

A Good Life with Osteoporosis

Key findings from research into the information and support needs of people with osteoporosis

Introduction

'A Good Life with Osteoporosis' was commissioned by the National Osteoporosis Society to focus on the support and information available to people with the condition. This latest research follows the landmark study about the impact of osteoporosis and fragility fractures on people's lives, 'Life with Osteoporosis: the untold story' published in October 2014. This paper summarises some of the key findings.

We recognise that, for people living with osteoporosis, access to good quality information and support focused on their experience and their needs is important. This study provides us with invaluable insight that will help us shape our services over the coming years.

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 men

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



Every year there are 300,000 fractures

That's almost 1 fracture every 2 minutes



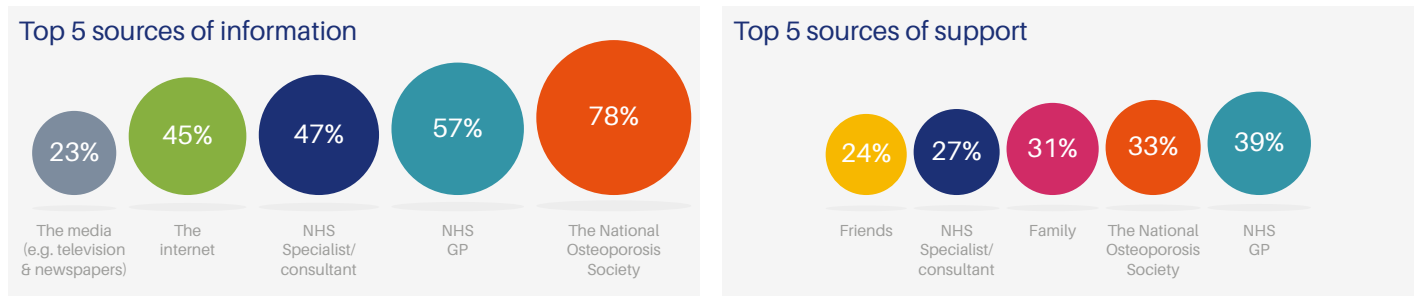
Only 25% of adults are familiar with the term osteoporosis



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

Where do people look for information and support?

We asked respondents where they have obtained information and support relating to their experience of osteoporosis. When it comes to looking for information the National Osteoporosis Society is the top source of information, followed by the patient's GP and this order is then reversed when it comes to support.



We also asked participants how they access information and support. Leaflets are the most frequently used source of information, followed by speaking to others, face-to-face and websites. For support the people in the study look to face-to-face contact, the telephone and support groups.



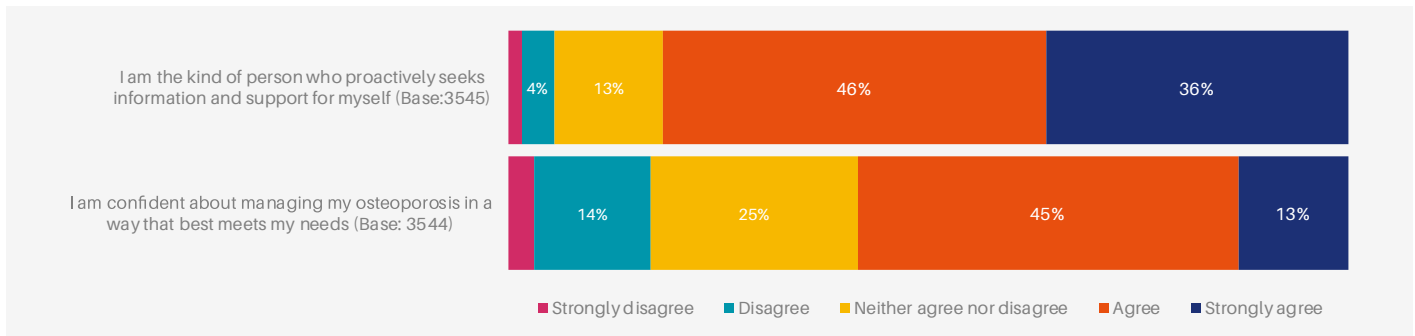
Getting online

The people in our study ranged in age from 23 to 98 and just over 50% were aged 70 or older. 80% of our sample use the internet at home and 80% of them go online every day. 31% of people using the internet do so via a mobile phone.



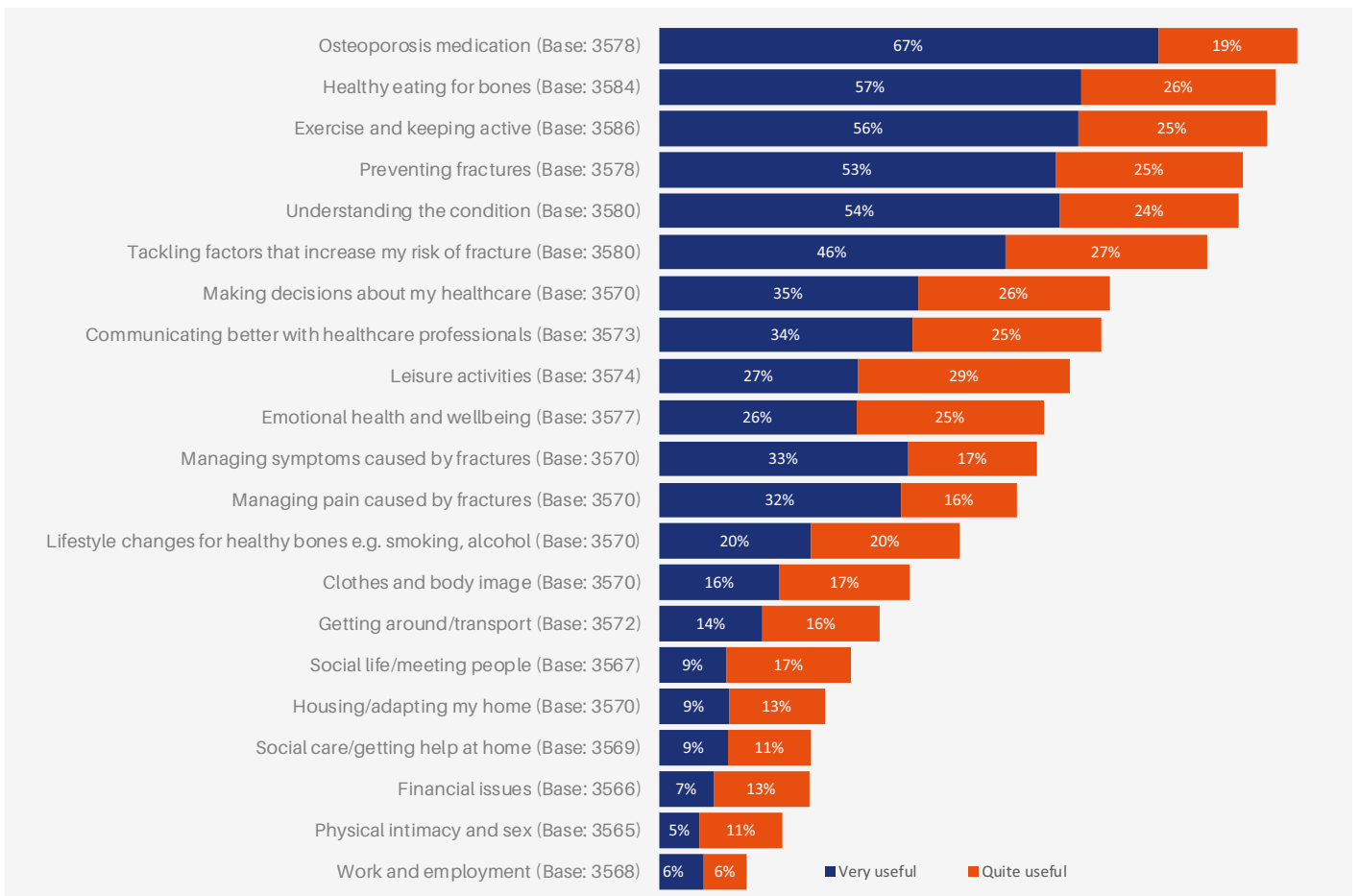
How confident are people in managing their own condition?

Over 80% of people see themselves as proactively seeking information and support. 58% are confident they are managing their condition in a way that best suits their needs with a further 17% much less confident.



What information and support would people find useful?

People with osteoporosis are looking for information or support on a wide variety of topics with over 80% interested in medication, healthy eating, exercise and being active; over 70% see information and support around preventing and reducing the risk of fractures and managing their condition as useful. Interestingly 60% are looking for information and support on making decisions about their healthcare and communicating with healthcare professionals.



What piece of information and support have people found most useful?

We asked people what one piece of information or support they have found most useful; a selection of responses are provided below.

Dietary advice

"Dietary advice – to get calcium & other necessary minerals from food as much as possible."

Female, aged 67

Understanding the effects

"The article in NOS newsletter about the implications of spinal fractures and the problems that may arise due to loss of height."

Female, aged 86

Knowledgeable healthcare professionals

"The expertise and friendliness of the specialist team at my local hospital. From the initial diagnosis, they have explained what my treatment is and how it works, answer any queries that I have and effortlessly make me feel supported and confident."

Female, aged 68

National Osteoporosis Society

"At a particularly worrying time, I phoned the NOS helpline about my condition and was given very sensible information and support. I wasn't rushed and had great confidence in the nurse adviser, this wasn't the case with my GP."

Female, aged 59

Keeping active

"In the very beginning to take up load bearing exercise. I took up tai chi and twenty years later it stands me in good stead and helps with osteoporosis and other ageing problems"

Female, aged 78

Connecting with others

"The osteoporosis and pregnancy group I joined on Facebook, I finally didn't feel like the only person in the world that had this disease at such a young age."

Female, aged 37

Method

This study was conducted by an independent agency, Alterline. A questionnaire with both quantitative and qualitative questions was designed by Alterline in collaboration with the National Osteoporosis Society. 3597 people who have osteoporosis (or someone on their behalf) completed the survey between 1st September and 8th November 2015.

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