Osteoporosis is a ‘silent thief’ that can steal your bone’s strength and your ability to be active. It affects women (and men!) of all ages but, as one gets older, the risk of osteoporosis increases. Often people don’t even know that they have the disease until they break a wrist or fracture a hip.

I am really excited about supporting the campaign for stronger bones, Timeless Women, because it’s a campaign for independent women like me who live active, full lives and don’t want osteoporosis to slow us down or take us prisoner.

Like a lot of people, I knew very little about osteoporosis before I was diagnosed. When I found out I was shocked and refused to believe it! As far as I was concerned, osteoporosis was not for someone like me, a former Bond girl who travelled, swam, walked miles every day - and had a big garden to look after! I thought it would have slowed my lust for life.

As this report shows, with the right treatment, osteoporosis does not have to affect everyday life. I feel lucky that with the help of my doctor I can still be me, living life and doing activities that I want and expect to be able to do.

But you need to be aware, take care and speak to your doctor.

Osteoporosis has not stopped me, and it shouldn’t stop you either.
These are shocking statistics. But despite the fact that osteoporosis is a serious disease that can impact a woman’s life, society should not view women affected by the disease as frail ‘little old ladies’. The commonly held image of women with osteoporosis as fragile and hunched over is outdated. Today, women with osteoporosis work, travel and enjoy life with their families in a way that would have astounded their mothers. These women don’t want osteoporosis to slow them down and wish to continue living life to the full, year after year. In spite of their perceptions of themselves and the active lives they lead, are women with osteoporosis still viewed as the frail old women as they may have been a generation ago or the strong, positive individuals that as they really are today? Do women with osteoporosis and their doctors have the same perceptions of the impact of osteoporosis on a woman’s daily life? Do women with osteoporosis and their doctors have the same attitude towards treating and living with this disease?

The Timeless Women report aims to answer these questions and also explore the lifestyles, desires and attitudes of women who have osteoporosis. The research was undertaken among doctors who care for women with osteoporosis and women who are affected by the disease.

This report also aims to shatter the common perception that women with osteoporosis are frail and fragile. Today women over the age of 55 continue to lead full, active and challenging lives, maintain their independence, and continue to contribute to their families and society.

The Timeless Women report has been developed with the International Osteoporosis Foundation, the Medical Women’s International Association and Reader’s Digest, all of whom also supported the survey. This campaign is supported by an unrestricted educational grant from Novartis to help educate women about osteoporosis and empower them to live life to the full.
The picture that unfolds throughout this report is one of a mismatch between the opinions and attitudes of women with osteoporosis and the doctors who treat the disease.

How Women with Osteoporosis Surveyed Feel About Themselves:

- Less than a quarter of women would describe themselves as ‘frail and fragile’
- Nine out of 10 women say that they do not want their osteoporosis to prevent them from leading their life to the full; in fact 85% describe themselves as being active

What does this difference of opinion mean for the treatment of this silent epidemic?

Women may not always get the treatment they need:

- Almost three out of four women surveyed believe that treatments with a less frequent dosing schedule would better suit their lifestyle

How Doctors Surveyed Feel About Women with Osteoporosis:

- Over half of doctors describe women with osteoporosis as ‘frail and fragile’
- Six out of 10 doctors feel that osteoporosis prevents women from participating in everyday activities (e.g., socialising, going shopping, etc.)

Is there an answer?

Women need to speak up about their bone health and have more discussions with their doctor about the best treatment to suit their varied and active lives and to protect them from osteoporosis year after year.

This survey was carried out in July 2008 by an independent research company in five countries: France, Germany, Mexico, Switzerland and the UK. In each country, 100 doctors and 200 women with osteoporosis (55 years or over who were selected at random) were surveyed, with a total survey population of 1,500.
What is Osteoporosis?

- Osteoporosis is a disease that affects the strength of bones, making them more susceptible to breaks or fractures. In most instances, fractures affect the hip, spine and wrist.
- Bone is a living tissue, with new bone constantly replacing old bone: osteoporosis reduces the body’s ability to replace old bone with new, meaning bones become weaker and weaker over time.
- Although osteoporosis affects both men and women, it is more common in postmenopausal women because they have reduced levels of oestrogen, a hormone which is important for maintaining strong bones.

Did You Know?

- Osteoporosis is known as the ‘silent epidemic’ because there are no visible symptoms and patients do not feel ill, therefore women remain unaware that they have the disease.

In fact, most women are only diagnosed with osteoporosis once they have sustained a break or fracture, as this is usually the first ‘symptom’ of osteoporosis.
- Osteoporosis can be described as a ‘thief’ because it steals the strength of bones making them more likely to break or fracture.
- Genetic factors play a large part in determining whether an individual is at risk of osteoporosis. However, healthy habits, nutrition and exercise can also influence the rate of bone loss and have a key role in determining how well our bodies are able to replace old bone.

How Many People are Affected by Osteoporosis?

- It is estimated that over 200 million women and men worldwide suffer from osteoporosis.
- As a result, one out of three women over the age of 50 will suffer a fracture because of osteoporosis.

How is Osteoporosis Diagnosed?

- If a doctor thinks their patient has osteoporosis, they will recommend a bone scan called dual x-ray absorptiometry (DXA or DEXA for short) to measure their bone mineral density (BMD).
- BMD is a measure of the bone mineral content at a specific site, divided by the area measured:
  - Above -1 is considered normal
  - Between -1 and -2.5 means a person could have osteopenia, a condition that may lead to osteoporosis
  - Below -2.5 indicates a person has osteoporosis

One out of five women and men over 50 who have a hip fracture will die within a year because of its consequences.
- In Europe and the US, it is estimated that one in three postmenopausal women are affected by osteoporosis.
- In Latin America more than 10% of women suffer a spine fracture because of osteoporosis.

Facts about the ‘Silent Epidemic’
A low BMD does not necessarily mean a woman will suffer a break or a fracture. However, it is important that women know the value of their BMD and discuss this aspect and possible treatment options with their doctor.

BMD is currently the best single predictor of the risk of future fracture. However, several other skeletal and non-skeletal risk factors should be considered when assessing the fracture probability, including the FRAX® tool.

What is FRAX®?

If a doctor has no access to DXA facilities, the FRAX® tool can be used to calculate the ten year probability of fracture of an individual.

The World Health Organization (WHO) has launched a tool called ‘FRAX®’ which is a major milestone towards helping physicians to improve identification of patients at high risk of fracture for treatment.

What Treatments are Available for Osteoporosis?

It is an algorithm, combining risk factors such as age, sex, weight, smoking habits, etc., and femoral neck BMD if available. The practical web-based tool FRAX® gives a figure indicating a ten-year fracture probability as a percentage, which provides guidance for determining the need of treatment (www.shef.ac.uk/FRAX/)

Did You Know?

Osteoporosis literally means ‘porous bone’

The term osteoporosis was first coined in the 1820s in France

International figures with osteoporosis include Ursula Andress, Joan Rivers, and Britt Ekland.

It is a common myth that osteoporosis is an ‘old women’s disease’. However people as young as 25 can be affected, though it is more unusual and often caused by different risk factors, such as chronic therapy with steroids which treat other diseases e.g. rheumatoid arthritis or asthma.

What Treatments are Available for Osteoporosis?

A number of treatments are available for osteoporosis, which slow the progression of the disease, improve the density of the bone and therefore reduce the risk of fractures.

Studies have shown that, depending on the treatment and the woman, the risk of fractures can be reduced by 16-70%.

In addition to treatment, women with osteoporosis should ensure they take vitamin D and calcium, as these are important supplements for bone health.

In the past, there were only a limited number of treatment options available, however today there are a range of options from daily to once-yearly, helping women with osteoporosis find the most suitable treatment for their lifestyle.

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In the past, there were only a limited number of treatment options available, however today there are a range of options from daily to once-yearly, helping women with osteoporosis find the most suitable treatment for their lifestyle.
Today, mature women are doing more than ever before. Women over 55 are fitter and healthier than previous generations, often having energy, time and resources to spend on travel, leisure and new experiences. What's more, retirement is no longer considered the 'end of the road,' but rather the start of a new journey. Many women over 50 are employed and involved in voluntary work, and continue to contribute to society.

The fact that mature women are active and positive should not come as a surprise. These are, after all, women who have lived through and embraced massive social changes. They were among the first generations to have access to oral contraception, challenge men for jobs and shake-up the boardroom. They have continually broken down barriers and opened new doors for the generations that follow. Why would they want to give that up now?

Women with osteoporosis are no different to those without the disease; they want to live the same full and active lifestyle. They refuse to give up their current lives, reflecting this wider shift in society.

It is important that the reality of these women's lives is acknowledged by their doctors, as some may still hold different views of the lives and needs of women of this generation. This is NOT what these women want; today's women with osteoporosis want a treatment and protection from their osteoporosis which is convenient and fits in with their lifestyle, without making them feel like a 'patient'.

It is time for society at large to realise that women with osteoporosis are active and dynamic... so Timeless Women!

"I didn't take it seriously at all. I was not in pain, I felt good, and I assumed that since I was leading a healthy lifestyle I could simply ignore the diagnosis. I was not aware of the implications of osteoporosis or the importance of taking medication"

Roswitha Horn, Austria

What kind of women are we talking about? What do mature women today expect from life?
I suffer from osteoporosis. I discovered it by chance. In 1995, I began suffering very strong back pain, which forced me to reduce my physical activity. At that time I didn’t know that I had osteoporosis. As it is common in people of a certain age, I attributed the back pain to the ‘ageing effect’. But as time went on, it was more difficult to do the daily tasks at home and I lost agility and mobility. There was also the emotional damage that resulted from my loss of physical strength and the feeling that I needed to depend more and more on my family. This was especially difficult because I used to be a very active person, with multiple interests and jobs to perform, both at home and outdoors.

I went to visit my family doctor. This first visit demonstrated how deficient knowledge about this illness is among family doctors. He just prescribed some painkillers and advised me to change some habits and to stick to some soft sport. He also suggested that I resign myself to this because, in his opinion, all this was due to ageing and there wasn’t any other solution but “put up with it”.

For the next couple of years I followed all his indications but, in spite of it, the main problem didn’t improve. The pain was intense and my activity kept reducing itself. The doctor prescribed stronger painkillers then, but as they didn’t have any effect, he changed the prescription to anti-inflammatory drugs. It is true that they reduce the pain but they also cause several secondary effects.

During a visit to an old people’s home, I accidentally saw a poster with an interesting inscription: “If you care about your bones, take care of them.” There was also a phone number from the Spanish Osteoporosis Association. This phrase made me think that there could be a different approach to treating bone diseases.

Fortunately, my life has changed from those years. Actually, I’m into an adequate treatment that has really helped me to improve my health. I’m also more aware of the importance of doing sports and taking care of my diet. All these are very important weapons to fight against osteoporosis.

Now I’m back to my daily activity and I feel like myself again. I don’t need to depend on others anymore. But I lost three precious years that I could have used to improve my condition, to prevent the illness going further and to avoid pain and suffering.

There is indeed one thing I have learnt: that an accurate diagnosis, which is relatively simple, can save women from a lot of suffering, fractures and emotional damage.

Carmen Sanchez, Spain

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Living with Osteoporosis

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The Reader's Digest biannual European Health Survey 2008, was conducted across 11 countries with over 18,000 respondents. It aimed to explore how consumers feel about health issues, how they rate their own health and the steps they take to maintain it and how informed they are about health conditions.

Key Results

- 62% of Europeans believe their health to be good or excellent, which is slightly lower than in 2006 (65%)
- 1 in 3 Europeans claim to be worried about their personal health (35%), which is less than in 2006 (47%)
- Overall awareness of health conditions and treatments appears high (75%)
- Overall people are doing more to improve their health compared to 2006
  - Undertaking more exercise has seen the biggest increase, with 45% of respondents saying they are consciously doing more exercise to improve and maintain their health
- Regarding specific conditions, 12% of Europeans have osteoporosis, down 2% points from 14% in 2006; 42% of suffer from high blood pressure compared to 40% in 2006; 38% suffer from weight problems, up 1% from 2006

These results reinforce the findings of the Timeless Women survey as they show that people are interested and concerned in their overall well-being and keen to live more active lives in order to maintain good health.
Who is today’s woman with osteoporosis and what does her disease mean to her?

From the survey, it is clear that today women with osteoporosis are more active than ever, with careers, families and taking part in a wide variety of activities.

The fear of breaking a bone is not enough to stop these women from being active. Two-thirds of women surveyed chose not to limit activity to avoid breaking a bone.

With this in mind, for many women with osteoporosis their greatest concern is that osteoporosis will mean they lose their independence.

Maintaining their independence is vital for these women, with nine out of 10 women surveyed not wanting to be dependent on others to help with their day-to-day activities.

Two-thirds of women with osteoporosis surveyed are also concerned about becoming housebound and dependent on others because of their disease. As a generation of women who have spent their lives caring for family, friends and parents, they do not relish the idea of having to be cared for themselves. Independence is a priority for these women.

Women with osteoporosis are active and independent and wish to maintain this lifestyle.

“I was diagnosed with osteoporosis and became aware that I had to take care of my own body and change my lifestyle. At 64 I am able to practice the same physical activity that my younger colleagues perform – I dared to participate in three marathons!”

Celia Marcela Casals, Argentina
The perception that women with osteoporosis are frail and fragile is a myth from a bygone age but one which unfortunately is still believed by many people, including some doctors. Fortunately, many women with osteoporosis feel their doctor does see them as they really are: almost two-thirds of women surveyed claim their doctor has a good understanding of their needs.

These perceptions differ to those of women with osteoporosis.

What doctors surveyed think and feel:

- **69%** of doctors do not perceive women with osteoporosis to be very active.
- A significant proportion of doctors perceive female osteoporosis patients to be less likely to engage in a range of activities than non-osteoporosis patients of the same age.
- **Three-quarters of doctors** believe that osteoporosis has a negative impact on their patients’ outlook on life.

What women surveyed with osteoporosis think and feel:

- Only **23%** of women with osteoporosis describe themselves as ‘frail and fragile’.
- **More than 1 out of 5** women deem that their doctor thinks of them as being more frail and dependant than they really are.
- **Less than a third** of women with osteoporosis believe that the disease has a negative impact on their outlook on life.

Although the myth of ‘frail and fragile’ does not apply, much needs to be done. Women with osteoporosis and their doctors should work together to ensure they fully understand each other and that the needs and lifestyles of women with osteoporosis are taken into account.
While women with osteoporosis and doctors do have different perceptions, they share the same goal:

**effective & convenient treatment**

that allows women with the disease to maintain their lifestyle and manage their osteoporosis.

Women with osteoporosis require a treatment which suits their current lifestyle. The survey showed that **7 out of 10 women with osteoporosis have missed a treatment dose**.

This could result in an increased likelihood in breaking a bone, since patients who take their treatment less than half the time receive minimal or no fracture protection.

While some women forget to take their treatment, there are a number of other factors leading women to not take their treatment as prescribed, including:

- Treatment side-effects
- Confusing treatment instructions
- Do not think it is effective/do not notice results
- Treatment inconvenient and interferes with day-to-day life
- Believe they are not at risk of fractures

The right treatment is one that not only has to strengthen and protect women’s bones but also complements their active lifestyle.

While both the women with osteoporosis and doctors surveyed appear to be relatively satisfied with current osteoporosis treatments, they both agree that treatments with less frequent dosing would be beneficial and more convenient.

Almost three out of four women with osteoporosis believe that treatments with a less frequent dosing schedule would suit their lifestyle more.

Despite a range of treatment options available, less than half of women with osteoporosis can remember their doctors discussing alternate treatments with different administration frequencies.

Women need to speak up about their bone health and have discussions with their doctor about the best treatment; one which will not only help to protect them from osteoporosis year after year, but also one which suits their varied and active lives.
At the International Osteoporosis Foundation (IOF), our vision is a world without osteoporotic fractures. In addition to the scientific advances and policy reforms needed to drive positive change, attitudes and practices need to be assessed to understand where improvements may be achieved at a grass roots level. **This is why surveys such as this are important: they provide insights into individual mindsets which help us understand osteoporosis and the subsequent approaches to its prevention and management.**

One key focus for the future must be how doctors can be better empowered to help prevent the all-important first fracture without entirely compromising lifestyle. Surveys conducted by IOF have indicated that although physicians recognise the importance of preventing a first fracture in postmenopausal women, significant barriers exist that limit their ability to intervene in time to prevent the first and subsequent fractures. **Fractures are recognised as the most serious consequence of osteoporosis, resulting in a significant negative impact on women’s daily living and long-term health.**

On World Osteoporosis Day 2008, IOF will launch a two-year campaign which seeks to mobilise public opinion to generate change in osteoporosis healthcare policies. It will be a ‘call to action’ to the global osteoporosis movement, seeking to mobilise the power of millions of voters, tax-payers and concerned citizens to improve osteoporosis healthcare policies in government and private health care systems around the world.

For additional information visit: [www.iofbonehealth.org](http://www.iofbonehealth.org)
The Medical Women’s International Association (MWIA) is an international non-governmental organization (NGO) representing female doctors from all five continents. As an organization representing female doctors, our members understand the desire of women with osteoporosis to want to maintain their current active lifestyle, positive attitude, and continue to live a full life. We are involved in this campaign to help women with osteoporosis live the life they want.

Although osteoporosis is not only a disease of women, women are affected at a younger age than men. In many parts of the world, women in the osteoporosis age group are raising grandchildren, running the home and working outside the home as the main wage earner. They have the entire family depending on their good health. Healthy bones are part of this good health that keeps them active and able to continue these responsibilities.

In addition, education around good bone health and early detection and treatment of osteoporosis before fractures occur are important. It is well known that if you educate a woman, you educate the entire family. The MWIA believes that good education, diagnosis and treatment of osteoporosis fits well with their vision of promoting good health for all women and men, boys and girls, throughout the world.

What seems to resonate most from the findings of the Timeless Women Survey is the clear need for doctors to proactively address the hopes and fears of the women in their care to enabling them to see beyond the disease when they look at their own future post-diagnosis. Whilst osteoporosis, perhaps more than almost any other condition, is inevitably accompanied by an increased element of caution with everyday life, there is no reason why it should completely define the way one lives their life.

In addition, compliance is clearly an important issue, and again is an area where doctors have an important role. Many current treatments for osteoporosis can be difficult or inconvenient to take correctly, meaning that patients are often not fully compliant, and research has shown that if patients fail to take their medication even 50% of the time, they recieve minimal or no protection against the disease.

For additional information visit: www.mwia.net
“I encourage all women over 50 to go and see their doctor and get their bones checked out.”

This report makes it all too clear that many mistaken ideas about osteoporosis still exist. This perception is damaging to Timeless Women and clearly one that we need to change.

Society cannot write off women with osteoporosis as ‘little old ladies’. We are not, and we deserve better.

Osteoporosis affects one in three women, so we must raise awareness and get people talking and taking action. I encourage all women over 50 to go and see their doctor and get their bones checked out.

Then, if you’ve got osteoporosis, you need to maintain or adopt a healthy lifestyle and work with your doctor to find the right treatment for you – a treatment that suits your lifestyle, that you feel comfortable with, and that enables you to continue enjoying life to the full.

Let’s fight the ‘silent thief’ together!

For additional information visit: www.fortimelesswomen.com
Osteoporosis is a serious disease. Women need to speak up about their bone health and have discussions with their doctor about the treatment that best suits their varied and active lives and will protect them from osteoporosis year after year.
Checklist

Take this checklist with you when you next go to the doctor to discuss osteoporosis!

Checklist

► Be aware, take action and see your doctor about getting your bones checked out
► Explain any concerns to your doctor
► Take or ask your doctor to do the osteoporosis risk factor test [www.shef.ac.uk/FRAX/reference.htm](http://www.shef.ac.uk/FRAX/reference.htm)
► Make sure you discuss your current lifestyle and the life you want to lead
► Make sure your bones are protected, year after year
► Remember, speak up for your bone health

Report Photography:
(i) Image of Ursula Andress © Rolf Edelmann/Schweizer Illustrierte.
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