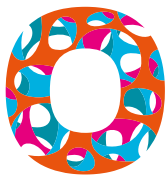


# Life with Osteoporosis 2021: the untold story...



**Royal  
Osteoporosis  
Society**

Better bone health for everybody

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# Welcome



Osteoporosis is a disease which causes bones to become weak and break easily. It affects over 3.5 million people in the UK – a figure set to rise further as the population ages.

Some people can live with osteoporosis and with an early diagnosis, the right medication and lifestyle advice, barely know they have it. But for others, it can be devastating both physically and mentally. For those people, osteoporosis can lead to unbearable pain, disability, distress, social isolation, depression and premature death.

Despite these severe effects, osteoporosis is often referred to as “the silent disease”, due to under-diagnosis, under-treatment and very low levels of public awareness. There’s a mistaken perception amongst many that curved spines and loss of height are generalised signs of ageing, rather than symptoms of a treatable condition. People living with the condition can often feel misunderstood and isolated.

The journey towards diagnosis and treatment can be very difficult for people living with osteoporosis. Often people only get a few minutes with their GP or other healthcare professional after being told they have osteoporosis and can be left bemused and with unanswered questions. Across the country, there’s a postcode lottery for quality services in

secondary fracture prevention, leading to extreme variation in experiences. Many people who live in the “wrong” area are being left to suffer multiple painful fractures before diagnosis. Follow-up and review for people put onto medication is too often lacking, causing anxiety and avoidable problems.

Our original Life with Osteoporosis study gave the people who live with the condition a voice. We heard striking accounts of long periods awaiting diagnosis and disappointing experiences of health services. We learned about the impact of the condition on daily life, work, leisure activities and relationships with family members. Following the experience of the COVID-19 pandemic, we decided to launch a similarly comprehensive study in July 2021. This report sets out what we’ve learned. We’ll be taking the findings to the heart of Whitehall and the devolved parliaments over the coming months.

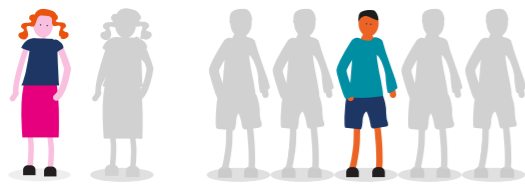
I want to thank everyone who took part in the study – all 3,266 of them – for their involvement and for sharing their stories with us. Understanding and defeating osteoporosis starts with giving them a voice. Here it is.

**CRAIG JONES**  
Chief Executive of the Royal Osteoporosis Society



# The story so far

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



**1 in 2 women and 1 in 5 men** over the age of 50 will **break a bone** as a result of poor **bone health**<sup>1</sup>



Osteoporosis causes **over half a million broken bones every year**<sup>2</sup> (that's almost one broken bone every minute)



Only **25% of adults** are **familiar** with the **term osteoporosis**<sup>3</sup>



**A fifth** of women who have broken a bone **break three or more before** even being **diagnosed**<sup>4</sup>



**64% of women and 43% of men** living with osteoporosis are **not getting the NHS treatment they need**<sup>1</sup>

Sources for osteoporosis facts on page 33

# Living with pain

Many live in constant, unbearable pain, which they do not believe will ever go away and do not have the support to manage.

Though osteoporosis and having weak bones in itself does not cause pain, the broken bones that result from it do, and these can be debilitating and incapacitating. Broken bones from osteoporosis often occur from just a minor bump or fall. Many who do not have weak bones would get up and carry on with their day after a bump or fall, however for those who live with osteoporosis, a minor fall can result in severe pain, for months, years or even a lifetime.

Almost two in three people from the “Life with Osteoporosis” sample have experienced pain which they link to their osteoporosis. Over one in four report long-term pain; in fact, 16% of those in long-term pain have experienced this for over a decade. Of those who are experiencing long-term pain, over one in three say their pain is constant and over one in three say it is severe or unbearable.

Whilst many show a great amount of resilience and determination in the face of constant pain, it has a huge impact on every aspect of daily living. People who live with long-term pain reported being unable to do normal day-to-day activities, such as shopping, domestic tasks and personal care.



Pain also has a colossal effect on the wellbeing of those who experience it. When pain is constant and people don't know whether it will end, they experience tiredness, frustration, anger, low mood, a feeling of vulnerability, a lack of confidence and fear. Even those who have not fractured live in constant fear of breaking a bone and the pain which would be the undoubted result.

**“I cannot lead a normal life because I am in continuous pain in my lower back.”**

Of those who have fractured, almost a third do not have enough information to manage their pain and almost a third feel they need more support to manage their pain. Over a quarter say they do not have effective medication to manage the pain they experience. The COVID-19 pandemic has exacerbated this feeling with many having less access to the support they need.



# FREDERICK'S story

## Pain

Frederick is 63 and was diagnosed with osteoporosis in 2021 after he had a vertebral fracture which causes him to have a curve in his spine.

I was diagnosed around a month ago after I turned around too quickly and jarred my back. I found out that I had fractured a vertebra. Due to the pain of the fracture, I had to take early retirement.

Now that I have returned home, my day-to-day life has changed completely. I have a jabbing pain in my back, which I feel with every movement. That, and my asthma which can result in recurring chest infections, means I feel out of breath when I move. I take paracetamol and morphine to help me to get in and out of bed - that is when the pain is at its worst. It's a jabbing pain, and my back gets very hot. I find it very difficult to wash, but I am able to if I sit down. I have a raised bed and have bought an electric recliner to help me to feel more comfortable when I sleep. I feel lucky if I'm able to get three hours of sleep at a time.

Walking is a problem for me, I can't walk for great distances. If I ever need to leave the house, I take a taxi as I am unable to walk far without the aid of a trolley and walking stick which I have recently bought. I always look for a lift when I'm at the hospital, as I take so long to walk up the stairs.

**“Now that I have returned home, my day-to-day life has changed. I have a jabbing pain in my back, which I feel with every movement.”**



**1 in 4** experience long-term pain with **16%** having been in pain which they link to their osteoporosis for **over a decade**



**Almost a third** who are in pain **do not have enough information** to manage it



**Over 1 in 3** who are in pain say it is **severe or unbearable**



**Over 1 in 4** who are in pain **do not have effective medication** to manage it

# My healthcare

Many people who have osteoporosis report a lack of confidence in the healthcare professionals who deal with their condition. This has been exacerbated as a result of the COVID-19 pandemic since patients are missing out on important face-to-face consultations.

For many, diagnosis, healthcare and intervention doesn't happen quickly enough to avoid multiple fractures. Almost three in four broke a bone (which they suspect was related to their osteoporosis) before their diagnosis and almost one in three broke more than one before they got a diagnosis. Most people wait between one and six months before osteoporosis is identified as the cause of their fracture. However, an alarming one in seven people are not diagnosed with osteoporosis for over five years following their first fracture.

Even once diagnosed, many don't think their medication is effective or that their condition is monitored well enough to provide confidence that the medication is working. People who take osteoporosis medication have serious concerns about the side effects of medication and the risk of long-term medication use. Many said they don't feel that the benefits and drawbacks have been fully explained.

Only 48% are confident they're on the right medication (and this is 10% fewer than in 2014)

Only 40% think their medication is effective

Only 54% feel the benefits and drawbacks of their medication are fully explained to them

57% are worried about the risks of taking their medication for prolonged periods of time

52% are worried about the potential side effects of their medication

“My GP just said I have osteoporosis and she will get a prescription ready for collection. There was no information, no guidance and all information I received was through my own research via the Royal Osteoporosis Society and a support group on the internet... I felt very scared and abandoned at the time.”



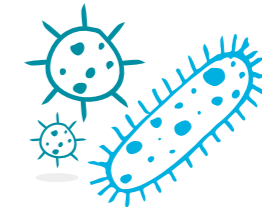
22% don't feel the healthcare professionals they talk to understand their osteoporosis



26% don't feel that their doctor takes their osteoporosis seriously



46% are dissatisfied with the current level of monitoring of their condition



2 in 5 feel COVID-19 has had a negative impact on their healthcare for their osteoporosis

Many people with osteoporosis are not satisfied with how healthcare professionals and the NHS deal with their condition. 22% don't feel the healthcare professionals they talk to understand their osteoporosis, 26% don't feel that their doctor takes their osteoporosis seriously, 46% are dissatisfied with the current level of monitoring of their condition, and 53% don't think the NHS gives osteoporosis the level of attention it deserves. When diagnosed with a new condition, fear and uncertainty are high and a lack of confidence in healthcare professionals and medication often leads to high levels of anxiety.

Two in five feel that COVID-19 has had a negative impact on their healthcare for their osteoporosis and 45% feel COVID-19 has had a negative impact on their ability to discuss their medication with a healthcare professional. People who have osteoporosis have been missing out on important conversations with healthcare professionals due to cancelled appointments. Many people do not feel confident or able to explain their experiences or receive advice over the phone in remote consultations, and others feel that sufficient monitoring of their condition can only be done in person.



# ZOE'S story Healthcare

Zoe is 46 and was diagnosed with osteoporosis in 2020. She had seven fractures in her hip, thigh, knee and pelvis in the space of nine months.

**“I feel that I would have benefited more from in-person GP appointments. I can't always understand the doctor on the phone, and I find it very easy to miss my appointment call.”**

In the space of nine months, I had seven fractures, spent 40 nights in hospital and three and a half weeks in a nursing home. During this time I was also diagnosed with osteoporosis. After my first fractures, I did start to go to physiotherapy and had sessions with the enablement team which helped me to feel more confident. However, these sessions were cancelled when the pandemic hit. I haven't been offered any help since.

I feel that I would have benefited more from in-person GP appointments. I can't always understand the doctor on the phone, and I find it very easy to miss my appointment call. The calls don't have caller ID so you are unable to call them back if you miss the phone call. I have to wait for a phone call which doesn't happen at the time arranged or doesn't happen at all.

I was started on alendronic acid, but this made me quite ill, so I was only able to take this for a few months. I'm now on risedronic acid but had to stop this temporarily due to my hip surgery. I am concerned about the risks the medication has for cancer. I haven't been given information about my medication from the doctors, so my information mainly comes from support groups on Facebook. I am making the choices myself about reducing painkillers based on advice from the support groups or ROS Helpline.

# Changes to my body

The physical effects of osteoporosis have a severe impact on self-confidence, self-esteem and body confidence. Many feel embarrassed about how they now look.



**Almost 3 in 5** have been **impacted physically** by osteoporosis

Almost three in five have been impacted physically by osteoporosis and two in five are currently physically impacted. 55% of those who have fractured as a result of osteoporosis say they have height loss or a change in their body shape which they link to their osteoporosis, 22% have digestive difficulties, 19% breathlessness, 10% incontinence and 9% have eating difficulties.

Many worry that their change in body shape has made them lose their waistline or given them a protruding stomach, which makes it seem that they have put on weight even if they haven't. Some people even felt that makes them look pregnant. Many have issues with finding clothes to fit them or clothes which they feel comfortable in. Those who experience incontinence often feel they have to take extra precautions to leave the house, such as finding out where the toilets are in advance and bringing extra supplies "just in case".



Those who feel breathless sometimes feel self-conscious about taking frequent breaks, particularly if they are in public and can be seen to be out of breath. These are changes which people don't get used to and feel there is very little which can be done to help them. This takes a toll both physically and mentally.

**“I feel absolutely terrible. Very depressed. I can't get clothes to fit. I am embarrassed going out. It doesn't help that my husband calls me a hunchback. I feel worthless.”**



# PAM'S story

## Changes to my body

Pam is 69 and was diagnosed in 2008, she has had 15 fractures and has a curve in her spine.

I have started getting a curve in the top of my back and I have lost an inch and a half in height. I try hard to keep my shoulders back, so the curve is not as obvious and I also try to keep exercising them. I used to go to physiotherapy and do my exercises religiously, but since being diagnosed with leukaemia in 2018 I have not done any exercises.

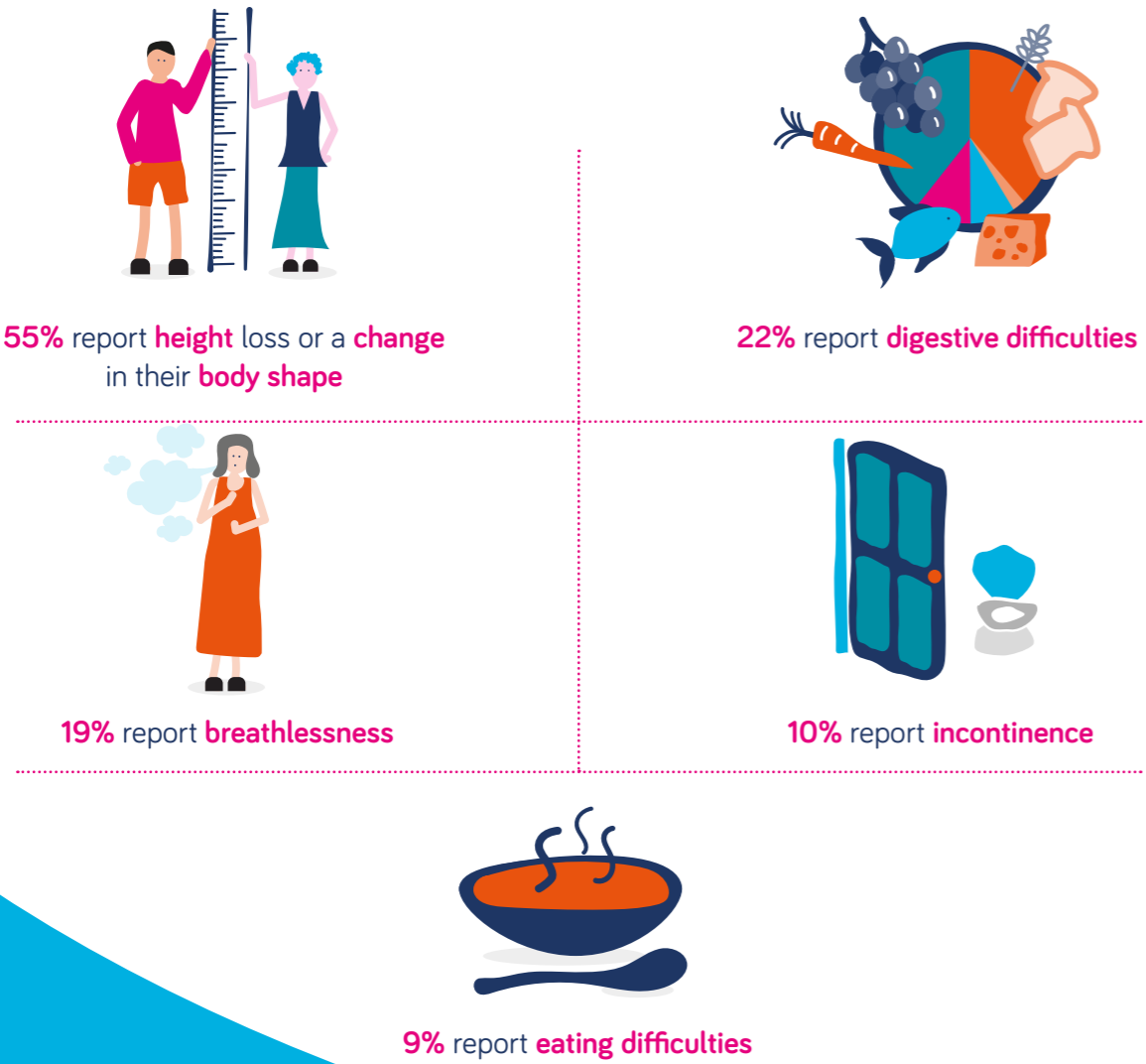
I've always been kind of tall and fairly slim. I am the same weight but now I have a pot belly. It looks like I have a weight problem, but it isn't a weight problem and I really hate it. I'm not able to wear the things I used to. There are lots and lots of styles that I wouldn't be able to wear. I wear jeggings a lot so I can just pull them on, or my jeans have to be a size bigger to fit over my pot belly. I always wear trainers. I have my shoes altered because one leg is longer than the other. I can only wear other shoes if I'm only walking for a short distance. I know this is just vanity and shouldn't be a thing, but it does bother me.

There's a lot I can't do now, but in my head I'm still quite young and fit - all of my friends are really fit and it's difficult to see them doing things which I can't. I've got two grandchildren and I've never been able to look after either of them or pick them up to take them out of their cot even. That has all been very upsetting, I've missed a lot of their lives.

I am worried that I will get more fractures in my spine and develop a hump on my back, which could happen easily as the fractures are not caused by trauma. In fact I am scared stiff of getting a hump and I desperately want someone to help me with preventing this. My osteoporosis has got a lot worse, I've always just coped with it and got on with it, but it's frightening me now.

“There’s a lot I can’t do now, but in my head I’m still quite young and fit - all of my friends are really fit and it’s difficult to see them doing things which I can’t.”

### Of those who have fractured...





# The things I have stopped doing

Physical effects of osteoporosis can cause difficulty completing day-to-day tasks which were a normal part of everyday life before.

42% have difficulty with domestic tasks and chores, and 38% have issues with day-to-day shopping or errands. Cooking, cleaning, looking after pets, gardening and looking after children or grandchildren were all things that people report being unable to do or now have difficulty with. Needing support with these things can make life much more difficult, especially if that person does not have someone in their household who they can rely on to help. Asking for help can also be a difficult task in itself, with many finding an element of embarrassment involved in reaching out.

“[I] am now very wary of falling and cautious of standing on step ladders etc. I have limited ability to do housework, decorating, hedge-cutting etc. I now have to pay to get these done.”

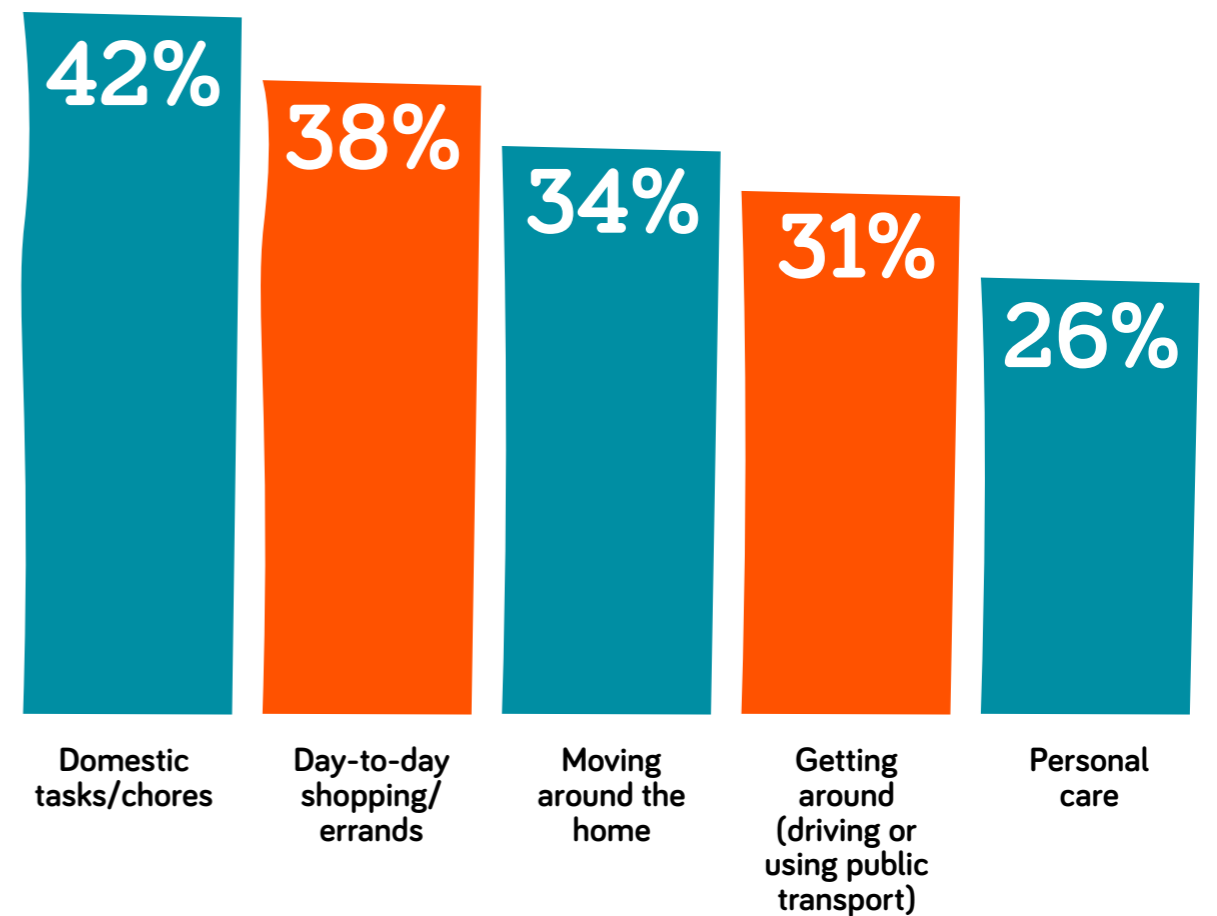
34% have difficulty moving around the home. The ability to bend, walk (either long or short distances) or pick up heavy items is affected by the presence of weak bones. 31% have difficulty with getting around (driving and using public transport) and 26% have difficulty with their own personal care.

Many report being cautious when carrying out day-to-day tasks because they are anxious about hurting themselves. Some consider their plans for the day based upon how they feel, as they are not able to complete as much as they used to. A lack of energy, tiredness and fatigue which often results from pain means they need to rest regularly throughout the day.

“I have had to adapt my levels and type of physical activity, to keep my spine as safe as I can.”



People with osteoporosis reported difficulty undertaking a number of daily activities, including...





# GEOFF'S story

## Day-to-day tasks

Geoff is 75 and was diagnosed in 2001, he has had multiple fractures in his spine.

“My pet hate is winter weather. It's very slippery and very icy, it's a great barrier to people like me who might injure themselves very badly with a fall.”

When I had my first scan, I was conscious of a degree of back pain brought on or worsened by lifting, moving around and carrying things. I have always shrugged it off as just one of those things. Having seen the scans and where the back problem is, I am much more conscious that is the problem. The pain was a gentle nagging that was always dull but ever present.

I find walking to be quite difficult. Each day is different to another, but walking is a labour rather than a pleasure. I find that I'm putting pressure on my back when I am walking. I am reluctant to walk too far, whereas others will head off into the horizon. My pet hate is winter weather. It's very slippery and very icy, it's a great barrier to people like me who might injure themselves very badly with a fall.

The other day I did have to get the lawn mower out as the gardener was ill. I did not feel any ill effects from this, as it is an intermittent thing, it doesn't happen every time. But it is something that I am conscious of, if I tire myself too much then my back is the first to feel it. My wife and I know that if I can't do something, she will do it or vice versa. The relationship revolves around it.

# The people I love

Stopping activities due to pain or mobility issues can cause people with osteoporosis to feel distant to, or isolated from, others.

Osteoporosis can have an impact on relationships and social lives which can cause some to feel socially isolated. 33% of people in the “Life with Osteoporosis” study said they feel at least a little socially isolated as a result of their osteoporosis.

Pain, mobility issues, fear of fracturing, fatigue, low mood and a lack of confidence mean that many people also stop or reduce taking part in social activities. 72% who played sport or exercised have reduced or stopped this completely, 51% have reduced or stopped their hobbies or interests and 47% have reduced or stopped social activities. The inability to continue with hobbies stops people from feeling they are getting the most out of their social lives and results in people feeling distant from family and friends.

“I have lost contact with the groups of friends I had through sporting activities. I get a bit down that I am not able to do as much physically for my family as I used to do.”



33% feel socially isolated



36% reported an impact on their relationship with their partner



31% experienced an impact on their relationships with family



39% say osteoporosis has an impact on them being intimate

Many have reduced or stopped going on holiday (50%) and visiting relatives (39%) as a result of their osteoporosis. Travelling can be difficult due to mobility issues or pain while sitting for long distances or periods of time. Worries about accessibility in unfamiliar places also has an impact on this.

Some feel their friends or family view or treat them differently since their diagnosis and sometimes feel as though they are a burden on them since they have become more reliant.

“Circles [of friends] feel they need to make allowances for me. It makes meeting up or events difficult. Sometimes I don't get the choice to decide for myself about what I do, I don't get invited in the first place because they assume I wouldn't go because of my health.”

## RINA'S story

### The people I love

Rina is 59 and was diagnosed with osteoporosis in 2016. She has had three fractures which caused her to have a curve in her spine.

In 2017 I was on my way home from seeing family overseas when someone pulled out the high stool I was about to sit on. I fell to the floor and fractured my pelvis and cracked my hips. I was advised to stay in hospital for three months to heal, but self discharged and made my way back to the UK. Being all alone in the hospital was very traumatic. I am now wary of travelling abroad again to see my family. I worry that I would not be able to get insurance to travel with my health issues.

Some of my friends do not understand my condition. For example, I was invited on a road trip to France and Spain by one friend. My son and I decided that I would not be able to do a long-haul drive as I am not able to sit for long periods. I no longer have the stamina for my social life and I miss the spontaneity of being able to travel easily.

My life feels fragile and the smallest thing could change everything. I am now afraid of sexual intimacy because I am afraid that I could break as my pelvis is too weak. This makes me lonely. Since I fell, I have not felt confident being out by myself. I will not sit in a high stool in a restaurant or café now, I don't go near them as I am very wary of them. I used to love playing football with the local kids in the park behind my house. I now won't do it. The children kick the ball so hard, I sometimes worry I've done something, but I don't want the children to worry that they've hurt me.

I am unable to talk to people about my issues. I do speak up when I'm unable to do something, such as lifting heavy things, but I feel upset and embarrassed that I have to explain this to people, so I try not to put myself in those positions.

“I am now afraid of sexual intimacy because I am afraid that I could break as my pelvis is too weak. This makes me lonely.”





# My work and finances

Needing to give up work and pay for new things to cope with osteoporosis, causes stress and anxiety when some struggle to make ends meet.

Almost three in ten of those who are of working age (aged 65 and under) have had either their own or their partner's working life impacted by their osteoporosis. Over a quarter of those affected have had to give up work, while almost one in five have had to take early retirement.

The loss of a job causes many people to feel less valuable and lose the identity that their job once gave them. Some who continue to work, worry about their future prospects if they are unable to undertake the roles and responsibilities of their job to its full capacity or are limited in their scope for professional development.

**“It has further eroded my self esteem. I have felt for a long time I no longer serve a purpose in life.”**

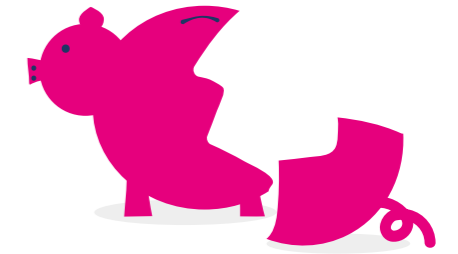
Three-quarters of those who have had their working lives impacted feel at least a little bit financially burdened by the amount they spend managing their osteoporosis. Almost one in ten feel the money they spend is a severe financial burden. Paying for private healthcare, buying medication, attending classes, paying for cleaners or gardeners, buying items to help with accessibility or paying for transport are all additional expenditures which have been described as a burden. This is especially pertinent as many now have lower incomes. Many have had to rely on benefits, savings, pensions or other financial support.

For these people, budgeting much more carefully is imperative and they are now less likely to have money to spend on luxuries. The stress and anxiety which accompanies these new responsibilities is difficult to cope with and some struggle to make ends meet or are in debt.

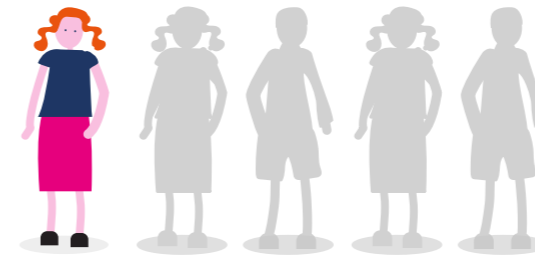
**“It’s a depressing life and we are only 64 and 68. I’m constantly stressed and depressed about our lack of quality of life because we haven’t enough money.”**



Almost **three in ten** have had their **working lives impacted**



Osteoporosis has a **severe financial impact** on almost **one in ten** of those who have had their **working lives affected by osteoporosis**



Almost **one in five** of those whose **working lives** have been **impacted** have had to **take early retirement**



**Over a quarter** of those whose **working lives** have been **affected** have **had to give up work**



# My living arrangements

Many need to make changes to their living arrangements or need support to live independently.

Osteoporosis and the resulting fractures can have a huge impact on people's ability to get around and do day-to-day tasks. As a result, over one in four of those who have fractured have had to change their living arrangements in some way in order to cope.

**“I have moved from a house to a bungalow but [I’m] beginning to feel I may need sheltered housing as my physical abilities reduce.”**

Around half of those that have made changes have had to make modifications to their home. Just under a third now receive practical help or care to help them to live in their own home. Others have had to move in with family or friends, or into a retirement or nursing home.

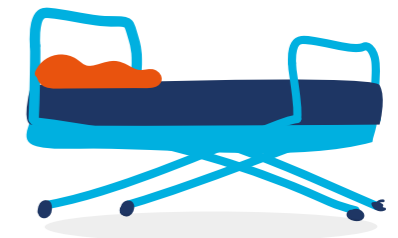
As well as impacting living arrangements, mobility issues and pain from broken bones can result in a need for more support from others. 37% of people with osteoporosis feel it has made them more reliant on other people. Independence declines with increasing severity of osteoporosis. 66% of those who have had five or more fractures and 61% who have a curve in their spine say they are more reliant on other people.

Many do not get the support that they need to live as independently as they can. Only just over half (56%) said they are getting the right level of support to live independently.

**“I have moved into an adapted housing association home and am still having adaptations done. I receive practical help and care.”**



Over one in four of those who have fractured have had to change their living arrangements



Around half of those that have made changes have had to make modifications to their home



Only 56% are getting the right level of support to live independently



37% now feel more reliant on other people



# KRISHNACHANDRA'S story

## My living arrangements

Krishnachandra is 80 and was diagnosed with ankylosing spondylitis and osteoporosis. He has had vertebral fractures which cause him to have a curve in his spine.

**“When you become disabled, your whole family becomes disabled.”**

When I first started to have issues with pain I became bed-bound and wheelchair-bound. Social Services helped to modify our house. They built a special toilet, bath and bidet, and space for my wheelchair. They installed a hoist so I could lift myself. Before I had this, my friend made a makeshift hoist for me so I could stand up and my children would help to wash me. When you become disabled, your whole family becomes disabled.

We later moved due to my wife's job and studying opportunities. An occupational therapist came to help her look for appropriate houses. Once we had moved in, they built another room for me. There is an overhead hoist which I can use to transport myself from my bed to the bathroom. I use a sling to use the bath and shower. This operates with remote control and the bathroom has swing doors. The bathroom is also designed to be used when I'm in my wheelchair, such as the height of the washbasin has been adjusted. We have also installed a porch entrance to the house, with a ramp up to it. This allows me to be able to stay in the porch when waiting to be picked up, rather than going straight out into the weather.



## My emotions

Anger, frustration, resentment, sadness and grief are all emotions which some people who have osteoporosis described feeling as a result of the condition.

Almost half said osteoporosis has affected their emotional health. Many expressed feelings of anger, frustration, resentment, sadness or grief over the activities that they can no longer do. Some people that exercised to maintain good emotional and mental wellbeing now feel unable to do so because of their osteoporosis.

**“[I] feel depressed not being able to do what I could not very long ago. [I am] envious of people older than me appearing to have no mobility problems and having plenty of energy.”**

Pain that people attribute to their osteoporosis impacts heavily on their emotional wellbeing. They described their emotions when they are in pain as: being short-tempered, sad, depressed, teary or lacking motivation.

**“I feel terrible. I cry most days... Being in constant pain is awful.”**

The perception of how they are ageing can also impact people's emotional health. Being diagnosed with osteoporosis and living with the symptoms of it day-to-day can result in people feeling that they are “old before their time” and self-conscious.



# MARIE'S story

## My emotions

Marie is 71 and was diagnosed with osteoporosis in 2011. She has had six fractures which cause her to have a curve in her spine.

When I was having my first DXA scan, the person doing the scan suggested that I had potentially broken my back while coughing as I had recently had the flu. This amazed me and I was upset and terrified.

When I felt another pain in my back, I went to my GP. He referred me to another doctor, and I asked for an x-ray. I was told that I couldn't have one, they said "what difference would it make if you've got another fracture" and I was sent away with painkillers. I felt that I had run out of steam because no one wanted to listen to me. I later got an MRI, but I was so concerned that if I was to lie in the MRI scanner, I wouldn't be able to get up because I was in so much pain. This MRI showed that I had several fractures.

I was referred to a spinal surgeon who suggested I get cement injections in each of the fractures – this terrified me. When I asked my GP about the injections, he said "if you were my mother, you would not be having those injections". This made me afraid, but I decided I would go ahead. However, I did not hear from the spinal surgeon again, so I did not have any cement injections.

I often feel breathless and suffer from heartburn and incontinence. I was advised to ask to be referred to an incontinence clinic, but at this moment in time I do not have enough energy to start another hard journey, I don't have the willpower.

I am proud that I survived through the pandemic, but I had a horrendous two years. I did wonder at times "why am I bothering to live? Wouldn't I be better off out of all of this?" because there is no pause in my pain. I don't want to burden other people and I don't want to worry them. I don't like having to explain myself and my pain.

I feel that GPs can't do anything for me as they are busy people, especially since the pandemic hit. I feel abandoned. It's a complete and utter nightmare because I don't know what the future holds. I don't know if I will get better or worse. I was told that the fracture would never heal and the pain would never go away, and I just have to get on with it.

"I am proud that I survived through the pandemic, but I had a horrendous two years. I did wonder at times why am I bothering to live? Wouldn't I be better off out of all of this?"



48% say osteoporosis has had an effect on their emotional health



Pain heavily impacts on emotional wellbeing



Cutting out activities can cause frustration and sadness





# Thinking about the future

Fear for the future is a constant worry in the minds of many people who have osteoporosis, who do not know when just one fall could take their independence away from them.

92% of people with osteoporosis are concerned about falling or fractures in the future. Fractures in the spine or hips are mentioned specifically as types of fractures which they are particularly concerned about, as it is felt these would have a severe impact on their lives.

Over seven in ten said being afraid of fractures has an impact on what they do. Many said their fear of fracturing was all-consuming, resulting in hypervigilance over their actions and also loss of confidence.

**“I am very anxious about breaking bones in situations I wouldn’t have thought twice before about, such as opening the dishwasher or bending down to put my shoes on.”**

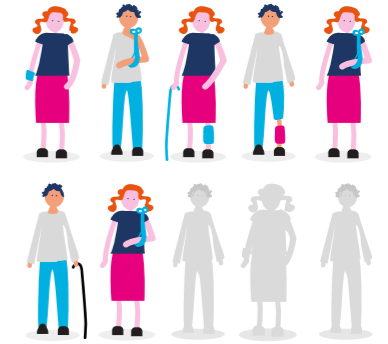
The majority are concerned about not being able to do the things they like to do, losing their mobility, and coping with day-to-day activities. 83% are worried about losing their independence and having to rely on assistance from others in the future. Those that live alone worry about how they will look after themselves.

When thinking about the future, four in five said they were worried about changes to their physical appearance and the pain they might be in. Some were concerned about preventing future deterioration and wanted to know if there were steps they could take to reduce this. Other worries include becoming socially isolated and the impact of their condition on loved ones.

Many were concerned about how seriously osteoporosis would be treated within the healthcare system. They were concerned about whether there would be appropriate care in the future, how effective treatment would be, the side effects of treatment and what happens if they stop treatment.



92% are concerned about future falls or fractures



Over 7 in 10 said being afraid of fractures has an impact on what they do



83% are worried about losing their independence



4 in 5 are worried about changes to their physical appearance



# BARBARA'S story

## My future worries

Barbara is 60 and was diagnosed in 2016. She has had two fractures, one of which was in her spine.

**“I’m a very independent person, so the thought of losing my independence would take my world away. I do not have family to call on, I do everything myself.”**

When I was told about my osteoporosis diagnosis, the doctor said “it’s about as bad as it can get” which made me feel that everything in my world had collapsed. I envisioned my bones getting thinner and being a tube with nothing inside of them, and they would eventually break and crumble. It completely terrified me and I thought that my life was basically over.

When it was first suggested that I had osteoporosis, I wasn’t too bothered and felt it was one of those things as you get older. I didn’t feel that it would affect me and my life. However, when the doctor told me how bad it was, I felt lonely and frightened, there was no need to instil that fear. I felt that I had been delivered a death sentence.

I was scared stiff that if I was to have a knock, I was going to break. I am no longer spontaneous, it has been replaced by fear. Now I think about things just in case, what if I fall over? I’m terrified of falling over.

I’m a very independent person, so the thought of losing my independence would take my world away. I do not have family to call on, I do everything myself. I sold my house because I was worried if something were to happen to me, I would no longer be able to pay the mortgage. I bought a house with a smaller mortgage so that no one could take my house away. It was a massive life change and I wish I had not done it because I loved my old home.

# Osteoporosis

## inequalities

People with lower household incomes in the “Life with Osteoporosis” study were more severely affected.

While osteoporosis does not affect everyone in the same way, there are certain groups who seem to be impacted more severely and disproportionately than others.

### Financial position

A notable finding in the “Life with Osteoporosis” study was the impact of people’s financial situation. Those who have a household income of under £20,000 a year or do not own the home which they live in were more seriously impacted by osteoporosis in most of the areas which the study looked into: the number of fractures they have, the pain they are in and the physical impact it has. They are also more likely to have their day-to-day working and emotional lives affected, their living arrangements impacted, and feel negatively about the support and healthcare they receive.

### Age

Those aged 80 and over in the “Life with Osteoporosis” study were more likely to be in long term pain, be physically affected by osteoporosis, have had their living arrangements affected and be more reliant on other people. However, under-60s were more likely to be affected emotionally and to be unhappy with their current level of monitoring. Under-60s were also more likely to

feel COVID-19 has negatively impacted the healthcare they receive, that they don’t have enough information to cope and to feel a lack of confidence about managing their osteoporosis in a way which suits their needs.

### Differences compared to the 2014 study

While the 2021 “Life with Osteoporosis” study shows broadly similar results when compared with the 2014 study, it does suggest there have been some improvements since 2014, with fewer people in the sample reporting long-term pain or having difficulty getting around and more people taking their medication correctly. It does however also suggest there have been some declines. Fewer people in the 2021 sample have a good awareness and information about things they can do to manage their pain and more are worried about fractures in the future, what this could mean for the things they can do and their independence. Fewer people reported confidence in healthcare professionals, the NHS and the medication they have been given. Some of these differences could be driven by the COVID-19 pandemic.





# Income based inequalities:

## Physical impact

HOUSEHOLD INCOME UNDER £20,000 PER YEAR.



**23%** have five or more fractures.  
**36%** are in long-term pain.  
**68%** say they are physically affected by osteoporosis.

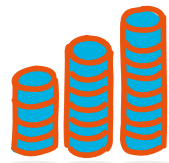
HOUSEHOLD INCOME £30,000 AND OVER PER YEAR.



**17%** have five or more fractures.  
**21%** are in long-term pain.  
**52%** say they are physically affected by osteoporosis.

## Work and finances

HOUSEHOLD INCOME UNDER £20,000 PER YEAR.



**46%** said their working lives are affected by osteoporosis.  
**16%** say osteoporosis has a severe financial burden.

HOUSEHOLD INCOME £30,000 AND OVER PER YEAR.



**24%** said their working lives are affected by osteoporosis.  
**2%** say osteoporosis has a severe financial burden.

## Living arrangements and relationships

HOUSEHOLD INCOME UNDER £20,000 PER YEAR.



**31%** said their living arrangements had been affected by osteoporosis.  
**48%** are more reliant on other people due to osteoporosis.  
**9%** feel severely socially isolated.

HOUSEHOLD INCOME £30,000 AND OVER PER YEAR.



**12%** said their living arrangements had been affected by osteoporosis.  
**32%** are more reliant on other people due to osteoporosis.  
**3%** feel severely socially isolated.

## Information and support

HOUSEHOLD INCOME UNDER £20,000 PER YEAR.



**44%** need more support to manage their pain.  
**25%** don't have enough information to help them cope with their osteoporosis.  
**15%** don't receive the right level of support to live independently.

HOUSEHOLD INCOME £30,000 AND OVER PER YEAR.



**32%** need more support to manage their pain.  
**18%** don't have enough information to help them cope with their osteoporosis.  
**6%** don't receive the right level of support to live independently.

# About the project

“Life with Osteoporosis 2021” follows on from “Life with Osteoporosis 2014”. In 2014 the Royal Osteoporosis Society (ROS) commissioned Alterline to embark on a two-year programme of research and consultation to inform the development of ROS’s strategic direction and planning. “Life with Osteoporosis 2014” was a landmark study of 3,228 people who have osteoporosis, commissioned by the charity to explore and document the impact osteoporosis has on people’s lives.

In 2021 the Royal Osteoporosis Society commissioned Alterline to repeat the study to provide updated, fresh evidence about the lived experiences and needs of people living with osteoporosis. This report details findings from the research about the impact which osteoporosis has on the lives of people who have it.

Central to the 2021 research is a survey completed by (or on behalf of) 3,266 people who have osteoporosis between 7 June and 7 July 2021. Ten of those respondents completed the survey over the phone with the rest completing the survey online. 26 of the responses were completed on behalf of someone who has osteoporosis, with the rest being completed by the person who has osteoporosis themselves. The Royal Osteoporosis Society promoted the survey in 2021 to their own members and through their own channels and contacts. In 2014 the survey was promoted in the same way but with the addition of a booster sample which was not collected through Royal Osteoporosis Society channels. Following the

survey in 2021, 15 people took part in in-depth video interviews to give us further depth of insight into the reality of people living with osteoporosis. Case studies were developed based on these interview responses and have been included in this report.

The timing of the 2021 project during the COVID-19 pandemic should be taken into account when thinking about differences in results between the 2014 and the 2021 project. The findings represent the thoughts and feelings of the people in the 2021 sample.

### Sources for osteoporosis facts on page 4

<sup>1</sup> International Osteoporosis Foundation. ‘Broken Bones, Broken Lives: A Roadmap to Solve the Fragility Fracture Crisis in the United Kingdom’, 2018

<sup>2</sup> British Orthopaedic Association. The Care of Patients with Fragility Fracture, 2007

<sup>3</sup> Echo – Global Research. Protecting Brands and Reputation. Brand Awareness & Audience Insights Study [Internal report commissioned by Royal Osteoporosis Society (formerly National Osteoporosis Society)], 2013

<sup>4</sup> Royal Osteoporosis Society (formerly National Osteoporosis Society). Stop at One Survey, 2013

# We need *your* help

Millions of people with osteoporosis are living every day in pain and fear, their lives are shrinking along with their bodies, and they are struggling to hold on to the things and people they love. We want to end the pain of osteoporosis and make sure everyone has a life free of fragility fractures. We can't get there alone, we need your help.



## Talk to us

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

Call our free osteoporosis Helpline on 0808 800 0035 or email [nurses@theros.org.uk](mailto:nurses@theros.org.uk)

Become a member by calling 01761 473287 or emailing [membership@theros.org.uk](mailto:membership@theros.org.uk)

Find expert information on our website. [theros.org.uk/information-and-support](https://theros.org.uk/information-and-support)



## Talk about it

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



## Write to your MP

Your MP is there to represent you. Visit our website for a template letter to share your concerns with your MP, or your elected official in Scotland, Wales and Northern Ireland.

[theros.org.uk/how-you-can-help/campaign-with-us](https://theros.org.uk/how-you-can-help/campaign-with-us)



## Support us

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

[theros.org.uk](https://theros.org.uk)



## Our vision

A future without osteoporosis

## Our mission

We will:

- Improve the bone health of our nation and prevent osteoporosis.
- Influence healthcare providers and professionals to deliver high quality healthcare so that people are assessed and treated for osteoporosis earlier.
- Provide the best information, support and services to help people with osteoporosis live well.
- Drive the research and development of new treatments and therapies that will ultimately beat osteoporosis.

## Get in touch

Helpline: 0808 800 0035

[theros.org.uk](https://theros.org.uk)

[info@theros.org.uk](mailto:info@theros.org.uk)



[info@theros.org.uk](mailto:info@theros.org.uk)



[@RoyalOsteoSoc](https://twitter.com/RoyalOsteoSoc)

President: HRH The Duchess of Cornwall

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