Keep Good Records

As you may well know, ALS is a complicated disease that takes a lot of time and energy. Developing a filing and recording system that is easy and works for you is a good way to make your daily life simpler and reduce your stress level when it comes to your care. At first, it may be easier for a caregiver or patient to start recording the information. Later someone else can take over if necessary. This is the place to record when you order drugs. When you talk to your insurance company, record who you talk to and what they agree to do for you. Record data when you interact with your respiratory specialist. At your doctor’s visits, record measurements and conversations. Having all this information in one place will empower you to follow up effectively and to focus your mental energy in other areas.

Sleep Well

Be sure to get a good night’s sleep. This helps you have the energy to do what you want to do. With ALS, if you have low energy, you have to prioritize what you can do in a day. Sleeping well at night prevents you from missing out on things you want to do. A few routines can help you sleep better. Drinking a sleepymtime tea with your medications about an hour before going to bed is one of them. Also, having someone help you do stretches in bed before going to sleep can help you relax. If you wake up regularly in the middle of the night, soothing music to relax your mind or stretching out your arms and legs helps. If you are sleeping with your spouse and have to wake them up during the night to turn you, it’s helpful to have satin sheets and wear satin or nylon clothing so that you can roll over more easily.

Feed your Body

Although it is initially difficult for many patients to realize, feeding tubes are not a stage of disease, they are a convenience item. Why take two hours to get a meal in when you can get your calories and energy in within 20 minutes? Then you can do what you want to do and get on with your life – go to the store, work, etc. Having a feeding tube doesn’t prevent you from still appreciating the tastes you enjoy. By enabling you to keep weight on and freeing up time, they actually enhance your life rather than limit it.