

THE WAITING ROOM

THIS WAY IN

The Risks of H1N1 Flu

In all the coverage of the H1N1 (“swine”) flu, you may not have heard that people with a number of neurologic conditions should also be at the top of the list to receive vaccinations first.

The Centers for Disease Control and Prevention (CDC) recommends that people ages 25 and older who have underlying conditions putting them at high risk of complications from influenza be at the front of the line for the vaccine. And many of those “underlying conditions” are neurologic. Children with at least one chronic high-risk neurodevelopmental condition—including epilepsy, cerebral palsy, or developmental delays—make up 67 percent of the at least 36 children who have died from H1N1 complications since the disease first surfaced last spring. Adults with amyotrophic lateral sclerosis (ALS), muscular dystrophy, and multiple sclerosis (MS) also appear to be at higher risk of complications from H1N1, and should therefore receive the vaccine early as well, says Abbigail Tumpey, a spokesperson for the CDC.

For people with MS, H1N1 has two complicating factors, explains John Richert, M.D., executive vice president for research and clinical programs with the National MS Society. “First, people with advanced MS, or those with less advanced disease who have any breathing difficulties, are at particular risk for complications from H1N1. Second, any viral infection, including H1N1, can precipitate an exacerbation in anyone with MS.”

Approximately one-third of all MS exacerbations are caused by a viral infection, notes Dr. Richert. “The government estimates that about half of people who do not get the H1N1 vaccines are likely to become infected with the flu virus, which means that about half of all unvaccinated people with MS are likely to develop it as well.”

Dr. Richert adds that people with MS should only get the injectable H1N1 vaccine, not the nasal mist, because the mist contains some live attenuated virus and potentially could itself provoke an exacerbation.

The ALS Association recommends that people with ALS—as well as their family members and caregivers—get the H1N1 vaccine as soon



People with neurological conditions may be at an increased risk of serious complications from H1N1.

as possible. “People with ALS are already at increased risk for respiratory problems associated with viral and bacterial infections,” wrote Edward Karsarskis, M.D., Ph.D., director of the University of Kentucky ALS Association Multidisciplinary Center in Lexington, KY, on the Association’s Web site.

Dr. Kasarskis also recommends the injection rather than the nasal spray vaccine for ALS patients, since many people with ALS have problems with thick secretions in their mouth and throat that can make nasal administration difficult and uncomfortable. Indeed, most recommendations are that anyone with an underlying neuromuscular condition not receive the nasal mist vaccine.

The government has ordered a total of 250 million doses of the vaccine. Daniel Kantor, M.D., who is head of the Florida MS Society and agreed to operate an H1N1 vaccine clinic in his community, was still waiting on November 3 for doses of the vaccine that had been promised two weeks earlier. Because of the high demand, Dr. Kantor suggests that people with neurologic conditions that place them at higher risk of complications ask their neurologist to intervene. “Get your neurologist to write a letter to the primary care doctor, or to whoever is operating the vaccine clinic,

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and try to get pushed to the front of the line," he says.

Some people considering receiving the vaccine have been concerned about an increased risk of Guillain-Barré Syndrome (GBS), a disorder in which the body's immune system attacks the peripheral nervous system, causing muscle weakness and even paralysis. During the last U.S. outbreak of H1N1, in 1976, a vaccine for the flu appeared to be associated with a small increased risk of GBS.

"The association is still controversial," says Gary Gronseth, M.D., professor of neurology at the University of Kansas. "Some studies say the vaccine did not increase the risk of Guillain-Barré, some say it did. The implication is that if there is any increased risk of GBS following immunization, the magnitude is extremely small, and it has to be balanced

with the significant potential benefit of not getting the flu."

Today's H1N1 vaccine is made using a very different process than that used in 1976—one similar to the seasonal flu vaccines, which are given every year without any known increased risk of GBS. Even so, neurologists have been asked to monitor their patients for any potential new cases of GBS after vaccination.

That small potential risk, say most neurologists, pales beside the risk of severe complications from H1N1 for many people with neurologic and neuromuscular conditions. "Of course, individuals should consult with their own neurologist first to ensure that there aren't other factors that may be an issue for them," says Dr. Richert "but in general, we believe our patients should get vaccinated as soon as possible." —*Gina Shaw*



NEUROLOGY NEWS

Guidelines for ALS Treatment

The American Academy of Neurology (AAN) has just issued guidelines for the care of people with amyotrophic lateral sclerosis (ALS).

According to lead author Robert G. Miller, M.D., of California Pacific Medical Center, "While we are waiting for a cure, people need to know that a lot can be done to make life easier and longer for people with ALS."

Also known as Lou Gehrig's disease, ALS is a degenerative neurological disease in which motor neurons that control voluntary movement mysteriously die. Death often comes by respiratory failure. Although most people die within two to five years from the onset of symptoms, 10 percent survive for 10 years or more. I am one of them.

Dr. Miller and his team scoured medical journals for information on the treatment of ALS and then graded the studies for the quality of evidence they produced. Here are the recommendations:

You should be offered riluzole. Riluzole is the only drug approved by the Food and Drug Administration (FDA) for ALS. It extends life by two or three months. The guidelines recommend riluzole regardless of disease stage because, as Dr Miller explains, there is insufficient evidence to say who would benefit from it. Clinical trials typically exclude anyone with symptoms longer than five years duration, and participants must have a forced vital capacity (FVC) of 50- to 60-percent of normal. As a result, there is little data about how riluzole affects people in the later disease stages. (An FVC of 50 percent means your breathing capacity is 50 percent

of the capacity of a healthy person of your age, sex, and height.)

If you have trouble swallowing and chewing, you should be offered a feeding tube. Because the insertion of the tube is done under sedation, people should have the procedure done when their forced vital capacity is above 50 percent of normal. Although the tube has been shown to stabilize weight or cause a small gain, there is no information on how much it prolongs life.

You should be offered noninvasive ventilation at the earliest signs of respiratory insufficiency. Noninvasive ventilation consists of an assisted breathing device, often a BiPaP, that stays

outside your body. Invasive ventilation, on the other hand, requires a surgical procedure known as tracheostomy. Noninvasive ventilation slows the rate at which FVC drops and prolongs life. One study found quality-of-life benefits such as decreased fatigue, clearer thinking, and less daytime sleepiness.

If you have a weak cough, you should be offered an assisted cough device. As the respiratory muscles weaken, it becomes harder to clear secretions from the upper airways and lungs. If these secretions linger, they may become a source of infection. A device such as the Cough Assist™ may be helpful in clearing secretions.

You should attend a specialized multidisciplinary ALS clinic. A multidisciplinary ALS clinic includes specialists in neurology, pulmonology, speech and swallowing, nutrition, and social services. These specialists work together to provide coordinated care for the patient. Studies show that compared with a nonspecialized neurology clinic, patients attending an ALS multidisciplinary clinic were more likely to use riluzole, have a feeding tube, and employ noninvasive ventilation. As a consequence, they survived longer and had a better quality of life.

If you have excess saliva that doesn't respond to oral medications, you should be offered

botulinum toxin. Excess saliva in combination with facial muscle weakness can cause drooling. If oral medications don't work, the same botulinum toxin that is used for cosmetic effect can be used on the salivary glands to reduce excess saliva. The treatment is expensive, and some insurance companies may not cover it.

You should be screened for cognitive and behavioral impairments. Estimates of the percentage of patients with cognitive or behavioral impairments range widely. A small number of people with ALS develop frontal temporal lobe dementia. Such patients often refuse life-prolonging interventions. The guidelines say nothing about the consequences of milder cognitive or behavioral impairments.

The authors found no or insufficient information about many important subjects, such as how to break the news of a diagnosis of ALS. Many of my ALS friends say they were given no hope. While the doctor must convey the seriousness of the diagnosis, in my opinion, she should also state that there are ways of prolonging and improving the quality of life. There are also no guidelines on relieving constipation, spasticity, cramps, anxiety, insomnia, depression, or on the assessment of communication strategies. —*Cathy Wolf*

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QUICK TIPS

Making Holiday Shopping Easier

Having multiple sclerosis (MS) for 30 years has given me many opportunities to learn shortcuts that make my life easier. Here are a few of the tips and techniques I use to save time and energy so I am able to enjoy the holidays. (But don't add to your stress by thinking you have to try all of them!)

SHOP ONLINE: With the Internet, it's easy to shop from home, and the stores are always open. I try to select gifts based on the recipients' hobbies, interests, or talents—and shopping online makes this easier because you can search by keywords.

GIVE GIFT CERTIFICATES: I often give gift certificates (from specialty stores, sporting good suppliers, or restaurants) and tickets (to plays, concerts, or movie theatres). It's easy to charge my purchases and have certificates or tickets mailed to the recipient or me. If I can't buy them online, I'll go to a shopping mall; the mall office usually offers gift certificates that can be used in any store. Most big-box stores also offer gift cards, which the receiver can put toward the cost of a higher-priced item.

PLAN AHEAD: I'm one of those people who actually likes shopping. However, to streamline my trips and make sure I come home with everything I need, I make a list, check the newspaper for sales, and plan my route. Sometimes I'll use the phone to locate the merchandise and compare prices. Many stores will hold merchandise for 24 hours, especially if you tell them why you might be delayed in picking it up. I ask the clerk for the best pickup time—generally early mornings and late evenings

on Tuesday, Wednesday, and Thursday are the quietest times for most businesses.

AVOID THE POST OFFICE: For gifts that must be sent, I make sure I have addresses when I purchase the gift and have the items mailed directly from the store. There will be a mailing charge, but the gift will be wrapped properly and sent without extra effort on my part. For smaller gifts, the post office sells festive gift bags and boxes that need no wrapping; just slip your gift inside, apply an address label, and it's ready to go.

SECURE PARKING PRIVILEGES: Living in the Midwest means that the weather can be frigid and parking lots snow-covered and icy. Years ago, when I was still walking—albeit unsteadily—I contacted the state Department of Motor Vehicles about obtaining disabled parking privileges. I needed a signed statement from my physician verifying my need for a permit. If your health or ability to walk is an issue, you may qualify for a disabled parking permit that will allow you to park in specially designated stalls, usually near the entrance to the stores.

USE A WEBCAM: I remember as a child how much I liked opening presents, so I rarely give checks or gift certificates to elementary school children. With a computer, a special "Webcam" camera (for about \$20) that works with the computer, and Skype (a free Internet program), I can watch the gift opening from my home even when I can't be with family members who live in other parts of the country (provided they have the same set up on their computers.)

WRAP IT UP: One more thought. If wrapping gifts is difficult, try:

- ▶ Colorful boxes, bags, and canisters that do not need additional wrapping
- ▶ Having children decorate lunch or grocery bags using crayons, markers, and stickers
- ▶ Wrapping the gift in a pretty towel and tying it with thick yarn or ribbon
- ▶ Using aluminum foil, eliminating the need to use scissors and cellophane tape
- ▶ Hiring a middle or high school student to help

So plan ahead, look for shortcuts, and enjoy the holidays! —*Shelley Peterman Schwarz*

MEMORY SCREENING

November 17: National Memory Screening Day

As research continues to mount about the effectiveness of memory screenings, the Alzheimer's Foundation of America (AFA) will hold its annual National Memory Screening Day on November 17.

The event offers free, confidential memory screenings and educational materials about memory concerns, successful aging, and local resources in communities nationwide.

"Memory screenings and open dialogue between health care professionals and their patients can lead to answers and appropriate interventions," says Eric J. Hall, AFA's president.

The test results do not represent a diagnosis, and screeners encourage those with below-normal scores as well as those who still have concerns to pursue a full medical exam.

For information about AFA's National Memory Screening Day, visit nationalmemoryscreening.org or call 866-AFA-8484.

CONTEST

2010 Neuro Film Festival: Win Money and a Trip to the Festival in Toronto!

Do you have a story to share about living with a neurological disorder or caring for someone who does?

Submit a short video to the 2010 Neuro Film Festival, an event by the American Academy of Neurology (AAN) Foundation to help raise awareness about brain disorders and the need to support research into preventions, treatments, and cures.

You could win up to \$1,500 and a chance to have your video shown at the Neuro Film Festival in Toronto in conjunction with the AAN's 62nd Annual Meeting.

Video submissions should be made at neurofilmfestival.com by February 16, 2010. Videos should be three to seven minutes in length and include the phrase, "Let's put our brains together and support brain research."

You can find a complete list of contest rules at neurofilmfestival.com, at youtube.com/neurofilmfestival, and via Facebook.