

This report was developed in collaboration with the IOF, MWIA, Reader's Digest and Osteoporosis Canada  
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# Timeless Women

The Campaign for Stronger Bones




Osteoporosis Canada

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# Introduction from Ursula Andress



Ursula Andress ®

**O**steoporosis is a 'silent thief' that can steal your bones' 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.

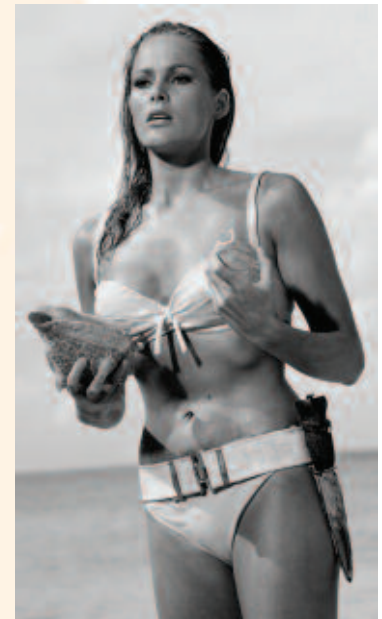
Like a lot of people, I knew very little about osteoporosis before I was diagnosed. When I found out I was shocked and refused to believe it! As far as I was concerned, osteoporosis was not for someone like me, a former Bond girl who travelled, swam, walked miles every day - and had a big garden to look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

Ursula Andress



Ursula Andress as Honey Ryder  
in *Dr No*, 1962 ®

# Uncovering the Truth



## Known as the **silent epidemic**<sup>1</sup>

osteoporosis is a global health concern affecting 200 million men and women worldwide<sup>2</sup>.

**1** out of **3**

women over the age of 50 will break a bone (fracture) because of osteoporosis<sup>3</sup>, and nearly one out of four men and women over 50 who have suffered a hip fracture will die within a year<sup>4</sup>.

In Canada

**1** out of **4**

women has osteoporosis<sup>5</sup>.

**2** million

Canadians may be at risk of osteoporotic fractures<sup>5</sup>.

**1** out of **4**

men and women who fracture a hip will die in less than a year<sup>6</sup>.

Loss of function and independence among post-fracture patients

is profound. **25%** of hip fracture patients in Canada who survive for one year still cannot walk without assistance<sup>5</sup>. This makes diagnosis and treatment even more critical.



**T**hese 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 condition.

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, Osteoporosis Canada, 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 fullest.

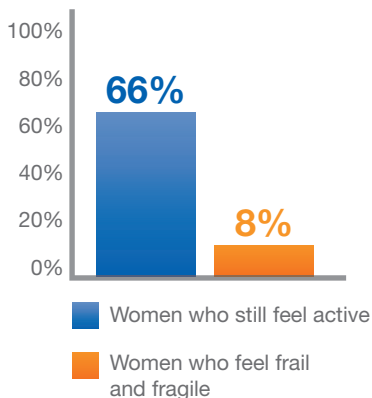
# The Situation at a Glance



**T**he 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 Feel About Themselves:

- ▶ Less than one out of ten women describe themselves as 'frail and fragile'.
- ▶ More than four out of five women say that osteoporosis has not prevented them from participating in day-to-day activities; in fact 66% describe themselves as still being fairly or very active.



## How Doctors Feel About Women with Osteoporosis:

- ▶ Six out of ten doctors describe women with osteoporosis as 'frail and fragile'.
- ▶ More than half of the doctors surveyed feel that osteoporosis prevents women from participating in everyday activities (e.g. socializing, going shopping, etc.).

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

Women may not always get the treatment they need:

## How does this affect women?

- ▶ In the survey, nearly all doctors think their patient has missed a treatment dose, citing 'simply forgetting' as the most common reason.
- ▶ In fact, more than two out of five women with osteoporosis reported having missed a treatment dose.

## 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.

These surveys were carried out between October 2008 and February 2009 by independent research company Harris/Decima. 503 surveys were conducted with Canadian women with osteoporosis 50 years or older from Harris/Decima's online panel. 91 surveys were conducted by telephone with Canadian physicians who treat women 55 years of age or over with osteoporosis.





# Facts about the 'Silent Epidemic'

## 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<sup>8</sup>.
- ▶ 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<sup>9</sup>.
- ▶ Although osteoporosis affects both men and women, it is more common in postmenopausal women because they have reduced levels of estrogen, a hormone which is important for maintaining strong bones<sup>9</sup>.
- ▶ 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<sup>10</sup>.
- ▶ 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<sup>11</sup>.

## 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.

## How Many People are Affected by Osteoporosis?

- ▶ It is estimated that over 200 million women and men worldwide suffer from osteoporosis<sup>2</sup>.
- ▶ 2 million Canadians may be at risk of osteoporotic fractures during their lifetime<sup>5</sup>.

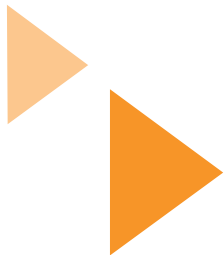
- ▶ One out of six North American women over the age of 50 will suffer a fracture because of osteoporosis<sup>19</sup>.
- ▶ One out of five women and men over 50 who have a hip fracture will die within a year because of its consequences<sup>4</sup>.
- ▶ In Europe and the US<sup>2</sup>, it is estimated 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<sup>12</sup>.
- ▶ In Canada, one in four women over the age of 50 has osteoporosis<sup>5</sup>.

## How is Osteoporosis Diagnosed?

- ▶ If a doctor thinks their patient has osteoporosis, they will recommend a test called dual x-ray absorptiometry (DXA or DEXA for short) to measure her bone mineral density (BMD).



- ▶ BMD is a measure of the bone mineral content at a specific site, divided by the area measured<sup>13</sup>:
  - Above -1 is considered normal;
  - Between -1 and -2.5 means the woman could have osteopenia (low bone density), a condition that may lead to osteoporosis;
  - Below -2.5 indicates a person has osteoporosis.
- ▶ 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 testing is the only medical diagnostic tool to confirm osteoporosis. However, several other skeletal and non-skeletal risk factors should be considered when assessing the fracture probability, such as age, gender, fracture history and steroid use.



## Did You Know?

- ▶ Osteoporosis literally means 'porous bone'<sup>18</sup>.
- ▶ The term osteoporosis was first coined in the 1820s in France<sup>14</sup>.
- ▶ International figures with osteoporosis include Ursula Andress, Joan Rivers, and Britt Ekland.

## 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<sup>7</sup>.
- ▶ Studies have shown that, depending on the treatment and the woman, the risk of fractures can be reduced by 16-70%<sup>6</sup>.
- ▶ In addition to treatment, women with osteoporosis should ensure they take vitamin D and calcium, as these are important supplements for bone health<sup>6</sup>.
- ▶ 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.

- ▶ It is a common myth that osteoporosis is an 'old woman'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<sup>15</sup>.



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“A diagnosis of osteoporosis does not mean one has to give up an active and enjoyable lifestyle and become sedentary and isolated. Osteoporosis was not going to control my life. I was going to control my osteoporosis. I took my diagnosis as a challenge to find out more about the condition and how to live with it.”

Cherylle Unryn, Manitoba

# Timeless Women: Real life



## What kind of women are we talking about? What do mature women today expect from life?

**T**oday, 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<sup>16</sup>.

**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<sup>17</sup> and involved in voluntary work<sup>16</sup>, 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 followed. 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 life. They refuse to give up their current lifestyle, 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 lifestyles 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'<sup>7</sup>.

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



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"I tried several treatment options before settling on one that works for me, so I know my bones are protected. Thus, I'm feeling quite optimistic about my future. While I need to take more care in the activities I do, I'm still very busy and am enjoying life."

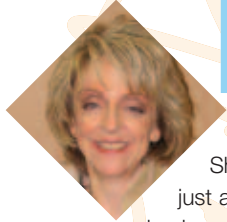
Danielle Mercier-Benoit, Montreal



# Living with Osteoporosis



## The story of Christine Thomas from Ottawa



**F**or the first year of her daughter's life, Christine Thomas didn't pick her up. She couldn't. It began just after she and her husband brought their

newborn home: "I was bending over the crib to pick her up to change her," says Christine. "I felt something, and then nearly passed out from the excruciating pain." It took months before she discovered the cause – spinal fractures caused by osteoporosis. Only 42, Christine had just come through a difficult pregnancy that required her to take a blood thinning medication and spend several months confined to bed rest. Both contribute to bone loss, and Christine is also small-boned with a family history of osteoporosis. Looking back, she realizes, "I was an accident waiting to happen." Still, it took many months of doctors' appointments, tests and a hospital stay before the diagnosis was confirmed.

"Part of me was relieved because I had a diagnosis," she says. "At the same time I was shocked because I was so young."

Her specialist told her she could not lift her daughter for a year because her risk of re-fracturing was too high. She and her husband had to hire a nanny to care for both

Thomas and her daughter. The emotional toll was high and Christine struggled with depression. "I felt like I was on the sidelines," she says. "It was really, really difficult." And then there was the pain caused by the fractures, even after they healed. "The two years after my daughter was born are a blur," she says, "because I spent most of it trying to manage excruciating pain."

In the years since, she has learned to cope with the realities of the disease. She remains on osteoporosis medication and adapts all her movements to reduce the chance of another fracture. Even her daughter, now seven years old, learned long ago to crawl into her mother's lap rather than reach to be picked up.

"The pain comes and goes," Christine says. "I go for periods now where I find it much better, but I have to be cautious and conscious of what I'm doing. Even putting dishes in the dishwasher, laundry in the washer, leaning over to put something in the fridge – you know the proper motions, but it's difficult to do them."

Her experience has made Christine a strong osteoporosis advocate. Now Chair of the Ottawa Chapter of Osteoporosis Canada, she wants to see more energy and resources devoted to educating individuals,

health professionals and policymakers on the need to prevent osteoporosis and the fractures it causes. That includes ensuring access to medication for individuals who need it.

"Compared to the cost of fractures," she says, "it's pennies to be paying for prevention."



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# Inside the Hearts and Minds of Women with Osteoporosis



## Who is today's woman with osteoporosis and what does her disease mean to her?

From the survey, it is clear that today's 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. Nearly half of women surveyed chose not to limit activity to avoid breaking a bone<sup>7</sup>.

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 more than half of women surveyed concerned with becoming dependent on others and two-thirds concerned with not being able to do normal day-to-day activities<sup>7</sup>.

Two-thirds of women with osteoporosis surveyed are also concerned about becoming housebound and dependent on others because of their disease<sup>6</sup>. 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.

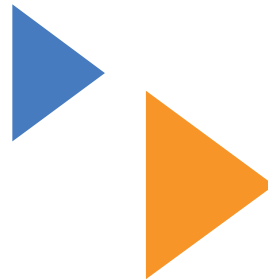


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“I have osteoporosis and am at high risk of fracture; thus, many of my previous activities are no longer part of my routine, like curling (ice is slippery!). But I do love to bicycle.

Each summer, my husband and I, along with our daughter and son-in-law, spend a couple of weeks cycle-touring. We hang some bags with our clothes (*panniers*) on our bikes and take off on a two-week adventure.”

Marg MacDonell



# Women with Osteoporosis and Doctors Working Together



**T**he 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<sup>7</sup>.

However, it is important that women with osteoporosis and their doctors continue to work together to better understand the needs of those affected by the disease. One of the key findings of the survey is that women with osteoporosis have different perceptions from doctors of the impact osteoporosis has on their life.

## What doctors surveyed think and feel:

- ▶ **Three-quarters 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.

- ▶ **Eight out of ten doctors** believe that osteoporosis has a negative impact on their patients' outlook on life.

**These perceptions differ from those of women with osteoporosis.**

## What women surveyed with osteoporosis think and feel:

- ▶ Only **8%** of women with osteoporosis describe themselves as 'frail and fragile'<sup>7</sup>.
- ▶ **Less than 1 out of 5** women feel that osteoporosis has stopped them from participating in day-to-day activities<sup>7</sup>.
- ▶ **14%** of women with osteoporosis believe that the disease has a negative impact on their outlook on life<sup>7</sup>.



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.

# Women with Osteoporosis and their Doctors – A Shared Goal



**W**hile 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

**2 out of 5** women with osteoporosis have missed a treatment dose<sup>7</sup>.

This could result in an increased likelihood of breaking a bone, since patients who take their treatment less than half the time receive minimal or no fracture protection<sup>18</sup>.

While some women forget to take their medication, there are a number of other factors leading women to not take their treatment as prescribed, including<sup>7</sup>:

- ▶ Find side-effects unpleasant.
- ▶ Prefer natural remedies.
- ▶ Find treatment inconvenient for their lifestyle.
- ▶ Do not think they need treatment.

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

Both women with osteoporosis and doctors surveyed agree that treatments with less frequent dosing would be more appropriate.

- ▶ Despite a range of treatment options available, only 12% of women with osteoporosis have asked their doctor about alternative treatments to the ones they are currently on.

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.



# A Word from the Experts – Osteoporosis Canada



**E**stablished in 1982, Osteoporosis Canada (OC) was the first national organization for osteoporosis in the world. OC is the only national charitable organization serving Canadians who have, or are at risk of, osteoporosis.

The **vision** of Osteoporosis Canada is a Canada without osteoporotic fractures. Its **mission** is to work towards a future where all Canadians will:

- ▶ be knowledgeable about osteoporosis;
- ▶ be empowered to make informed choices about their bone health;



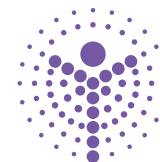
- ▶ have access to the best osteoporosis care and support;
- ▶ benefit from research into the prevention, diagnosis and treatment of osteoporosis.

Osteoporosis Canada works to educate, empower and support individuals and communities in the risk-reduction and treatment of osteoporosis.

In the fall of 2008, Osteoporosis Canada launched their national report card on osteoporosis care, *Breaking Barriers, Not Bones*. The research behind the Report Card reveals that access to bone mineral density testing is far from adequate and that access to drug treatment that can help reduce the risk of fractures varies across the country. In some provinces, individuals with osteoporosis are restricted from accessing effective treatment options. Action is required. Osteoporosis Canada is calling for a national strategy, and parallel provincial/territorial strategies, to provide coordinated osteoporosis care and to reduce debilitating fractures that have such a devastating impact on individual lives and the healthcare system.

For additional information visit:

[www.osteoporosis.ca](http://www.osteoporosis.ca)



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# A Word from the Experts – The Medical Women's International Association



**T**he 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 enable 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 receive minimal or no protection against the disease.**

For additional information visit:

**[www.mwia.net](http://www.mwia.net)**





## Final Word from Ursula Andress

“I encourage all women over 50 to go see their doctor and get their bones checked out.”

**T**his 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 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](http://www.fortimelesswomen.com)



# Call to Action



Osteoporosis is a serious disease. Women need to speak up about their bone health and have discussions as part of their annual check-up with their doctor about the treatment that best suits their active lives and will protect them from osteoporosis year after year.



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# Checklist



**Take this list with you when you next go to the doctor to discuss your osteoporosis!**

## Checklist

- ▶ Be aware, take action and see your doctor about getting your bones checked out.
- ▶ Explain any concerns to your doctor.
- ▶ 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.

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