

UNDERSTANDING ARTHRITIS

A parliamentary guide to musculoskeletal health



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Arthritis Research UK

Arthritis Research UK is the leading authority on arthritis in the UK, conducting scientific and medical research into all types of arthritis and other musculoskeletal conditions. It is the UK's fourth largest medical research charity and the only charity solely committed to funding high quality research into the cause, treatment and cure of arthritis.

Our remit includes arthritis and musculoskeletal conditions, which are disorders of the joints, bones and muscles – including back pain – along with rarer systemic autoimmune diseases such as lupus. Together, these conditions affect around ten million people across the UK and account for the fourth largest NHS programme budget spend of £5 billion in England.

Arthritis is the biggest cause of pain and disability in the UK, and each year 1 in 5 of the general population consults a GP about a musculoskeletal condition. As a charity we fund research, provide information to patients and educational resources for health professionals.

1. WHAT IS MEANT BY ARTHRITIS AND OTHER MUSCULOSKELETAL CONDITIONS?

Arthritis is a general term that most people use to mean painful joints. Medically, it refers to a number of different conditions leading to inflamed or damaged joints. The term *musculoskeletal conditions* is often used to include a broad range of health conditions affecting bones, joints and muscles, pain syndromes and rarer conditions of the immune system such as lupus.

Arthritis and other musculoskeletal conditions are primarily long term conditions. Common features of these conditions are pain, joint stiffness and limitation in movement. The symptoms fluctuate in severity over time and often cause depression. Pain is invisible and people are sometimes not aware how severely musculoskeletal conditions can impact on people's lives. Untreated arthritis leads to pain, disability and loss of quality of life.

Broadly there are three groups of musculoskeletal conditions. The first group is inflammatory conditions such as rheumatoid arthritis, where the immune system attacks and destroys the joints and sometimes the internal organs. These conditions are usually treated in hospitals by specialists known as rheumatologists and require drug treatments.

The second group includes conditions of musculoskeletal pain such as osteoarthritis and back pain. In osteoarthritis there is painful wear and degeneration of joints. These conditions are normally treated by GPs in primary care, affect large numbers of people and management usually involves physical activity and pain management. Severe cases of osteoarthritis can result in the need for joint replacement, which can give people back their mobility.

The third group is osteoporosis and fragility fractures. These happen when frail bones break, sometimes after a minor trip or fall (including falling from standing height). Fragility fractures affect large numbers of people and are commonly caused by osteoporosis where bones weaken with age. Identification of those at risk of a fragility fracture takes place mainly in primary care where treatments, including medication, can be prescribed. Broken bones, however, require hospital treatment which can require surgery. Long term pain and loss of independence are common, and older people may not survive the trauma of a major fracture.

Figure 1: What are the common characteristics of musculoskeletal conditions?

Arthritis and other musculoskeletal conditions include over 200 conditions.
Common symptoms across musculoskeletal conditions include pain, joint stiffness, limitation in movement and fluctuation in severity over time.

Group one: inflammatory conditions	Group two: conditions of musculoskeletal pain
<p><i>Example: rheumatoid arthritis</i></p> <p>Common features:</p> <ul style="list-style-type: none"> » Age: affects any age » Progression: often rapid onset » Prevalence: less common, around 1% of the population » Impact: internal organs can be affected » Location of treatment: urgent specialist treatment in hospital needed, including drugs » Interventions: treated by a range of drugs » Risk factors: genetics, smoking 	<p><i>Example: osteoarthritis</i></p> <p>Common features:</p> <ul style="list-style-type: none"> » Age: rare in the young » Progression: gradual onset » Prevalence: very common, around 8.75 million people in the UK have sought treatment for osteoarthritis » Impact: affects the joints and pain system » Location of main treatment: treatment based in primary care » Interventions: treated with physical activity, pain management; for severe cases, joint replacement surgery may be necessary » Risk factors: age, physical injury, obesity, gender

Osteoporosis is a silent weakening of bone and in itself is painless.
Fragility fractures caused by osteoporosis happen when frail bones break causing pain and disability.

Group three: osteoporosis and fragility fractures*

Example: broken bone after falling from standing height

Common features:

- » **Age:** affects mainly older people
- » **Progression:** osteoporosis causes gradual weakening of bone; fragility fractures can happen due to a minor trip or fall
- » **Prevalence:** very common
- » **Impact on person:** hip, wrist and spinal bones are most common sites of fractures
- » **Location of main treatment:** prevention is based in primary care, fractures may require surgery
- » **Interventions after fracture:** surgery may be needed; bone-strengthening medication and falls prevention services reduce risk of further fractures
- » **Risk factors:** age, gender, smoking, alcohol, genetics, inflammatory conditions, poor nutrition, insufficient vitamin D levels, low levels of physical activity

*Fractures can also be due to trauma, such as a broken bone owing to an injury. In this report we have focused on fractures that are due to an underlying musculoskeletal condition.

2. WHO ARE THE HEALTH PROFESSIONALS INVOLVED IN MUSCULOSKELETAL HEALTH?

There are a number of different health professionals involved in the treatment of people with arthritis and musculoskeletal conditions. People with inflammatory conditions are generally referred to rheumatologists for specialist care. Orthopaedic surgeons may operate on severely damaged joints. Conditions of musculoskeletal pain such as osteoarthritis and back pain will mainly be cared for by GPs in primary care, unless joint replacement surgery is needed. Likewise, most people with osteoporosis are treated by their GP, unless they break a bone and need orthopaedic surgery. Not every person with the same condition will need support from the same health professionals and decisions should be made on the basis of need.



Figure 2: Diagram of health professionals involved in the treatment of people with musculoskeletal conditions

The person with a musculoskeletal condition			
Supported self management			
Primary care		Specialist care	
General Practice	Orthopaedics	Rheumatology	Pain medicine
e.g. assessment, diagnosis, routine care, referrals, care planning	e.g. specialist assessment and diagnosis, injections, surgery	e.g. specialist assessment and diagnosis, specialist drugs, injections	e.g. specialist assessment and diagnosis, specialist drugs, injections
With ongoing specialist input from: Physiotherapy, occupational therapy, podiatry, nursing, psychology and other health and social care professionals			

People with musculoskeletal conditions receive medical care from various medical teams including general practice, specialist medical (rheumatology) and surgical (orthopaedic) teams

3. ARTHRITIS AND MUSCULOSKELETAL CONDITIONS IN NUMBERS

AFFECTS OVER 10 MILLION PEOPLE IN THE UK

£5 BILLION NHS SPEND ON MUSCULOSKELETAL HEALTH BUDGET

4th LARGEST NHS PROGRAMME BUDGET

*Each year **20%** of the general population consults a GP about a musculoskeletal problem*



ONE IN FIVE PEOPLE IN THEIR 50s HAS OSTEOARTHRITIS IN THEIR KNEE

Over **80,000** hip replacements and over **84,000** knee replacements in 2011 alone

89,000 hip fractures each year in the UK

£14.8 BILLION indirect costs to the economy of osteoarthritis and rheumatoid arthritis. **£10 BILLION** indirect costs to the economy of back pain

£2 BILLION SPEND ON HIP FRACTURES A YEAR

4. WHAT IS THE IMPACT ON INDIVIDUALS, THE HEALTH SERVICE AND WIDER SOCIETY?

Arthritis and other musculoskeletal conditions cost the NHS around £5 billion per year¹. Arthritis and other musculoskeletal conditions are mostly long term conditions that can cause persistent pain resulting in substantial impact on quality of life over decades. Musculoskeletal conditions account for the largest proportion of years lived with disability in the UK².

Impact on the individual

The impact on the individual and their quality of life can be substantial. More than one third of the population aged over 50 years have arthritis pain that interferes with their normal activities.³

For the most common form of arthritis, osteoarthritis, nearly three-quarters of people with the condition report some form of constant pain with one in eight describing their pain as often *unbearable*.⁴ Osteoarthritis of the knee causes *pain and disability* to one in five people in their 50s, rising to one in three people by age 75 years.⁵

Over five million people in the UK live with osteoarthritis of the hand.⁶ Women are twice as likely to experience this *painful condition that limits the ability to perform and enjoy every day activities*.⁷

Rheumatoid arthritis is the second most common form of arthritis in the UK and is a progressive condition that can impair people's ability to plan their lives. People living with rheumatoid arthritis often talk about 'flare ups' where the condition is at its most painful. A third of people diagnosed with rheumatoid arthritis will have stopped work within two years of onset.⁸

Back pain is a major cause of both pain and lost work. Though often self-limiting, one in six adults aged over 25 years reports *back pain lasting over three months in the last year*.⁹

Fragility fractures are very common. One in two women and one in five men over the age of 50 will break a bone as a result.¹⁰

Impact on the health service

Each year 20% of the general population consult their GP about a musculoskeletal problem such as arthritis.¹¹ The majority of these primary care consultations are for osteoarthritis and back pain and these account for a substantial volume of GPs' work. About 8.75 million people in the UK over 45 years of age have sought treatment from their GP for osteoarthritis.¹² Rising obesity and an ageing population will cause this number to increase requiring additional primary care capacity to provide high quality care.^{13,14}

Good data is available for surgery such as joint replacements for osteoarthritis or to treat a hip fracture. We know that over 66,000 hip and over 77,000 knee replacements were performed in 2011 for people with osteoarthritis.¹⁵ There is a lack of data collected for people with severe arthritis who visit specialists in hospitals. Yet each year in England there are around 1.5 million hospital specialist consultations with rheumatologists for people with severe arthritis.¹⁶ The NHS does not routinely collect data about patients' conditions and treatments in outpatient appointments. This lack of data about arthritis and musculoskeletal conditions makes it challenging for health services commissioners to properly assess or plan local musculoskeletal health services.

Local authorities and Clinical Commissioning Groups in England have new duties to prepare a Joint Strategic Needs Assessment (JSNA) for their local population. JSNAs are intended to assess the health needs of the local population. The JSNA along with the Joint Health and Wellbeing Strategy (JHWS) informs and guides commissioning of services in the local area. As highlighted in the Chief Medical Officer's 2011 annual report, it is difficult to obtain accurate data on prevalence of conditions such as osteoarthritis.¹⁷ It is important that local JSNAs recognise both the prevalence of arthritis and musculoskeletal conditions, as well as the benefits of physical activity related to such conditions, so that services are appropriately planned for people living with these conditions.

Impact on society

Musculoskeletal conditions account for the largest proportion of years lived with disability in the UK. Present trends suggest that musculoskeletal disorders will increase further as our population ages.¹⁸ In the future, more people will live with the pain and disability of arthritis or a musculoskeletal condition.

In the UK hip fractures costs around £2 billion on annual clinical and social care costs.¹⁹ Owing to demographic change, the cost of treating and caring for hip fractures in the UK could rise to £6 billion by 2036.²⁰

Living with a painful musculoskeletal condition can cause depression, which is four times more common for those with persistent pain than without.^{21,22,23,24} Furthermore, 82% of people with osteoarthritis have at least one other long term condition such as hypertension or cardiovascular disease which can exacerbate the impact of osteoarthritis itself.²⁵

Each year around 7.5 million work days are lost because of musculoskeletal conditions, second only to mental health problems.²⁶ The costs of this, along with other indirect costs, come to an estimated £14.8 billion for osteoarthritis and rheumatoid arthritis,²⁷ with a further £10 billion of indirect costs attributable to back pain in the UK.²⁸

Musculoskeletal conditions, including osteoarthritis,²⁹ are an unrecognised public health priority. Many of the risk factors for musculoskeletal conditions such as lack of physical activity, obesity, poor nutrition and workplace injury, are amendable to public health interventions. A nationally co-ordinated approach via Public Health England is required to improve musculoskeletal health. This will both reduce people's risk of developing painful musculoskeletal conditions as well as enabling those with arthritis to lead full and active lives.

5. INFLAMMATORY CONDITIONS

In inflammatory conditions such as rheumatoid arthritis the immune system attacks the body's own tissues causing painful inflammation and damage to the joints and can harm the internal organs.

People with these conditions live with daily pain and stiffness, affecting their ability to work and get around. These conditions can flare unpredictably making it difficult for people with them to live their everyday life. Depression is common for people with these conditions, further reducing their quality of life.

People who develop an inflammatory condition require:

Urgent specialist referral: GPs must recognise the features of these conditions and refer urgently to specialist care for treatment. Early, intensive treatment can substantially reduce long term pain and disability. The NICE Quality Standard* for rheumatoid arthritis includes information on signs and symptoms that should trigger a referral.

Early, intensive treatment: Best practice care for people with inflammatory conditions such as rheumatoid arthritis requires urgent rheumatology assessment and initiation of appropriate treatment within six weeks of referral. A Best Practice Tariff (a Payment by Results financial incentive for rheumatology departments in hospitals) for early inflammatory arthritis is available to ensure that people get the right treatment, at the right time.

Supported self-management: People with inflammatory conditions can benefit from the support of health professionals and others living with similar conditions to enable them to take control of their health while living with complex, severe conditions.

Access to care planning: Care planning puts people with long term conditions at the centre of all decisions about their health. This approach has delivered important benefits in other serious conditions such as diabetes, including by linking up different aspects of care. People with inflammatory conditions require many types of care from multiple professionals and could benefit from a care planning approach.

Mental health support: Depression and anxiety are very common in inflammatory conditions such as rheumatoid arthritis.³⁰ People living with their conditions should be routinely asked about depression and anxiety, and offered support and a choice of treatments for their mental health as well as physical needs.

*Quality Standards are published by NICE and are a short set of statements to help drive improvements in quality of care.

A view of a personal experience of living with rheumatoid arthritis

'Since being diagnosed with rheumatoid arthritis four years ago my life has changed beyond all recognition – but one of the difficulties I face is that on the outside I still look to everyone else the same as I would have done five years ago. The other main problem is the variability of my condition. Some days I have been able to do 'normal' things, but sometimes even the most simple task like a supermarket shop feels like how I imagine running a marathon must feel.

"This makes it very difficult to plan – I am permanently nervous about making commitments that I don't know I can keep. It's one of the main reasons why I am now on long term sick leave from the job I loved. The emotional side of having a musculoskeletal condition such as rheumatoid arthritis is, in my opinion, also much ignored. I have found the loss of my career and previous lifestyle very hard to come to terms with and have been treated for depression. Overall my condition is constantly changing, as is the way in which I and those around me are able to cope with it."

- Eleanor Goddard, 38, person with rheumatoid arthritis

New developments in the care of rheumatoid arthritis:

The latest Quality and Outcomes Framework (QOF) includes four indicators on rheumatoid arthritis. The QOF is a financial incentive for GPs and rewards them for the management of the care for their patients. The QOF indicators for rheumatoid arthritis are aimed at improving care for those living with the condition. Find out more here: <http://www.nice.org.uk/aboutnice/qof/>

The Best Practice Tariff for early inflammatory arthritis is now being implemented in the NHS in England. The Best Practice Tariff is an incentive for hospitals to ensure people with early inflammatory arthritis get the early, intensive treatment that they need to prevent long term pain and disability. Find out more here: www.arthritisresearchuk.org/policy-and-public-affairs/policy-priorities-and-projects/musculoskeletal-health-services/best-practice-tariff-for-early-inflammatory-arthritis.aspx

6. CONDITIONS OF MUSCULOSKELETAL PAIN

Conditions of musculoskeletal pain such as osteoarthritis involve painful damage to joints over time, as well as conditions such as back pain. These conditions are uncommon in young people, and the onset is gradual.

When severe, the pain and disability of these conditions can be debilitating, stopping people living full lives. Over one hundred and forty thousand people each year in England and Wales have a joint replaced to relieve the pain of osteoarthritis and restore their quality of life.

People living with musculoskeletal pain need:

Supported self-management: Appropriate support and high quality information from health professionals and others living with similar conditions can enable people to manage their own symptoms. Physical activity and weight loss can substantially reduce the pain of arthritis. By developing coping strategies and addressing emotional and psychological needs, people can improve their quality of life.

To have their needs taken into account: Many people living with a long term condition will also have osteoarthritis. Unless specifically asked about their pain and disability, many will not raise this with their doctor. People with a long term condition should routinely be asked about their musculoskeletal health so they can access the therapies and support they need. For example, someone with diabetes and arthritis will benefit from exercise, but unless their arthritis is addressed, they may find this difficult.

Access to care planning: Care planning puts people with long term conditions at the centre of all decisions about their health. People with conditions such as osteoarthritis and back pain require a range of services and therapies to maintain quality of life. These may include physiotherapy and physical activity, weight loss support, psychological services, occupational therapy and medication. These must be tailored to personal preferences and needs. Many people with osteoarthritis will have another long term condition. A care planning approach allows them to prioritise their own health and wellbeing needs. Currently only 18% of people with osteoarthritis have a care plan³¹, despite NICE guidelines recommending that everyone with osteoarthritis should have an agreed management plan.³²

Mental health support: Living with painful conditions such as osteoarthritis can lead to depression and anxiety. GPs should routinely ask people with musculoskeletal conditions if they are experiencing depression and anxiety, and offer support and treatment for mental health as well as physical needs.

Appropriate referral to joint replacement surgery: Joint replacement surgery is a highly effective treatment for severe osteoarthritis, and can restore quality of life for people living in constant pain. People waiting for joint replacement surgery should be informed of their NHS Constitution right for consultant led-treatment within 18 weeks of GP referral.



A view of a personal experience of living with osteoarthritis

Terry has had severe osteoarthritis since her 50s and has had four joint replacements - both her shoulders, her left hip and left knee. She is having cortisone injections in her painful right knee, which will need replacing soon.

"My GP suggested a partial knee replacement, so I was absolutely shocked when I saw the surgeon who showed me the x-ray of my knee and there was no cartilage left at all, and I needed a total knee replacement", she says. "I thought that only happened to people who were really old, and I was only 58.

"I thought I'd get to retirement age and still be active and have a good quality of life, but now I'm not sure if that will be the case. I just hope that by the time my daughters and granddaughters are my age, there will be something that can be done other than joint replacement surgery." - Terry, 66, lived with osteoarthritis since her 50s

Figure 3: What is osteoarthritis and what are the risk factors?

Healthy joints move painlessly due to an even layer of smooth cartilage coating the ends of bones. In osteoarthritis, cartilage becomes thinned and pitted, and can wear away completely, which can cause severe pain and disability. The causes of osteoarthritis are not fully understood, but there are many factors which increase the risk of osteoarthritis:

Risk factors for osteoarthritis

Late 40's onwards

More common in women

Obesity

Previous joint injury or disease

Genetic factors

RISK OF OSTEOARTHRITIS

7. OSTEOPOROSIS AND FRAGILITY FRACTURES

Osteoporosis is a silent weakening of bone, which in itself is painless. The first sign of a problem may be when a fragile bone breaks, causing pain and disability. Healthy bones are sturdy and can easily cope with everyday knocks. For millions of people with osteoporosis a minor fall - even from standing height - can result in a major fracture.

There are 89,000 hip fractures every year in the UK.³³ Fragility fractures can rob people of their independence and mobility, sometimes causing persistent severe pain. Nearly 14,000 people die in the UK following a hip fracture.³⁴ People with osteoporosis are also at risk of severe spinal pain if a fragile spinal bone spontaneously collapses.

Following a fragility fracture, people need:

Access to fracture care: High quality care includes prompt assessment in A&E followed by rapid surgery if needed. Many people who break a bone have other, additional long term conditions such as heart or lung problems that can affect their recovery. Specialist medical care can therefore reduce complications and improve outcomes.

Access to rehabilitation: Over half of people who were previously independent are unable to walk independently in the year after a hip fracture.³⁵ Physiotherapy and occupational therapy therefore have an important role in restoring independence.

Effective pain management: The pain of fractures may last long after the initial break, particular for collapsed spinal bones. People with persistent pain need access to appropriate therapies including medication, surgery and physiotherapy, and referral to specialist pain management if necessary.

Accurate diagnosis: Collapsed spinal bones can be hard to detect, as the only symptom may be sudden severe back pain. It is important that people at risk of these fractures have the correct diagnostic tests performed if they develop these symptoms.

Support to prevent further fractures: People who have had a first fracture should receive care to prevent a second. Fracture Liaison Services (FLSs) linked to hospitals are a clinically proven and cost-effective way to prevent further fractures. Risk of future fractures is substantially reduced with an approach combining bone-strengthening medication, nutritional advice and support to prevent falls.

Fragility fractures in older people are often caused by a fall. The Falls and Fractures Alliance (FFA)* has been established to provide an integrated approach to prevention and management in these areas.

Three million people in the UK have osteoporosis and are at risk of a life-changing fracture. For many, understanding of the risk factors of this silent condition can help prevent them ever breaking a bone. The number of people affected by broken bones will rise owing to demographic changes: the cost of treating and caring for hip fractures in the UK could rise to £6 billion by 2036.³⁶ Risk factors include age, family history, gender, low body weight and some medications. Smoking and alcohol both weaken bone. Those with a family history of this condition are at increased risk which for women increases further after the menopause.

Availability of Fracture Liaison Services

A Royal College of Physicians and HQIP audit in 2010 found that only 37% of local health services in England provided any kind of Fracture Liaison Service.³⁷ There are many local areas without these services that can help prevent further unnecessary broken bones, the pain they cause and the additional cost to the health service.

* The National Osteoporosis Society (NOS) and Age UK have established the Falls and Fractures Alliance (FFA). For more information please see www.nos.org.uk

8. RECOMMENDATIONS TO IMPROVE HEALTH AND WELLBEING FOR PEOPLE LIVING WITH ARTHRITIS AND MUSCULOSKELETAL CONDITIONS

Much responsibility for running health services now rests with NHS England and with local health bodies. The Government holds NHS England to account via the NHS Mandate, which sets out the Government's high level priorities for the health service and via specific measures in the NHS Outcomes Framework. Local Clinical Commissioning Groups (CCGs) are in turn accountable for their performance to NHS England. Local authorities have a new responsibility for public health, with Health and Wellbeing Boards being a key local forum for identifying and driving the health needs of the local population.

To improve health and wellbeing for people living with arthritis and musculoskeletal conditions, Arthritis Research UK would like to see the following recommendations implemented:

1. NHS England should ensure they fulfill the NHS Mandate objective to offer everyone with a long term condition a personalised care plan.
2. Musculoskeletal conditions should be included in Public Health England's three year set of priorities from 2014-16.
3. Clinical Commissioning Groups should ensure a Fracture Liaison Service is linked to every hospital involved in the care of people with fragility fractures.
4. NHS England working with the Health and Social Care Information Centre should prioritise the systematic collection of data about patients' conditions and treatments in data-poor areas such as Rheumatology and Orthopaedic outpatient appointments and community care settings.
5. GPs should routinely ask people with musculoskeletal conditions if they experience depression and anxiety.

Questions to ask nationally through letters and parliamentary questions	Questions to ask your local Clinical Commissioning Group	Questions to ask your local Health and Wellbeing Board
Will Public Health England make musculoskeletal conditions one of their priorities for the next three years?	What services are available to cater for people who experience a fracture? Is there a Fracture Liaison Service?	Does your local Joint Strategic Needs Assessment (JSNA) include consideration of arthritis and musculoskeletal conditions?
Will NHS England collect data about patients' conditions and treatments in Rheumatology and Orthopaedic outpatient appointments? How will NHS England champion everyone with a long term condition including with arthritis being offered a care plan?	How are your local GPs identifying if people with arthritis also have depression and anxiety? Are your local GP surgeries engaged with the new Quality and Outcomes Framework (QoF) for rheumatoid arthritis and osteoporosis?	Is the relationship between osteoarthritis and obesity recognised in your JSNA and what are the local priorities for tackling obesity and encouraging physical activity?

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