

SPRING AND HAY FEVER

When you're a big nature lover and like to spend a lot of time outside, that doesn't really need to change that much when you get diagnosed as an ALS patient.

The coming of spring is the ideal time to take on outdoor activities again. Now that spring has arrived, it's a good start to do your daily activities outside more often. Breakfast, reading the paper or a book, working on your computer are things you can also do outside, on your terrace, patio or in the garden. Or just sitting down and looking at animals, the birds, people and feeling the wind on your skin and in your hair while you do so. You can also use your leisure time to plan weekend trips when your spouse, friends or family aren't at work and available to join you from your new vantage point, your wheelchair.

Many local and international parks are now open and spring is the perfect time to watch flowers in botanic gardens and arboreta. There are lakes which offer fishing and have wheelchair accessible piers. You can probably get this information through the available websites or you could also ask for information over the phone before you go. These days plenty of parks put wheelchair accessibility on their websites. If you live close to the ocean, strolling across the promenade in your wheelchair can be very relaxing: the mere rustling of the ocean and sound of the seagulls bring tranquility.

When you want some more action you can consider visiting zoos and amusement parks. These days they also make sure there's enough wheelchair accessibility there.

A lot of people, also including pALS, can suffer from hay fever in the spring. For people with ALS, however, this is more than an inconvenience. Especially if you already have difficulty coughing up mucus and/or trouble swallowing, hay fever can make it really hard for you.

Symptoms of hay fever are:

- Runny nose
- Watery eyes
- Blockage
- Sneezing often
- Itchy eyes, nose, palate or throat
- Swollen, blue colored skin beneath the eyes (allergic black eye)
- Coughing
- Facial pressure or pain

Hay fever can also cause the following:

- Insomnia
- Fatigue
- Irritability

ALS worsens the hay fever symptoms. Allergies boost the development of mucus and because of your decreased breathing capabilities you probably can't cough deeply enough anymore to free up your throat and lungs. Furthermore some allergy medicine cause drowsiness. This can cause complications for your breathing when you lie down.

However there are plentiful things you can do to feel better:

- The more you can decrease exposure to pollen and dust, which cause hay fever, the better you'll feel. Keep all windows shut, put a special air purifier with built-in filter on your heating or cooling system. Minimize the dust inside by vacuuming thoroughly with a vacuum cleaner with an allergy prevention filter. Vacuum cleaners that have 2 or 3 layered microfiltration dust bags filter a whole lot of these tiny particles with allergens from the vacuum air. Normal vacuum cleaners freely let through all of these tiny particles with allergens.
- Sufficient hydration helps to keep the mucus thin. That way they'll be easier to cough up. Use nose sprays for a stuffy nose.
- Talk to your doctor about which medicine you should take. Medicine such as Claritin® (Loratidine) treat a runny nose, watery eyes and sneezing. Usually people take one 10 mg tablet of this.
- Ask your apothecary or doctor to check if the hay fever medicine aren't interacting with the medicine you're already taking.
- Allergy medicine can be an option for you but they require several months before they actually work. Your doctor could perhaps refer you to an allergist, if that would turn out to be necessary.
- If you use a BiPAP, make sure you take in humid air. The extra humidity will help prevent your nose, mouth and throat to dry out and it'll make it a bit easier for you to deal with the extra mucus caused by the allergy.
- Talk to your neurologist about the advantages and the possibility of using a coughing device. It's a non-invasive therapy which safely removes mucus from people who can't (peak cough flow less than 270 l/m) really cough. It's easy to use. It exists in the shape of a mask that is placed over the nose and mouth, which is connected to a breathing machine with air tubes. It's not only good for ALS patients suffering from allergies, but it's also useful for many ALS patients in a certain stage of their disease.

Your enthusiasm for open air activities doesn't have to decrease because you're now using a wheelchair or due to hay fever. The next step is up to you: make plans, invite your friends and go!

HOW TO PREVENT THE RISK OF DEHYDRATION

On hot days ALS patients can suffer from dehydration more easily. The older you are, the higher the risk. Therefore ALS patients need to make sure they take in enough liquids, especially on those hot days. Dehydration makes the throat swell, which then makes it more difficult to swallow and to cough up the mucus, especially if you have a weak cough. Drinking enough water can largely prevent this from happening.

A good way to measure dehydration is to look at the colour of your urine. The kidneys keep as much liquids as they need and only the excess liquids are sent to the bladder. Dark yellow urine means you are dehydrated, light yellow urine means that you have enough liquids in the body.

As many ALS patients have swallowing problems, they will - more so than other people - tend to drink too little. People using a PEG should pay extra attention as they sometimes assume they are taking in enough liquids through their liquid food, but that is not always the case. Some patients report that they take in less liquids on purpose in order to prevent going to the bathroom. However, that is not a good idea!

Here are some **tips to avoid dehydration**:

- If you have problems swallowing, give Thick-It® a try. It is a powder that you can add to water turning it into a honeylike blend. That way the liquid flows more easily to your throat and can be swallowed more easily. It can also be useful for people having trouble closing their lips.

- ALS patients using a PEG should definitely make sure they also take in pure water. The liquid food does not contain enough liquid for a whole day if it is hot outside. When your husband, wife, caretaker or friend takes something to drink, get something, as well, using your tube. Copying others is a good way to know how much you need to drink because you are sharing the same environment. Alcohol is not recommended as it dehydrates the body. If you decide to drink alcohol anyway, make sure you drink some extra water to it.

- Apart from extra liquids it is also important to take in enough fibers to prevent constipation. Metamucil® is a powder that can be added to your food as a fiber supplement. Mix 1 teaspoon of water with the powder and then add it every day to the liquid food. Jevity® is yet another fiber supplement that can be added to your food. If you are using tube feeding, it is best to discuss these things with your dietician.

- If swallowing is not a big problem, you can keep some ice cubes at hand to lick on every once in a while. You can also consider ice cream or sorbet. They cool down, they offer extra liquids and they are very tasty on hot days.

- Do not worry about using the bathroom more often while travelling. While planning your trip you can count in some extra time allowing you to go the bathroom. Dehydration can have very serious consequences, you do not want to take the risk!

So, keep on drinking and enjoy the Summer!

Translation: **Magali**