

Core set of recommendations for patients with ankylosing spondylitis concerning behaviour and environmental adaptations

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Recommendations concerning AS patient behaviour and adaptation of their living and work environment – to be delivered to AS patients **early in the disease course, for instance in connection with the diagnosis.**

General statement: Ankylosing spondylitis is an inflammatory rheumatic disease which may lead to stiffening of the spine. The course of the disease is highly variable and effective treatment options are available. AS is not a malignant disease. Most patients with this disease can have an almost normal life and can successfully practice in their profession.

The following recommendations will help you to reduce fears you may have regarding the disease, and help you to contribute to a favourable disease course by appropriate behaviour and adaptation of your living and work environment.

- 1. Basic principle:** Maintain a proper posture at work, at leisure and when sleeping.
- 2. Sitting position:** Take care to keep a hollow back while sitting. To achieve this, a firm and plain sitting surface is better suited than a low soft sofa or a backwards sloping surface.
- 3. Walking:** Use sufficiently long steps (like in Nordic walking) to maintain hip joint extension. Well fitted shoes with shock absorbing heels and flexible soles facilitate pain-free walking.
- 4. Sleeping:** Try to sleep preferably on your back for an optimal extension of your back and hip joints. Sleeping with your upper body elevated on a large and thick pillow, which forces your thoracic spine into a flexed position, is not recommended. Use a sufficiently high quality mattress and firm frame.
- 5. At work:** Try to change positions between sitting, standing and walking at work, and take care to maintain a proper posture for your back. When choosing your profession take into consideration that occupations connected with strong bending, twisting, stretching and body vibrations are not recommended for patients with ankylosing spondylitis.
- 6. Exercises:** Daily disease-specific exercises are an essential part of the therapy of ankylosing spondylitis. Perform deep breathing exercises with pronounced thoracic breathing several times per day.
- 7. Sports and recreational activities:** It is important for patients with ankylosing spondylitis to remain physically active. Sports activities are the best way to attain physical conditioning, to stabilize blood pressure and heart rate, and to improve lung function capacity. Sports activities, however, are no substitute for disease-specific exercises. Which kind of sports is especially suited for you depends on the state of your disease and on whether you are already experienced in this type of sport or a beginner. Sports connected with a straight posture and stretching of the trunk (Nordic walking, hiking, swimming, cross-country skiing, tennis, badminton, archery, volleyball) are especially recommended.
- 8. Diet and life style:** A diet with less meat (less arachidonic acid), more fish (omega-3 fatty acid) and vegetarian meals may contribute to reducing inflammatory processes. Don't smoke because smoking has a proven negative influence on the course of the disease. Ankylosing spondylitis is often associated with osteoporosis. Therefore a balanced calcium intake via food and sufficient vitamin D supplementation (sun exposure, fish diet, also vitamin D tablets, if necessary) are essential.

9. Sexuality and pregnancy: Severe restrictions or limitations in love life should not occur in most cases with sensible and considerate interaction of the partners. Experimentation may be required in order to find pain-free and satisfying positions. Talk to your partner about the situation in order to avoid misunderstandings. Openness and impartiality contribute to a fulfilling sexual life. Fertility, pregnancy and giving child-birth normally do not constitute a problem in ankylosing spondylitis.

Even with fused sacroiliac joints or artificial hip joints a caesarean section is usually not required. Discuss the use of medicines during pregnancy and breastfeeding with your doctor.

10. Advantages of membership in an AS-specific patient organisation:

- Reliable information on the disease and on living with it, including patient education courses;
- exchange of experiences among patients with different disease durations;
- professionally supervised local AS-specific group physiotherapy;
- common sports and social activities;
- overcoming impending social isolation;
- advice in medical questions and social law;
- representation of patient interests in insurance and legislation.

Core set of recommendations for AS patient behaviour and environmental adaptation which are **important in addition in advanced disease** with spinal ankylosis and kyphosis.

- 1. Car driving:** With limited spinal mobility special aids (wide-view mirror, additional mirrors) and individual adaptations (head restraint as close to the back of the head as possible) may be necessary. Carry an individual emergency information card which makes first-responders aware of your diagnosis and special needs to be regarded concerning lying/positioning, and intubation for artificial respiration. A suitable card may be available from the ankylosing spondylitis patient organisation in your country.
- 2. Inappropriate sports:** Sports with increased risk of accidents (by physical contact with high energy like in boxing, football or hockey, or by increased fall risk like in down-hill skiing) are not recommended in case of advanced ankylosis of the spine.
- 3. Fall prevention:** Falls are much more dangerous for patients with a fused spine than for other people because of the increased risk of vertebral fractures. Therefore, do whatever you can to prevent falls (on staircases always use the handrail, avoid loose carpets, illuminate the way to the toilet at night, use shoes with extendable spikes for icy conditions, etc.).



Dear patient with ankylosing spondylitis,

Your doctor has given to you these recommendations which have been created in cooperation with experienced patients with ankylosing spondylitis. This leaflet gives you the possibility to integrate these recommendations into your daily life in order to favourably influence the course of your disease. You will see that this is not difficult.

Please inform us about your experiences with these recommendations and also about your own observations.

Living according to these recommendations is especially easy in contact with a strong group of like-minded people. Look for the address of the ankylosing spondylitis patient organisation in your country and a branch in your region in the website of the Ankylosing Spondylitis International Federation (ASIF) under <http://www.asif.info/en/index.cfm/membership/list-of-current-members/>

We hope very much that you find your way to a nice group of patients with ankylosing spondylitis in your country and wish you much success with the implementation of the recommendations.

The ASIF Executive Committee