



Life with Osteoporosis: the untold story

Key findings from research into the realities of life with osteoporosis

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Welcome

More than 3 million people in the UK are affected by osteoporosis¹. As the only charity offering nationwide support to people with the condition we aim to fully engage, assist and represent this large and growing group. It is with this goal in mind that we commissioned 'Life with Osteoporosis', a landmark research project intended to help promote a greater understanding of the lives of people affected by the condition.

This report presents the research results; moving stories and compelling statistics that demonstrate the seriousness of osteoporosis and its significance as a national healthcare issue. Our vision is of a future without fragility fractures. Such an ambition cannot be achieved without a comprehensive understanding of, and engagement with, the day-to-day realities of the condition.

I would like to take this opportunity to personally thank the thousands of people who made an invaluable contribution to this report by sharing their stories of life with osteoporosis. These will be used to help us ensure that the public, healthcare professionals and policymakers better understand the impact of the condition. Armed with the evidence, we can work together to achieve better diagnosis and treatment and a brighter future for people affected by osteoporosis.

Claire Severgnini, Chief Executive



The story so far

Half of all women and 1 in 5 men over 50 will break a bone due to poor bone health. In fact, every two minutes in the UK another bone breaks. For many of us, whether we know it or not, our fragile bones are a ticking time-bomb.



1 in 2 women and 1 in 5 men²

over the age of 50 will break a bone as a result of poor bone health



Every year there are 300,000 fractures³

That's almost 1 fracture every 2 minutes



Only 25% of adults are familiar with the term osteoporosis⁴



Just 22% of people with osteoporosis think the NHS gives it the attention it deserves⁵

Did you know?

Osteoporosis occurs when the struts which make up the mesh-like structures within your bones become thin, causing your bones to become fragile and break easily. These breaks are referred to as 'fragility fractures'. The terms 'fracture' and 'broken bone' mean the same thing.

**'I don't talk to
anyone about my
osteoporosis.'**

Breaking the silence

Osteoporosis is often referred to as ‘the silent condition’. Thousands of people took part in our landmark research project and told us their stories. It’s time to break the silence.

‘I don’t talk to anyone about my osteoporosis. I had no idea what osteoporosis meant, so I don’t expect anyone else to understand.’

For many, osteoporosis is seen as one of the inevitable consequences of ageing and something that simply has to be endured. Such a fatalistic perspective is no longer acceptable for many other similarly debilitating

conditions. It is time for osteoporosis to be proactively engaged with in the same way. We need to break the silence surrounding the condition.

There are many dimensions to the difficulty experienced by those living with osteoporosis. Breaking the silence surrounding osteoporosis means talking about the wide-ranging impact the condition has on people’s lives: giving up the things you love; emotional insecurity and fear of ridicule because of your changing body shape; fear of losing your independence; and not being able to hold the people you love.

Our research shows that life with osteoporosis can be devastating. For this reason complacency towards the condition can no longer be tolerated.

It is vital the condition is properly understood and tackled. Our vision of a future without fragility fractures is relevant to every person in the UK.



This report is based on the experiences of 3,228 people who completed our detailed questionnaire, and the 52 people who took part in an in-depth interview or kept a personal diary. Of the people we surveyed, 57% had fractured at least once, with 1 in 3 people who have fractured reporting five or more.

**'Nobody
understands what
it's like to live in
pain all day,
every day.'**

Living with pain

Osteoporosis means living with pain, or the fear of pain to come, every day of your life. Many people with osteoporosis feel their pain isn't seen or understood.

'Nobody understands how debilitating pain can be. I get scared and very depressed. I often cry a lot and I cannot do the things a woman of my age should be able to do. I feel alone...'

Constant pain makes people feel angry, frustrated and alone. Whilst many living in pain show a remarkable determination to go on living their lives as normal, the simplest of day-to-day tasks can become a major challenge.

42% of the people we spoke to who have experienced fractures are in long-term pain which they don't think will ever go away. This rises to 58% when people have had spinal fractures. 1 in 3 people in long-term pain describe it as severe or unbearable.

Many have already lived with this pain for a decade or more. They told us they need more support and better information. Only half of people suffering pain from their fractures report having effective medication to manage it.

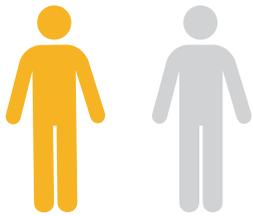
Did you know?

Fragile bones in themselves aren't painful but the broken bones that result can be painful and debilitating. Broken bones from osteoporosis often occur from just a minor bump or fall. They can occur in different parts of the body, although the wrists, hips and spine are most commonly affected.



40% of people in long-term pain have already suffered for **5 years or more**

1 in 3
people in long-term pain describe it as **severe or unbearable**



Only half
of people in pain say they **have effective medication** to help manage it



'I've had two children, but this was worse than labour.'

'I think I had fractures in my back two years before I was actually diagnosed. It all came to a head one day when I went over a bump in the car and my back became really painful.

The pain got more and more severe until on Christmas Eve I couldn't get into bed without screaming.

On Boxing Day we called out the doctor who diagnosed it as muscle pain and gave me painkillers. I was still in absolute agony. I've had two children but this was worse than labour. I asked to see a specialist who scanned me and found that I had at least six fractures in my spine.'



'I don't like to admit to anyone that I've become depressed about all the things I can't do.'

The things I can no longer do

Living with a broken hip or spinal fractures can dramatically reduce your independence. Fractures, pain and the fear of breaking a bone from a simple fall stop people from doing the things they love.

'It's the everyday things that make me so frustrated, getting into and out of the shower is impossible. Some days I could just scream with the pain of it all.'

One in three people who have experienced fractures have difficulty with domestic chores. People can find it hard to take care of themselves; everyday tasks like showering can become challenging and painful.

For some, these everyday necessities eventually become impossible. People have to rely on their loved ones, modify their homes, get extra support, or move into residential or nursing homes.

It's not only life's necessities that people find more difficult; osteoporosis can also force you to give up the things you love. Many of the people we spoke to have found that their lives are

shrinking along with their bodies as they stop walking their dogs, tending their gardens or visiting their friends.

Half of the people we spoke to who have experienced fractures have reduced the sport and exercise they do, a third have given up hobbies, and a third report socialising less. This may be because they are physically no longer capable. However, it may also be due to fear of injury and subsequent physical pain and incapacity.

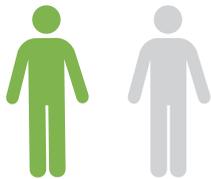
85%

of people are
worried about
fracturing again



1 in 3

people who have
fractured have
difficulty with
domestic chores



1 in 2

people who have
experienced fractures
have given up sport
or exercise or reduced
what they do

I never used to worry about walking my dog over the fields or when it snowed. Now I worry if I trip or fall, will I break another bone?

I can't lift anything of any weight so hoovering or carrying shopping becomes a problem, even washing my hair becomes trickier if I need to bend over!

Thursday 3rd July 2014

...I watched a little Wimbledon and got a bit upset. I am unable to play tennis anymore because of the risk of getting a fracture. My osteoporosis impacts a lot on the sporting activities which I used to enjoy. I have had to stop them all...

Extract from Judith's diary

'We haven't danced for years now and we both really miss it.'

'My husband and I danced together for twenty years. We were very active ballroom dancers and had won medals. I used to love the music, the social contact and just the movement of it.

We danced three nights a week when we were most active; we just adored it.

After I recovered from my first hip fracture I still danced, but what I was able to do was significantly reduced. After my second hip fracture I had to stop completely. We haven't danced now for years and we both really miss it.'



**'How can anyone
love me looking
like this?'**

Living with a curving spine

People who experience height loss and spine curvature from spinal fractures can hate the way they look, making them feel insecure, self-conscious and old. Physically they may find themselves breathless, struggling to eat and incontinent.

'The height loss and change in body shape has been the most miserable and life-changing part of osteoporosis for me. I feel grotesque.'

The physical effects of compression fractures in the spine are well known; a curved spine is one of the few visible signs that a person has osteoporosis. However, the emotional toll often remains invisible. The reality of spine curvature - the loss of height as spinal bones become squashed or compressed - can be terrifying. It can have a brutal effect on body image and self-confidence. Many people we spoke to felt insecure and ashamed about their bodies and this often had a profound impact on their relationships.

Did you know?

Spinal fractures, known as 'compression fractures', may lead to dramatic changes in body shape. They can cause significant height loss and curvature meaning there is less room for the internal organs. This may in turn cause shortness of breath, a protruding stomach, indigestion problems and incontinence.

A curved spine and height loss can affect every minute of daily life. Imagine not being able to reach your kitchen cupboards, or feeling like a child at a restaurant table that is too high for you. Such experiences cause frustration, embarrassment and trauma.

As the spine curves, there can be less room for the internal organs. It may become more difficult to swallow and at times impossible to eat a meal without heartburn and vomiting.

With spine curvature it may become difficult to breathe as the lungs struggle for space.

With less room for the bladder, incontinence, or having to rush for the toilet, are commonplace.

I feel stupid sitting in a restaurant feeling that I could use a booster cushion because my chin seems to be level with the table!

My stomach seems folded. If I eat sitting I can only eat a tiny amount before feeling full. If I try to eat more I get reflux and sometimes vomit.

It's frightening when I become breathless, it feels as though my insides are being crushed.

Thursday 3rd July 2014

'...I called in at a supermarket and did a little shopping. When I arrived home I tried on the camisole top I had bought and as I feared it was too long.

Since I have shrunk I have found it difficult to find things to wear. I am very aware of my bulging tum pushed forward by spinal curvature. The bed is often strewn with clothes when I am getting ready to go somewhere nice. I never regarded myself as being vain but this really gets me down.'

Extract from Jean's diary

54%

of people who have fractured have experienced height loss or a change in their body shape



1 in 3

people who have had at least one fracture in their spine have digestive difficulties



1 in 3

people who have had at least one fracture in their spine have experienced breathlessness



**'I feel I have lost
my purpose.'**

Work and money worries

Fear of fracturing or broken bones themselves can end people's working lives, and giving up work before they planned can add to feelings of social isolation and depression. People with osteoporosis can struggle financially if they lose their income, and osteoporosis can bring with it mounting monthly bills for things such as support around the home.

'We struggle to buy food and pay for heating. My daughter is a young teenager and it's hard to buy her shoes, uniform and clothes.'

Although many people with osteoporosis are coping financially, 30% of the people we spoke to find the amount of money they spend on coping with the condition to be a financial burden. This spending might be on a range of things such as prescriptions, extra support, or taking taxis because the bus is impossible with a broken hip or fractured spine.

In extreme cases, people are struggling to survive: some told us they were having difficulty paying their mortgages, having to choose prescriptions over food, and only buying second-hand clothes.



30% of people find the amount of money they spend relating to their osteoporosis to be a financial burden



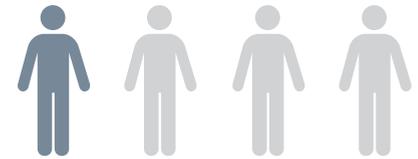
'I miss working. Being on benefits is not a life.'

Mounting monthly bills is one part of the story. However, for some of the working age people we spoke to, a diagnosis of osteoporosis made them think very carefully about the risk of a fracture at work. For others who have suffered fractures, broken bones and pain make their jobs increasingly difficult or impossible.

In fact, a quarter of people who were of working age when they were diagnosed reported that their working lives were affected by their osteoporosis.

For this reason people sometimes felt that their careers had been stifled by their osteoporosis. Others felt their working lives had been cut short because they were forced to leave or take early retirement.

For people who have worked all of their lives, suddenly finding themselves out of work can be a major shock, leading to feelings of depression and a loss of sense of purpose.



1 in 4

**people with osteoporosis
who were of working age at
diagnosis have had to give
up work, change their job
or reduce their hours**

'When I found out I had fractured my spine I had to quit my job.'

'Last year I just woke up one day with awful pain in my back and I could hardly move. I was taken to hospital - they found two fractures in my spine and diagnosed me with osteoporosis.

When I was first in pain I just called in sick and my employer was very understanding. When I found out I had fractured my spine I had to quit my job. I worked in a supermarket warehouse and there was no way I could carry on.

I'm really depressed and feel I've lost my sense of purpose. I'm only 56. I don't turn my telly on in the day because I don't want to feel like a scrounger on benefits.'



'I'm ruining my husband's life. He has to care for me when we should be enjoying our retirement.'

Holding on to the people I love

Relationships between loved ones are strained as people become more dependent on those around them. Osteoporosis stops people from seeing their friends and family, and from holding the people they love.

'I have lost confidence in myself and feel that I'm a burden on others.'

Osteoporosis can put a huge strain on people's relationships. In fact, 52% of people who have fractured said their osteoporosis had affected their relationship with their partner. Roles may change as people become more dependent. Physical closeness may diminish. Insecurities, negative body image and depression can make it harder for people to be intimate with their loved ones. People are in too much pain or are afraid they might break a bone if held. 49% of people who have fractured have had their physical intimacy affected by their osteoporosis.

Osteoporosis can also be very isolating. 1 in 3 people who have fractured are seeing friends, relatives and loved ones less than they used to because of the pain and difficulty in getting out and about. People's relationships may also be strained or weakened as they are no longer able to take part in the things they once could.

For many of the people we spoke to, one of the most heart-breaking effects of their osteoporosis was not being able to pick up and hold their grandchildren.

I always have to be on guard about people hugging me too strongly - one time my husband hugged me tightly I broke a rib.

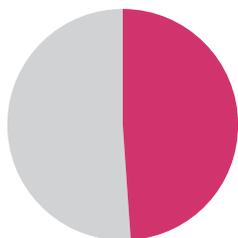
It was a case of my friends not asking me to go anywhere anymore because the things we used to do together were quite active. Eventually they stopped even ringing me to see how I was doing.

I have to be careful to pick up my grandson and cannot hold him for more than a minute. Picking him up worries me in case I get another fracture and when I hold him, I feel as if my spine is sinking into my pelvis.

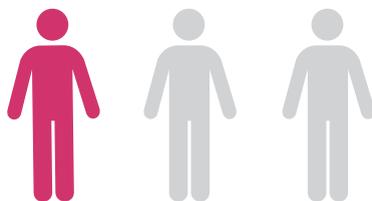
Sex is a problem, not only because of the pain but also because I'm frightened of breaking a rib.

I avoid meeting former colleagues and friends because I feel self-conscious and somewhat diminished.

I'm unable to visit family. I have to depend on them to visit me, as I cannot travel for any length of time.



49% of people who have fractured have had their **physical intimacy** affected by their osteoporosis



1 in 3 people who have fractured are **seeing friends and relatives** less than they used to

42%

of people said their osteoporosis has made them feel **socially isolated**

'I cannot physically hug my children and grandchildren. I cannot lift a baby or hold a child in my arms. This is extremely isolating and makes me very sad.'



About the project

The Life with Osteoporosis project was conducted by the National Osteoporosis Society in partnership with Alterline, an independent research agency. The questionnaire was directly promoted to subscribers of both the Charity's e-newsletter and members' magazine. It was promoted on the Charity's website and other communication channels and by the Charity's volunteer and healthcare professional networks. The majority of people completed the questionnaire online with a small number completing it over the phone. Alterline also ran the questionnaire with an existing research panel of members of the public with osteoporosis that had no association with the Charity.

The questionnaire covered many aspects of people's lives; it was developed by Alterline alongside the Charity and was informed by interviews with people who have the condition.

In total, 3,228 people completed the questionnaire between 4th June and 1st July 2014, offering us an unparalleled insight into life with osteoporosis in the UK. Following the survey, 27 people took part in in-depth face-to-face interviews and a further 25 people kept reflective diaries for a week.

Photographs and quotes

The quotes in this report are the real words of people who took part in the research. The photos used are of people who shared their stories of life with osteoporosis with us.

As well as those who are named within the report, we would like to thank Vivienne (front cover), Enilce (page 8), and Denise (page 20), who gave permission for their photos to be included in this report. A National Osteoporosis Society Helpline Nurse is featured in the photo on page 30.

For videos of the people in the report, visit the Charity's website at www.nos.org.uk

Sources of osteoporosis facts on pages 2 and 3

¹Calculated using mid 2013 population data¹ and osteoporosis incidence from²: ¹Office of National Statistics, 2014. *Annual Mid-year Population Estimates, 2013.* ²Kanis J, et al., 2000. Risk of hip fracture according to the World Health Organisation criteria for osteopenia and osteoporosis. *Bone* 27, pp.585-590. ³van Staa T, Dennison E, Leufkens H and Cooper C, 2001. Epidemiology of fractures in England and Wales. *Bone* 29, pp.517-522; ⁴British Orthopaedic Association, 2007. *The Care of Patients with Fragility Fracture*. London: British Orthopaedic Association; ⁵Echo - Global Research Protecting Brands and Reputation, 2013. *Brand Awareness & Audience Insights Study*, [Internal report commissioned by National Osteoporosis Society]; ⁶Alterline Research, 2014. *Life with Osteoporosis study* [Internal report commissioned by National Osteoporosis Society]

We've heard...

Through this project thousands of people with osteoporosis have told us how they really feel about their life with the condition. They have had the courage to talk honestly and openly and their words show just how devastating osteoporosis can be.

Frustrated Upset Self-conscious
Stupid Alone Scared Worried Old
Miserable Frightened Grotesque
Depressed Isolated Debilitated
Afraid Insecure Exhausted Agony
Misery Stress Nervous Annoyed
Unattractive Hate Ashamed Bitter
Embarrassed Sad Resentful Angry
Unhappy Lonely Tearful Invisible
Uncomfortable Useless Forgotten

Thank you

to all those who took part and told us their stories, making this project possible

**We are the only
UK-wide charity
dedicated to
ending the pain and
suffering caused
by osteoporosis.**

Our vision is a future without fragility fractures.

This would mean...



A life without pain and fear.

Feeling confident and beautiful.

Living life; doing all the things I want to do.



A life with purpose, and without money worries.

Being able to hold the people I love.



We are working to prevent future fractures and to help and support people now.



We're committed to helping people with osteoporosis live the lives they want to lead.

We:

- provide essential life-changing information
- offer practical guidance and vital emotional support
- bring this silent condition into the public eye and empower people to manage their bone health.

We support researchers and healthcare professionals to improve the prevention, diagnosis and treatment of osteoporosis and fragility fractures.

We:

- campaign vigorously to drive standards and improve services across the UK
- educate and inform health professionals to achieve first-rate osteoporosis care
- fund ground-breaking medical research.

We need your help

Millions of people with osteoporosis are living every day in pain and in fear; their lives are shrinking along with their bodies, and they are struggling to hold on to the things and people they love. Our vision of a future without fragility fractures must be pursued and it is urgent that we do so. We can't get there alone, we need your help.



Talk about it

Talk to your family, friends and colleagues about osteoporosis. Help us break the silence.



Support us

Become a supporter - visit our website today to make a donation or join as a member.

www.nos.org.uk



Talk to us

If you're worried about your risk of osteoporosis, talk to us. We're here to help.

Helpline: 0845 450 0230

With your help, we can achieve a brighter future for people with osteoporosis.

Our vision

A future without fragility fractures.

Our mission

Working together for a brighter future for people with or at risk of osteoporosis and fragility fractures across the UK, putting an end to preventable broken bones and helping people to live without pain and disability.

Our values

We are caring, innovative, excellent, influential, ethical and passionate in all that we do.

-  **0845 450 0230 (Helpline)**
-  **0845 130 3076 (General Enquiries)**
-  **www.nos.org.uk**
-  **info@nos.org.uk**
-  **Camerton, Bath BA2 0PJ**

President:

HRH The Duchess of Cornwall

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