

# Osteoporosis-

## What can I do?



Upfront Information for those who are interested or affected



Alliance for Self-Help Osteoporosis  
Umbrella Association of Osteoporosis Alliance for Self-Help

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**Dear reader,**

Osteoporosis is an affection of the bone structure metabolism. According to the rating of the World Health Organization WHO it is stated that this disease belongs to ten of the most spread diseases world wide.

The "Report of the European Association 1998" marks Osteoporosis as "creeping disease", as the starting of the disease does not show any pain nor discomfort.

To receive an early diagnosis is mostly difficult. Only when high level of pains or the first bone breaks come up; one can recognize the disease in total. This affects the costs for the treatment. Round about two milliard Euros are yearly needed for the therapies of Osteoporosis patients. Where as a good portion of costs could be saved through early diagnosis and preventative measure.

Osteoporosis is not only based on genetic nature. It also is based on loss of calcium, lack of exercises and hormone deficiency. But also the long use of cortisone or a lack on sex hormone can abet the disease. As slow as it comes, as slow the healing process also is.

The medical therapy is the fundament. Patients are advised to join existing self-help groups in their local areas. It is most important not to lose courage and to do the daily exercises as well as to go along with the long term therapy. Therefore it is advisable to join a group of people with the same diagnose which is effective and motivating. We are convinced that our brochure can give you a helping direction.

We hope and wish that our brochure receives the necessary attention and achievement from doctors as well as patients. Prevention is better than healing. With the existing disease a long term and consequent therapy can only bring success.

Yours sincerely

Alliance for Self-Help Osteoporo

## The European-Report

To receive the latest information's about the whole extent according the disease the European Parliament for all member states ordered an Osteoporosis Report to be done. By the way, this was the first time that this was done for a disease. The aim for this was to open up sufficient arrangements for prevention. The report was published 1998 the first time. A reissue came out 2008.

### **Important achievements shown in a nut shell:**

Up to the year 2050 there will be double an amount of people suffering Osteoporosis than now. Every 8th citizen of the EU over 50 will be affected having spine breaks according minimization of the bone structure.

Every 30 seconds someone in the EU will be diagnosed suffering fracture conditionally on osteoporosis. Every year doctors will be treating more than one million patients in the EU with fracture conditionally on osteoporosis; including 400.000 fracture of the neck of the femur and 400.000 fracture of wrist. Only half of the fracture of the neck of the femur will be diagnosed correct.

The risk dieing on complications of a femoral fracture is for women exactly the same as to die on breast cancer.

### **Therefore the editors of the EU report recommend:**

Health campaigns showing citizens in Europe what they can do by themselves at any age stabilizing their bone structure

Guidance for doctors so that risky patients - receive accurate advise - get diagnosed promptly and the correct therapy is given - get good and competent support for aftercare (Tip: Osteoporosis compendium for doctors as well as for patients has been set up and can be viewed under [www.osteoporose-deutschland.de](http://www.osteoporose-deutschland.de)).

Refund of costs for diagnostic and therapy for patients been classified as osteoporosis or fracture risk person.

Self-helping groups supporting people concerned to stabilize, to cope daily problems and motivate dealing with the disease.

All involved are requested to continue actively against Osteoporosis.

## Diagnoses Osteoporosis

Osteoporosis is a chronic disease. When receiving the diagnose one is first of all shocked. But one has to face the situation and start reacting.

Many questions arise: Why me? How is life going to continue? Did the doctor tell me everything?

What am I aloud to do and what not?  
Take the opportunity to get to know about Osteoporosis.

Consult your doctor, a self-help group or your local medical insurance company.

Only if you know your disease, you will be able to handle it.



With growing knowledge about the disease pattern of Osteoporosis your doctor, chemist, family and the self-helping group will become your closests confederates. Osteoporosis is not a unsolvable fate. With a individual set up treatment plan and active works on behalf of the patient the disease can be stopped.

## What is Osteoporosis?

"Bone-Hard" – that is the embodiment for solidity and stability. This picture is unfortunately wrong. Bone/skeleton is absolutely not made as steel and are massive. The structure changes as we get older. The skeleton grows, adjusts exposure or become stunted when not been used.

**Lexicon:** Osteo = bone  
porosis = diaphanous/porous, perforated

Bone grows during life period. It changes structure/shape being adjusted to exposure (stroke and pressure). When having broken bone or crack in the bone, bone heals on its own building up new bone tissue to make the harmed good.

A continuous 'rebuilding' takes place with the bone. Bone gets degraded and recovered through building up new bone tissue. With this process we humans are undertaking a constant change in the bone mass ('regeneration of material').

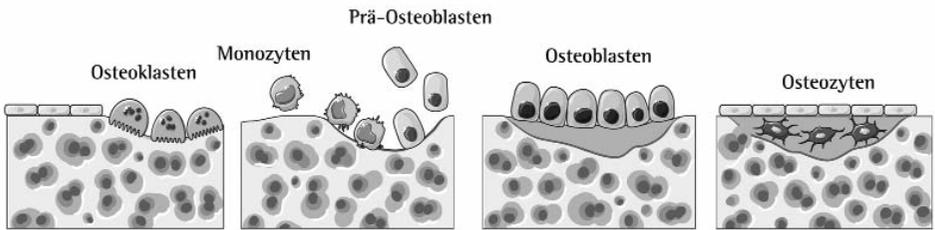
**Notice:**

- Osteoklasten = decrease bone structure/tissue
- Osteoblasten = build up bone structure/tissue
- Osteozyten = emerge from Osteoblasten and affect production of Osteoblasten and Osteoklasten

Bone structure decreasing at the inside surface of the bone column dissolve the bone tissue and leave small antra behind

In the next stage skeletal system gets into these antra and stay there to build up new bone tissue

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© Servier

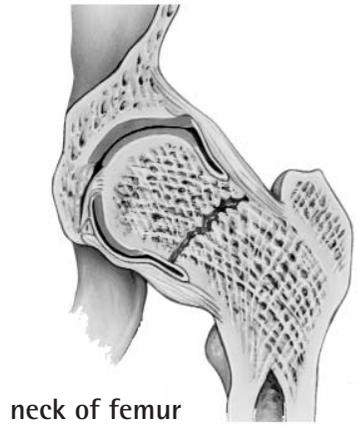
Between the age of 25 and 35 we have the highest level of bone mass. From there on and getting older the bone mass starts slowly to degrade. This is absolute normal and is combined with many other body functions degrading in age.

Is the rebuilding process disturbed, is the degradation of the bone higher than the rebuilding. The bone structure gets thinner. This is what is called Osteoporosis.

According scientific definition Osteoporosis is a systemic disease of the skeleton decreasing bone mass and worsening the micro architecture.

The bone density can be measured with special machines. The results are compared with the normal bone density of a 30 year person – where as woman and man is also specified. Is the result under a specific suitable measuring, high risks for bone breaks gets possible.

With already existing bone breaks we talk about a manifested Osteoporosis.



© MSD, Haar

Typical break points when being diagnosed Osteoporosis

## Osteoporosis does not have a consistent clinical picture!

*Osteoporosis shows two different structured pictures: the primary and the derivative disease.*

*The reason for the primary Osteoporosis depends on the bone metabolism and their hormone influence. So it is based on the bone structure rebuilding process.*

*With the derivative Osteoporosis the reason comes from a different disease. Osteoporosis arises as secondary disease or on behalf of other complications. Diseases such as: chronic gastro-intestinal disease or in specific rheumatism (taking to much cortisone) can give an accessory symptom of Osteoporosis.*

*The derivative Osteoporosis can arise after chemotherapy being a cancer patient or also having anti-oestrogen as breast-cancer patient (such called Aromatase-Hemmer).*

*Osteoporosis is not an inescapable fate to be suffered. It is a disease where prevention can already be done in young years. When you know about the risk factors and the reasons for Osteoporosis then you can already take first steps for preventing.*

Being active and targeted you can prevent dreaded bone breaks (neck of femur)  
For aged people one has to minimize falling risks.

The main reason for Osteoporosis is loss on estrogen which women suffer from after menopause. There as men hardly suffer on loss of testosterone.

But men can also get Osteoporosis. Every 5th person concerned is now a days a man.

## Test yourself how high your risk is

Bone breaks are momentous effects of Osteoporosis and can often give chronic pain, limitation of life quality and challenges for patients in need. Therefore it is important to recognize soonest if a risk for bone break is given and an Osteoporosis diagnostic could be made. Therefore it is important diagnosing at early stage if there is a risk given for bone breaks which could end up you having Osteoporosis.

### Concerning: Women up to the age of 60 / Men up to the age of 70:

Have you already had a for Osteoporosis typical swirl body break?

- Yes                       No

### Concerning: Women in the age of 60 – 70 / Men in the age of 70 – 80:

Have you already had on small occasions a swirl body break, a break of your forearm, wrist or thigh?

- Yes                       No

Did your father or mother have a break of neck of femur?

- Yes                       No

Do you smoke?

- Yes                       No

Is your body activity highly affected, for example being ill, exploring abducing nerve paralysis, being challenged as patient in need, etc.?

- Yes                       No

Do you suffer on underweight with BMI with unter 20?

- Yes                       No

Do you fall more than once per year without any influence?

- Yes                       No

### Concerning: Women older than 70 / Men older than 80:

Woman: Are you older than 70? Man: Are you older than 80?

- Yes                       No

These questions show a high risk for bone breaks and at the same time the risk of being diagnosed as Osteoporosis patient. Answering a question with 'yes': You are highly risked and should consult your doctor about Osteoporosis and should undertake yourself an examination. (Risk test according to the guideline of the umbrella association of Osteoporosis.)

## Which disorders/pains arise with Osteoporosis?

At the beginning of the disease you only have little pain such as occasionally back pains. Therefore the expression: 'creeping disease'.

Typical for the proceeding Osteoporosis are bone breaks without any reason. Consequences are loss on body height and changing of the posture (see illustration).



The breaks cause high pains. Putting to much weight wrong on can again cause strong muscle cramps.

With the Aged-Osteoporosis neck of femur breaks (neck of femur fracture) occurs frequently.

Breaks of vertebral bodies are typical for the hormone originated Osteoporosis and are often diagnosed wrong as lumbago. Through the breaks the patient gets smaller; getting a round back – the so such called: **widow back**.

## How is diagnose for Osteoporosis done?

For diagnosing Osteoporosis one has to undertake oneself a thoroughly anamnesis/medical history considering important risk circumstances such as family exposure, early estrogen loss, non-healthy food and so forth (view also risk factors).

The patient must be examined according the bone system. The wingspan from the short length and the actual body height must be measured.

Next, a 2-level x-ray picture must be done of the spine. The bone density must be examined as well as the laboratory parameter of serum (blood), spontaneous urine and 24-hour-urine.

On this behalf the situation of a patient can be sufficiently enough characterized and a individual therapy can be started.

### Measuring the bone density

Measuring the bone density is an important significance for Osteoporosis. Bone density measurements are absolute necessary diagnosing Osteoporosis and following up during the disease period. Up to now there is no other method controlling the start-status or success of the therapy.

The umbrella association for Osteoporosis (DVO) as well as the Patient Guide for Osteoporosis (details can be required from Geschäftsstelle des Bundesselbsthilfverbandes für Osteoporose e.V., Kirchfeldstr. 149, 40215 Düsseldorf) recommend the DXA-method doing bone density measurement (Osteodensitometry); further more on limited base the QCT and the pQCT.

You also have the synographical (ultrasound) method which is mainly used for the areas of the heel bone and the fingers. The synographical method does not measure the bone density or mass. It measures the consistency of the bone. The results are unfortunately insufficient for setting up therapy plans.

At the moment the costs for the bone density measurement only get refunded from health fund for existing bone breaks. The patient must cover the costs on his/her own if no bone breaks exist. The costs are normally from EUR 30 to EUR 50.

Ultrasonic measuring always goes on own costs.

## What can one do, having Osteoporosis?

Important is an early basic therapy before having the first bone break. Once the body has lost bone mass, a recovering is a long-winded process. Aim of the therapy is to get stabilization of well built skeleton structure and loss of skeleton structure; to help prevent bone breaks.

Calcium rich food and exercising are corner pillars preventing of getting Osteoporosis. But also with existing Osteoporosis besides an individually set up medication therapy the factor 'bone friendliness' food and exercises are a must for a successful therapy.

### Balanced food

**Calcium** Calcium is the most important mineral avoiding Osteoporosis as well as treating to stop Osteoporosis. An adult has more than 1 kilogram calcium in the body. 98 percent are found in the skeleton and teeth.

Prevention of Osteoporosis already starts in childhood; building up the skeleton. Food enriched with calcium is the indication and building material so that you are covered up to the age of 25 for building up the bone density of an adult-skeleton.

#### **Main calcium supplier in food:**

- Milk and milk products
- Green vegetables (for example: borecole/green cabbage, broccoli, leek, fennel, celery, garden cress), salads, herbs
- Nuts
- Sardines in oil, sprat
- Mineral water (> 200mg/l calcium – watch out on label)

Bei Patienten mit Milchallergie bieten sich besonders Fruchtsäfte und Mineralwasser mit einem hohen Kalziumgehalt an.

Patients being allergic against milk should consider drinking fruit juice and mineral water with high concentration of calcium.

An additional input of calcium tablets should be discussed with your doctor.

It is important to know about the so called ,calcium raider' blocking the calcium input or increase of calcium deposition.

So it is useless taking care about eating food enriched with calcium and not taking care about the calcium raider

## Calcium Raider

### Obstructing calcium input

Fat  
Alcohol  
Dietary fiber (phytic acid  
- settled in the outside skin of  
grain)  
phosphate (for example in meat,  
sausages, e-coded  
products, additives in prefabricated  
food)  
oxalic acid (for example beetroot,  
black tea, pieplant, mangold, spinach  
and cacao)

### increase of expulsion

caffeine  
salt (in high dosis)  
protein/egg white



Fortunately there are also substances that can be intestinal covered; such as:

Vitamin C  
Vitamin D

**By the way:** It is sufficient enough taking daily sun bathes or having walks in summer so that the body produces enough vitamin D. During the winter period as the sun stand is different we will not get enough input for building vitamin D on our own. One also has to bear in mind that older people do not have anymore the practical vitamin D performing.

Vitamin D should be taken as vitamin-d-calcium combined tablets through out the complete year.

**In general according to the subject ,food' you should take care of:**

- calcium rich food (view above)
- be careful about calcium raider
- diversified, rather little in fat content mixed food
- lots of fresh vegetables and fruits
- not more than 2 – 3 meat meals per week
- lots of fresh fish
- at least 2 – 3 liter mineral- or spring-/rock water
- not more than 4 cups of coffee per day
- minimize your drug consume (alcohol, cigarettes)

## Exercises

It is important to do enough exercising to strengthen the bone. Exercises improve the build-up of bone tissue.

The musculoskeletal system (bone, axis, joints and muscles) are there to work against the gravity and to loco motivate. With every movement the axis's forward the pull and pressure of the muscle on to the bone structure. This physical impulse motivates the bone cell to produce new bone mass. The age of the patient is not depending.

Not training, you lose round about five up to ten percent muscle mass per life year. This also means loss of bone mass.

Bone and muscle are according form and function a on each other depending system.

Three training forms in combination are recommended and effective:

mobility  
endurance  
energy

Following sports are good preventing Osteoporosis:

Building up muscles, weight training  
Quick and speedy walk (power walking)  
Slow jogging  
Hiking  
Cycling  
Golf / Tennis  
Swimming  
Dance  
Gymnastic (possible in different variations)



If you are diagnosed having Osteoporosis then consult your doctor to discuss about which sport/moving training is suggested to be good for you. Visiting a rehab clinic where you received recommended trainings and get to various programs can also support you.

Self-helping-groups offer constant rehab sports. Very important is the overlooking control of the trainer as it is important to link up correctly with the exercises to have a successful rehab for the patient.

A further positive point of joining a self-help-group is the automated dynamic of the group and the motivation received.

### Medicated therapy

Your doctor will choose which treatment concept will be the correct one for you according to your individual disease and situation.

At this stage we only would like to give you a few information's about current and approved treatment options (methods of first choice according to the current Osteoporosis Patient Guideline):

#### **Bisphosphonate**

Bisphosphonate's blocks bone degradation over the cells which are relevant for decreasing the bone mass.

#### **Raloxifen**

Raloxifen belong to the substance class of the SERMS (selective estrogen receptor modulator). Raloxifen decreases after menopause of women the signs for swirl body breaks and keeps the bone mass stabile. Further it prevents breast cancer.

#### **Strontiumranelat**

Strontiumranelat blocks bone degradation and has a recovering bone effect. That means it has an dual effect on the bone structure.

#### **Parathormon**

Parathormon is a hormone which gets produced in the parathyroid. The main function of parathormons is to increase the calcium concentration in the blood. Injection on daily basis can support new building of bone substance.

If the methods of the first choice can not be used you can use alternative medicine. Such as: Calcitonin, aktive vitamin D-compounds (Alfacalcidol), Fluoride, Etidronat.

#### **Calcium und vitamin D**

Calcium und vitamin D are responsible for the mineralizing of the bone mass and are in generell recommended to use as basic therapy.

## Activity in your own surrounding

When you are suffering on Osteoporosis risks getting bone breaks are very high.

Check out your surrounding to minimize all possibilities and prevent of falling:

- set up your home that you are safe from falls
- wear flat shoes with rubber so that you can not slip
- take care of well lightened home and prevent from stumbling blocks
- On days where you have glaze outside on your ways don't necessarily leave home
- Have your vision checked regularly
- Some medications such as sleeping tablets, tablets against allergy, high blood pressure and anti depressives can have an impact on your reaction. Watch yourself how your body reacts on the medicine you are taking. Consult your doctor for alternative therapy possibilities.

A local self-helping group will gladly provide you with further tips and suggestions.

## Perspective

Without doing anything Osteoporosis will creep further and will cause on longer terms many bone breaks and heavy bone pains. The loss of mobility and the constant pains can cause disability; you will be in need of the help of others.

Prevention and treatment of Osteoporosis can in many cases prevent of getting Osteoporosis, decrease the disease and can work against complications.

# German Association of Self-Help for Osteoporosis e. V. (BfO) Umbrella Association for Self-Helping Groups for Osteoporosis

Supporting, informing, motivating

With several local self-helping groups and with organized lobby works nationwide through the German association, the German Association of Self-Help for Osteoporosis is a much asked partner from those who are reflected with Osteoporosis as well as doctors, therapists and scientist.

**In August 1987** concerned people and doctors founded the German Association of Self-Help for Osteoporosis. Since then more than 300 self-helping groups with round about 16.000 members were created within the German Association of Self-Help for Osteoporosis. Therewith the association is nationwide a representative contact organization for people having to deal with Osteoporosis and will assist you in practicing self-help.

The German Association of Self-Help for Osteoporosis is the stakeholder for people concerned. Within the groups the patient is able to interchange, can discuss problems and being active influence positive on the progress of the health situation. Many of the local groups organize lectures; make representations about questions according to food and offer promotion weeks to present the complete spectrum of possibilities to show prevention.

The umbrella association provides teaching aids and handouts for those people being active in the single groups, trains and advises the volunteers and insures financial support. They also take care of advanced trainings for education in the Osteoporosis directory.

Bundesselbsthilfeverband für Osteoporose e.V.  
(The German Association of Self-Help  
for Osteoporosis)  
Kirchfeldstr. 149 / 40215 Düsseldorf  
Telefon 0211 - 30 13 14 - 0  
Telefax 0211 - 30 13 14 - 10  
[www.osteoporose-deutschland.de](http://www.osteoporose-deutschland.de)



## Handouts that you can order:

- Osteoporosis Risk Test  
 Topic brochures, for example:
- Osteoporosis and pain
  - Osteoporosis being a man
  - Osteoporosis and food
  - Osteoporosis and exercise

Leaflets

Osteoporosis-Address-directory

Magazin "Osteoporose Aktuell" (Osteoporosis Current)

Edition: 17.000, 4 x yearly



## Please also use our Doctor-Hotline:

0211 - 30 13 14 - 0

(Appointments can be checked out on internet, the magazin , "Osteoporose Aktuell" (Osteoporosis Current) or at the branches)

Website: [www.osteoporose-deutschland.de](http://www.osteoporose-deutschland.de)

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## Subscription

Please use capital letters or fill out with typing-machine!  
 Yes, I want to subscribe as member of Bundesselbsthilfverbandes für Osteoporose e.V. supporting the aims and works of the association. I hereby acknowledge my entry from: date: .....

I have taken acquaintance that I can cancel membership only in writing, 3 months before years end.

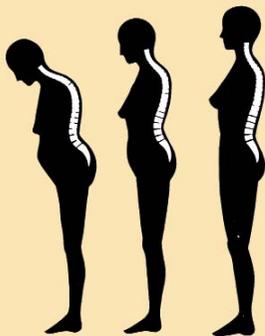
- \_\_\_\_\_
- as basic member (28,- € per year)  
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Membership fee

- I have settled into your bank account.  
 I have enclosed a cheque for deposit only.  
 I will volunteer within the self-helping group.  
 I want to found a self-helping group.



# Help applied for self-help having Osteoporosis

German Association of Self-Help for Osteoporosis  
[www.patient-library.org](http://www.patient-library.org)