blaring, etc")

2. While I didn't want to become obsessive about symptoms, it helped to keep track so that when I was asked how often something happened, or what triggered it, or how long it lasted, etc, I had an answer and didn't have to think on the spot.

3. I tried to take someone with me to office visits - four ears are almost always better than two!

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4. I tried not to ask questions of the neurologist that either they couldn't answer or were beyond their scope of practice. Yes, I needed a neurologist, but I also needed a good family doctor, and sometimes, I needed a urologist or a physical therapist who was knowledgeable about MS. A good MS neurologist has a wide base of specialists they can refer their patients to.

I also asked: How do you think that your medical knowledge assisted, or conversely, hindered your ease of communication with your neurologist?

Interesting question! This was entirely provider dependent. I met some who seemed uncomfortable and tried to minimize findings so as not to alarm me. (They say that medical students often fear they have serious illnesses when they develop minor symptoms because of what they have read or seen. I was never one of those medical students. In fact, until I got sick, I was one of those doctors who felt invulnerable to significant disease.) These 'minimizing docs' were not helpful to me. In fact, sometimes I felt they were assuaging their own fears* rather than addressing my symptoms. (*fear of not being 'right', or another intangible fear, "If this could happen to her - and she's a doc - this could happen to me.")

The best docs - and they are out there - were the ones who weren't put off by my being a doc, but who also knew that I was an OB-GYN and not a neurologist. They sought out what I already knew and then expanded on it.

I should add that once I found the neurologist I had confidence in, I let him be the neurologist - let him keep up on the latest advances. That doesn't mean I wasn't interested or involved, I just didn't read everything I could on MS or try to micromanage my care. At least I don't think I did - you'd have to ask him, I suppose!

One other thought about the best three things I have done for my medical care since my diagnosis:

I found a reputable neurologist who specializes in MS and who oversees the big picture of my MS management - what medications to be on, how to manage

exacerbations, etc. He is at a medical center away from my home, so I see him every year or two.

I established myself with an excellent family doctor who not only coordinates my MS care and manages my exacerbations according to the neurologist's recommendations, but also sees to my overall health care. It's easy to think that if you have one diagnosis, you might escape other more mundane things like hyperlipidemia or hypertension. Or it's easy to think that a new symptom is MS-related. A good primary care doctor is essential to help figure that out.

I attended a comprehensive MS program early on (an MS CanDo program - at the time it was the Jimmie Heuga Program). It was a unique opportunity to meet with doctors and physical therapists and exercise physiologists and occupational therapists and psychologists - all of whom were knowledgeable about MS and who helped me formulate an approach to the rest of my life in a way that no one else had been able to do.

Not only did I stop thinking of myself as having an illness, I gained tremendous respect for a team approach to medical care. And, I now have a network of medical folks who specialize in MS and would help or advise me as I need it. 🚩

MSQLP Support Groups

MSQLP's Seaside Support Group

Oldemeyer Multi-Use Center
986 Hilby Avenue, Seaside
General and Caregiver Support group
2nd Saturday of each month
11:00 am to 1:00 pm

MSQLP's Salinas Support Group

Salinas Valley Medical, Downing
Resource Center
General Support Group.
3rd Friday of each month,
11:00 am to 1:00 pm

National MS Society-Sponsored groups

United Way, Santa Cruz:
4450 Capitola Road, Suite 106
Capitola (behind AAA building)
3rd Saturday of each month,
10:30 am to 12:30 pm
Call Ada Shannon: 440-1211 🚩

To do your part and contribute effortlessly to MSQLP, get your free S.H.A.R.E.S. card. Call the MSQLP office at 333-9091



The Answer to Disability is... Mobility!

—Amy Lamb Heckel RDH

Dr. Randy Schapiro believes so deeply in the above concept that he asked the entire audience to repeat it several times during his May 10 presentation in Monterey. Dr. Schapiro has been working with MS patients for over 35 years and had some very succinct advice to offer us. For instance, instead of keeping a “symptom journal” (which often gets bogged down in minutiae), he suggested keeping a record of changes in function. Any change in function can then be addressed by the patient and doctor together. He emphasized the need for a team approach to MS care where the patient is actively engaged in treatment decisions.

Dr. Schapiro noted that at least 65% of MS patients will experience cognitive difficulties at some time. That, combined with common MS bladder and bowel problems, will often lead to social isolation. That tendency does not surprise him: he confirmed what most of us have discovered—that stress makes MS symptoms worse. However, Dr. Schapiro cautions against diminished social interaction because it has been his experience that it is those very interactions that help to keep our minds active.

Dr. Schapiro unabashedly discussed some of the more typical sexual problems that MS patients experience. He pointed out that a solution cannot be achieved until communication takes place. He suggested that honesty and communication between partners may go a long way toward helping everyone to feel more relaxed about a very emotional subject. Communication between the MS patient and their doctor is extremely important. As he questioned, “How can we help our patients find a solution if we are not clear on what might be the problem?”

Knowledge is Power! Understanding Relapsing MS

On Saturday, July 23, 2011, at our next educational event, the featured speaker will be Dr. William R. Schaffer, MD, a neurologist practicing at the North Colorado Medical Center.

Don't miss this opportunity to listen to a healthcare professional, to ask your questions, meet others living with MS, and to learn more about relapsing MS treatment options.

Embassy Suites, Monterey Bay – Seaside, 1441 Canyon Del Ray, Seaside, CA 93955.

Registration 10:00 am. Program 10:30 am. Breakfast will be provided.

To register, call toll free 1-877-969-1722 or visit

<http://events.signup4.com/2011mslifelinesprograms>

Sponsored jointly by EMD Serono, Inc. and Pfizer, Inc. 

NEWS FROM OTHER ORGANIZATIONS

We'd like to hear from you if you know of activities that your fellow MSers would benefit from and enjoy.

MSQLP CALENDAR

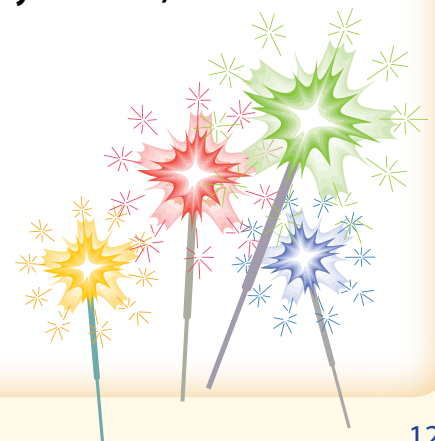
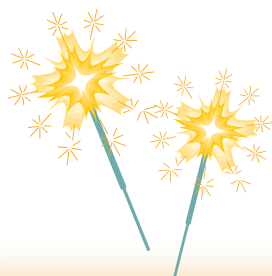


July

- 1: Water Aerobics, Monterey Sports Center 12–1 pm**
- 6: Water Aerobics, Monterey Sports Center 12–1 pm**
- 8: Water Aerobics, Monterey Sports Center 12–1 pm**
- 9: Support Group, Oldemeyer Center, Seaside 11 am–1 pm**
- 13: Water Aerobics, Monterey Sports Center 12–1 pm**
- 15: Water Aerobics, Monterey Sports Center 12–1 pm**
- 16: Support Group, NMSS, Santa Cruz, 10:30 am–12:30 pm**
- 20: Water Aerobics, Monterey Sports Center 12–1 pm**
- 22: Water Aerobics, Monterey Sports Center 12–1 pm**
- 23: Educational Event, Dr. Schaffer 10 am–1 pm**
- 27: Water Aerobics, Monterey Sports Center 12–1 pm**
- 29: Water Aerobics, Monterey Sports Center 12–1 pm**

August

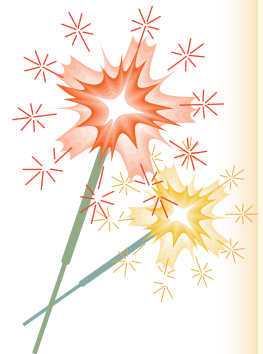
- 3: Water Aerobics, Monterey Sports Center 12–1 pm**
- 5: Water Aerobics, Monterey Sports Center 12–1 pm**
- 10: Water Aerobics, Monterey Sports Center 12–1 pm**
- 12: Water Aerobics, Monterey Sports Center 12–1 pm**
- 12: Support Group and Caregiver Group, Oldemeyer Center, Seaside 11 am–1 pm**



- 13: NMSS Ed Event: Marina Public Library
Healthcare reform one year later: Discover what it means for persons living with MS and their families 10 am–1:30 pm**
- 17: Water Aerobics, Monterey Sports Center 12–1 pm**
- 19: Water Aerobics, Monterey Sports Center 12–1 pm**
- 20: Support Group, NMSS, Santa Cruz, 10:30 am–12:30 pm**
- 24: Water Aerobics, Monterey Sports Center 12–1 pm**
- 26: Support Group, Salinas Valley Hospital 11–1 pm**
- 26: Water Aerobics, Monterey Sports Center 12–1 pm**
- 27: Support Group, NMSS, Monterey, Community Hospital, 7–8:30 pm**
- 31: Water Aerobics, Monterey Sports Center 12–1 pm**

September

- 2: Water Aerobics, Monterey Sports Center 12–1 pm**
- 7: Water Aerobics, Monterey Sports Center 12–1 pm**
- 9: Water Aerobics, Monterey Sports Center 12–1 pm**
- 10: Support Group and Caregiver Group, Oldemeyer Center, Seaside 11 am–1 pm**
- 14: Water Aerobics, Monterey Sports Center 12–1 pm**
- 16: Water Aerobics, Monterey Sports Center 12–1 pm**
- 17: Support Group, NMSS, Santa Cruz, 10:30 am–12:30 pm**
- 20: Support Group, Salinas Valley Hospital 11–1 pm**
- 21: Water Aerobics, Monterey Sports Center 12–1 pm**
- 24: Walk N Roll – Fundraising, Social gathering, BBQ, and free giveaways!
(More information will be available in the following months)**
- 23: Water Aerobics, Monterey Sports Center 12–1 pm**
- 28: Water Aerobics, Monterey Sports Center 12–1 pm**
- 30: Water Aerobics, Monterey Sports Center 12–1 pm**



October

- 8: A new play by Tom Parks, Paris is Paris is Gertrude Stein is Paris
(More information will be available in the following months)**

In Memory Of...

Jana Davis

Josephine Henshaw

Mario D'Olivo

