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# The Adherence Gap: Why Osteoporosis Patients Don't Continue With Treatment

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A European report highlighting the gap between the beliefs of people with osteoporosis and the perceptions of their physicians



There are many medically-proven treatments for osteoporosis. The International Osteoporosis Foundation (IOF) does not endorse or recommend any specific treatment. Such decisions must be made by the patient and the physician

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# Why Do We Need This Survey?

Osteoporosis - literally "porous bones" - is a debilitating and widespread chronic disease which is increasing in prevalence across the world. A third of postmenopausal women and one in five men over the age of 50 are affected by osteoporosis.<sup>1</sup> Bones lose density, become fragile and can easily fracture with a subsequent devastating impact on mobility, independence, quality of life and mortality (around a third of patients who suffer a hip fracture die within the year).<sup>2</sup> Yet osteoporosis is now a largely treatable condition and, with a combination of lifestyle changes and appropriate medical treatment, many fractures can be avoided.

Today several classes of effective drugs are available for osteoporosis, of which the most commonly prescribed is a class of drugs called bisphosphonates. However, for these drugs to be effective, they need to be taken long-term and for at least a year. The tragedy is that, although at least a year of treatment is needed, the majority of people prescribed bisphosphonates stop taking them within a year,<sup>3</sup> for a number of reasons that have been identified by this research. Many individuals fail to tell their general practitioners they have stopped treatment and, when they go on to fracture bones, their physicians may believe bisphosphonates are intrinsically less effective than is the case.

Stopping treatment may leave patients vulnerable to fractures. As physicians have become increasingly aware of the extent of the problem, they have begun to reinforce the benefits of treatment to their patients. Little is known about the effectiveness of educating patients on the consequences of stopping treatment early. Ultimately we all need to understand more about why patients fail to complete a course of treatment in order to address the underlying problem effectively.

The International Osteoporosis Foundation (IOF) is the only worldwide organisation dedicated to the fight against osteoporosis. It brings together scientists, physicians, patient societies and corporate partners. Working with its 170 member societies in 84 locations, and other healthcare-related organisations around the world, the IOF encourages more research into how the lives of people with osteoporosis can be improved through better support and treatment.

This report outlines the key findings of a new survey, carried out by Ipsos Health, that sought to understand why patients stop treatment and what would make them more likely to stay on therapy. Importantly, it also assessed the extent to which physicians are aware of the underlying reasons for patients discontinuing treatment and explored what they think would remedy the problem. Research into this area is vital to help discover the factors that influence patients to take their bisphosphonate treatment as directed and, ultimately, improve the management of osteoporosis.

The findings of this report are illuminating in revealing the disparities between what patients believe and the perceptions of their physicians. In order to have an effect on the long-term impact of osteoporosis on the individuals and society as a whole, it is essential that patients have access to, and stay on, the therapies prescribed by their health care provider. Any insights into why some patients are more willing to stay on their treatment for longer should be further explored to encourage a greater understanding between patient and physician and, thereby, improve the long-term management of osteoporosis. This, in turn, should help reduce fractures, improve patient health and provide a better quality of life for people with osteoporosis. The International Osteoporosis Foundation is, therefore, pleased to publish this important European survey.

Dr Daniel Navid  
Chief Executive Officer, International Osteoporosis Foundation

# Executive Summary

## About the survey

*The Adherence Gap: Why Osteoporosis Patients Don't Continue With Treatment* is a five country European survey involving 500 physicians (primary care physicians and rheumatologists) and 502 women with postmenopausal osteoporosis. All of the women surveyed were over 60 and had either taken a bisphosphonate in the past or were currently taking one.

The study was conducted in January-April 2005 by IPSOS UK. It was supported by an unrestricted educational grant from Roche and GlaxoSmithKline (GSK).

## Survey objectives

It is acknowledged that currently available bisphosphonate therapies for osteoporosis have drawbacks. They need to be taken regularly, in a specific manner and over the long-term (for at least a year) in order to be effective in maintaining bone mineral density and protecting against fracture. However, data have shown that many patients do not continue taking their medication over time, as directed, with a large number stopping within the first year.<sup>3,4</sup>

The term adherence refers to a combination of taking medication correctly (compliance) and continuing to take medication for the recommended amount of time (persistence on therapy). Women whose adherence is poor, show smaller gains in bone mineral density<sup>5,6</sup> and have a greater number of fractures<sup>7,8</sup> which could have consequences on their quality of life, and incur greater healthcare costs.

The reasons why women stop therapy have previously been unclear. Women are told that osteoporosis puts them at risk of fracturing bones and that long-term treatment will guard against this; yet osteoporosis is a symptom-free disease until a fracture occurs and the lack of discernible symptoms may afford a sense of false security. If women feel that their treatment is making no

difference to their personal risk of bone fracture, they may be inclined to discontinue their medication. As current bisphosphonates need to be taken according to a somewhat restrictive regimen and are associated with gastro-intestinal irritation, this temptation may be even greater.

**Up to 60% of patients who take a once-weekly bisphosphonate and nearly 80% who take a once-daily bisphosphonate discontinue treatment within a year<sup>3</sup>**

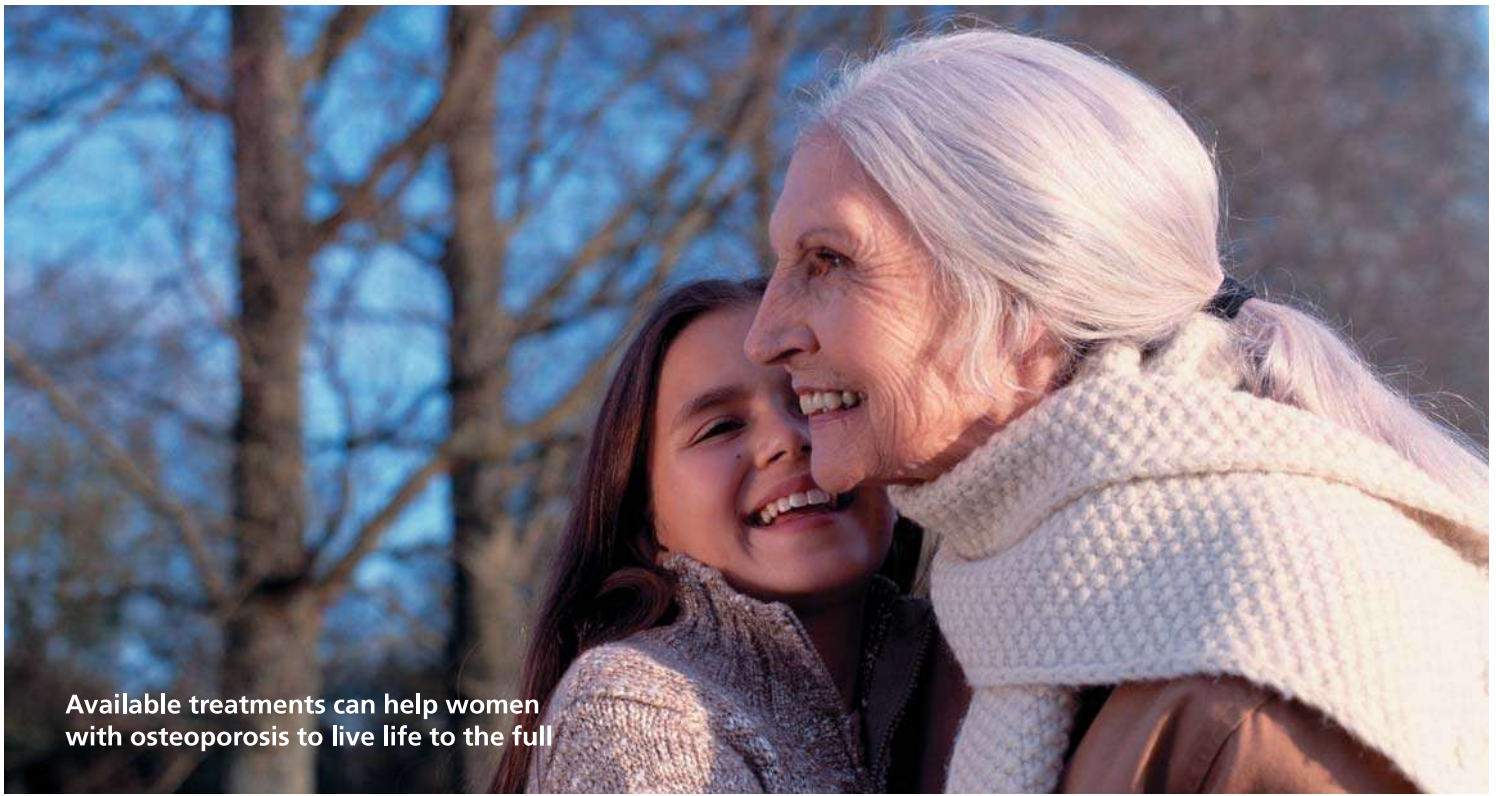
The aim of this study was to probe the differences in perception between women and their physicians on issues surrounding osteoporosis, current treatments and adherence difficulties. It sought to discover why some women stay on therapy while so many others do not. It aimed also to find out from physicians, and from the patients themselves, which factors might help motivate women to stay on their osteoporosis treatments and how these could best be implemented.

## Key findings

### • *Stopping treatment*

This survey was designed to ensure that the opinions of those women who had stopped taking therapy were sought alongside those still taking a bisphosphonate. Over a third (38%) of the women taking part in the survey were lapsed bisphosphonate users<sup>9</sup> (i.e. had previously taken a bisphosphonate but had discontinued with this treatment). Of those women in the survey who were currently taking a bisphosphonate, or had previously taken one, the majority said they experienced drawbacks.<sup>9</sup>

While side effects and inconvenience-related reasons were amongst the most commonly-cited factors reported by women as deterrents to staying on therapy, many physicians attribute non-adherence to a lack of patient understanding only.<sup>9</sup>



Available treatments can help women with osteoporosis to live life to the full

Some 85% of physicians had prescribed a bisphosphonate to a patient who had subsequently discontinued treatment. Seven out of 10 physicians did not know why their patient had stopped taking an osteoporosis treatment.<sup>4</sup>

Despite 82% of physicians reporting that they advise their osteoporosis patients to stay on treatment for between '1 year' and 'indefinitely', just over half (51%) of women could not recall being advised how long to remain on their osteoporosis treatment.<sup>9</sup>

It is clear from this research that physicians have an important role to play in terms of providing advice to patients who are considering stopping treatment as 39% of women who had discussed this issue with their physician had been convinced to continue with treatment.<sup>9</sup> However, there would still appear to be some room for improvement given that 12% of patients reported that their physicians gave no further advice when they informed them that they had stopped treatment.<sup>9</sup>

#### • *Staying on treatment*

Some confusion was highlighted in the survey about the length of time women had been instructed to remain on therapy. The majority of physicians say they want patients to stay on treatment long-term – between '1 year' and 'indefinitely'.<sup>9</sup> However, just over half (51%) of the women surveyed could not recall being advised how long to stay on their treatment and a few women believed they need only remain on therapy for six months or until their present course was finished.<sup>9</sup>

There were also differences in opinion between women and physicians about the best means of motivating women to stay on therapy.

#### *The Patient Viewpoint:*

- Knowing they were doing something to help themselves was the primary factor motivating women to stay on medication (27%)<sup>9</sup>
- Followed by doing something to prevent fractures (15%)<sup>9</sup>
- 64% gave a positive motivating factor (for example, wanting to stay independent) as their reason<sup>9</sup>

***The Physician Viewpoint:***

- 41% of physicians believe the best way to motivate patients to continue on treatment is to ‘explain to’ or ‘remind’ them about the risks and complications of fracture if they abandon treatment<sup>9</sup>
- In addition, a further 9% favoured an in-depth explanation of the dangers of not following treatment<sup>9</sup>
- Only 13% would motivate patients by explaining treatment benefits<sup>9</sup>

These results would seem to indicate that whilst many physicians are attempting to motivate their patients by emphasising the negative (fear-related) consequences of non-adherence, it may be better to adopt a more positive approach that stresses the benefits of staying on therapy.

**• Need for improved treatment regimens**

Although bisphosphonates are widely used for the treatment of osteoporosis, only 22% of physicians were completely satisfied by the acceptability of the treatment to their patients and 83% felt improvements in treatment were needed if the disease is to be effectively managed.<sup>9</sup>

**• Improving dosing of current therapies**

Less frequent dosing options for bisphosphonates emerged as a popular option among both women and physicians as a means of improving acceptability of, and adherence to, treatment.

***The Physician Viewpoint:***

- 93% of physicians felt that altering the dosing frequency would influence adherence to therapy<sup>9</sup>
- Three-quarters of physicians believed it would have a strong influence because of the greater convenience it would offer to patients<sup>9</sup>

***The Patient Viewpoint:***

- Four out of five women expressed an interest in a less frequent dosing option<sup>9</sup>

# Current Challenges With Bisphosphonate Therapy

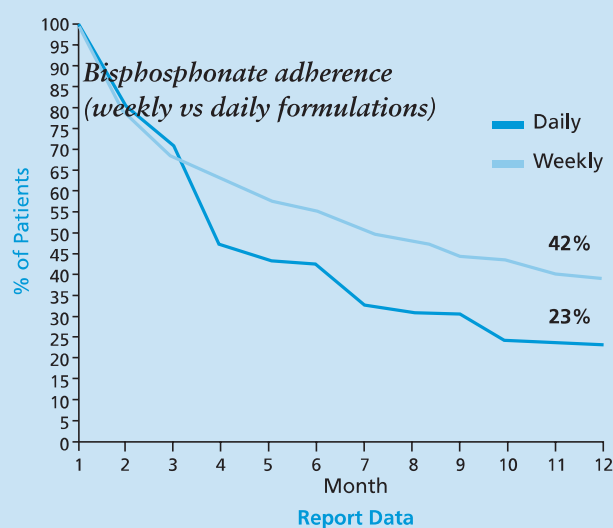
Osteoporosis is a chronic, progressive, mostly asymptomatic disease. The fact that osteoporosis is asymptomatic may mean that patients find it difficult to appreciate that treatment is necessary or understand the benefits. In addition, osteoporosis therapy may take a while to produce noticeable results (i.e. an increase in bone mineral density as monitored by a DEXA scan) which could lead to discontinuation of treatment.

Treatment of osteoporosis with a bisphosphonate can significantly reduce the risk of fracture according to evidence from clinical trials.<sup>8,10,11,12,13</sup> However, the results seen in a trial setting may not apply in a 'real life' situation when poor adherence is taken into account. Many treatments prescribed for osteoporosis (bisphosphonates, SERMs, HRT) are associated with adherence problems. In the case of bisphosphonates, data have shown that nearly 80% of patients on a daily, and almost 60% on a weekly, treatment stop taking medication before the end of a year.<sup>3</sup>

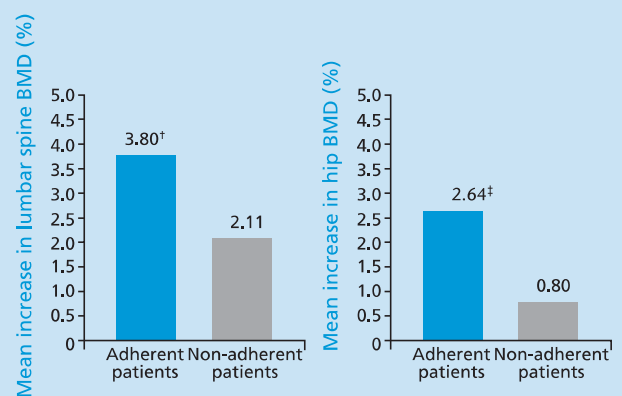
Educating people with osteoporosis about the benefits of staying on a treatment is, therefore, essential. In addition, ensuring treatments are as effective and easy to take as possible should encourage adherence and, ultimately, help prevent more fractures.

In the case of the bisphosphonates, if they are taken incorrectly, or not taken long-term, the patient will not receive the full benefits of the treatment. Analysis of prescribing information in the US has shown that the relative risk of fracture is 26% lower among compliant versus non-compliant patients and 21% lower in persistent versus non-persistent patients.<sup>8</sup> Other studies on the impact of non-adherence to bisphosphonates on long-term treatment effectiveness have shown that patients who use their medication inconsistently do not attain the benefits of bisphosphonate therapy as demonstrated in clinical trials (i.e. improvements in bone mineral density and reduction of fracture risk).<sup>7,8,14</sup>

## Poor adherence leads to reduced bone mineral density (BMD) gains



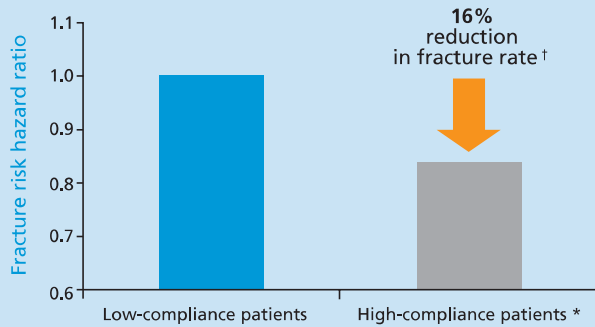
Source: DIN-Link data, ComputerFile Ltd, December 2004



N = 176 previously untreated women with postmenopausal osteoporosis (PMO) receiving estrogen or bisphosphonates  
 Adherent patients: ≥66% compliance;  
 Non-adherent patients: <66% compliance  
 Compliance = number of months of drug therapy  
<sup>†</sup> p < 0.0056; <sup>‡</sup> p < 0.0056;

Data in: Yood RA, et al. Osteoporos Int 2003;14:965-8

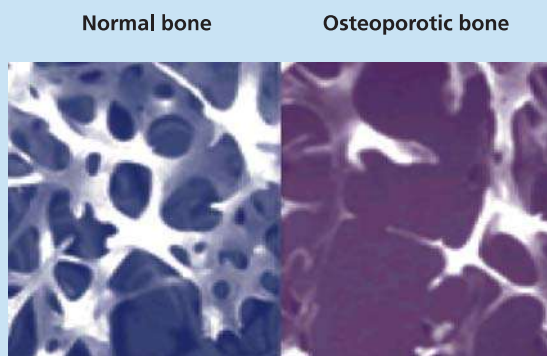
### Good adherence positively impacts on fracture risk



\* High compliance = drug available to cover  $\geq 80\%$  of time  
 †  $p < 0.005$  vs low compliance patients

Data in: Caro J et al. The impact of poor compliance to osteoporosis treatment on risk of fractures in actual practice. *Osteoporosis International*, 2004,14: P277

In addition to prescribed therapy, it is important that any patient with osteoporosis has sufficient daily intake of both calcium and vitamin D. Supplements may be required for the elderly if dietary calcium intake is inadequate and in patients with vitamin D insufficiency. Regular weight-bearing exercise, such as walking, can also help maintain bone mass and improve muscle strength and balance, which may help prevent falls.

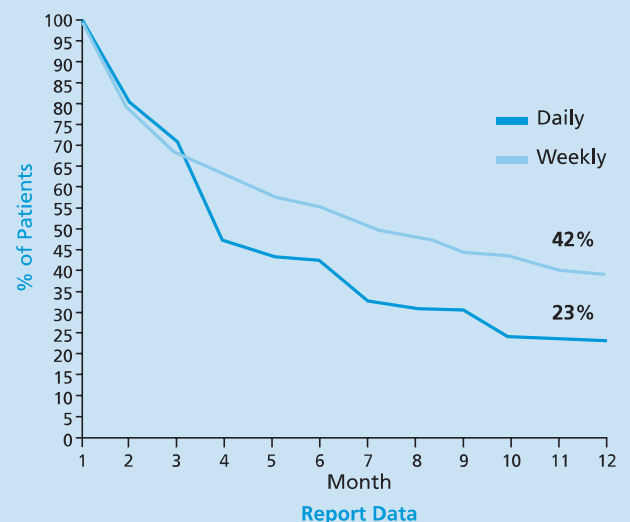


### Staying on therapy

Tight restrictions govern the way bisphosphonates are administered. To improve bio-availability (i.e. to ensure sufficient active drug is absorbed into the system) and to avoid the occurrence of gastrointestinal side effects, bisphosphonates have to be swallowed with plain water on an empty stomach. Patients must take their medication first thing in the morning and eat nothing for at least half an hour afterwards. After swallowing a tablet, patients need to remain in an upright position to ensure the quick transit of the tablet from oesophagus to stomach and avoid oesophageal irritation and the risk of ulceration.

The strict regimen interferes not only with eating and drinking but also with the taking of other medications especially if these need to be taken with food. This may explain why adherence is shown to be better when patients take treatment on a once-weekly basis.<sup>15</sup>

### Bisphosphonate Adherence (weekly vs daily formulations)

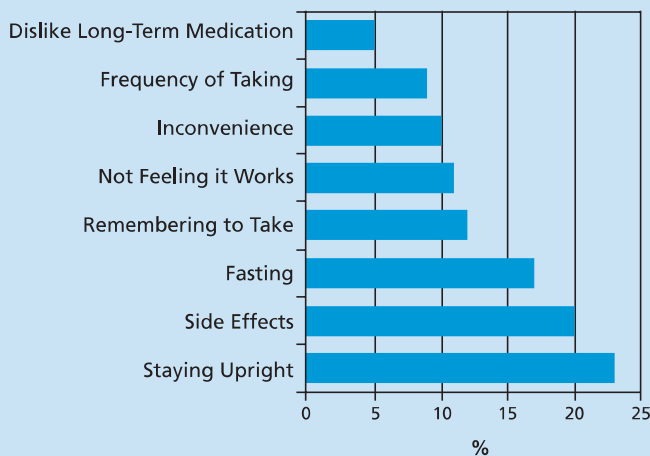


Source: DIN-Link data, ComputerFile Ltd, December 2004



In this survey over a third of women were lapsed bisphosphonate users (i.e. had previously taken a bisphosphonate but had discontinued with this treatment). Some of these had chosen to take calcium or vitamin D supplements, whilst others (15%) were now on no treatment at all.<sup>9</sup> Side effects and inconvenience were the most commonly cited reasons deterring women from staying on therapy with French women reporting the highest side effect rate (41%) compared with 32% overall.<sup>9</sup> Over half of the women in the survey (55%) had experienced drawbacks with bisphosphonates with the most common being having to stay upright.

*Drawbacks associated with bisphosphonates*



Women experiencing drawbacks	Total (n = 275)
Staying upright	23%
Side effects	20%
Fasting	17%
Remembering to take it	12%
Don't feel it works	11%
Inconvenience/hassle	10%
Frequency of taking (NET)	9%
Dislike taking long-term medication	5%

NB. Some women stated more than one drawback



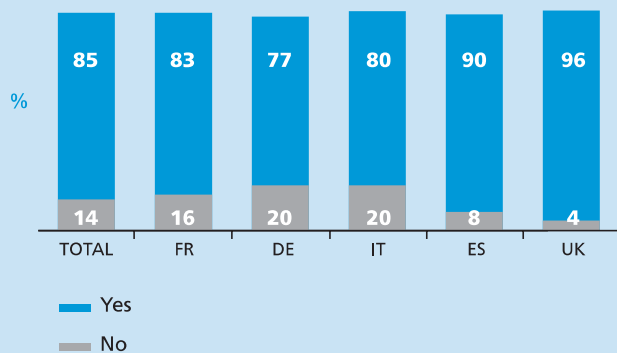
**An open doctor-patient relationship is essential to ensuring good adherence to therapy**

However, 'lack of understanding' on the part of the patient was the reason most often cited by physicians (12%) for why patients might discontinue treatment.<sup>9</sup> Interestingly, although 85% of physicians reported having had a patient discontinue therapy, 71% acknowledged that they did not know why their patients had discontinued with treatment.<sup>9</sup> A real opportunity presents itself here for an improvement in communication between patients and physicians. If physicians understand why women are discontinuing treatment they may be able to find ways of helping them to stay on therapy.

*“If we can truly understand the needs of the patients and the reasons they are stopping their medication we will be in a much better position to help them continue on treatment and avoid fracture”*

Professor Jean-Yves Reginster  
Professor of Epidemiology, Public Health and  
Health Economics, University of Liege, Belgium

### Number of physicians who have had a patient discontinue treatment<sup>9</sup>



More than half of physicians (56%) have actually told a patient to discontinue their bisphosphonate treatment - in the majority of cases (85%) this was because of side effects, largely gastro-intestinal (GI).<sup>9</sup>

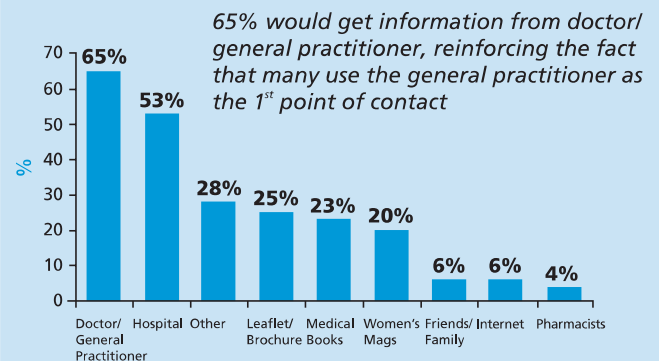
The majority of women experienced drawbacks when taking current therapies with the biggest being the need to remain upright afterwards (13%), followed by side effects (11%) and the need to fast before and after taking treatment (9%).<sup>9</sup>

More than 70% of women prescribed bisphosphonates were taking other prescribed medicines with most taking three or more.<sup>9</sup> British women took most with an average of 5 or more.<sup>9</sup> Women were much more likely to stop osteoporosis treatment than their other medications,<sup>9</sup> which may indicate that osteoporosis is considered to be less serious than other conditions.

### Advice about treatment

Women in the survey had primarily obtained information about the disease from their physicians, to whom they turned for advice and diagnosis, rather than from leaflets or women's magazines, family or friends.<sup>9</sup> This emphasises the important role physicians have to play in terms of educating patients and providing support.

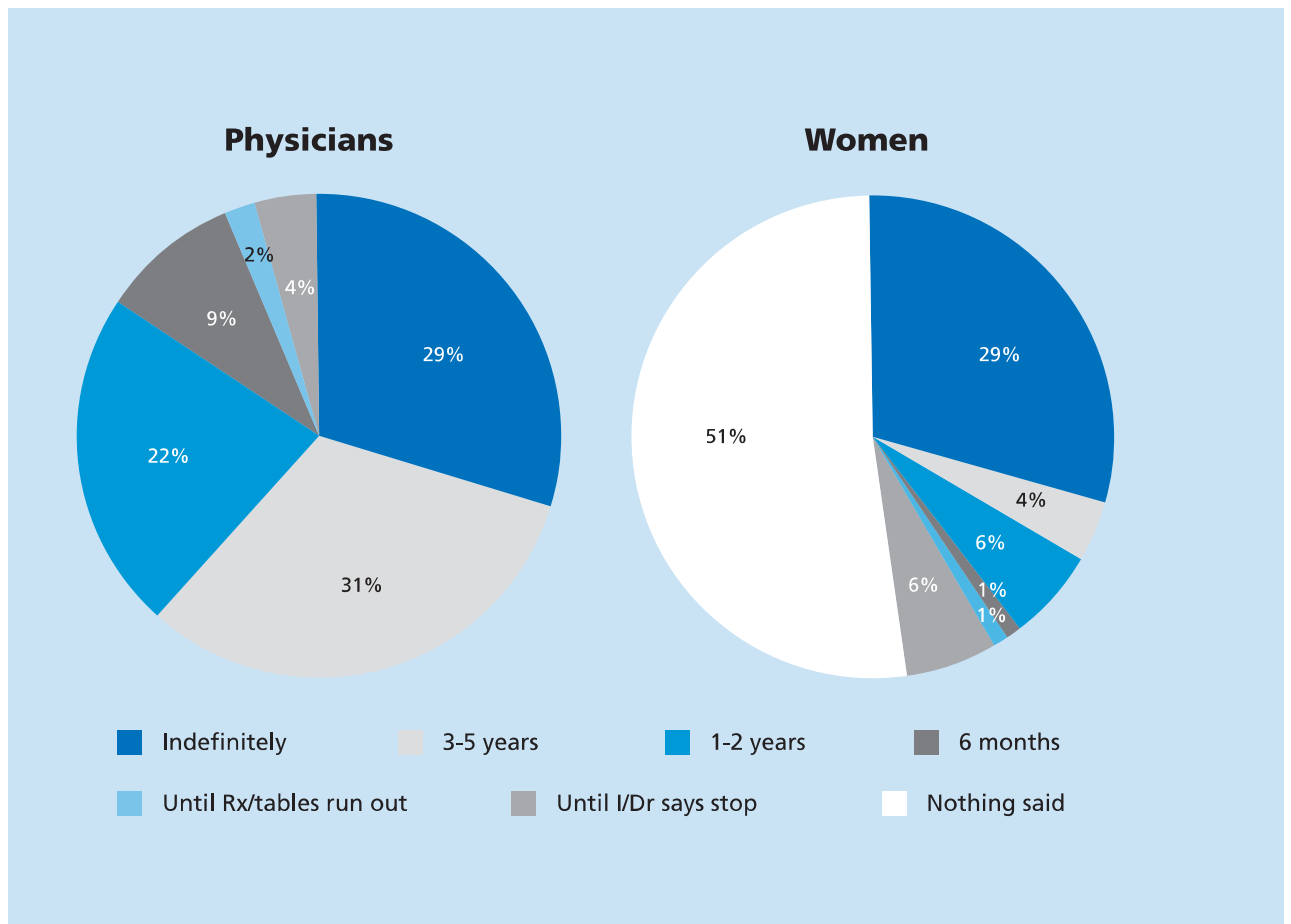
### Popular sources of information for women with osteoporosis<sup>9</sup>



Almost all physicians (97%) had initiated discussions about osteoporosis with their patients, although 80% reported that women themselves were initiating more discussions than in previous times,<sup>9</sup> perhaps because of increased awareness of this disease. The fact that women feel motivated to raise the topic indicates that they are becoming more aware of the need to protect their own health, something that physicians can capitalise on in terms of encouraging patients to adhere to treatment.

The survey highlighted some evidence of confusion about how long women should expect to remain on therapy. Just under half (49%) of women in the survey reported that they had been told how long they should take their treatment, ranging from 34% in the UK to 70% in Italy.<sup>9</sup> Some women thought they need only remain on therapy until their present course was finished. However, most physicians (60%) reported that they had told patients they should continue with treatment for three to five years or indefinitely.<sup>9</sup> The survey would seem to indicate that although physicians are advising patients to stay on therapy long-term, patients do not currently understand the significance of this point. Given the importance of staying on treatment in terms of successful prevention of fractures, it is essential that this message gets through.

*Length of time physicians advise patients to stay on treatment vs. length of time women recall being told to take medication<sup>9</sup>*



- A third of physicians report that they have explained the risks of osteoporosis to their patients<sup>9</sup>
- 99% of doctors recognise the importance of patients staying on bisphosphonate treatment for at least one year<sup>9</sup>
- 60% of doctors say they advise patients to take osteoporosis medication for more than three years, with 29% recommending it indefinitely<sup>9</sup>



This picture shows a patient having a DEXA scan, which measures bone mineral density and is a key way to diagnose and monitor osteoporosis. Poor adherence to treatment could lead to reduced bone mineral density and increased risk of fracture.

“Strong communication between patient and physician is so important in ensuring that people with osteoporosis get the treatment they deserve. This report has highlighted some areas in which changes could be made to improve understanding between the two parties and I would encourage this.”

Frau Dr Jutta Semler  
President, Kuratorium Knochengesundheit e.V.  
German Patient Society

“Osteoporosis is a serious and widespread disease affecting women and men all over the world. As the report suggests, we need to ensure people with osteoporosis are diagnosed early, given the right kind of advice and encouraged to stay on their chosen treatment.”

Professor Thierry Thomas  
Secretary, Groupe de Recherche et d'Information  
sur les Osteoporoses  
French Patient Society

It is disappointing, given that so many women in this survey (90%) acknowledge the seriousness of osteoporosis,<sup>9</sup> that a considerable number of patients discontinue bisphosphonate treatment at a relatively early stage.

Side effects and restrictions around how medication must be taken were the main drawbacks associated with treatment by the women in the survey, with 'staying upright' cited as the biggest inconvenience.<sup>9</sup>

Reassuringly, the majority of women in this survey said they would not consider stopping treatment without first discussing it with their physician,<sup>9</sup> which further highlights the important role physicians have to play in encouraging women to stay on therapy. The findings below highlight some areas where patients may benefit from education:

#### *The Patient Viewpoint:*

- Over a quarter of the women (27%) in the survey felt their risk of fracture was the same regardless of whether they took their treatment or not<sup>9</sup>
- Twenty percent of women were unaware of treatment benefits<sup>9</sup>
- A further 17% did not believe their treatment had any benefit at all<sup>9</sup>

Physicians in this survey were under the impression non-adherence was due to a lack of understanding on the part of the patients, even though patients reported side-effects and convenience-related factors as the main reasons they stopped treatment. This may indicate the need for stronger communication between physicians and their osteoporosis patients.

Physicians are aware that there is a level of dissatisfaction with current treatment among patients and 83% see a need for improvement in current osteoporosis treatments if disease management is to be effective.<sup>9</sup>

#### *Motivating patients to stay on therapy*

Nine out of ten patients surveyed acknowledged that osteoporosis is a serious disease as did almost the same proportion of physicians (88%).<sup>9</sup>

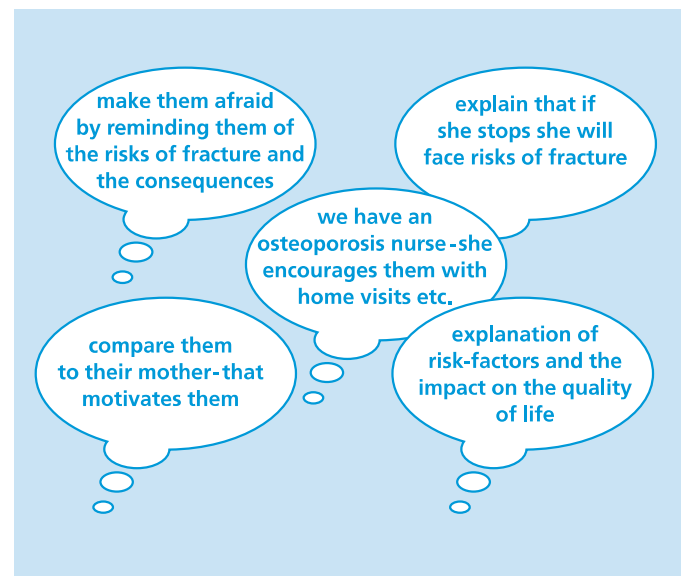
Despite agreeing on this point, there still seem to be some gaps in understanding between patients and physicians.

Physicians are aware that a large proportion of their patients discontinue treatment, however...

- 71% reported that they did not know why patients stopped therapy<sup>9</sup>
- The vast majority of physicians (86%) were unsure about how best to motivate patients to continue their medication<sup>9</sup>
- 41% had attempted to motivate their patients by stressing the possibility of risks and complications<sup>9</sup>

However, interviews with the women in the survey reveal that negative motivators may not necessarily be the best approach, as what motivated women most was knowing that they were doing something to help themselves.<sup>9</sup>

*When prompted to give further detail about their motivational tactics the following comments were made by doctors:*



**What motivated women to stay on their therapy most of all was knowing that they were doing something to help themselves<sup>9</sup>**

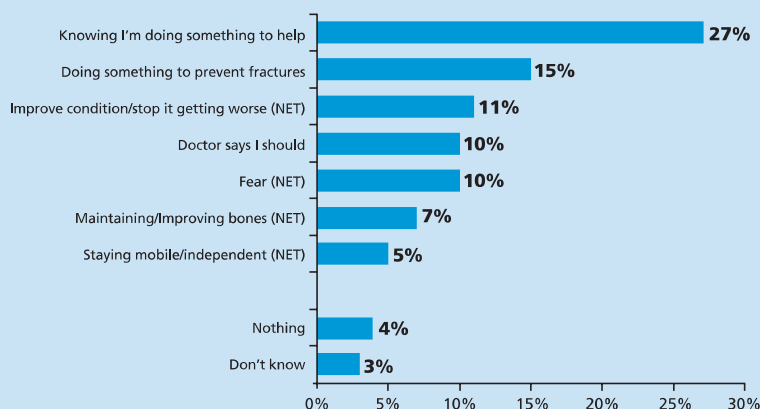
This would seem to point towards the need to positively encourage patients by highlighting the benefits of treatment rather than making them afraid of the negative consequences of non-adherence.

*“The women in this survey would appear to want to take a motivated and positive outlook towards treatment. If we approach them in a way that they relate to we can help ensure that they stick with therapy on an ongoing basis”*

**Frau Dr Jutta Semler**

President, Kuratorium Knochengesundheit e.V.  
German Patient Society

#### *Factors motivating women to stay on their osteoporosis treatment<sup>9</sup>*



NB: The remaining 8% cited reasons such as not wanting to suffer like a family member, not wanting to be disabled and the need to take it.

Half of the osteoporosis patients in the survey reported forgetting to take their treatment at times. When asked about what measures might prompt patients to take their treatment, the following response was given by the physicians:

#### *The Physician Viewpoint:*

- Approximately half (45%) supported the idea of calendars<sup>9</sup>
- 53% felt that reminder stickers would serve as a useful prompt<sup>9</sup>

- Exactly half favoured reminders being sent by postcard, e-mail or text message<sup>9</sup>
- Support was shown by more physicians (70%) for conducting audits and clinics to identify particular patients not adhering.<sup>9</sup> This would enable them to target those requiring education more effectively

Lack of feedback on how treatment is improving bone density may also help explain the lack of patient adherence. Knowing that the treatment is working may help motivate patients to stay on medication - however, in this survey 40% overall (and 63% in the UK) didn't know if treatment was working or not.<sup>9</sup> German patients were more satisfied with their treatment and 84% said they knew it was working.<sup>9</sup> Only 17% of Spanish patients felt they knew a lot about the disease.<sup>9</sup>

**For all the advice they received concerning the benefits of treatment, overall, 27% of women thought their risk of fracture was the same regardless of whether or not they were taking osteoporosis medication<sup>9</sup>**

There was a difference of opinion between women and physicians about the best means of motivating women to stay on therapy long-term. Of those patients who had talked to their physician about stopping treatment 39% overall, (and 50% in the UK) had been persuaded to continue.<sup>9</sup> With the right sort of support and motivation for patients, physicians might be able to increase these numbers - perhaps by using a combination of regular audits, reminder tools and clear, positive communication that effectively relates to women's priorities.

**Reducing the dosing frequency**

The survey revealed that, although bisphosphonates are widely used, a certain level of dissatisfaction currently exists. Seventy-four percent of the physicians in the survey were dissatisfied to some extent with the frequency with which patients took treatment.<sup>9</sup> Dissatisfaction ranged from 60% in Spain to 89% in the UK.<sup>9</sup> Having to take medication less often was one of the first things women suggested as a solution to improve adherence.<sup>9</sup>

Less frequent dosing emerged as a popular option as a means of improving adherence to treatment.

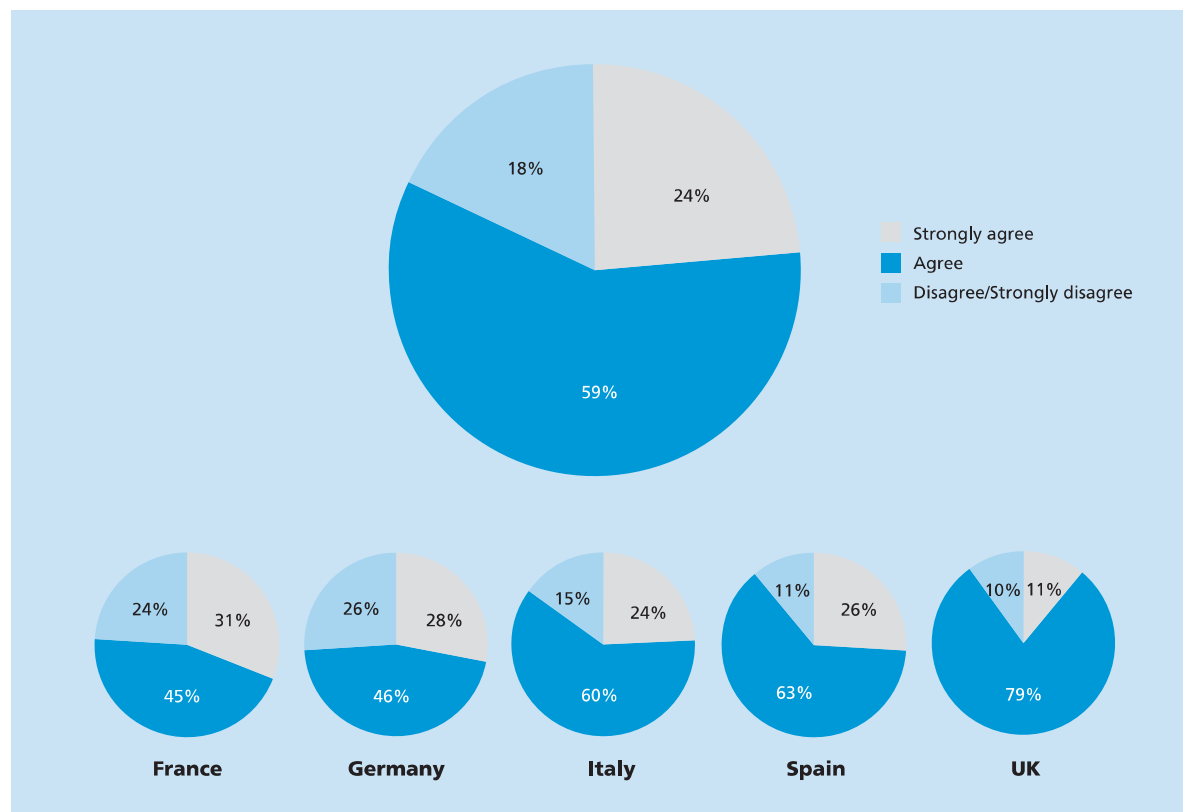
- Three quarters of physicians think reducing the dosing frequency would have a strong influence on patients continuing treatment (with only 7% believing it would have no influence at all)<sup>9</sup>

This could be because less frequent dosing has the potential to reduce both the inconvenience surrounding current dosing regimens and the frequency of side effects.

- 78% overall, and 94% of UK physicians, were not completely satisfied with the level of treatment acceptability to patients<sup>9</sup>
- 83% saw a need for improvement in osteoporosis treatments<sup>9</sup>

Reduced side effects and having to take medication less often were the first two things women suggested as factors that would improve adherence<sup>9</sup>

*Number of physicians who agreed that improvements in treatment are needed if the disease is to be effectively managed<sup>9</sup>*





# Key Findings By Country

*7 out of 10 physicians questioned admit to not knowing why so many patients spontaneously stop taking their bisphosphonate medication<sup>9</sup>*

France	–	64%
Germany	–	81%
Italy	–	61%
Spain	–	51%
UK	–	98%

*60% of physicians believe that bisphosphonate treatment should last either indefinitely or for between 3 and 5 years<sup>9</sup>*

France	–	Indefinitely: 11%	3-5yrs: 44%
Germany	–	Indefinitely: 15%	3-5yrs: 49%
Italy	–	Indefinitely: 31%	3-5yrs: 16%
Spain	–	Indefinitely: 19%	3-5yrs: 21%
UK	–	Indefinitely: 70%	3-5yrs: 24%

*...and yet 51 % of patients said that they were not told for how long they should continue their medication<sup>9</sup>*

France	–	56%
Germany	–	55%
Italy	–	29%
Spain	–	48%
UK	–	66%

*9 out of 10 patients surveyed acknowledged that osteoporosis is a serious disease<sup>9</sup>*

France	–	89%
Germany	–	95%
Italy	–	95%
Spain	–	79%
UK	–	91%

*...along with a similar proportion of physicians<sup>9</sup>*

France	–	78%
Germany	–	95%
Italy	–	96%
Spain	–	79%
UK	–	93%

*Three-fifths of patients questioned felt that focusing on the positive outcomes of treatment provided the greatest motivation for continuing their therapy<sup>9</sup>*

France	–	49%
Germany	–	65%
Italy	–	70%
Spain	–	71%
UK	–	67%



*41% of physicians believe the best way to motivate patients to continue on treatment is to explain to or remind them about the risks and complications of fracture if they abandon treatment<sup>9</sup>*

France	–	45%
Germany	–	29%
Italy	–	46%
Spain	–	40%
UK	–	46%

*Three-quarters of physicians felt that altering the dosing frequency would have a strong influence on adherence because of the greater convenience it would offer<sup>9</sup>*

France	–	73%
Germany	–	84%
Italy	–	49%
Spain	–	80%
UK	–	87%

# A Vision For The Future

## Moving forwards – the future for osteoporosis patients

Over the last twenty years the field has witnessed great improvements in the diagnosis and treatment of postmenopausal osteoporosis. However, there is still much to accomplish to ensure that our patients have access to the appropriate services for diagnosis and to effective fracture prevention therapies.

As the population ages the problems of osteoporosis will increase and, in order to make an impact on the total burden of this debilitating and crippling disease, we need to maximise the tools available to us, e.g. wide and open access to diagnosis and screening facilities and open access to fully reimbursed therapy options. We also need to better understand the issues underpinning adherence so that we use our healthcare funds wisely and effectively.

In the immediate future we expect to see the advent of therapies which require less frequent dosing, which we believe will be more acceptable to our patients and which, consequently, should do a better job in protecting them.

As physicians we understand that our patients must stay on their therapy longterm in order to achieve effective fracture risk reductions. However, this survey shows that while women are being diagnosed, and do receive initial treatment for osteoporosis, there is a lack of understanding about why women are not staying on therapy. Given that around 60% of osteoporosis patients do not stay on their bisphosphonate medication, this could have potentially serious consequences in terms of disease management. We know from the survey that women understand the seriousness of the disease and have a desire to help themselves. It is, therefore, important that we use the right kind of language and approach to provide the encouragement these women need.

Organisations like the IOF and affiliated local osteoporosis groups have worked hard to raise awareness of osteoporosis and this survey shows that women are better informed about the disease and the benefits of treatment. In other areas of healthcare, such as breast cancer, women have demonstrated that they can secure much needed improvements in health services and they are not afraid to ask for them.

Already women in some European countries are lobbying for DEXA screening programmes and, as health care professionals, we must offer our appropriate support. Over three quarters of physicians (77%) in this survey reported that screening for osteoporosis in their country was not sufficiently widespread.

This survey has shown that women are likely to seek the advice of their physician and we need to ensure that we use this opportunity to encourage and support people with osteoporosis. Early identification of the disease, better communication and instigation of effective treatment are the key to preserving bone health and ensuring patients live a long, healthy and active life.

### Professor Jean-Yves Reginster

Professor of Epidemiology, Public Health and Health Economics, University of Liege, Belgium  
IOF General Secretary

## APPENDIX: DISEASE BACKGROUND &amp; IMPACT

# Osteoporosis: What It Means

## *More about osteoporosis*

Osteoporosis is a common chronic condition among older people and its prevalence is rising as the world population ages. Almost all physicians (88%) and patients (90%) in the survey rightly see it as a serious condition.<sup>9</sup> But its occurrence is not an inevitable accompaniment to old age, a position supported by 40% of physicians in this survey.<sup>9</sup>

Since 1994 osteoporosis has been officially classified by the World Health Organisation (WHO) as "a disease characterised by low bone mass and micro-architectural deterioration of bone tissue, leading to enhanced bone fragility and a consequent increase in fracture risk."<sup>16</sup>

## *Diagnosis*

The three main sites of fracture are the wrist, hip and spine. When fractures occur at these sites, or patients start to lose height, osteoporosis is a strong suspect as the cause.

Most women suffering from osteoporosis will suffer pain or fractures that require medical intervention, advice and treatment. In many cases physicians will have discussed the condition and ways of preventing it as women reach the menopause, or soon after. In the survey over 60% of physicians said they raised the subject in this way.<sup>9</sup> Information provided was largely to do with medical treatment options rather than diet, exercise or lifestyle advice.<sup>9</sup>

Usually, osteoporosis is diagnosed following a bone mineral density (BMD) assessment conducted using a painless and non-invasive scan (DEXA Scan). According to WHO criteria, osteoporosis is present when an individual's bone mineral density is more than 2.5 standard deviations from the average bone mineral density of healthy young people.<sup>16</sup> One standard deviation represents a 10-12% decrease in bone mineral density.<sup>17</sup>

Scans are widely available in Europe, though not necessarily reimbursed, and most women in the survey, although not all, had received one.<sup>9</sup> Women from the United Kingdom had the lowest scan rates (69%) and Germany the highest (84%).<sup>9</sup>

## *Risk factors for osteoporosis*

Osteoporosis is a complex disease and its aetiology is uncertain. However, certain risk factors are associated with its development including:

- Being female (eight out of ten sufferers are women, with postmenopausal women affected most frequently)
- Advanced age
- Oestrogen deficiency (e.g. following menopause in women)
- Personal history of fracture as an adult
- Caucasian race (although all ethnic groups are affected to a greater or lesser extent)
- Low body weight and body mass index
- Family history of osteoporosis
- Smoking
- Alcoholism
- Chronic use of corticosteroids
- Low testosterone in men

## *Symptoms and outcomes*

Osteoporosis is often a silent disease with the first symptoms occurring at the time of fracture. Developing osteoporosis can restrict activity from its onset. About two-thirds of women in the survey reported some impact, although they experienced this in different ways. After fracture, the impact is obviously much greater. Not only do fractures account for most of the disability associated with osteoporosis but they also result in substantial costs for hospital or nursing home care.

From the age of 50, Caucasian women have a 40% lifetime risk of fracturing their spine, hip or distal forearm.<sup>18</sup> Spinal fractures are more common, leading to height loss and kyphosis (curvature of the spine, the so-called Dowager's hump). Hip fractures are also common and can prove extremely disabling, with many women never regaining mobility and independence. Even more worryingly, around a third of patients who suffer a hip fracture die within a year.<sup>2</sup>

# Further Information

## International Osteoporosis Foundation

<http://www.osteofound.org>

Please contact the IOF to find an osteoporosis patient society in your country.

## Contact details for osteoporosis organisations in each country:

### United Kingdom

*National Osteoporosis Society*

<http://www.nos.org.uk>

### Italy

*Lega Italiana Osteoporosi*

<http://www.lios.it>

### Spain

*AECOS (Asociación Española contra la Osteoporosis)*

<http://www.aecos.es/default.cfm>

### Germany

*Kuratorium Knochengesundheit e.V.*

<http://www.osteoporose.org/>

### France

*Groupe de Recherche et d'Information sur les Osteoporoses*

<http://www.grio.org>

The International Osteoporosis Foundation (IOF) is a worldwide organization dedicated to the fight against osteoporosis. It brings together scientists, physicians, patient societies and corporate partners. Working with its 170 member societies in 84 locations, and other healthcare-related organizations around the world, IOF encourages awareness and prevention, early detection and improved treatment of osteoporosis.

Osteoporosis, in which the bones become porous and break easily, is one of the world's most common and debilitating diseases. The result: pain, loss of movement, inability to perform daily chores, and in many cases, death. One out of three women over 50 will experience osteoporotic fractures, as will one out of five men. Unfortunately, screening for people at risk is far from being a standard practice. Osteoporosis can, to a certain extent, be prevented, it can be easily diagnosed and effective treatments are available.

Find out if you are at risk, take the IOF One Minute Risk Test at: [www.osteofound.org](http://www.osteofound.org)

## Glossary of terms

### *Adherence*

The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes - corresponds with agreed recommendations from a healthcare provider.

### *Administration*

The way in which a medication is given. For example, orally in tablet form or by intravenous infusion.

### *Bioavailability*

The degree to which a treatment is absorbed or becomes available at the site of physiological activity after administration.

### *Bisphosphonates*

Non-hormonal drugs, which help maintain or increase bone density and reduce fracture rates by slowing bone turnover. They inhibit bone resorption, increasing bone mineral density levels by slowing down or stopping the action of osteoclasts.

### *Bone Mass*

The total amount of bone tissue in the skeleton.

### *Bone Mineral Density*

A measure that is used to describe how solid bones are.

### *Compliance*

The extent to which a patient, when taking a drug, complies with the clinician's advice and follows the treatment regimen.

### *Fracture*

A sudden break of a bone which occurs when the internal stress produced by load exceeds the limits of strength.

### *Hormone Replacement Therapy (HRT)*

Oestrogen replacement for women going through the menopause, which helps maintain bone density and reduce fracture rates for the duration of therapy.

### *Persistence*

The time a patient stays on therapy, from initiation of treatment to completion/discontinuation of treatment.

### *Post-Dose Fast*

A period of time after administration of a specific treatment, when a patient must not eat or drink anything except water in order to ensure optimum bioavailability of that treatment.

### *Selective Estrogen Receptor Modulators (SERMs)*

Drugs which act in a similar way to oestrogen on the bone, helping to maintain bone density and reduce fracture rates, specifically at the spine.

### *Treatment Regimen*

A formalised and prescribed method of administering a treatment that describes the types of drugs, their doses, how they are given, and how often they are given to the patient.

## References:

1. International Osteoporosis Foundation (on behalf of the European Parliament Osteoporosis Interest Group and EU Osteoporosis Consultation Panel). Osteoporosis in Europe: Indicators of Progress. February 2005
2. Keene GS et al. Mortality and morbidity after hip fractures. *British Medical Journal* 1993; 307: 1248-50
3. DIN-LINK data, CompuFile Ltd, December 2003. NB: Patients are excluded from the analysis at the point where they stop taking therapy altogether or have failed to comply fully
4. Åkesson K et al. Patient Preference for Once-Monthly Over Once-Weekly Bisphosphonate Treatments. Abstract presented at Fifth European Congress on Clinical & Economic Aspects of Osteoporosis & Osteoarthritis (ECCEO), Rome, 16 – 19 March 2005
5. Finigan J et al. Adherence to osteoporosis therapies. *Osteoporosis International* 2001; 12: S48-S49. Abstract P110
6. Eastell R et al. Influence of patient compliance with risedronate therapy on bone turnover marker and bone mineral density response: the IMPACT study. *Calcif Tissue Int* 2003; 72: Abstract P297
7. Caro J et al. The impact of poor compliance to osteoporosis treatment on risk of fractures in actual practice. *Osteoporosis International* 2004; 14: P277
8. Ethel S, Siris MD et al. Adherence to bisphosphonate therapy: relationship to bone fractures at 24 months in women with postmenopausal osteoporosis. Abstract 397 presented at Sixth International Symposium on Osteoporosis, National Osteoporosis Foundation, Washington DC, 7 April 2005
9. IPSOS Health, European Survey of Physicians and Women with Osteoporosis, January – April 2005. Sponsored by Roche/GSK
10. Adami S and Viapiana O. Ibandronate: New options in the treatment of osteoporosis. *Drugs of Today* 2003; 39 (11): 877-86
11. Chesnut III CH et al. Effects of oral ibandronate administered daily or intermittently on fracture risk in postmenopausal osteoporosis. *J Bone Miner Res* 2004; 19 (8): 1241-49
12. Black DM, Cummings SR, Karpf DB, et al. Randomised trial of effect of alendronate on risk of fracture in women with existing vertebral fractures. *Lancet* 1996; 348: 1535-41.
13. Harris ST, Watts NB, Genant HK et al. Effects of risedronate treatment on vertebral and nonvertebral fractures in women with postmenopausal osteoporosis: a randomized, controlled trial. *JAMA* 1999; 282(14): 1344-52.
14. Sebaldt RJ et al. Impact of non-compliance and non-persistence with daily-regimen bisphosphonates on longer-term effectiveness outcomes in patients with osteoporosis. Poster M423 presented at 26th Annual Meeting of the American Society for Bone Mineral Research, Seattle, 1-5 October 2004
15. Cramer JA et al. Bisphosphonate Dosing Regimen Influences Treatment Adherence in Postmenopausal Women. Abstract presented at Fifth European Congress on Clinical & Economic Aspects of Osteoporosis & Osteoarthritis (ECCEO), Rome, 16 – 19 March 2005
16. WHO 1994 Technical Series 843. Report of World Health Organization Study Group. Assessment of fracture risk and its application to screening for postmenopausal osteoporosis.
17. National Osteoporosis Foundation: BMD Testing, What the numbers mean. <http://www.nof.org/osteoporosis/bmdtest.htm> (Last accessed May 2005)
18. Riggs BL and Melton LJ. The worldwide problem of osteoporosis: insights afforded by epidemiology. *Bone* 1995; 17 (5) Supplement 505S – 511S



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