International Osteoporosis Foundation

Invest in your bones

Quality of Life

Why prevent the first fracture?

Written on behalf of the IOF Committee of Scientific Advisors by Paul Lips,
Department of Endocrinology, VU University Medical Center, Amsterdam, The Netherlands.
Dr. Lips is Chairman of the IOF Working Group on Quality of Life in Osteoporosis.

Osteoporosis is

a silent disease. Osteoporosis is a disease characterized by low bone density and the deterioration of bone tissue. As the bones become more porous and fragile, there is an increased risk of fracture – even after a minor bump or in the course of normal daily activities.

There are usually no symptoms until the first fracture occurs. Fractures, particularly those of the hip and vertebra, cause untold suffering, lasting disability, and a greatly diminished quality of life. Not only do a high percentage of patients who experience hip fractures require permanent nursing care, the fractures are also a significant cause of mortality in elderly people.

a global epidemic. Around the world, it is estimated that osteoporosis affects one out of every three women and one out of eight men over the age of 50. In Europe the increase in the ageing population will result in a doubling of the number of osteoporosis patients in the next 50 years. Demographic studies also indicate that osteoporosis may soon reach epidemic proportions in the developing world. By the year 2050, it is estimated that one in two hip fractures resulting from osteoporosis will occur in Asia and Latin America.

a major socioeconomic burden. Aside from the human cost, the socio-economic burden of the disease is enormous. Escalating direct costs for health and hospital care are paralleled by the rising indirect costs that result when patients lose their independence and require nursing care. It is estimated that the annual direct cost of treating osteoporotic fractures of people in the workplace in the USA, Canada and Europe alone is approximately US$ 48 billion.

a disease that can be treated. Unlike some diseases, osteoporosis can be easily diagnosed and treated. A bone-healthy lifestyle and early detection by means of a safe and painless bone mineral density (BMD) measurement are the keys to preventing the first fracture. Today an increasing number of effective medications are available to help treat osteoporosis. Effective treatment has been shown to reduce the risk of fragility fractures by 50% as early as one year after treatment begins.

"Invest in Your Bones: Quality of Life – Why prevent the first fracture" is the third in a series of popular publications, released on World Osteoporosis Day, October 20. Much of the information in this booklet is derived from the IOF Quality of Life Working Group, established in 1994 by the European Foundation for Osteoporosis (EFFO), one of the two precursors to IOF. The Working Group has designed and developed a quality of life questionnaire for patients with osteoporosis and vertebral fractures *(Qualeffo-41 – see Appendix)*.

Invest in your bones

Quality of Life

Why prevent the first fracture?

Introduction

In Costa Rica, Sarah Padilla had always been a healthy woman. 1n 1979 when she was 52, Sara fractured her hip for the first time. One year later she fractured her other hip. Her life changed. She has to be more careful and has not regained full independence. Today, Sarah can't even take a bus because the steps are too high. Sadly it was not until 17 years after the first fracture that Sara learned she was suffering from osteoporosis and that the two fractures were not just the result of her being "careless".

In April 2002, Luciano Santi from Italy slipped in the bath and had severe back pain. X-rays revealed two crushed vertebrae and for a while Luciano was unable to work, he had to rely on his family to help him through the ordeal of getting out of bed and washing and dressing. After a kyphoplastic intervention (re-expansion of the crushed vertebral body with a special material) the back pain disappeared but a month later he suffered another three vertebral crushes.

Luciano now realizes that it all really began many years earlier when he began to suffer from severe headaches to the point that he had to stop working. After trying various treatments, he began therapy with a high-dose corticosteroid and he was able to return to work and live a normal life. Unfortunately, nobody had informed him about the long-term effects of corticosteroids on bone, and of the necessity to actively prevent bone loss.

True, painful stories like these are far too common.

IOF believes that, while it is essential to properly treat osteoporotic fractures, it is perhaps even more important to prevent fractures from occurring.

This publication offers the argument "why", by spelling out the consequences of what happens to people if you do not prevent the first fracture. Current statistics show that one out of every three women and one out of every eight men over 50 years of age will experience the distress of osteoporotic fractures. (Ref. 1, Melton L.J., 1992) This publication also provides advice on preventive actions we can all take.

Why prevent the first fracture?

The arguments are persuasive:

- *The number of osteoporotic fractures typically increases with age; women are more likely to break a bone than men.*
- *Incidence is rising rapidly. Worldwide, the number of hip fractures could rise from 1.7 million in 1990 to 6.3 million by 2050. (Ref. 2, Cooper C., 1992)*
- *The occurrence of a vertebral fracture increases two-to-five-fold the risk of another fracture within the next year. (Ref. 3, Johnell 2001 / Ref. 19, Lindsay R.,2001)*
- *A vertebral fracture may cause severe pain which continues for weeks or months. A patient with one or more vertebral fractures most frequently has problems with simple activities of daily living such as dressing, cleaning, cooking and washing dishes. Sport activities are impossible, social activities are difficult; this may cause feelings of fatigue, loneliness and fear of losing independence.*
- *While the direct mortality from hip fracture operations may be 1%-5%, the total mortality up to one year after hip fracture is about 25%. Many patients die in the first few months after operation due to complications of accompanying diseases. Up to 30% of patients have to give up independent living and are transferred to some form of institutional care.*

Introduction

- *For public health systems and insurance companies, the costs of surgery, hospitalization and rehabilitation of hip fractures is astronomical and increasing, placing a major burden on health budgets.*

It is clear that individuals, physicians and health policy officials have both an economic and moral responsibility to prevent the first fracture. Osteoporosis places an immense financial burden on governments and health care systems worldwide. More important, osteoporotic fractures cause untold suffering for millions of people.

Had Sarah Padilla known about her risk of osteoporosis early on she might have been able to avoid that first fracture or at least have obtained proper diagnosis and treatment when the first physical damage became apparent.

IOF's actions

IOF has very specifically made the concept "prevent the first fracture" a major theme of its work, with tangible results:

- *The European Parliament Osteoporosis Interest Group calls on national health authorities and health insurance agencies to implement clear actions to prevent the unnecessary suffering and costs caused by osteoporosis-related fractures. The work is on-going and involves the IOF, IOF member societies and other concerned groups and professionals.*

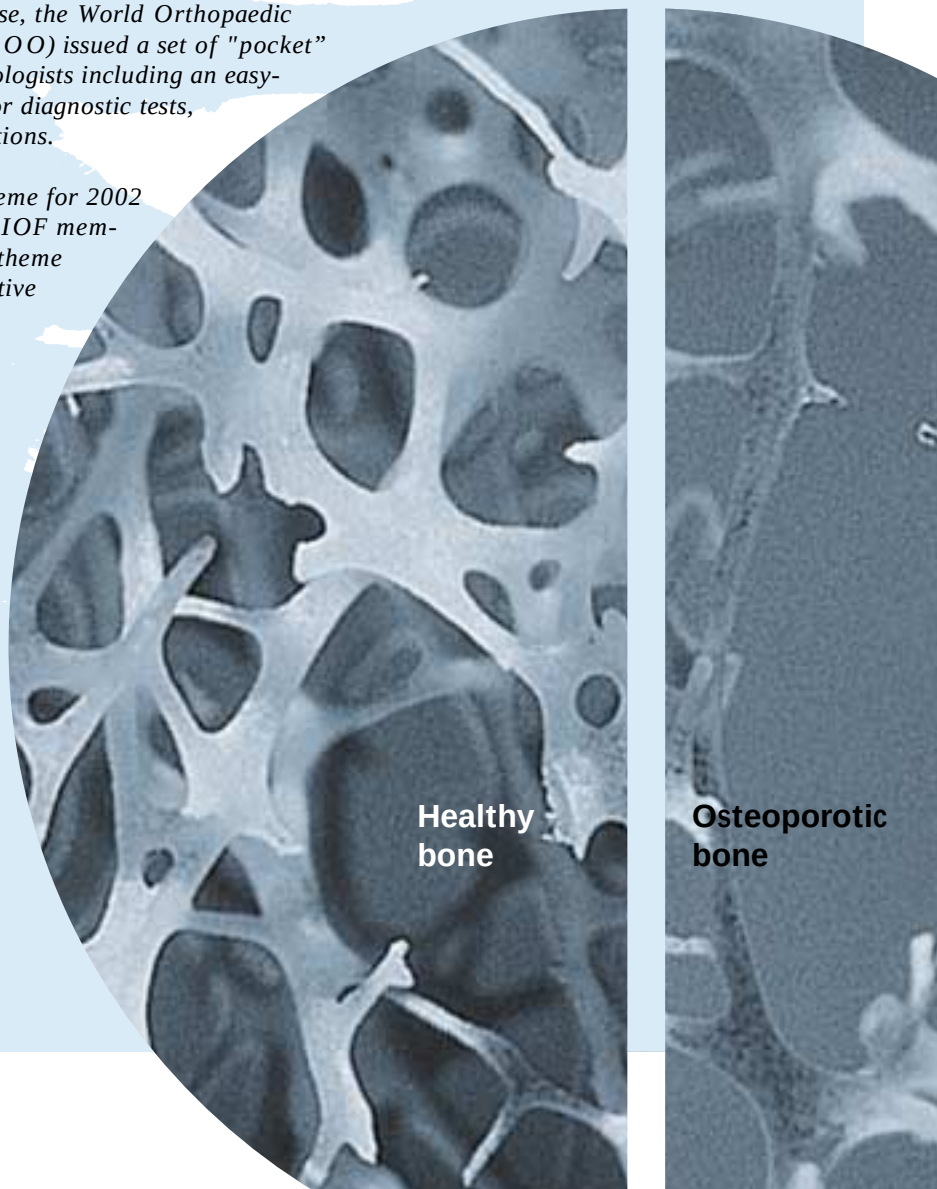
- *The 13 international women leaders who participated in the IOF Women Leaders' Roundtable, in Lisbon, Portugal on the occasion of the IOF World Congress on Osteoporosis in 2002, issued a strong call to action about the need to prevent the first fracture.*

- *An IOF / Bone and Joint Decade 2000-2010 multi-national study of 3500 orthopaedic surgeons showed that orthopaedic surgeons are poorly trained to recognize and treat osteoporotic fractures. In response, the World Orthopaedic Osteoporosis Organization (WOOO) issued a set of "pocket" guidelines for surgeons and radiologists including an easy-to-use flow chart with options for diagnostic tests, referral and therapeutic interventions.*

- *The World Osteoporosis Day theme for 2002 was "Prevent the first fracture". IOF members around the world used this theme for a broad spectrum of imaginative national activities.*

- *The IOF international TV and print advertising campaign launched in early 2003 encourages women and men to understand their risk of getting osteoporosis by taking the One Minute Risk test prior to the first fracture.*

So the message has been widely circulated – **prevent the first fracture.**



Is the first fracture inevitable?

All people lose bone mass as they get older. However, in people with normal bone mass the risk of fracture is relatively low.

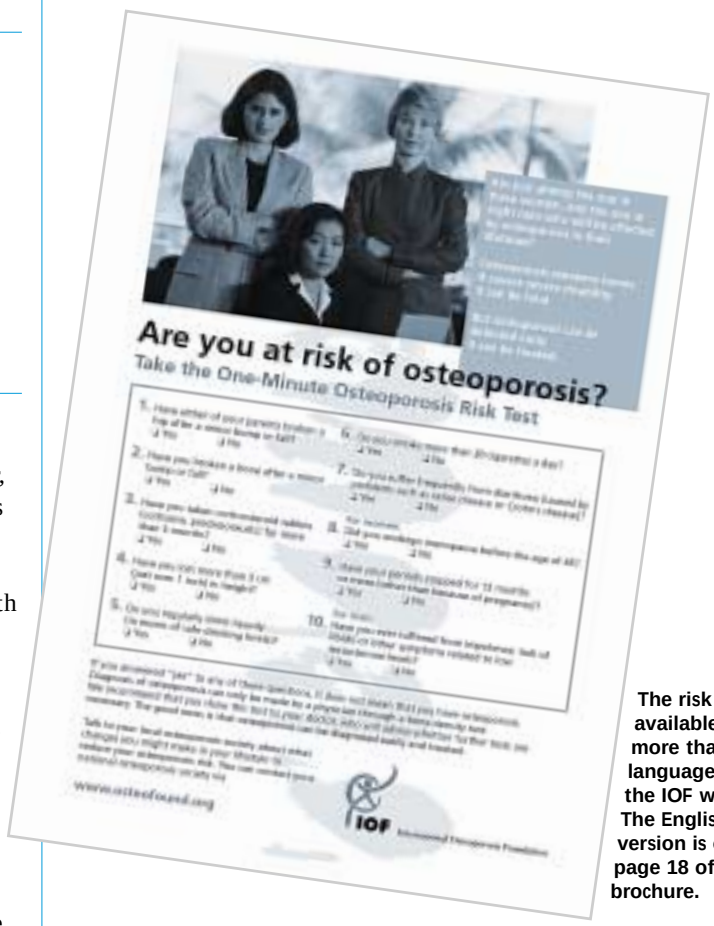
Bones break as a result of trauma, and even people with strong bones can suffer fractures following a fall or an accident. When the skeleton is osteoporotic, however, the bone mass is greatly reduced, the bones are more fragile, and the individual is likely to break a bone following a relatively minor shock. Sometimes a movement as seemingly benign as getting up too quickly from bed can shatter a bone.

Osteoporosis is often referred to as a "silent epidemic" because it attacks quietly, and often the only time that the patient realizes they have a problem is when they break a bone – and even then the diagnosis is often overlooked by doctors unless they call for a bone mineral density test.

A major problem is that about 50% of all osteoporotic fractures occur with patients who have osteopenia and not yet osteoporosis as defined by bone mineral density.

Bone mineral density (BMD) measurement serves as a clinical indicator of bone strength. A BMD test is a painless and non-invasive scan which, depending on the technology used, measures bone density in the hip, spine, wrist or heel.

BMD measurements are often expressed as a "T-score", representing the number of standard deviations (SD) the patient's BMD is above or below the peak bone mass of a healthy young adult of the same sex. Osteoporosis is diagnosed if the "T-score" is more than 2.5 SD below the mean BMD of young adults, (i.e. the T-score is lower than –2.5). Osteopenia (low bone mass) is diagnosed if the "T-score" is between -1 and -2.5 SD.



The risk test is available in more than 15 languages on the IOF website. The English version is on page 18 of this brochure.

How can we prevent fractures?

The first approach is through primary prevention in which a strong skeleton is developed during youth. As we get older, maintaining skeletal strength during adulthood is the key to secondary prevention.

Maximum bone mass can be attained by diet, including a sufficient intake of calcium, protein and vitamin D, and appropriate life style, including physical exercise. Alcohol abuse and smoking should be avoided. Physical exercise is recommended for people of all ages since it contributes to bone formation and decreases bone loss.

The IOF brochure, "Invest In Your Bones – How diet, life styles and genetics affect bone development in young people" explains this aspect further.

A step everyone can take is to determine if you are at risk of osteoporosis. You can learn your own, or someone in your family's risk factors, initially through a simple do-it-yourself exercise known as the One Minute Risk Test. If you have risk factors your physician may recommend the more comprehensive bone mineral density test.

Risk factors include osteoporosis in the family (mother having had a hip fracture), prolonged immobility or lack of exercise, low body weight, (less than 60 kg in women) and corticosteroid use such as prednisone *(Ref. 4, Dutch Guidelines, 2002)*. **Fractures, particularly in people 50 years of age and older, should always be a warning sign to the physician that a bone density test is called for.**

After the first fracture

Three types of first fracture and their implications

The three classical osteoporotic fractures are fractures of the wrist, spine, and hip. Wrist fractures typically occur around 55 years of age and vertebral fractures around 65 years of age *(Ref. 5, Lips P., 1997)*; hip fractures generally occur in elderly patients, at the age of 75 or older. However these ages are not absolute – fractures may occur even at a very young age, depending on the severity of trauma and the fragility of the bones. As told on page 14, Salima Ladak-Kachra from Canada broke her spine at age 25.

A useful way to express the risk of fractures is the lifetime risk *(Ref. 1, Melton L.J., 1992)*. In 50-year-old women the lifetime risk of hip fracture is 17.5% (one in six). The risk of vertebral fractures is 16% and wrist fractures is also 16%. In a 50-year-old man, the lifetime risks are 6% for hip fracture (one in 17), 5% for vertebral fracture and 2.5% for wrist fracture.

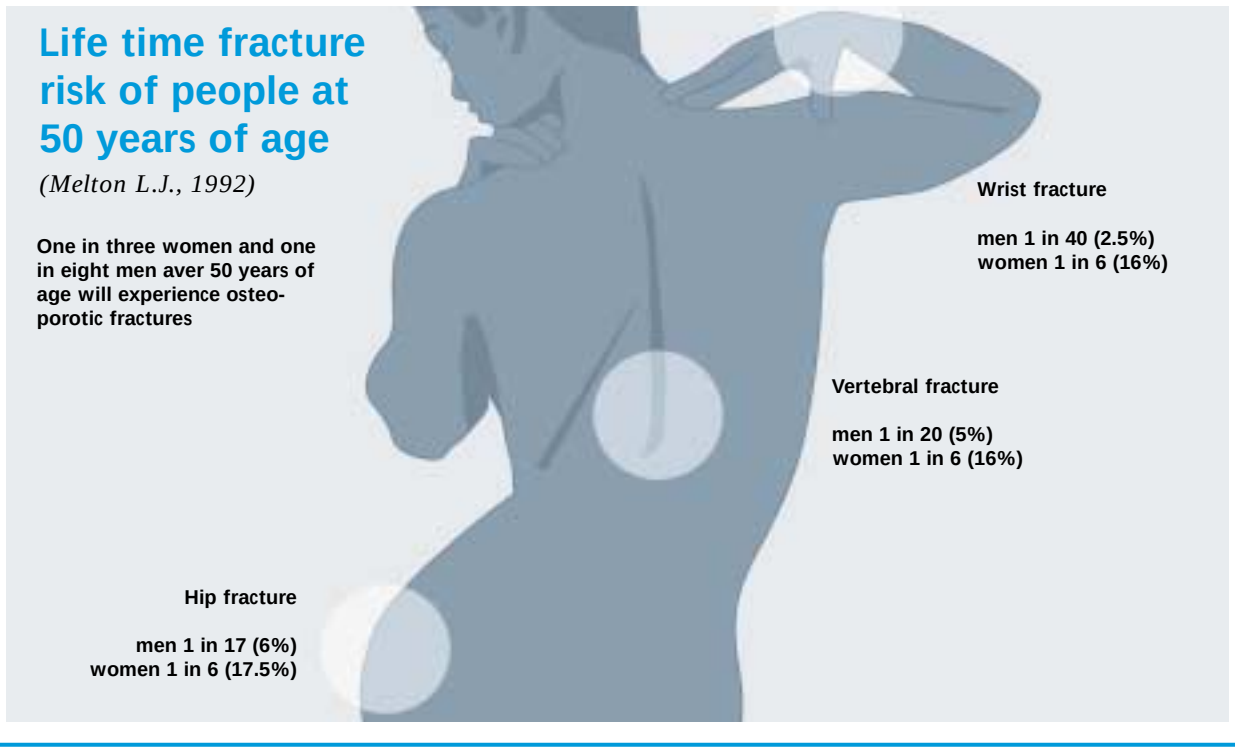
In Malmö, Sweden, the lifetime risk for a 50 year old woman is 20.8% for wrist fracture, 22.9% for hip fracture, 15.1% for vertebral fracture and 12.9% for humerus fracture or 46.4% for any of these fractures. In a man of 50 years in Malmö, these risks are 4.6% for wrist fracture, 10.7% for hip fracture, 8.3% for vertebral fracture, 4.1% for humerus fracture or 22.4% for any of these fractures *(Ref. 27, Kanis J.A., 2000)*.

Other fractures which often occur in patients with osteoporosis are breaks of the upper arm, pelvis and rib *(Ref. 6, Van Staa T.P., 2001)*. The number of osteoporotic fractures typically increases with age, with women more likely to break a bone than men.

What happens after the first fracture of the wrist?

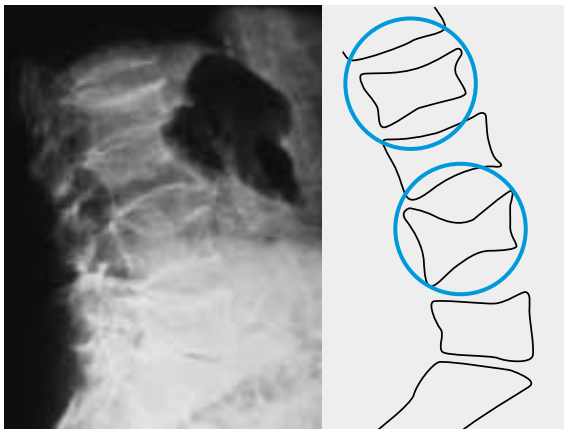
Often, the first fracture in a patient with osteoporosis is a distal forearm or wrist fracture. It occurs through a fall on the outstretched hand. Usually it concerns a 55 to 60-year-old woman. Wrist fractures are, not surprisingly, more prevalent during slippery winter conditions, especially when streets are frozen.

The common western treatment includes repositioning and immobilizing the break with a plaster cast for four to six weeks. After healing, the wrist is stiff, and



patients complain they are unable to use keys, to open screw-top jars, wash the dishes or to play the piano. After a year approximately 90% of patients have regained full function of the wrist, but some have not. *(Ref. 7, Dolan P., 1999).*

Vertebral fractures in lumbar spine



What happens after the first fracture of the spine?

The first fracture may also be a vertebral fracture. This may occur as a result of a lifting movement, or bending. The result is a height loss of the vertebra on the frontal side or in the middle of the bone. This may cause severe pain which continues for weeks or months, interfering with daily personal activities such as bathing, dressing, and using the toilet. Sleep may be disturbed. Shopping, cleaning and cooking may also create severe problems. Even the least handicapped patients have trouble in their daily life. Sports activities are impossible, social activities are difficult, as are visits to friends and relatives. This may cause feelings of fatigue, lack of energy, loneliness, and fear of losing independence and in some cases, depression. *(Ref. 8, Lips P., 1999) (See Appendix, table 1, Qualeffo-41 questionnaire).*

A major problem is that a first vertebral fracture is often not-diagnosed. The patient might think that the back pain is an inevitable consequence of ageing. The physician might not call for an X-ray or bone density test, but simply prescribe pain-killers and muscle relaxants. It is estimated from clinical trials that about two out of three new vertebral fractures pass without being brought to the attention of a doctor

(Ref. 9, Ross P.D., 1997 / Ref. 10, Ettinger B., 1999)

In practice, only one in five to one in ten patients with a first vertebral fracture will receive adequate medical attention, including assessment of bone mineral density and medical treatment. Those who do not have proper treatment have a 20% to 25% risk of suffering a new vertebral fracture within three years *(Ref. 10, Ettinger B.,1999).* Approximately 20-25% of women over the age of 50 have one or more vertebral fractures. *(Ref. 11, Melton L.J., 1997)* Adequate medical treatment can prevent 50 to 60% of new vertebral fractures, so early diagnosis and treatment is of utmost importance. *(Ref. 12, Delmas P.D., 2002)*

What happens after the first fracture of the hip?

In older people, the first fracture can also be a hip fracture, which is actually a break through the upper part of the femur, the large thigh bone. There are two main types of hip fractures, trancervical and trochanterical.

Hip fractures result from a fall on the hip when the surrounding tissues cannot absorb the energy of the fall and the hip bone has been made fragile by osteoporosis. Nearly all patients with hip fracture are admitted to the hospital and more than 95% have surgery *(Ref. 13, Holmberg S., 1987)* The patients often have to wait one or two days or more before surgery. Perhaps this is because there are other emergencies that take priority, or the patient is not strong enough. The hip fracture results in a large bruise with half a liter of blood or more. The patient may have been lying on the floor for a few hours or sometimes half a day and so is dehydrated. There may be problems with medication for diabetes or other comorbidity. Often the patient has to be seen by an internist. During a cervical hip fracture operation, the head of the femur is usually replaced by a prosthesis.

A hip fracture through the trochanter, the “ball” part of the hip joint.

Trochanteric fractures are typically treated with a screw and a plate. Sometimes, complicated fractures are treated with a total hip replacement. The operations are usually done under general anesthesia or sometimes spinal anesthesia. While the direct mortality of the operation is low (less than 5%) many patients die in the first few months after operation due to complications or accompanying diseases. *(Ref. 14, Keene G.S., 1993)*

The frightening realities

The mortality at three and 12 months after hip fracture in Sweden was 12% and 22% respectively. The mortality is three times higher in those elderly suffering a hip fracture in an institution than in those admitted from their homes *(Ref. 13, Holmberg S., 1987)*. One year following the hip fracture, 16% of people who had been living independently before the hip fracture and 46% of people who had been living in institutions, have died. Similar statistics come from England with 33% death rate at one year after hip fracture for all patients. Mortality at one year after hip fracture rose from 3% at below 60 years to 51% at over 90 years. *(Ref. 14, Keene G.S., 1993)*

More than 70% of patients need physiotherapy or rehabilitation after the operation and are transferred to a rehabilitation center or a nursing home. Rehabilitation often fails. *(Ref. 15, Braithwaite R.S., 2003)*

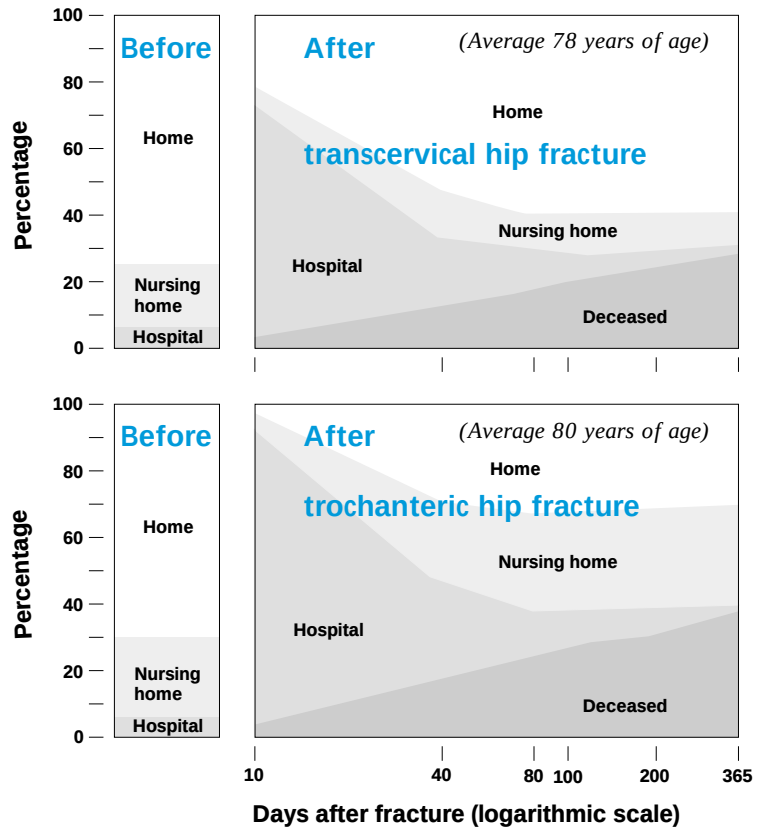
One year after the hip fracture, one in four patients has died, one cannot walk and two of the four can walk again but often not to the same degree as before the operation.
(Ref. 16, Miller C.W., 1978)

Up to 30% of the patients have to give up independent living and are transferred to some form of institutional care. The outcome is worse for patients with trochanteric (extracapsular) hip fractures than for those with true femoral neck (intracapsular) fractures *(Ref. 14, Keene G.S., 1993)*. The same study showed that just 40% of the patients walking unaided before the hip fracture could walk unaided one year after the fracture, while 34% required canes and 23% required walking frames.

It should be clear that every hip fracture has a severe impact on one's quality of life. The activities of daily living (ADL) and mobility are compromised either for months or for the remaining lifetime.

In conclusion, the consequences of a hip fracture are often devastating and many hip fractures result in permanent disability and loss of independence or even death.

Where elderly people live before and after hip fracture



(Ref. 14, Keene G.S., 1993)

While in western countries the outcome of hip fractures is severe, the outcome in other parts of the world may be even more devastating. Only a few non-western reports are available, but the example of Russia shows how dire the situation can be. In Russia, many patients with hip fracture never receive surgery, leading to permanent walking disability in the best case and death in the all-too-frequent worst case *(Ref. 17, Lesnyak O., 2001)*. Mortality is very high due to complications such as decubitus ulcers, pneumonia, thrombosis and pulmonary embolism. Doctors in Yekaterinburg reported a 45% mortality in the first year following fracture. Of the survivors, almost half are housebound and one third are bed-ridden.

After the second fracture

The distal forearm, or wrist

In many patients, the first fracture heals but the underlying cause of the fracture – osteoporosis – is not investigated.

Assessment of bone mineral density occurs in less than 25% of patients with a fracture of the distal forearm. Yet this fracture often predicts a new fracture, either a distal forearm fracture on the other side or a vertebral fracture. The second fracture occurs between 5-10 years after the first, because the median age for wrist fracture is about 55-60 while vertebral fractures become quite frequent at about 65 years of age *(Ref. 18, Klotzbuecher C.M., 2000)*. Even then, the bell may not ring with patient or physician.

Fractures of the spine

Once a woman suffers a first vertebral fracture, there is a five-fold increase in the risk of developing a new vertebral fracture within one year. That is why it is critical to prevent the first fracture *(Ref. 19, Lindsay, R.,2001)*

In addition, chronic complaints may occur, as two fractures in the spine cause more instability and more pain due to the anatomical changes. Some women patients have said the pain from vertebral fracture is greater than the pain experienced in childbirth.

Quality of life in the patient with multiple vertebral fractures

The non-treated patient with one or two vertebral fractures will eventually fracture more vertebrae.

The quality of life decreases steadily as the number of vertebral fractures increases. This applies to pain, physical function including activities of daily living (ADL) and mobility, social activities and the perception of being healthy. Fractures in the lumbar spine have a greater impact on quality of life than thoracic fractures.

The quality of life decreases more when the patient is older. This suggests that an older patient with vertebral fractures adapts less well than a younger patient. *(Ref. 20, Oleksik A., 2000)*

Patients with two or three vertebral fractures have a two to three times greater risk of problems with three or more activities of daily living compared to people without vertebral fractures. In addition, patients with three or more vertebral fractures have a high risk to have to stay in bed for more than three days per month and to have more than three days per month of limited activities *(Ref. 21, Pluijm S.M.F., 2000)*

A typical problem in a patient with multiple vertebral fractures is the loss of postural stability. The forward curvature (kyphosis) of the spine increases steadily, and the point of gravity which normally is inside the body, moves to a point in front of the body. As a result the patient tends to fall forward. Eventually, the patient cannot walk without a walking aid.

Another important problem is height loss. This causes an increase of waist size as the contents of the abdomen are pushed forward. Clothes do not fit anymore. In addition, the increased pressure in the abdomen and in the stomach causes great discomfort. The patient has to eat small meals and often feels heartburn or regurgitation and has to take medication for that condition. When the pressure in the abdomen is high and the opening in the diaphragm is too large, a part of the stomach may slide upwards into the thorax causing a hiatus hernia. These problems are difficult to treat.

A vertebral fracture increases the risk for a second vertebral fracture to such a degree that treatment should probably be started in any patient with a vertebral fracture unless it is obviously the result of a severe trauma *(Ref. 3, Johnell O., 2001 / Ref. 18, Klotzbuecher C.M., 2000 / Ref. 19, Lindsay R., 2001).*

Hiatus hernia: in a patient with multiple vertebral fractures, the stomach can move upwards into the thorax and cause great discomfort.

Rising costs – a major socio-economic burden

For public health systems and insurance companies, the costs of surgery, hospitalization and rehabilitation of hip fractures is astronomical and increasing, placing a major burden on health budgets.

As well as considerable human distress, escalating direct health and hospital care costs are paralleled by rising indirect costs when patients lose their independence and require nursing care.

- The cost of treating a hip fracture for the first year has been estimated at about US$ 20,000 in Sweden and the United States *(Ref. 22, Johnell O., 1997).* In Switzerland, one study calculates the direct cost of each hip fracture as more than US$35,000 *(Ref. 23, Schurch A., 1996).*

- The annual incidence of hip fractures in the EU is estimated to more than double, from more than 414,000 to 972,000 over the next 50 years *(Ref. 24, Johnell O., 1992,)*

- It is estimated that the annual direct cost of treating osteoporotic fractures of people in the workplace in the USA, Canada and Europe alone is approximately US$48 billion. *(Ref. 25, Osteoporosis in the Workplace, 2002)*

- In many countries, fractures caused by osteoporosis are responsible for more days of hospitalization among women over 45 years of age than any other disease. The annual combined medical costs of treating 2.3 million osteoporotic fractures in both Europe and United States is currently $27 billion. *(Ref. 25, Osteoporosis in the Workplace, 2002)*

- In the European Union, osteoporosis now costs more than euro 4.8 billion annually in hospital healthcare alone – a staggering 33% increase over three years. The number of hospital day beds associated with osteoporosis is higher than for many other diseases, including diabetes, myocardial infarction and breast cancer in women over 45 years of age. *(Ref. 26, EU Osteoporosis Consultation Panel Meeting – September 2002 Report)*

Most patients with osteoporosis have a lot of courage. While pain and problems with activities of daily living (ADL) and mobility are very common after a vertebral fracture, mental and emotional problems are relatively rare. Patients with osteoporosis often mention a lack of energy but they are not usually depressed.

Whose responsibility is it to prevent the first fracture?

The role of the individual

Every adult, especially those older than 40, should be aware of the fact that a fracture is a warning sign for osteoporosis and more fractures in the future. They should also be aware of the other risk factors and take the One Minute Risk Test *(See page 18)*. The most frequent warning signs (risk factors) are: previous fractures, previous vertebral fractures, family history of osteoporosis, low body weight, immobility, corticosteroid use, early menopause, hysterectomy, no exercise, anorexia, excessive drinking and smoking.

The role of the general practitioner

The general practitioner should ask about previous fractures and should be aware of special risk factors such as osteoporosis in the family and previous corticosteroid treatment or particular diseases such as anorexia nervosa. In these cases, the physician can order a bone mineral density measurement and initiate treatment.

The role of the radiologist/ orthopaedic surgeon

Every surgeon should consider that any fracture in a person 50-years or older might be an osteoporotic fracture. This is especially true for vertebral, wrist and hip fractures, humerus fractures, pelvic fractures and many rib fractures. The surgeon, who is often the first physician to see the patient, should start the diagnostic procedure or refer the patient to the general practitioner or internist for investigation (including bone mineral density assessment) and treatment. IOF has published requirements for the medical curriculum for orthopaedic surgeons. The radiologist should be aware of the radiological characteristics of osteoporosis and mention the possibility of osteoporosis in the report. IOF has recently published a course on osteoporosis and metabolic bone diseases for radiologists, it is available from the IOF website.

The role of the nurse

Nurses are key in ensuring crucial information, such as awareness of risk factors, is shared and understood by the general public. Education, and early diagnosis and treatment, are paramount in helping prevent osteoporotic fractures.

The role of the patient group

Patient contact groups play an important role in the exchange of information on osteoporosis and in psychological support. The national patient societies in the IOF and their patient contact groups, help in initiating and stimulating these contacts. To contact an IOF member society please see: www.osteofound.org

How patients can improve their quality of life after a first fracture

Pain medication and anti-osteoporotic medication should be started as soon as possible by the general practitioner, or specialist. Nutrition should be adequate, particularly protein intake and calcium. A calcium supplement should be considered when dairy consumption is low and vitamin D should be taken when sunshine exposure is inadequate. Standing and sitting position and mobility can be improved with help of a physiotherapist. Physiotherapy also may decrease back pain. An ergotherapist can give advice on problems with activities of daily living or adaptations in the house.

People with osteoporosis need to:

- Learn about the disease
- Seek out a patient support group run by an IOF member osteoporosis society
- Find a physician who is experienced in diagnosing and treating osteoporosis
- Take appropriate medication
- Ensure proper nutrition and lifestyle changes including exercise
- Be alert to risk factors in family and friends

Case histories

A healthy and optimistic Ovidiu, at about twenty years of age, while still at the foremen's school (top) and later in early 2003.

Ovidiu Pochlitaru, Romania

Ovidiu Poclitaru, aged 64, lives in the village of Gura Humorului (Moldavia), Romania. Ovidiu was formerly the foreman at the local timber factory, but had been enjoying his well-deserved retirement for several years. Although his football playing days were long over, Ovidiu continued to lead a fairly active and independent life and had become an avid reader.

One day in February 2003 while on the way to the library to borrow another book, Ovidiu slipped on ice hidden beneath a thin layer of snow. He fell on his right hip, got up on his feet again in an instant, wiped his clothes clean and went on. After walking 20 meters his right leg felt "funny" – it was slightly painful and felt like it was not responding properly, almost as though he were walking on a sponge. Never even thinking that anything serious could have happened after such an everyday fall, Ovidiu assumed that he might have simply injured his heel.

He grabbed hold of a nearby fence for support and was able to find someone to drive him to the nearest clinic. The doctor diagnosed a "crack" in his hip and recommended bed-rest for 45 days. But even after 30 days there was no improvement. He was not able to use his leg and was experiencing dreadful pain, especially during the night. Ovidiu decided to see a doctor in a bigger medical center located in Suceava, the closest city.

The specialist there diagnosed a femoral neck (hip) fracture. Three months after his fall, Ovidiu arrived at the medical center in Targu Mures, where he underwent total hip arthroplasty. An ultrasound test revealed that he has advanced osteopenia. Unfortunately, no DEXA machine (which would give a more accurate diagnosis) was available in the region.

In retrospect, Ovidiu recognizes that there were several lifestyle factors that could have alerted him to his increased risk for osteoporosis. These include a lack of calcium-rich dairy products in his diet, a history of heavy smoking, colitis between the ages of 30 and 50, regular alcoholic consumption and a thin physical build. Ovidiu is now "proudly" wearing a hip prosthesis and is working hard towards rehabilitation. Like anyone who suffers the debilitation caused by hip fracture, Ovidiu sometimes feels depressed – when we requested a photo from his youth for this patient story, Ovidiu said "yes, it would be good indeed, just to see the difference to the physical wreck I have become…"

Mrs. Lee Kong Siu and Ms. Lee Siu Fun, Hong Kong, PRC

Mrs. Lee Kong Siu, 86, lives by herself and seldom sees a doctor even when she is ill. She used to live with the pain associated with her degenerative hip disease (a different disease from osteoporosis) and always thought it was "normal", until one day she fell and experienced excrutiating hip pain. "She was in extreme pain when she called me," her daughter Ms. Lee Siu Fun recalls. "She said that the pain was so strong that she almost fainted."

Ms. Lee Siu Fun immediately took her mother to the hospital. After an X-ray, Mrs. Lee was found to have an osteoporotic hip fracture. After she had been discharged from the hospital, she was referred to the Jockey Club Centre for Osteoporosis Care and Control, at the Chinese University of Hong Kong, for further treatment. She was then prescribed medication for osteoporosis and also given a calcium supplement. Mrs. Lee Kong Siu now has to use a walking aid when her daughter accompanies her on her daily walk.

Alerted by her mother's agonizing experience, Ms. Lee realized that the disease can be very debilitating and extremely painful. "If my mother had sought an early treatment, her sufferings would have been greatly reduced." Ms. Lee says, "It's important to get an early diagnosis to prevent the first fracture."

While Ms. Lee keeps her life active and positive, to her surprise, she herself was diagnosed with osteopenia. "A few months ago, I accompanied my mother to the hospital for a follow-up visit. Since I was already there, I also took a bone densitometry examination," she says. "I am 52 but it never crossed my mind that something like this would happen to me, since I jog and swim, and drink soy milk."

Because she had a family history of fracture and had undergone menopause before the age of 45, the doctor advised the daughter, Ms. Lee, to take good care of her bone health. She maintains a healthy lifestyle with an adequate calcium intake and continues her walking and jogging everyday.

"You don't have to put up with that pain and distress. Stay alert and take appropriate action and you can change the quality of your life," she advises.

Luciano Santi, Italy

Despite his ailments, Mr. Luciano Santi, is an active and positive 56 year old man. Almost 17 years ago, he began to suffer from very severe cluster headaches. Very soon, the crises became so frequent that they dramatically reduced his ability to live a normal life. After different therapeutic trials, 12 years ago he began a therapy with high-dose corticosteroids. This therapy was quite effective. The frequency and intensity of the headaches progressively decreased and Luciano returned to a more acceptable life style.

Unfortunately, nobody told him about the long-term effects of corticosteroids on bone, and of the necessity to actively prevent bone loss. At the same time, Luciano continued to smoke and to have a poor calcium intake, approximately 500 mg/day.

In April 2002, he slipped in the bath and suffered severe back pain. X-rays revealed two crushed vertebrae (T11 and T12) and for a while Luciano was unable to work, he had to rely on his family to help him deal with simple daily tasks. Washing and dressing became an ordeal and walking with his friends or playing with his grandchildren were impossible. After a kyphoplastic intervention (re-expansion of the crushed vertebral body by injecting a special material) in July, the back pain disappeared but a month later, he suffered another three vertebral crushes (T8-T9-T10), apparently without having had any kind of fall or accident.

Another kyphoplastic intervention was required. This time, the orthopaedic surgeon sent him to a center specializing in metabolic bone diseases where he had his BMD measured for the first time. He received dietary counseling and began a therapy with a bisphosphonate.

One year later, Luciano has not suffered any new fractures and he is stable, apart his occasional headaches. He considers himself fortunate to have been able to return to work.

Sara had to wait about 17 years before getting a correct diagnosis

Salima with daughter Ashyana-Jasmine

Sara Padilla, Costa Rica

Sara Padilla had always been a healthy woman. She had never visited a medical clinic or been in hospital – in fact, she even gave birth to her five sons at home.

In 1979, when she was 52, Sara fractured her hip. She was watching one of her sons change a light bulb when he fell from the ladder. Sara was knocked down so badly that she required complex surgery to repair her hip. The recovery process was long and difficult.

One year later she fell while walking in her home, and experienced another fracture, this time of the other hip. She underwent surgery for a second time and the doctors sent her back home, with some painkillers and rehabilitation instructions.

After the two hip fractures, Sara's life changed. She has had to be more careful, and has not regained full independence. Today, Sara can't even take a regular bus because the steps are too high for her to get in.

It wasn't until a few years ago (about 17 years after her first fracture!) that Sara learned she was suffering from osteoporosis, and that the two fractures were not just a result of her being "careless". She now takes her medication, has received education about osteoporosis, and better understands what happened and how she can cooperate with her medical team. Sara is very optimistic, especially after seeing the improved results of her bone densitometry and laboratory tests.

In Costa Rica, the Fundacion Costarricense de Osteoporosis is actively working to increase knowledge of osteoporosis among the public and health professionals. The Foundation's work will ensure that in the future no one will have to go without proper diagnosis and treatment as Sara did.

Salima Ladak-Kachra, Canada

Salima is president of The Bone Wellness Centre, a facility for osteoporosis detection, prevention and awareness. This story was originally published in the Osteoporosis Society of Canada's newsletter, Osteoblast.

A personal story of compression fractures

At the age of 25, I sustained four compression fractures in my spine when I slipped and fell on a ceramic floor. When I hit the floor, I felt unbearable pain course down my back. For a moment, I thought I was paralysed. I couldn't stop crying. I knew something terrible had happened.

The next thing I knew, I was in the emergency department. An X-ray showed that I had crushed my vertebrae. The emergency physician said the damage to my back looked as though someone had hammered it with a baseball bat.

Most people who fall and land on their backs usually have little discomfort or minor soft tissue injury. However, I experienced excruciating pain, and was not able to walk, shower, eat or dress myself without assistance. I truly felt physically handicapped. I discovered that I had lost one inch in height and my waist increased from 18 to 22 inches. I had trouble performing daily tasks such as cooking, doing the laundry and cleaning. I felt as though as I was eighty years old – fragile and weak.

I kept asking myself: Why is this happening to me? I was so young and newly married and was planning on having children in the near future. With the constant pain in my entire back, I began to suffer both physically and emotionally and went through a period of depression. This depression also put a strain on my marriage as I had trouble communicating and being intimate due to the unbearable pain. The pain medications made me feel sleepy and lethargic, but thank goodness they worked.

Prior to my fractures, I had complained to several physicians about my back pain. The apparent risk factors I had for osteoporosis were ignored, probably due to my young age. After all, osteoporosis had always been associ-

ated with hunched-over elderly women. I have a very strong family history of osteoporosis on both sides of my family. I also have a petite body frame and I am of Asian descent. I had low calcium intake throughout my adolescent years, because I had difficulty tolerating dairy products and never focused on being physically active.

In addition, my menstrual cycle was irregular virtually from its onset. At age 20, after suffering a severe weight loss (a pixie-like 87 pounds – 40 kilograms), nausea, and headaches, my new family physician ordered comprehensive blood and diagnostic tests. These revealed that I had hyperprolactinemia. This condition, along with the other aforementioned factors, were preventing me from attaining my peak bone mass, and as a result, my bones were thin.

It was only the very painful experience of four vertebral fractures that forced an investigation of my bone health. A bone density examination revealed severe osteopenia in both my spine and femur regions, requiring immediate measures to be taken. To this day, I still have back pain and my body neither feels nor looks the same as it once did. I still have trouble cleaning the house, vacuuming, making the bed or being in one position for a prolonged period of time. I am now committed to preventing anyone from enduring the same experience that I did.

It is vital for one to have optimal calcium intake, to practice regular weight-bearing exercise, restrain from excess caffeine or alcohol consumption, and to not smoke. These are only a few of the risk factors for osteoporosis. Osteoporosis is a multi-factorial disease that can happen to anyone regardless of gender or ethnic background or age.

Mrs Anna Poen, The Netherlands

Mrs Anna Poen, 75, lives with her husband Jan in a quaint house on a canal in Amsterdam.

“I’ve had bone problems since I broke my pelvis 45 years ago,”she says. Today she has severe kyphosis that is typical of patients with osteoporosis and has lost ten cms in height. She had back pain for more than 20 years, but she was told that back complaints were a normal part of aging and that she “had to live with it”. Ten years ago she started to stoop. A year ago her back pain became “the most excruciating pain I’ve ever had”. A doctor ordered an X-ray of her spine. The diagnosis was osteoporosis with vertebral fractures. Next, she was sent to a rehabilitation clinic where she was told “we cannot do anything for you”. “But”, added Mrs. Poen, “they ordered a scootmobile for me, a stable electric transporter somewhere between a scooter and a wheelchair”.

Now she cannot walk more than 50 meters. She cannot lift her grandchild of 9 months.

She cannot bend or reach to take something from a shelf. She needs help with cleaning the house. “Cooking and washing the dishes are a real problem for me. I choose my clothes rather wide, so that my back cannot be seen”. While it is impossible for Mrs. Poen to use public transport, she can visit nearby friends with her scootmobile.

Recently, Mrs. Poen saw an advertisement in a local newspaper announcing a clinical trial for a new osteoporosis medication. She volunteered; new X-rays of her spine showed that she had suffered six vertebral fractures. Her osteoporosis was so severe that she was denied participation in the clinical trial and was instead referred to a clinic where she is finally receiving appropriate medication.

“I became involved with osteoporosis after my grandmother and my mother both tragically died as a result of this crippling disease. My mother was only 72. Then, only eight years ago, osteoporosis was seldom discussed, rarely diagnosed and usually attributed to old women with so called “dowager’s hump”. My family knew nothing about osteoporosis. The local GP was kind and sympathetic but he, like us, was able to do little to alleviate the terrible pain my mother suffered so stoically. We watched in horror as she quite literally shrunk before our eyes. She lost about 8 inches in height and became so bent that she was unable to digest her food properly, leaving her with no appetite at all… I believe that the quality of her life became so dismal and her suffering so unbearable that she just gave up the fight and lost the will to live.”

Excerpt from speech given by Mrs. Camilla Parker-Bowles, President of the National Osteoporosis Society of the UK, at the Women Leader’s Roundtable event, in Lisbon, May 2002

Appendix

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Appendix

Qualeffo-41

Quality of Life questionnaire

Work commenced in 1993 on an osteoporosis disease-specific, thoroughly validated questionnaire for health professionals to measure the health-related quality of life of osteoporotic patients with vertebral fractures in the context of a survey or clinical study. This questionnaire, first published in 1999, is now available in various languages on the IOF website. In 2000 work began on a second validated questionnaire to measure the decline in health-related quality of life for people suffering from wrist fractures, which is available in more than six languages. This is still work in progress.

The 14 of 41 questions of Qualeffo-41 that best distinguish patients with osteoporosis from control subjects of a similar age are:

- 1. How often have you had backpain in the last week?
- 2. How severe is your back pain at its worst?
- 3. How is your back pain at other times?
- 4. Do you have problems with dressing?
- 5. Can you do the cleaning?
- 6. Can you prepare meals?
- 7. Can you wash the dishes?
- 8. Can you get up from a chair?
- 9. Can you bend down?
- 10. Can you climb stairs to the next floor of a house?
- 11. Have you been affected by the changes of your figure due to osteoporosis (for example loss of height, increase of waist measurement, shape of your back)?
- 12. Can you do your gardening?
- 13. For your age, in general, would you say your health is: excellent, good, satisfactory, fair or poor?
- 14. Do you feel full of energy?

As part of the campaign to prevent the first fracture, the new IOF print advertisements encourage women to take the IOF One Minute Osteoporosis Risk Test

Are you among the one in three women, and the one in eight men who will be affected by osteoporosis in their life-times?

Osteoporosis weakens bones.
It causes severe disability.
It can be fatal.

But osteoporosis can be detect-ed early.
It can be treated.

Are you at risk of osteoporosis?

Take the One-Minute Osteoporosis Risk Test

1. Have either of your parents broken a hip after a minor bump or fall?
   ❑ Yes ❑ No
2. Have you broken a bone after a minor bump or fall?
   ❑ Yes ❑ No
3. Have you taken corticosteroid tablets (cortisone, prednisone,etc) for more than 3 months?
   ❑ Yes ❑ No
4. Have you lost more than 3 cm (just over 1 inch) in height?
   ❑ Yes ❑ No
5. Do you regularly drink heavily (in excess of safe drinking limits)?
   ❑ Yes ❑ No
6. Do you smoke more than 20 cigarettes a day?
   ❑ Yes ❑ No
7. Do you suffer frequently from diarrhoea (caused by problems such as celiac disease or Crohn's disease)?
   ❑ Yes ❑ No

For women:

8. Did you undergo menopause before the age of 45?
   ❑ Yes ❑ No
9. Have your periods stopped for 12 months or more (other than because of pregnancy)?
   ❑ Yes ❑ No

For men:

10. Have you ever suffered from impotence, lack of libido or other symptoms related to low testosterone levels?
    ❑ Yes ❑ No

If you answered "yes" to any of these questions, it does not mean that you have osteoporosis. Diagnosis of osteoporosis can only be made by a physician through a bone density test. We recommend that you show this test to your doctor, who will advise whether further tests are necessary. The good news is that osteoporosis can be diagnosed easily and treated.

Talk to your local osteoporosis society about what changes you might make in your lifestyle to reduce your osteoporosis risk. You can contact your national osteoporosis society via

www.osteofound.org

IOF International Osteoporosis Foundation

International Osteoporosis Foundation

IOF is an international non-governmental organization which represents a global alliance of patient, medical and research societies, scientists, health care professionals and the health industry. IOF works in partnership with its members and other organizations around the world to increase awareness and improve prevention, early diagnosis and treatment of osteoporosis.

Although osteoporosis affects millions of people everywhere, awareness about the disease is still low, doctors often fail to diagnose it, diagnostic equipment is often scarce, or not used to its full potential, and treatment is not always accessible to those who need it to prevent the first fracture. IOF's growing membership has more than doubled since 1999, reflecting the increasing international concern about this serious health problem. There are over 150 member societies in more than 75 locations worldwide (September 2003).

For more information about IOF and to contact an IOF member society in your country visit: www.osteofound.org

IOF
5 Rue Perdtemps
1260 Nyon
Switzerland
Tel: +41 22 994 0100
Email: info@osteofound.org
Website: www.osteofound.org

Credits

Compiled, and written by Paul Lips, Department of Endocrinology, VU University Medical Center, Amsterdam, the Netherlands

Project advisors: Cyrus Cooper, Professor of Rheumatology, University of Southampton, Southampton UK / Olof Johnell, Department of Orthopaedics, Malmö General Hospital, Malmö Sweden / John Kanis, WHO Collaborating Center, Sheffield, UK / Professor René Rizzoli, chairman, Committee of Scientific Advisors, International Osteoporosis Foundation; WHO Collaborating Center, Geneva, Switzerland

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International Alliance of Patients' Organizations
A global voice for patients

“Every day, millions of men and women in every one of our countries, are losing their mobility, their independence, their hope…

even their lives. The key to ending this tragedy is to take action before the first fracture.”

Queen Rania of Jordan, IOF Patron,
speaking at the IOF-Women Leaders’ Roundtable,
Lisbon, May 2002

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