

Just Diagnosed—Now What?

Get up to speed with the information you need

BY ORLY AVITZUR, M.D.

After going through tests and feeling lousy, you finally receive a diagnosis. Your neurologist explains what it means, discusses treatment options, and answers your immediate questions. But by the time the information finally sinks in, you've already left the office. So what can you do to learn more about your condition and make the best possible decisions about treatment?

CONTACT ORGANIZATIONS

There are organizations for practically every neurological condition, and their trained staff can offer practical advice, educational materials, and excellent resources for the latest research findings, treatment options, and clinical trials. That help can also extend to legal concerns, insurance questions, and work-life challenges.

Donna Diener is glad she reached out to one such organization. Six years ago, she experienced a relapse of multiple sclerosis that left her so dizzy and off-balance that she was unable to stand or walk. Having been in remission for 22 years, she turned to the National Multiple Sclerosis Society (NMSS) for information.

"When I first picked up the phone, I cried," says Diener, "but the local NMSS chapter rep just listened to me for two hours. From that point on, they were just there for me." Diener has since made good use of the organization's wide variety of educational materials—pamphlets, magazines, an Internet-based educational program, and for those without computers, a large lending library. The NMSS also underwrites much of the costs of local support groups and exercise classes such as Tai chi, yoga, and aquatics programs.

Diener also joined a support group that was organized by the NMSS. "I met others there who were just as frustrated as I, and with whom I could share ex-

periences," she says. After three years of attending meetings, she is now a trained group leader. "The members of that original group helped me so much through friendship and understanding and support," says Diener. "It is a privilege to do the same for others."

VISIT TRUSTED WEBSITES

"When I first tell patients they have a serious neurological condition, they often have trouble absorbing the information, so I provide them with a list of resources, including informative websites," says Neil A. Busis, M.D. The chief of the neurology division at the University of Pittsburgh Medical Center Shadyside Hospital teaches courses about the medical Internet to other neurologists and has designed several neurology websites. His favorite sites for patients are Medline Plus, medlineplus.gov, and the National Institute of Neurological Disorders and Stroke (NINDS), ninds.nih.gov; these sites are authoritative, evidence-based, and free of commercial bias, he says.

"My patients return with a stronger base of knowledge, and that helps us have a better discussion about further diagnostic and treatment options," says Dr. Busis. "Information itself is a form of therapy for patients—just knowing more about their condition makes them and their families feel better."

Naomi Miller, manager of consumer health information at the National Library of Medicine, agrees. Patients often tell her that they become reassured about their conditions after searching through MedlinePlus. A good place to start that search is with "Health Topics," a collection of 750 librarian-created pages of

links to reliable medical information. The section "Brain and Nerves" covers a wide variety of neurologic diseases, and the interactive health tutorials are an easy way to learn about procedures and tests. MedlinePlus also includes a comprehensive medical encyclopedia, information about drugs and supplements, and the latest news on conditions.

Marian Emr, director of the office of communications and public liaison at NINDS, says the NINDS Web information is useful as a supplement to material provided by doctors. The site describes numerous neurological disorders, and contains information on diagnosis, treatment, prognosis, and research. It also

provides links to other agencies that can provide information and services, referrals to specialists, and support groups. The site had more than 1.6 million visits in November of 2006, and an average of more than 150,000 page views per day. The most popular pages were those describing shingles and carpal tunnel syndrome,

followed by Parkinson's disease, stroke, Huntington's disease, Guillain-Barre Syndrome, autism, back pain, cerebral palsy, and MS.

ASK FOR RECOMMENDED 'READS'

"Doctors usually only have time to summarize answers to a long list of questions, so patient-oriented books or flyers can help fill in the gaps," says University of Maryland neurologist Lisa M. Shulman, M.D., who co-authored *Parkinson's Disease: A Complete Guide for Patients and Families* (Johns Hopkins University Press) and is the editor of a book series for patients from the American Academy of Neurology (AAN).

"[It's] a form of therapy for patients. . . . Knowing more makes them feel better."



The AAN series includes easy-to-read guides to management of Alzheimer's disease, epilepsy, pain, stroke, migraine, peripheral neuropathy, and other neurological conditions. Upcoming titles will address quality-of-life issues such as insurance, assistive devices, and how to use the media to find reliable information. Visit aan.com/storefront/Patient_Education_C20.cfm for a complete list and ordering information.

In addition, organizations such as the NMSS, the American Stroke Association, and the Epilepsy Foundation can recommend a reading list of books that have been compiled by staff and experts.

VISIT AN ONLINE COMMUNITY

If you live too far from in-person support groups, or are too disabled to leave your home, support can be had with just a click of your mouse to one of many virtual online communities focused on specific neurological conditions.

Brain Talk Communities, for example, hosts more than 300 support groups devoted to neurological diseases and disorders; check the site out at

<http://brain.hastypastry.net/forums>. Members say that the benefits extend beyond support. Patients and caregivers receive advice, discuss various treatments, and talk about their daily lives. Some have been steered to tests that have led to a diagnosis of their condition, to therapies that made significant differences in their lives, to specific neurologists, or to medication side effects.

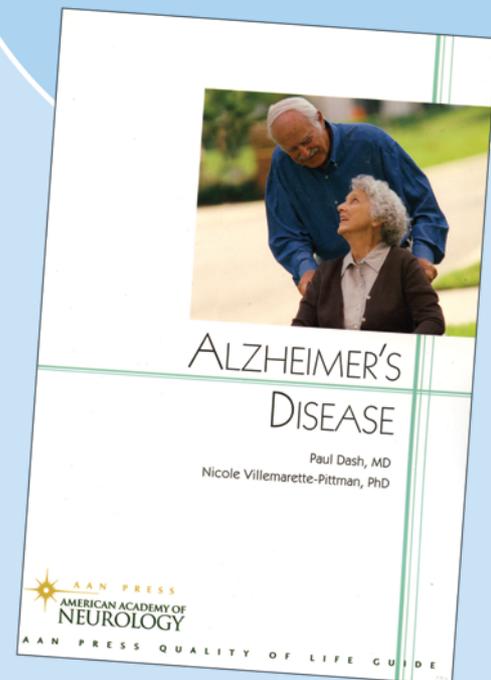
Daniel B. Hoch, M.D., Ph.D., assistant professor of neurology at Harvard, says that the community has grown to around 50,000 registered users at its peak and 500,000 people looking in. And the site is quite active; according to an independent company that tracks web usage statistics, BrainTalk averages about 6,000 posts per week. 

Dr. Orly Avitzur is a neurologist in private practice who holds academic appointments at Yale University School of Medicine and New York Medical College.



For more on reliable information sources about your condition, see RESOURCE CENTRAL on page 46.

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