



..... Living a good life .....  
**with Bechterew's disease**

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A Sandoz Brand

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The glossary contains important medical terms related to **Bechterew's disease**. These are highlighted in bold in the text.

# Dear Patient,

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Your doctor has given you this brochure because you have been diagnosed with "**Bechterew's disease**".

With this brochure, we would like to inform you about the causes and treatment options for this disease. We will also give you some tips on the things you can do yourself to help your treatment be successful and to have a positive influence on your quality of life.

Even if **Bechterew's disease** may accompany you throughout your life, you should not let the disease determine your life! With the right therapy and lifestyle, your symptoms can be reduced to such an extent that you can live well with your disease and integrate it into your professional and private everyday life.

Do not hesitate to discuss further questions you may have about your disease and your therapy options with your treating physicians.

We wish you all the best!

**Your Hexal Team**



# What is Bechterew's Disease?

**Bechterew's disease**, also known as ankylosing spondylitis or AS for short, is the most common subtype of **spondyloarthritis**. This term comprises various inflammatory rheumatic diseases which involve **chronic** inflammation, especially around the spine. In contrast to an **acute** illness, **chronic** means that it is a long-lasting illness. It is often incurable, but the inflammation can be reduced or even inactivated by treatment.

**Bechterew's disease** is a chronic inflammatory rheumatic disease that belongs to the group of autoimmune diseases, whereby the immune cells in your immune system attack your own body and trigger an inflammatory reaction in your joints.

**Bechterew's disease** is a disease which occurs in the axial skeleton and is **chronic** in nature. The bones that form the torso and head are affected: the skull, spine, chest and ribs. As the disease progresses, inflammatory processes occur and lead to ossification in the joints of the spine, which subsequently stiffen. Mainly the lower sections of the spine are affected. These include the sacrum, with its connections to the pelvis where the **sacroiliac joint** is located, as well as the region of the lumbar spine. The upper areas of the spine, such as the thoracic and cervical spine, may also be affected. In addition, other areas of the skeleton such as the knee joint or tendon attachment points like the Achilles tendon may also become inflamed.

In up to half of all those affected, **Bechterew's disease** occurs in combination with fatigue, **psoriasis**, inflammation of the iris in the eye (**uveitis**) and/or chronic inflammatory bowel disease (e.g. **Crohn's disease** or **ulcerative colitis**).

## Who is affected?

Approximately

**0.5%**

of all adults have  
Bechterew's disease in  
Central Europe.



Bechterew's disease usually appears  
between the ages of

**20 and 40.**



In Germany, approximately

**340,000**

people are affected by  
ankylosing spondylitis.



**61.5%** of those  
affected are males,  
whilst females  
only account  
for **38.5%**.



Since Bechterew's disease progresses  
more slowly in females, it is detected less  
often, or at a later point in time.

## How does Bechterew's disease manifest itself?

**Bechterew's disease** usually begins with pain in the spine, which is known as inflammatory back pain. Pain often occurs in the sacroiliac joints first and then in the lower lumbar vertebrae. It can also be perceived as buttock pain when experienced in the sacroiliac joints. Back pain occurs especially after longer periods of rest, i.e. at night or in the morning after sleep.

As the disease progresses, back pain then also occurs in the upper section of the lumbar vertebrae, in the thoracic spine and also in the cervical spine.

During the course of the disease, certain cells (**osteoblasts**) can be activated by the inflammation present in the joints; these are responsible for the formation of bone material. They trigger the formation of new bone tissue between the individual vertebrae. As a result, these bone formations, which are known as ossifications, can lead to the spine becoming stiff, poor posture and thus to painful muscle tension. Movements, such as bending or turning the head, can be difficult. Body posture which bends slightly forwards (**kyphosis**, "hunchback") and rigidity in the chest that restricts respiratory volume are typical symptoms of **Bechterew's disease**. The pelvis may also become misaligned. Ossification of the spine can also increase the risk of spinal fractures.

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Inflammation at the tendon attachment points (**enthesitis**) is also characteristic for **Bechterew's disease**. This can lead to pain in the heel, for example when the Achilles tendon is inflamed. Some patients also develop joint inflammation in an entire finger or toe, which is called **dactylitis** or – due to the resulting swelling – "sausage fingers" or "sausage toes". In addition, bone density decreases in most of those affected (**osteopenia**), which can lead to bone atrophy (**osteoporosis**). There is also an increased risk of bone fractures.

If **Bechterew's disease** becomes severe, inflammation can also pass to other organs. This may lead to comorbidities such as chronic inflammatory bowel disease (e.g. **Crohn's disease** or **ulcerative colitis**), inflammation of the iris in the eye (**uveitis**) or **psoriasis**. In these cases, the characteristic symptoms of these diseases also occur.



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## What are the causes?

It has not yet been clarified what leads to the malfunction of the immune system causing **Bechterew's disease**. However, up to 95% of patients have a specific genetic characteristic, which is known as **HLA-B27**, in their cells. This gene is responsible for the white blood cells (**leukocytes**) carrying a certain protein on their surface, which plays a role in controlling the immune system. Therefore, there could be a connection between the presence of this gene and how the immune system malfunctions in **Bechterew's disease**. However, there are also many people who are **HLA-B27** positive and do not suffer from **Bechterew's disease**.

Experts therefore suspect that, while this characteristic may not itself be responsible for the development of the disease, it may result in an increased predisposition to its development. In addition, certain infections may trigger the disease. In addition to cells of the immune system (**scavenger cells**, **T** and **B cells**), pro-inflammatory messenger substances, known as **cytokines**, play a decisive role in the development of the inflammation. For example, an important **cytokine** is **tumour necrosis factor alpha**, or **TNF $\alpha$**  for short. The discovery of this connection has led to the development of new therapies that specifically target these inflammatory substances.

## Good to know:

Inflammatory back pain differs from mechanical back pain, which occurs due to muscular tension or being overloaded, for example. Inflammatory back pain worsens overnight and patients often wake up with pain in the second half of the night. Getting up and walking around reduces the pain.



# Living well with Bechterew's Disease

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**Bechterew's disease** is a **chronic** disease. However, the disease can progress in very different ways. Disease progression can be continuous for some of those affected. For others, their disease is relapsing, i.e. phases of the disease alternate with episodes in which the symptoms can subside or even disappear completely. In some patients, the disease progresses mildly without any severe discomfort or restriction of movement. Receiving appropriate treatment early can prevent or at least slow down the development of mobility restrictions at a later date.

However, if left untreated, inflammation in the spine can lead to a severe reduction or loss of mobility. On top of that, other general complaints can significantly limit your quality of life, as well as your social life. Therefore, it is important to start treating the disease as early as possible.

Depending on the progression and severity of the disease, your doctors may combine different treatment methods. At the same time, you can also do some simple things in your daily life to help treatment be successful and maintain your quality of life.

## Good to know:

The goal of treatment is to reduce pain and progressive joint stiffness due to ossification, as well as to maintain your physical capabilities and thus your quality of life.



## My treatment options

### Non-drug therapy:

- Physiotherapy and exercise therapy: various exercises can be used to maintain mobility, reduce pain, improve posture and coordination and prevent falls.
- Physical therapy: methods such as cold or heat therapy can be used to alleviate pain.
- Occupational therapy: practising joint relieving movements and learning how to use aids correctly in everyday life.

### Drug therapy:

- **Non-steroidal anti-inflammatory drugs (NSAIDs):** painkillers that can also inhibit inflammation.
- Basic medication (conventional synthetic **disease modifying anti-rheumatic drugs [DMARDs]**).
- In the event of an inadequate response or intolerance to basic medication, switch to **biologics/biosimilars**.
- **Biologics/biosimilars** are biotechnologically produced drugs (also biological **DMARDs**). There are various active substance classes, which, just like the conventional, synthetically produced **DMARDs**, lower the overreaction of the immune system. They intervene in one of the various processes of the body's own immune response, and can thus reduce inflammation.

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### Psychotherapy:

- Coping with psychological problems that occur due to the disease, comorbidities and **chronic** pain.

### Social medical measures:

- Rehabilitation: e.g. regular exercises for patients with Bechterew's disease

### Surgery (only for severe disease progression and if other measures are not successful):

- Replacement of a hip joint (total endoprosthesis) in the event of damage to the hip joint
- Stabilisation of vertebral fractures
- Reconstructive surgery for patients with Bechterew's disease who can no longer look straight ahead



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## Getting back to life with Bechterew's disease. With full speed ahead.

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"My next goal:  
from Switzerland  
back to Berlin.  
**I have already  
found the way:  
my own."**

- Andreas, year: 1980



Find out more about Andreas and discover valuable advice on how to deal with the disease in everyday life on [www.hexal.de/patienten/feelinx](http://www.hexal.de/patienten/feelinx)

## Sports and exercise

Sports can have positive effects on **Bechterew's disease**. Therefore, it is important to exercise regularly in addition to taking your medication. The goal of physical activity is to maintain and strengthen your muscles in order to stabilise or even improve your posture. At the same time, you can increase your fitness, improve your circulation and expand your breathing capacity. The types of sports suitable for you depend on the stage of the disease and your individual symptoms.

### Recommended sports are:

- Swimming
- Cross-country skiing
- Hiking/walking
- Cycling
- Gymnastics
- Volleyball



Talk to your doctor before starting a new sport. They can help you to assess whether the sport is suitable for you. Be careful not to overstrain yourself (especially if you may be suffering from other diseases) and stick to your own physical limits. Using the right equipment and remaining cautious is also important in order to prevent accidents.

## Relief in everyday work

In most cases, you can continue to practice your profession even after being diagnosed with **Bechterew's disease**. However, you should make sure that your work is not too physically demanding and that your posture remains upright, not curved or bent over for prolonged periods. A job where you can alternate between standing, sitting and walking would be ideal. You should also be able to work in a dry environment free from draughts. Due to the increased risk of breaking bones, you should avoid jobs which involve a high risk of accidents.

Especially if you are performing a seated activity, you should ensure that your seat is set at the correct height. If your hip mobility is limited, it may help to adapt your chair in line with this limitation. A slanting tabletop or an adjustable desk attachment can also ensure that your posture remains upright.



## Recommendations for everyday life

**Bechterew's disease** can have a wide variety of forms and progresses differently in every patient. However, you can have a decisive influence on the progression of your disease by implementing certain tips in your everyday life. If you notice that your neck becomes very sensitive to tension, you should wear a polo neck jumper or a scarf. Shoes with thick, springy soles can cushion the spine from vibrations when walking and thus prevent you from adapting a relieving posture. Orthopaedic shoe specialists can customise your shoes with an appropriate heel.

Having a car seat that is properly positioned is particularly important for long car journeys. Do not set the seat too low. If the seat is tilted too far back, a seat pad that is thinner at the front and thicker at the back can ensure a more upright sitting position. Headrests should be at the correct height and not far from the head when sitting normally. They are essential, especially when the spine is extremely stiff, in order to prevent a cervical fracture in the event of an accident.

### Good to know:

If the mobility of your spine is severely restricted, it can be difficult to look over your shoulder. In this case, you should install appropriate mirrors on your car to expand your field of vision and avoid putting yourself and others in danger.

## The optimal bed and lying position

- Ensure that your mattress is firm.
- Choose the right shape of pillow (your head should be in line with your body; avoid too many or overly large pillows).
- Avoid lying on your side for too long; turn onto your stomach for some time every night.
- In the event of inflammation in joints other than the spine: Place them in a functional position, e.g. stretch the knee joint or bend the ankle at a right angle.
- Do not lie with crossed legs if your hip, knee or ankle joints are affected.

You can find further suggestions for dealing with your disease on a daily basis here:

[www.hexal.de/patienten/feelinx](http://www.hexal.de/patienten/feelinx)



## Smoking

If you have **Bechterew's disease** and you also smoke, this may accelerate the progression of your stiffness. Compared to non-smokers, those patients who smoked experienced:

- Disease symptoms which occurred earlier
- More severe pain
- Rapid stiffening of the spine and associated impairment of functionality

If you suffer from **Bechterew's disease**, it is therefore recommended to quit smoking or significantly reduce the amount you smoke.



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## Pregnancy and breastfeeding

If pregnancy starts in a phase where you're not experiencing any symptoms, the probability that you'll experience a flare-up during the next 9 months is approximately the same for pregnant as for non-pregnant patients. However, the risk of a flare-up increases if disease activity is heightened during conception.

When planning a pregnancy, discuss with your physician if you should continue your medication, switch or discontinue. The same applies to breastfeeding: some medication can pass into the breast milk and should therefore only start being taken again once you have stopped breastfeeding your child. Fertility and pregnancy should not be negatively affected in patients **Bechterew's disease**. Despite stiffened sacroiliac joints or artificial hip joints, a Caesarean section is usually not necessary and a natural birth is possible.



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# Questions for your physicians

If you have just been diagnosed with “**Bechterew’s disease**”, or perhaps your physicians have suggested a new kind of treatment to you, you probably have a lot of questions. To ensure that you do not forget anything when talking to your physicians, you should create a list of questions in advance. We have listed a few of the most common questions to help you.

- How severe is my disease?
- Which kind of treatment would you recommend to me?  
How does this work?
- What side effects can the treatment have?
- How often must I come in for check-ups?
- What can I do to support my treatment?
- What happens if the treatment does not have a sufficiently positive effect?
- Will the disease/treatment affect my daily life?
- Can I continue to work?
- How can I get in touch with other patients?
- Where can I find further information on the disease/treatment?



# Your notes

A series of horizontal dotted lines for taking notes.

# Useful addresses

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For further information on **Bechterew's disease**, we have put together various addresses of patient organisations, information pages on self-help and professional societies.

## **Deutsche Vereinigung Morbus Bechterew e. V.** **[German Association for Bechterew's Disease]**

Metzgergasse 16  
97421 Schweinfurt, Germany  
Tel.: 09721 22033  
Fax: 09721 22955  
Email: [dymb@bechterew.de](mailto:dymb@bechterew.de)  
Website: [www.bechterew.de](http://www.bechterew.de)

Network for self-help for patients suffering from Bechterew's disease or related inflammatory spinal diseases.

## **Deutsche Morbus-Bechterew-Stiftung** **[German Foundation for Bechterew's Disease]**

Metzgergasse 16  
97421 Schweinfurt, Germany  
Tel.: 09721 22033  
Fax: 09721 22955  
Email: [stiftung@bechterew.de](mailto:stiftung@bechterew.de)  
Website: [www.dmb-stiftung.de](http://www.dmb-stiftung.de)

Foundation promoting research into the field of Bechterew's disease and related inflammatory spinal diseases.

This brochure does not replace the professional advice provided by your physicians. For further information about your disease, please contact them.

## **Deutsche Rheuma-Liga Bundesverband e. V.** **[Federal German Rheumatism League]**

Welschnonnenstr. 7  
53111 Bonn, Germany  
Tel.: 0228 766060  
Fax: 0228 7660620  
Email: [bv@rheuma-liga.de](mailto:bv@rheuma-liga.de)  
Website: [www.rheuma-liga.de](http://www.rheuma-liga.de)

Self-help organisation that independently informs and advises those affected and offers practical help.

## **Deutsche Gesellschaft für Rheumatologie e.V.** **[German Rheumatology Society]**

Wilhelmine-Gemberg-Weg 6  
10179 Berlin, Germany  
Tel.: 030 24048470  
Fax: 030 24048479  
Email: [info@dgrh.de](mailto:info@dgrh.de)  
Website: [www.dgrh.de](http://www.dgrh.de)

German medical/scientific society active in the field of rheumatology. It promotes rheumatological science and research and operates as an independent society.

## **Berufsverband Deutscher Rheumatologen e. V.** **[Professional Association of German Rheumatologists]**

Dr med. Silke Zinke  
Dr.-Max-Str. 21  
82031 Grünwald, Germany  
Tel.: 089 904141413  
Fax: 089 904141419  
Email: [kontakt@bdrh.de](mailto:kontakt@bdrh.de)  
Website: [www.bdrh.de](http://www.bdrh.de)

Represents all rheumatologists who practise professionally. Provides information and help to patients with rheumatological diseases in their search for a competent rheumatologist.



# Glossary

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**Acute:** sudden and usually short-term disease; opposite of chronic.

**B cells:** also: B lymphocytes; a group of white blood cells that are able to form plasma cells that, in turn, form antibodies against pathogens; belong to the immune system.

**Biologics:** Biologics are medicines with a complex structure and high molecular weight which are produced biotechnologically, i.e. using biological organisms.

**Biosimilars:** Biosimilars are biological medicines that are comparable to the original medication already available in terms of safety, efficacy and quality. To this end, biosimilars are tested using a strict approval route.

**Chronic:** a long-lasting disease (more than four weeks), often not curable; opposite of acute.

**Crohn's disease:** chronic inflammatory bowel disease, which can lead to inflammation of the entire bowel. Part of the small intestine and the large intestine are primarily affected.

**Cytokines:** messenger substances for signal transmission for the immune system.

**Dactylitis:** inflammation of a finger or toe.

**Disease Modifying Anti-Rheumatic Drugs (DMARDs):** various medicines that can slow the progression of a disease on the rheumatic spectrum. Divided into synthetically manufactured (sDMARD) and biologically manufactured (bDMARD) medicines. The tsDMARDs (targeted synthetic/targeted drugs) belong to the sDMARDs, together with the conventional synthetic csDMARDs.

**Enthesitis:** inflammation of tendon attachment sites.

**HLA-B27:** gene from the group of human leukocyte antigens (HLA), which play an important role for the immune system; the presence of HLA-B27 increases the probability of developing Bechterew's disease (ankylosing spondylitis).

**Immune system:** the body's own defence system against pathogens and foreign bodies; consists of various organs, cell types and messenger substances.

**Kyphosis:** forward curvature of the spine; also known as having a hunchback.

**Leukocytes:** also: white blood cells; present in the blood, bone marrow and lymphatic organs and play an important role in the immune system.

**Non-steroidal anti-inflammatory drugs (NSAIDs):** painkillers that can also inhibit inflammation.

**Osteoblasts:** certain cells that are responsible for the formation of bone tissue in the context of bone remodelling.

**Osteopenia:** decrease in bone density; precursor of osteoporosis.

**Osteoporosis:** also: bone atrophy; increased breakdown of bone tissue due to illness.

**Psoriasis:** also: psoriasis vulgaris; most common form of psoriasis with inflammatory, sharply-defined, reddened skin areas covered with silvery-white scales.

**Sacroiliac joint:** tight joint with limited mobility, located between the sacrum and intestinal bone; creates a connection between the spine and pelvic bone.

**Scavenger cells:** also: macrophages; a group of large, motile, white blood cells that play a central role in the immune reaction and destroy penetrating disease-causing microorganisms; belong to the immune system.

**Spondyloarthritis:** this term refers to various inflammatory rheumatic diseases in which chronic inflammation occurs, especially in the spinal region; a distinction is made between a form that is mainly axial (axial, i.e. on the spine or near the torso; this includes Bechterew's disease) and one that is mainly peripheral (peripheral, i.e. located at the edge, e.g. knee, ankle, toe, hand and finger joints).

**T cells:** also: T lymphocytes; a group of white blood cells; belong to the immune system and perform various functions there.

**Total endoprosthesis (TEP):** artificial replacement of a complete joint.

**Tumour necrosis factor alpha (TNF- $\alpha$ ):** messenger substance of the immune system that is involved in inflammatory processes.

**Ulcerative colitis:** disease in which the immune system causes inflammation in the large intestine. Other symptoms include abdominal pain and diarrhoea.

**Uveitis:** also: inflammation of the iris; inflammation of the uvea.

You can find further suggestions for dealing with your disease on a daily basis here:

[www.hexal.de/patienten/feelinx](http://www.hexal.de/patienten/feelinx)



#### How to reach us:

You have important questions about our medicines or you would like to order materials?  
Call us toll-free at **0800 439 25 23!**

You can reach us from Monday to Friday  
**from 8:00 a.m. to 6:00 p.m.**

Please contact your physician if you have any questions about your treatment.

#### Hexal AG

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D-83607 Holzkirchen

