

Ankylosing Spondylitis: What does this mean?

Ankylosing spondylitis (AS, in Latin: *spondylitis ankylosans*) is a chronic inflammatory disease which is not curable by conventional medicine and which often leads to bony stiffening of the spinal column.

Additional joints or other organs can also be involved. As a cause, a misguided immune system is discussed, released e.g. by an infection in the intestine or urinary system. Possibly also physical or mental injuries can contribute to the disease onset.

In German-speaking countries as well as in Northern and Eastern Europe, the expression „*Morbus Bechterew*“ has become popular (Morbus is again Latin and means disease). The term reminds of the Russian neurologist Professor Wladimir BECHTEREW who did, however, not discover the disease, but only contributed a publication on the disease which became well known in these countries.

First complaints and diagnosis

In the initial stage the complaints are usually nonspecific and are therefore often misinterpreted. There are, however, criteria, on the basis of which an experienced rheumatologist can come to a reliable diagnosis. Nevertheless, many years often pass between first complaints and a definite diagnosis.

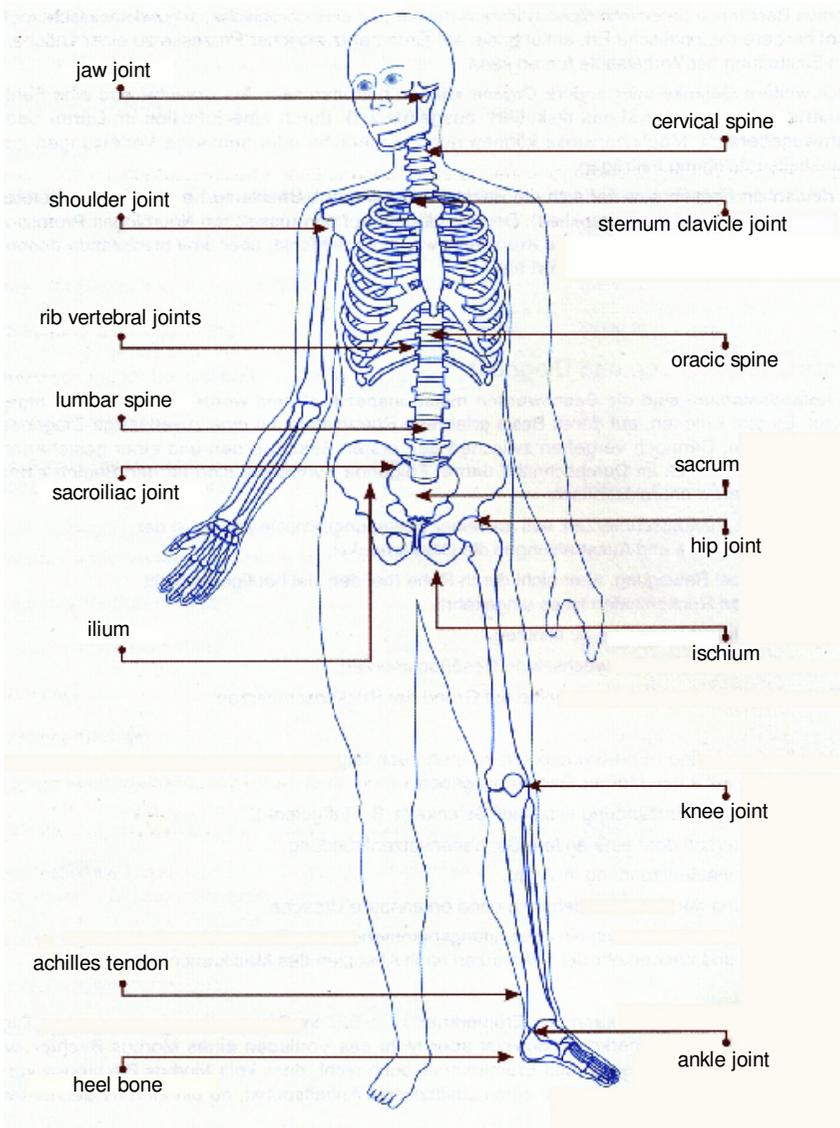
The following symptoms are characteristic for the beginning of an ankylosing spondylitis:

- Low back pain, possibly with mobility restriction in the lumbar spine and radiation into the thighs,
- improvement with movement, but not with rest (with the more frequent non-inflammatory back pain the reverse is true),
- morning stiffness lasting longer than 30 minutes,
- buttocks pain changing between left and right side,
- awakening in the second night half due to back pain.

In addition to these frequent first symptoms, the following findings can together also give an indication to ankylosing spondylitis:

- Asymmetrical inflammation of single joints (e.g. hip joint),
- heel pain or another tendon insertion inflammation,
- iris inflammation in the eye (iritis),
- restriction of the thoracic mobility without recognizable cause,
- definite improvement by anti-inflammatory drugs within 48 hours and worsening after withdrawing the medication.

In most of the patients, the genetic factor *HLA-B27* can be identified in blood samples. This finding does, however, not prove the presence of ankylosing spondylitis, nor does its absence prove that no ankylosing spondylitis is present. The findings give however an additional reference point to the physician whether an ankylosing spondylitis is probable or not.



In ankylosing spondylitis often or occasionally involved joints and tendon insertions. Normally the disease begins with inflammation of the sacroiliac joints. If there are no definite changes in X-rays of the sacroiliac joints, physicians speak of a “non-radiographic axial spondyloarthritis”.

Usual course of the disease

Quite different courses are possible in ankylosing Spondylitis. In some patients, pain caused by inflammation predominates, in others stiffening plays a dominating role. The disease can be quite aggressive or – on the other hand – so mild that it never will be definitely diagnosed. In most patients the disease concerns exclusively the spine, in others also joints of the limbs or internal organs are involved.

The course of the disease is characterized by temporary inflammation flares and intervals of remission. It is characterized by a tendency to progressing stiffness (*ankylosis*) and deformation (*kyphosis*) of the spine. By appropriate therapy and adaptation of the patient's own behavior, the extend of restrictions can, however, be significantly influenced.

In a late stage of the disease, the stiff spine tends to bone porosity (*osteoporosis*). Prophylaxis against it is possible by regular physiotherapy and physical activity in form of appropriate sports. The ankylosed and porous spine is at risk of spinal fractures, even in connection with a banal or no trauma. Therefore, patients with a longer disease duration have to be careful to prevent even apparently harmless accidents and have to take appropriate security measures.

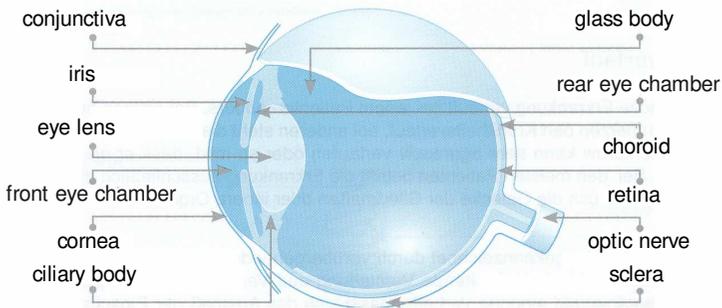
Despite of the progressive character of the disease, nine of ten patients with ankylosing spondylitis do not depend on assistance by others, even after a long disease duration. Most of them are able to execute their profession in normal manner.

Concomitant complaints

Make your doctor aware of your ankylosing spondylitis when you visit him because of other complaints which have apparently nothing to do with your ankylosing spondylitis. As a layman one can hardly decide which complaints may be caused by changes in the spine. And even the specialist having expertise in his field of activity, does not immediately recognize that for instance ear complaints may also have their cause in the nerves or blood vessels which lead through narrows in the cervical spine. Of course, you can also – like every other person – have complaints which have in deed nothing to do with ankylosing spondylitis.

Sometimes ankylosing spondylitis affects also joints beyond the spine. Most often these are the hip joints, knee joints or ankle joints. Only after long-lasting inflammation a durable mobility restriction may remain.

Even apart from joints, pain at bones may appear. Inflammation of tendon insertions may be the cause in this case. Pain at the heel bone sometimes is the very first discomfort connected with ankylosing spondylitis.



Longitudinal profile of the eye with the iris as front part of the uvea (= iris + ciliary body + choroid) which tends to inflammation flares in patients with ankylosing spondylitis

About 40% of patients with ankylosing spondylitis have an *iritis* (inflammation of the *iris*) once or several times during their life. One recognizes it by eye hurts (predominantly when the pupil has to narrow itself due to great brightness differences), pressure sensitivity and red colour of the eye. In this case you must go immediately to an ophthalmologist and make him aware of your ankylosing spondylitis! A treatment is necessary immediately, to avoid permanent damage. Only an ophthalmologist can decide surely whether you have an *iritis* or another eye affection.

In a late stage of ankylosing spondylitis, also internal organs (lung, heart, kidneys, nervous system) can be affected by the disease. We forget too easily that ankylosing spondylitis is not a spine disease but a “system disease”. The misguided immune system affects most obviously the spine, can however likewise affect other organs.

Related diseases

An inflammatory spine disease can also appear in combination with *psoriasis* or with chronic intestine inflammation (*Crohn's disease* or *ulcerative colitis*). In the case of immediate occurrence after a bacteria infection one speaks of “*reactive arthritis*“, and in the special case of a combination with an urethra inflammation and a conjunctiva inflammation of „*Reiter's syndrome*“.

All these diseases which are related to ankylosing spondylitis and are also favored by the genetic factor *HLA-B27*, are collected into the disease group of “*spondyloarthritis*“ (inflammatory spine and potentially other joint disease). The DVMB is the self-help organization not only of patients with ankylosing spondylitis but of all patients with a „*spondyloarthritis*“.

Possibilities of treatment

Ankylosing spondylitis is until today not curable by conventional medicine. To avoid severe attitude damage, patients must continuously take care of an upright attitude and sufficient physical activity. Physician, therapist and patient play an equally active role in the treatment of ankylosing spondylitis.

Alpha and Omega of the spondylitis ankylosans therapy are regular exercises. Appropriate exercises, at best daily in the morning hours, are an effective means not only against the stiffness, but also against pain.

A valuable help for regular exercises are the local groups of DVMB: Weekly group physiotherapy in almost 400 cities and communities in Germany offer ankylosing-spondylitis specific physiotherapy under professional instruction.

Rehabilitation courses with intensive physiotherapy, balneotherapy and radiation therapy combined with disease-specific patient education are offered in hospitals for rheumatic diseases and form a valuable intensive addition to the therapy possible at your place of residence.

An individually adapted therapy with anti-inflammatory medication is necessary if the pain can otherwise not be controlled.

Some patients have made positive experiences with unconventional therapy methods like traditional Chinese medicine, homeopathy, enzymes, and psychological therapy approaches like, for instance, the „*Neurocognitive therapy*“ by which many patients (mainly those without progressed severe stiffness) have even lost their complaints and have reached stable remission without further treatment.

In rare cases surgery is necessarily in a late stage of the disease, for instance hip joint replacement to make the hip joint mobile again, or spinal surgery to correct a severe curvature of the stiff spine in order that the patient can again look straight forward, or to stabilize a vertebral fracture.

Further information on the disease, on their treatment and on what the patient can do himself in order to contribute to a favourable course of the disease, can be found in the brochure „Morbus Bechterew – ein Leitfaden für Patienten“ (Ankylosing spondylitis – a guidebook for patients, number 1 of the DVMB publication series) which can be ordered under

www.bechterew.de

and which every new DVMB member gets as welcome gift.

Extended information is also available in DVMB's quarterly membership journal „Morbus-Bechterew-Journal“ which every DVMB member gets regularly free of charge.

Deutsche Vereinigung Morbus Bechterew (DVMB)

For many patients a blessing in disguise!

For long time, extended information for patients and encouraging the exchange of experiences were neglected in many hospitals for rheumatic diseases. Patients had to try completely alone to get along with the disease. Thus it was a luck for all of us when the German ankylosing spondylitis association (Deutsche Vereinigung Morbus Bechterew) was created in 1980.

The DVMB executive committee consisted from the beginning exclusively of patients with ankylosing spondylitis, in contrast to similar associations with an executive committee with physicians, health insurance functionaries and patients.

Aims of DVMB

Only few patients are alone able to cope with a chronic disease with all its connected consequences. Persons affected need understanding for their situation. They need Information and assistance, in order to feel at ease with all the external and internal loads. Here the DVMB offers comprehensive support. Also the common representation of interests in politics and society can only be successful if many affected put their weight together.

By the meeting with other affected persons many of our members have won new vital energy.

In common we can reach more:

- Common AS-specific group physiotherapy under professional supervision,
- exchange of experience by meeting fellow sufferers in common events,
- manifold medical and legal information by lectures, by our membership journal and the DVMB series of publications,
- close cooperation with physicians, therapists and similar associations,
- promotion of scientific research on our disease,
- representation of patients' interests alone and together with similar associations in society and legislative,
- improvement of physical and mental health as well as working and earning ability of affected persons

are the most important goals of our self-help organization.

A detailed list of our goals can be found in the statutes of DVMB under www.bechterew.de



Group exercises and games bring alternation and pleasure into the therapy program.



Our Motto: „AS patients need physical activity, meetings and also consultation.“

Exercising and meeting

The local groups of DVMB

The local groups represent the basis of our work. For the execution of the daily exercises at home which are so crucial for the further course of the disease, much self-discipline is necessary. The weekly group physiotherapy is there a valuable source of motivation and suggestions. Physiotherapy under professional supervision is at the same time a good prevention against bad pain-preventing posture.

Besides this, many groups also invite physicians, physiotherapists, psychologist and specialists for health and social matters to give lectures. Such meetings, informal get-togethers and common excursions offer additional opportunities for contacts and the exchange of experiences and thus to defend against threatening isolation.

Regular gathering with other affected persons represents for many patients in the phase of confrontation with the disease in its early state a substantial social support and a great help to cope with the daily loads at work and in the family. There are patients who have won by their contacts in the DVMB group new vital energy.

Movement and the feeling, not to be left alone with the disease, are particularly important for patients with a chronic disease.

DVMB groups in about four hundred cities and communities with extensive programs like lectures and opportunities for intensive exchange of experiences.

Suited sports like – for example – cross-country skiing, nordic walking or volleyball supplement the extremely wide variety of offers.

Network of young patients with AS

In all federal countries of Germany there are special offers for young affected persons who have, of course, other requirements and interests than older patients. Contact persons in the regional organizations of DVMB organize various activities, from spontaneous informal meetings to weekend seminars for young AS patients. Also these offers can be found under

www.bechterew.de

Network of female patients with AS

After female patients with AS get their diagnosis often more delayed than males and their problems connected with the disease are often underestimated, a network of female patients has been established within DVMB. The realization that the course of AS is often different in women than in men, is regarded in this network. Contact persons in the regional organizations of DVMB organize special offers (for instance seminars) for female AS patients.

The names and phone numbers of the group leaders as well as of contact persons for the network of young patients and of contact persons for the network of female patients with AS can be found in the internet under

www.bechterew.de

You can also ask the DVMB office:

[Metzgergasse 16](#)
[97421 Schweinfurt](#)

Tel: 09721 22033

Fax: 09721 22955

Email:

dvmb@bechterew.de



Young AS patients at a weekend seminar with access to a forest climbing garden.



Water physiotherapy at a weekend seminar of the network of female patients with AS.

Regional support and cooperation: The regional organizations of DVMB

The organization of group activities is an important and responsible task. The group leaders need support and exchange of experiences with other group leaders. This is the main task our regional organizations in der federal countries of Germany.

The regional organizations offer by annual member meetings important Information in the form of lectures also for those members who do not belong to one of the particularly active groups in which apart from weekly group physiotherapy also for instance monthly lecture meetings take place.

The regional organizations also organize AS-specific training seminars for the therapists of their groups.

The executive committees of the regional organizations consist (like the executive committee of DVMB) by majority of AS patients. Most regional organizations have one or more medical advisors who are prepared to answer medical questions and to give lectures at meetings of the organization.

Altogether the regional organizations do not see themselves as end in itself. Their main goal is to support the work in the local groups. The addresses of the regional organizations can be found in “ ” and under www.bechterew.de.



Office locations of DVMB and their regional organisations.



Regular training of our local group leaders improve the quality of local support for patients with AS



AS-specific training seminars for our group physiotherapists enable them to treat our members goal-oriented.

Comprehensive information, consultation and assistance: DVMB and its federal office

It would be an unnecessary expenditure if each regional organization had to take care of their own membership list, their own membership fee administration, their own legal advice for their members or an own membership journal. This is the role of our federal DVMB association and their office where employees have specialized themselves for these tasks and master them centrally. They know more than others the difficulties and troubles of patients with AS. More than 500 letters and 1000 emails are answered by this office every month.

Telephone consulting hours

The DVMB office hours are Monday until Friday from 8.00 to 16,30 h. The office can be reached under the telephone number 09721-22033.

In addition, each first Monday of a month an experienced office member is available under the same number between 17.00 and 19,00 h to answer questions concerning the disease.

Legal advice for DVMB members

Which patient is familiar with the jungle of our social laws? DVMB had as first self-help association in Germany an own legal advisor with experience in social laws who is prepared to give advice to DVMB members in legal questions and also to give lectures in DVMB seminars. DVMB is also today one of the few self-help associations who can offer such a service.

The acknowledgment and classification of patients with AS as legally being severely disabled, the refunding of costs for rehabilitation courses in Germany or abroad, the enforcement of pension claims and similar problems belong to the focus of activity of DVMB's legal advisor.

Medical advisors

The medical advisors of DVMB, of their regional organizations and their local groups earn our thanks for answering often quite unusual questions which sometimes require even literature researches or the consultation of medical colleagues.

Seminars

Special seminars of DVMB are addressed to the special problems of freshly diagnosed patients, to questions in connection with the psychological consequences of the disease and to other topics. The seminars are regularly announced in the membership journal “ and in the DVMB website under

www.bechterew.de.

Our membership journal

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A substantial contribution to the competence of our members and thus to the management of their disease is our membership journal

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It informs quarterly all DVMB members about new medical and psychological research results, about news in social law and communicates experiences of patients with living with the disease. Of course, reports on activities in DVMB, the regional organizations and groups are also part of this journal.

The Journal is also read with interest by physicians and therapists and contributes thereby substantially to the reputation of our association.

Newsletter

Members of DVMB can order a newsletter under www.bechterew.de, which irregularly informs on actual topics. Non-members receive it several times as an introductory offer.

DVMB Literature

The DVMB publication series forms a further substantial contribution to live with the disease.

Beside 18 booklets of this series, the DVMB office offers also a variety of books interesting for patients with AS. A list of these offers and an order form can be requested from the DVMB office or found in the Internet under www.bechterew.de. The order can also be made by the internet.

