



NARCOMS

North American Research Committee on Multiple Sclerosis

It's a Hot Summer! Keep Cool!

The Faces of NARCOMS

The following article was written for this newsletter by Carole G., a NARCOMS Participant:

I am 64 years old.

I was finally diagnosed with secondary progressive MS at age 48. I say *finally* because I had struggled with the symptoms since I was 10 years old!

I've had them all: vision loss, trigeminal neuralgia, fatigue, weakness in limbs, cognitive problems. The list goes on and on.

I was bedridden at 48. Having a nursing background, I knew I needed to get therapy or never get out of bed.

I began water therapy. I love the water and can do anything in it. Sixteen years later, I still do water therapy. I walk most days 1-3 miles. I do water aerobics and have learned to control my spasms, both body and bladder, by mild doses of meds and EXERCISE.

Keep moving! It's the most important part of your rehabilitation. I'm living proof.

— Carole G.

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We encourage you to share your MS story with other readers. If interested, please write your story and send it to MSregistry@narcoms.org for publication in a future issue of the newsletter or for posting on the NARCOMS website.

NARCOMS Publications

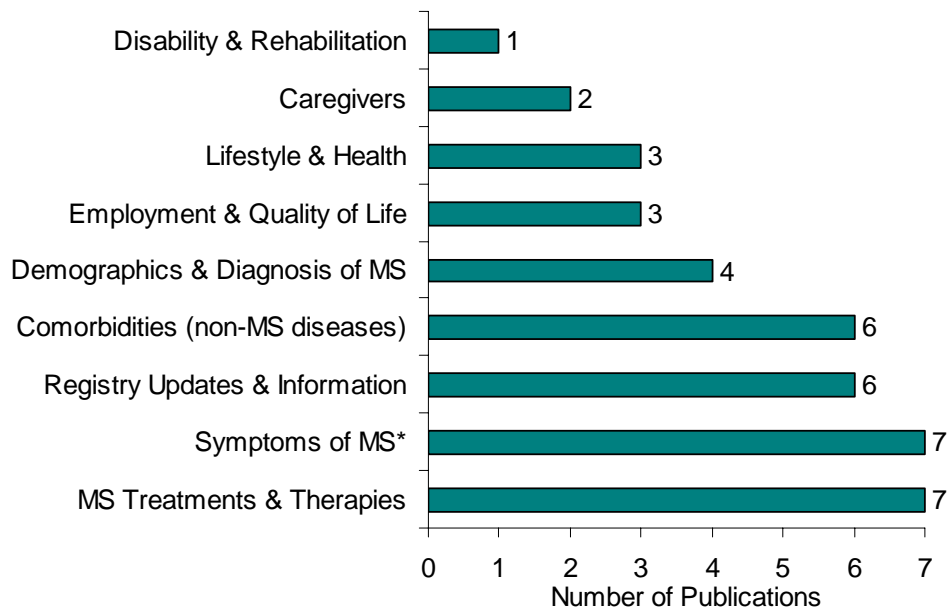
The Value of Participating Over Time

Every time you complete a NARCOMS update, there are standard sets of questions that you see every 6 months and a new section that is unique to each update. It may not seem obvious to you but each of these sections can be directly utilized for research:

- **Longitudinal Data:** The sections that are asked each time are used for what is called longitudinal information – that is a fancy way of saying that we track changes over time.
- **Cross-sectional Data:** The unique sections on the updates are used for cross-sectional research; that is, a “snap-shot” of the NARCOMS participants on how they answer those questions at that specific time.

For example, every update asks for information on your current and past medications and therapies you use for your MS. Since 1999, seven articles have been published that describe and characterize the use of MS medications over time. NARCOMS data have been featured in 39 peer-reviewed articles and almost 100 scientific posters and presentations.

Primary topic areas of peer-reviewed publications from 1999-2010



*Symptoms include: depression, fatigue, pain, bow el, bladder, spasticity

Medication Assistance Resources for Help

Speaking of medications...finding effective medications and paying for them have become major issues in the United States. In the Spring 2010 update there were several questions about programs that assist persons with MS in paying for all or part of their medications. We've had inquiries about this issue and while NARCOMS cannot provide assistance we did want to provide some more detailed information on available resources.

The National MS Society website: <http://www.nationalmssociety.org/index.aspx>. Search for “Finding Lower-Priced Prescription Drugs” or “medication assistance” to find information on various assistance programs.

Disclaimer: NARCOMS is not affiliated with any of these programs or services

The NARCOMS newsletter is a complementary benefit we offer exclusively to our participants. To view the rest of this and other past issues, please join!