

Most people with ALS have healthy lungs, but over time develop increasing problems with breathing. Just like the other muscles in your body, ALS affects the muscles that control breathing. As your breathing muscles weaken, you may experience shortness of breath, shallow breathing, fatigue, difficulty sleeping, morning headaches and difficulty thinking clearly. Your specialist doctor will periodically order tests of your breathing (FVC – forced vital capacity, for example), but it is important that if you experience any of the symptoms noted above you should let your doctor know, because there are things you can do and equipment available to improve your quality of life.

Firstly, do whatever you can to stay healthy and avoid infection. Wash your hands, wear a mask or avoid crowds during cold and flu season. Get out of bed every day and stay as active as you can. Eat small and frequent meals rather than large meals to avoid pressure on the diaphragm (the major muscle of breathing, located below the lungs). Keep up with your vaccinations and practice good oral hygiene.

There will come a time, though, when some help is required to allow you to get enough oxygen. Breath stacking exercises, equipment such as a Cough Assist, a Suction machine and a BiPAP machine (bi-level positive airway pressure) are all helpful devices. Talk to your specialist care team about their recommendations for you. Equipment like this can be expensive, so always check with your private healthcare insurance provider and with the ALS Society of New Brunswick and Nova Scotia before buying these items.

These pieces of equipment can take some tweaking, and some getting used to, but can improve your quality of life and increase your energy levels. The decision to accept these forms of assistance is yours, but remember that they do not prolong life, or slow the progression of disease, but increase your comfort level and maintain intellectual function. Inability to exchange air in your lungs through breathing leads to a buildup of carbon dioxide (bad air) and a reduction in oxygen levels in your lungs, and thus to your body and brain.

The use of ANY assistive equipment is your choice and sometimes the choice is a difficult one. Discussing your wishes early and setting up the appropriate legal way for someone to make your wishes known when you are no longer able to do so, is critical. It is not easy to make decisions like this early in the course of your disease, but it should be done. It is your way of maintaining agency and controlling your destiny.

There is no time when advance decision making is more important than when it comes to deciding what you want to do when non-invasive methods such as BiPAP are no longer sufficient to maintain breathing and thus life itself.

Once you require the use of BiPAP 24 hours a day, you may be offered the option of a tracheostomy. A tracheostomy is a surgical procedure to create an opening in your windpipe (trachea) allowing a plastic tube to pass directly into the trachea and air to enter the lungs. A ventilator (machines that act as bellows to move air in and out of your lungs) is attached to the tube, so that air enters the lungs without any effort on your part. Use of a ventilator may prolong life, but does not alter the course of the disease. Depending on where you live, what supports are available to you at home (including 24 hour nursing and respiratory care) and the provision of the ventilator itself, some ventilated persons spend the remainder of their lives in a hospital or other advanced care institution.

Learn about your options ahead of time so you fully understand what your decision entails. Talk with medical professionals, ask questions, and discuss with the loved ones who would be involved in your care.

Once you make a decision, be sure to update your advance directives so that your wishes are clear to loved ones and medical professionals. If you change your mind later, you can always go back and update your advance directives, as long as your ability to communicate your wishes remains intact.