

LIVING WITH ALS AND STILL STAYING ACTIVE

Professional, social or in the community

For pALS who were professionally or socially very active or who played an active role in the community before their disease, a big chance exists that they will get bored very easily. This is because they cannot be involved in the same way at the workplace.

Nevertheless it is perfectly possible to stay active. You only have to approach it in a different way. You will have to focus less on your physical presence and you will have to focus more on the organizing tasks.

Think about your strengths and which tasks you prefer to be involved in. You will notice that it will take more time to carry out those tasks, especially when ALS progresses.

Here are some considerations which you can make. Maybe you can be involved in the meetings by phone? Maybe you can cooperate via Facebook? How can the computer be adapted to make sure you can continue working? Can the meetings take place at home instead of at the workplace? Could it be easier for you to communicate by phone, mail or text message?

A good example of this is Sandra Leshner Stuban. She was working as a nurse in the army when she received the ALS diagnosis at the age of 38. Although she is completely paralyzed and uses a ventilation equipment, she still leads an active life as the person in charge of her nursing unit. She writes and sends the monthly e-newsletter to all 600 members, sends welcome e-mails to new members and sends reminders for unpaid invoices. She does all this work on her computer at home. Communication with colleagues and the management takes place via mail.

Another example is Stephen Hawking. Hawking was born on 8th February 1942. In 1963, at only 21 years old, he received the diagnosis of ALS and was told that he had only two years to live. Nevertheless he continued his studies at the University of Cambridge and he became a brilliant researcher and professor. He is even considered as one of the most brilliant scientists since Einstein. At the moment he is the scientific director of the Institute for Theoretical Cosmology. He received about ten honorary doctorates during his career. Stephen Hawking also wrote several scientific books, which are easily accessible for the general public. 'A Brief History of Time' was an international bestseller.

Volunteering also becomes more and more popular. At the moment 1 to 6 people volunteer and according to research done by the Dutch website www.vrijwilligers-werk.be this number can be much higher as the large majority of people is open to this.

Staying active in sports

PALS who used to practice a lot of sports experience more and more significant and unpleasant mobility problems over time. And when summer approaches, you realize that many things you always liked to do, will now become very difficult, sometimes almost impossible even. You realize that recreation and free time will not mean the same as before. Just going somewhere now means a lot more effort and then you ask yourself if it has all been worth it. The question is: can you deal with recreation and free time in a different way from now on, with more desire, joy and nice expectations?

This problem is certainly one of the major attitudes you will have to change as a sporty ALS patient. Because it is certainly possible and also necessary for your mental wellbeing to accept your life with ALS and to learn to enjoy it in a different way. Maybe you used to play golf in your free time, trained for a marathon, played tennis... Mentally, you will slowly have to make the switch from an active sportsperson to an involved sportsperson who is mentally concerned with his or her sport. From now on you will have to shift your interest in sports from the physical to the mental aspect.

You should not become frustrated and think therefore that you lose talent and capability. You will have to look positively to the future and have to try things out. Reflect on how you can deal best with this and consider this as a new challenge

Some small ideas to get you started are illustrated below:

- Invite friends at home to watch your favourite sports team and favourite sports events on TV together. It is more fun to watch it together with your friends.
- Ask your friends if they can take you to sports games and sports events. All large sports stadiums of sports like basketball, soccer, hockey, tennis are easily accessible for wheelchair users.
- Improvise with your favourite sport and put your own team together. Newspapers offer those kind of prognosis games. You can play along with the Gouden Elf (the Golden eleven), de Gouden Klassiekers (the Gol-

den Classics), de Gouden F1 (the Golden F1), de Gouden Tour (the Golden Tour) and the Gouden cross (the Golden Cross). The prognosis consists of putting your own team together with your favourite players and giving your team its own name. You will have to pay a small contribution to participate. All participants play for the most points depending on whether the players of their team get the best results in official games, and they may win great prizes.

- Look forward to major sports events which will take place like the Olympic Games.
- Discover and play online games on your computer. Yahoo Games <http://games.yahoo.com> is one of the many websites that offers a wide variety of games.

STAYING ACTIVE WITH ALS

Doctor Charlotte Chatto works as a professor of physiotherapy at the Georgia Regents University and is also a physiotherapist at the ALS Association Certified Treatment Center of Excellence in Georgia. She has worked with ALS patients and their caregivers for many years. Her objective is to help people who are suffering from ALS and to get the best out of their lives. Doctor Chatto gives the following tips:

1. "Moderate" is the key word

ALS patients and their caregivers have to realize that ALS weakens the body. "But", so Doctor Chatto says, it is very important to stay active and to do things you like to do." She encourages people to be in harmony with their body, to find out what is the most important thing in their lives and how they best use their energy.

According to Doctor Chatto this means moderate physical exercise for some people, which can be advantageous for people with ALS. What is meant by "moderate"? Imagine physical exercise as a continuum: on one hand there is passive mobility in which case someone moves your limbs for you. On the other hand, there is weightlifting until you have reached your maximal capacity. "Moderate" physical exercise is between those two extremes. You have to move your body yourself but do not force your body to build up strength. How much and which kind of physical exercise depends on each individual.

Working as a volunteer

ALS patients, who like to play an useful role and are looking for an occupation, are always welcome at the ALS League. We are looking for volunteers who can assist with several tasks. Do you like to be busy with numbers, do you have a knack for languages, are you interested in research, do you like to work with a computer... ? It is all possible because the ALS League is looking for all kinds of volunteers who can help a bit with the League's administration. We are still looking for an event organizer, an accountant, a fund raiser and translators. Because of the great diversity of tasks, there will certainly be something you want to cooperate with. A small selection of the administrative tasks: translations, research on the Internet, compiling information to a file, drafting letters... The requirements are not too high but being able to work with Internet and mail and knowledge of Word and Excel is a plus.

Doctor Chatto has published two surveys about physical exercise and ALS which you can discuss with your physiotherapist.

2. Working to stay mobile

Loss of mobility as well as loss of flexibility often occur with ALS. Muscles or joints can become stiff and can even cause inconveniences.

Thanks to the constantly improving technology a lot is possible. It is just about examining and using all possibilities. This is in the first place to keep yourself active and to seek out entertainment that can distract your thoughts from the disease. A great example in the ALS League is our chairman Danny Reviers, he has been an ALS patient for 37 years already and the League's chairman for 12 years. He can witness like no other how difficult it can be to live with this horrible disease and how important it is to keep up the morale. According to him the best way is to stay active as well as possible.

It would be nice if you could join us at the office in Leuven, but there are also enough tasks which can be executed at home. Interested? Contact us now at 016-23 95 82 or send an e-mail to info@alsliga.be

If you, or a friend or relative, have difficulties to move your arms or limbs, do not hesitate to ask for help. According to Doctor Chatto, a referral to a physiotherapist

or to an occupational therapist is preferable. They can give professional help or assistance to maintain the mobility and comfort of muscles and joints.

3. Investigate if tools are useful

Physio or occupational therapists can also prescribe a splint to avoid the loss of mobility. If you or your friend/relative lose the mobility of a limb, splints can help in this case to put them in a good position during the moments that you do not stretch or do not do motion exercises.

Physio or occupational therapists can also help to decide whether energy saving tools are necessary. An ALS patient who for instance is able to walk but who has difficulties to balance can wear out his muscles and body because of the constant battle for balance. A physio or occupational therapist can help to decide if a walking stick or walker can be energy saving.

4. Learn important breathing and coughing techniques

ALS patients are more easily infected by pneumonia or other breathing problems. According to Doctor Chatto, ALS patients and their caregivers should learn the diaphragmatic respiration (also referred to as deep abdominal respiration) to maintain the breathing function. She teaches her patients and caregivers a coughing tech-

nique which can help ALS patients to dissolve excess mucus. You can watch a video of doctor Chatto which demonstrates this technique on <http://www.toxtalk.com/>. Click on the link "breathing techniques for ALS patients".

5. Ask the right questions

When choosing a physiotherapist, the answers to some simple questions can make a huge difference. Choose a therapist who has sufficient knowledge and experience to treat you or your friend/relative correctly and safely.

Always ask those three questions to a potential new therapist:

1. Are you familiar with ALS?
2. Have you ever treated someone with ALS?
3. Are you familiar with the evolution of this disease?

If the therapist answers "no" to one of those questions, it is preferable to go on with your search.

Don't you know how to start? We advise you to consult our website for centres/hospitals specialized in ALS in your neighbourhood. You can find all the information on our website: <http://als.be/en/collaborations>

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