



Information for people with bone and joint problems

Getting the most from your local health services



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Section 1

How reading this
booklet can help



Millions of people in England live with disorders of bones, joints and other tissues, such as ligaments. These are known as musculoskeletal conditions and they affect adults and children.

There are over 200 musculoskeletal conditions, including all forms of arthritis, back pain, osteoporosis, connective tissue diseases such as scleroderma, and soft-tissue rheumatism.

Musculoskeletal injuries such as broken bones caused by accidents – for example in the home or on the road – can have short-term effects, but often result in longer-term or sometimes permanent disabilities.

This booklet is for you if:

- you have a musculoskeletal condition, or you are a parent or carer of someone who has;
- you've felt frustrated about not being able to get the treatment or advice you need from your health service when you need it; or
- you are getting good care from your local health and social-care services, but feel you could be getting even more out of them.

“Being able to make your own decisions is one thing, but you have to have the knowledge, so access to the right information is crucial.”

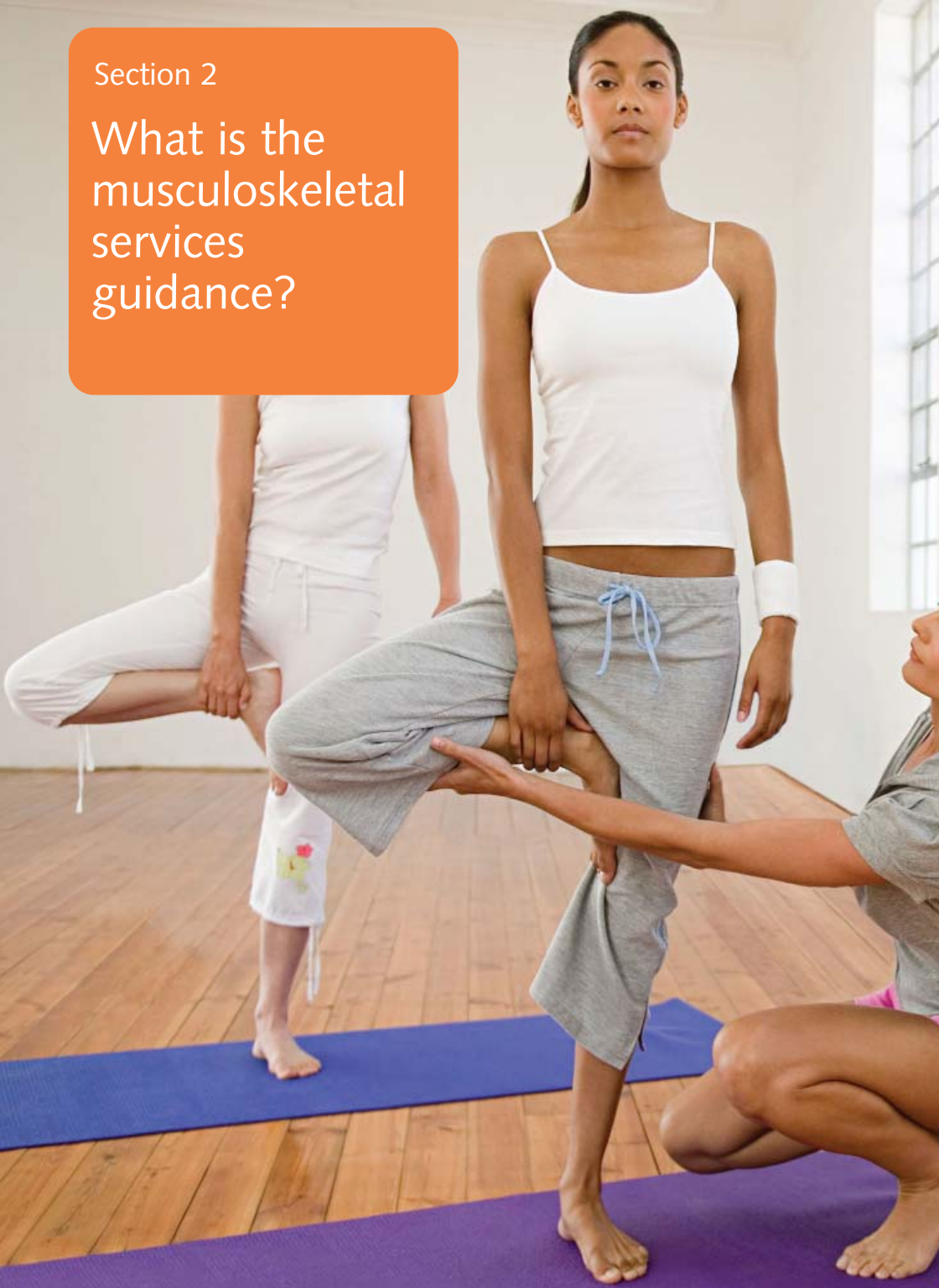
Arthritis Care and the Department of Health have come together to produce this short guide to tell you about changes to improve the services you receive, whether you are newly diagnosed or have a long-standing condition or injury.

The changes are described in **new guidance for the NHS and social services** designed to help improve the care offered to adults and children with musculoskeletal conditions, whether caused by a disease, such as arthritis, or an injury. You can find out more about the guidance by following the link to the Department of Health website on page 27.

This booklet has been written to explain how GP practices, physiotherapy, occupational therapy, other community services and hospitals can work together to provide services focused on the needs of you and your family. The information will help you work with health and social-care staff to make sure you get the right care, from the right person, at the time it will benefit you most.

Section 2

What is the musculoskeletal services guidance?



“Getting the right care can be such a maze. It feels like you’re on a treadmill, and sometimes you fall off and have to go all the way back to the beginning.”

The musculoskeletal services guidance describes a different way of organising musculoskeletal care and support. This will make sure that you receive high-quality care at every stage – wherever you live and whatever your background.

- *Patient led teamwork*

The guidance emphasises that all the people involved in your care – including GPs, physiotherapists, podiatrists, nurses, occupational therapists, rheumatologists, surgeons, chiropractors, osteopaths, social services professionals and, crucially, you – will need to work together and share your care. For children, young people and families, the team includes people working in early years centres and schools. You will be involved in making decisions about your care, and be supported to have the choices you want – for example, choosing to consult a physiotherapist rather than a GP first.

- *Evidence for high-quality care*

It is based on good practice in co-ordinating care, and in the choice of treatments, such as physical techniques, technology, medicines and orthopaedic surgery. For example, if people injured in traffic accidents are given expert care early, the level of their potential later disability is significantly reduced.

- *A smoother journey*

It encourages all health and social-care organisations to work with you to help you get the most from every contact you have with the services. You will move smoothly from one part of your care to another and you will have the opportunity to discuss your options with trained professionals along the way. The links between the different areas of your care will improve through good communication, information and better working arrangements between professionals.

The guidance has been put together with a great deal of input from patients themselves, and from many organisations such as Arthritis Care which represent the interests and real experiences of millions of people with musculoskeletal conditions.

Section 3

Why are things changing now?



“When I was diagnosed my GP was really good. I was referred immediately to a rheumatology clinic and everything was done really quickly. My GP took it seriously and his communication was excellent.”

Musculoskeletal conditions have a significant effect – not only on you as an individual, but on the whole country:

- Twenty per cent of all GP visits are about musculoskeletal problems.
- It is estimated that 8–10 million people in the UK have arthritis, including 1 million adults under the age of 45, around 12,000 children, and 70% of 70-year-olds.
- Sixty per cent of people on long-term sick leave say musculoskeletal conditions are the reason for their absence.
- As a society, the population is increasing and we are living longer. This means there will be more people with conditions such as osteoarthritis and osteoporosis in the future.

The NHS and social services are responsible for providing you with a wide range of services – from simple advice to highly technical surgical and other treatments. Working effectively together leads to fewer delays in assessment, diagnosis, treatment and support. It helps you reach the best possible level of health, which will improve your overall quality of life and your ability to work.

“I’m really annoyed at having to keep repeating all my information every time I see the doctor.”

There is now an urgent need to bring musculoskeletal services up to date. The new guidance sets out improvements that can be made to achieve that. It also reflects the Government’s main aim of creating an NHS where health services are organised around your needs and your choices.

The new guidance, and the changes it calls for, is the link in making the Government’s priorities an everyday reality for people with musculoskeletal conditions.

Section 4

What does
all this mean
for me?



The health needs of one local community will always be different from those of another. So local health and social-care services will each want to work out what new services their patients need and what improvements will help them most.

There are, however, some important changes that everyone can expect to see as local health organisations get to grips with this new approach to musculoskeletal services.

“I wanted clear, direct information at the point of diagnosis.”

i) Better information and advice

Many people who have minor neck, joint and back pain may want to treat themselves rather than visit their GP straight away. This is known as self-care. Some people can convince themselves that nothing can be done and they lose hope. *But the reality is that something can always be done.*

In all cases, good quality, accurate information that is relevant to you is essential. It can help you learn how to reduce your pain, avoid more severe symptoms, get moving again, and make more informed decisions about whether you need to see a GP or other health or social-care professional.

Local health and social-care organisations will be developing information tailored to meet your needs. This information will be available through things like booklets at your GP surgery, and more information about local self-help groups. There will also be a greater role for community pharmacists who can be an excellent and approachable source of advice on healthy living, and on medicines or other treatments.

ii) More support to help you manage your own condition

Your GP and the wider range of professionals working in your community will be important sources of ongoing support to help you manage your own symptoms more effectively.

- Your GP surgery could help you learn more about your condition. Their knowledge, combined with yours, will be crucial in helping you remain healthier, independent and able to work.
- You will be given advice on how to maintain a healthy lifestyle to reduce any risks that could make your condition worse. This could include advice on how to lose weight, give up smoking and take up safe exercise.
- Together with patient organisations such as Arthritis Care (see page 24 for more details), they will be able to put you in touch with a wide range of help, including local support groups and networks run by people with similar conditions to yourself.

- Even if you have a complex complaint, your health and social-care team will want to involve and support you in your care – perhaps linking you up with occupational therapists in your local authority so you get the equipment and support you need to live your life to the full. There are also many things you can do to help manage your condition yourself – your healthcare team will be able to support you in this.

“It’s frustrating waiting months for an appointment with the physiotherapist. I can’t wait – it compounds the problem. If I go to my GP I know I’ll get an appointment, but it’ll all be such a hassle.”

iii) Faster, more convenient access to a health or social-care professional can help you

If your symptoms are more severe, you will usually want to see a health professional to help you diagnose the problem and decide on the best treatment. And if you’ve had your condition for some time, you may need ongoing health and social-care services, such as support, advice and equipment.

Up until now, most people have gone to their GP first if they have a musculoskeletal problem – when really they might need the skills of a physiotherapist, a podiatrist, a nurse, chiropractor, osteopath, an assessment by an occupational therapist or advice from a community pharmacist. Some people who are confused about who to turn to, wait until their condition becomes worse and end up in their local accident and emergency department.

While GPs will continue to have a central role, you will be able to access your local health and social-care services more easily. These will offer you choices by:

- making it possible for you to arrange your own appointments with a wider range of professionals – for example a physiotherapist, nurse with specialist knowledge of musculoskeletal conditions, podiatrist, chiropractor or osteopath. Or, for children, a community paediatrician, health visitor or school nurse;
- making it easier for you to access a wider range of professionals in local settings like GP surgeries and NHS walk-in centres. These places are often much closer to where people live and don't involve long journeys or, say, time off work.

These professionals will have wide knowledge of the range of treatments available and will discuss them with you. They will also have the specialist skills to provide help when you need it and, importantly, they will have a good knowledge of how to get help from other professionals.

“An early diagnosis would have saved me pain, fear and money.”

iv) Faster diagnosis and earlier treatment

It is important that you see a health professional early when you first get symptoms. This is because earlier treatment can prevent deterioration and even disability. Better communication between everyone involved in your care is important so you get the best service.

- Setting up a service run by a range of different professionals – Clinical Assessment and Treatment Service (CATS) – is one new approach described in the new musculoskeletal services guidance. These services are likely to be run by a range of health professionals – such as physiotherapists, GPs or specialist consultants – with a mix of other staff such as nurses, pharmacists, podiatrists, orthotists, chiropractors or osteopaths. Consultant medical practitioners and other hospital staff will usually be involved too. This will bring together all the skills and resources needed to assess, diagnose, advise and treat you. The service might be based anywhere in the community.
- If the assessment you or your child has received suggests that more specialised care in hospital may be needed, the clinic will act as a co-ordinator. This means working closely with rheumatologists, orthopaedic surgeons, paediatricians and others to make sure that you are referred to hospital at the right time for you, that it happens quickly and that you choose the right hospital clinician or clinic for you. This is already happening in some parts of England, but we now need to make sure everyone benefits from similar arrangements.

- In some circumstances, the CATS may also:
 - book your surgery;
 - carry out checks to make sure you are fit for your operation; and
 - give you all the information you need about being in hospital.

v) A better experience if you do need hospital care

If you do need hospital care, you will want to be confident that you are getting the best treatment for you – and that you receive it as quickly as possible. The guidance stresses the need for hospitals and primary care services to work together to make sure that fast access to hospital care can be arranged when you need it.

The guidance covers the following points:

- You need to have access to the most appropriate investigations, surgical techniques and medicines.
- Newer medicines (such as anti-TNF alpha drugs for inflammatory arthritis) that have been proven to be effective should be available for you, if considered necessary by your medical team.
- Hospitals need to support their clinical staff to develop and maintain their skills, to share their expertise with others in the wider region and to deal with the rapid developments in technology and treatments for people living with musculoskeletal conditions.

- If you need specialist treatment such as complex shoulder or spinal surgery and you have to travel a little further than your local hospital, your treatment will be carried out by experienced clinicians with up-to-date expert knowledge of that procedure.
- If you are admitted to hospital for treatment, staff will need to think about the sort of follow-up care you will need when you leave hospital, during the early stages of your care. The hospital team will communicate with your GP, other healthcare professionals and social services, so the continued support you need is in place as soon as you leave hospital.

“When I went into hospital to have a knee replacement revision, no one asked me what support I had at home. It would have been nice to have been asked whether I would be able to cope or even what equipment I would need from social services.”

As well as providing high-quality care for you, this approach will help shorten the waiting time – from when your GP refers you to specialist care, to the time you are actually seen in the hospital. At present, you should be waiting no longer than three months to see a hospital consultant (for example an orthopaedic surgeon) as an outpatient, and no longer than six months for inpatient treatment. By the end of 2008, your total wait from GP referral for investigations and hospital treatment should be no longer than 18 weeks.

vi) A closer focus on the needs of children and their families

Musculoskeletal conditions caused by disease or injury are a major cause of pain and physical disability among children, and a significant factor preventing them reaching their educational, social and physical potential.

But children are not 'little adults' and have particular needs of their own when it comes to better, more joined-up health and social-care services. So, while children and their families will benefit from all the improvements outlined in the new musculoskeletal guidance, there are other more specific changes which should change their care for the better.

These include better pain-management services, for example in accident and emergency departments, and bringing in more professionals with specialist knowledge of assessing and treating musculoskeletal conditions in children.

Teenagers have their own issues – it is important to help young people with musculoskeletal conditions, and their families, to cope with moving from children's services to those for adults.

Section 5

When will I start to see real changes in my local services?



“Before I had my diagnosis I went to my GP. He kept track of my condition and chased up other health professionals He pushed and pushed to get a diagnosis and I really felt he was working for me.”

Making all these changes happen will be a challenge for local health organisations. Most of the good practice described in the guidance is already happening somewhere in the country, which proves it can be a reality right across the NHS and social services.

Such improvements will take time – for example, setting up Clinical Assessment and Treatment Service that bring together a wide range of professionals and skills will mean a lot of local planning. Each area will be responding to the changes differently, as the new guidance is a practical way forward for local health and social-care organisations rather than a set of rules.

But, local health and social-care organisations will be required to:

- support the Government’s 18-week initiative. This means that, by the end of 2008, people should be treated within an 18-week period from the time their GP refers them to hospital for treatment. Waiting times for orthopaedic surgery have already improved dramatically, but the new guidance will help to make sure that the improvements continue; and

- deliver on national standards and priorities – which include the changes to musculoskeletal services.

But of all the factors that will drive forward these improvements for people with musculoskeletal conditions, you – the patients and carers – are possibly the most powerful. Just by knowing about the changes which are now underway, you can feel confident about discussing with health professionals how the new guidance should be affecting your care for the better.

Although the improvements won't happen overnight, you should start to experience their effects on your own care in the near future. Arthritis Care and other organisations representing the interests of people with musculoskeletal conditions will also be campaigning to make sure services improve.

If, however, you don't feel that your local services are changing, ask your GP or other health professionals about them. See Section 6, 'Where can I get more information and support?'

Having your say about your local services

If you have any comments to make about your local services, or you would like more information, you can contact your local Patient Advice and Liaison Services (PALS). These have been set up in every primary care trust and NHS hospital trust to provide information and support to patients, as well as acting as a focal point for feedback from patients to inform service developments

You can contact PALS by:

- phoning your local hospital, clinic, GP surgery or health centre and asking for details of the PALS; or
- phoning NHS Direct on 0845 4647.

Trust contact details can be found by looking at NHS organisations on www.nhs.uk

Section 6

Where can
I get more
information
and support?



There are many organisations which can support you. Many provide excellent information – such as leaflets, booklets and websites – to help you understand and manage your condition. A number also offer confidential support, often through telephone helplines. They can also tell you about other resources if you need them.

A small number of organisations and their websites are listed below. You can also refer to the *Guide to Websites and other Resources* which, like this booklet, is published as a companion to the musculoskeletal services guidance on the Department of Health's website shown below. It provides information for anyone who is interested in musculoskeletal conditions, including patients, carers, staff or the general public.

Arthritis Care is the UK's largest voluntary organisation working with and for all people with arthritis. It runs a number of self-management programmes. It provides information and support on a range of issues related to arthritis, including exercise, independent living, managing care and improving quality of life. It also produces a lifestyle magazine called *Arthritis News*.

Arthritis Care campaigns locally and nationally to make sure people with arthritis have access to the treatments and services they deserve. It can also give you more details about local networks.

Arthritis Care is also a good first contact for people living with other musculoskeletal conditions and can put you in touch with more specialist organisations.

- Call Arthritis Care's freephone confidential helpline service on 0808 800 4050 from 10am to 4pm Monday to Friday.
- Email Helplines@arthritiscare.org.uk
- Visit the website at www.arthritiscare.org.uk

The Arthritis and Musculoskeletal Alliance (ARMA) brings together professional and research organisations, and over 30 support groups. These are all groups working in the fields of arthritis and other musculoskeletal conditions. ARMA has also produced the *Standards of Care* to help improve the lives of people with musculoskeletal conditions.

Contact them and find details of members on their website at www.arma.uk.net

Arthritis Research Campaign raises funds to promote medical research into the cause, treatment and cure of arthritic conditions and provides information to people affected by arthritis.

Contact them on 0870 850 5000
or visit www.arc.org.uk

BackCare helps people manage and prevent back pain by providing information, promoting self-help and funding research into better back health.

Contact them on 0845 130 2704
or visit their website at www.backcare.org.uk

Carers UK is a national support organisation led by carers for carers. They run a free advice service, CarersLine, on 0808 808 7777 or visit their website at www.carersuk.org

Contact a Family offers a helpline, support groups and contacts for families with disabled children.

Contact them on 0808 808 3555
or visit www.cafamily.org.uk

The National Osteoporosis Society is dedicated to improving the prevention, diagnosis, and treatment of osteoporosis.

Contact them on 0845 450 0230
or visit www.nos.org.uk

National Rheumatoid Arthritis Society provides support and information for people with rheumatoid arthritis and juvenile idiopathic arthritis, their families, friends and carers, and health professionals with an interest in rheumatoid arthritis.

Contact them on 0845 458 3969
or visit www.rheumatoid.org.uk

Whizz-Kidz is a national children's charity that provides mobility equipment like wheelchairs and tricycles (that are not available from the NHS) to disabled children.

Contact them on 020 7233 6600
or visit www.whizz-kidz.org.uk

Other useful contacts

NHS Direct is a 24-hour service providing confidential health advice if you're feeling ill and you're not sure what to do, or information on looking after yourself, different conditions and treatments, and details of local health services. Visit www.nhsdirect.nhs.uk, go to NHS Direct Interactive on digital satellite TV or call 0845 4647. Calls to NHS Direct are charged at BT local rates. Other phone service providers, including mobile operators, may charge different call rates. For patients' safety, all calls are recorded.

The Benefit Enquiry Line for Disabled People is run by the Department for Work and Pensions.

Contact them on 0800 882200.

Disability Alliance produces a wide range of guides on social security benefits for disabled people.

Contact them on 020 7247 8776
or visit their website at www.disabilityalliance.org

The Department of Health website includes the full musculoskeletal services guidance document and other important documents relating to improving care for people with long-term conditions. See www.dh.gov.uk and follow the links to publications.

Section 7

Making sense of jargon and titles



As you navigate your way through the health and social-care services, you may come across some titles and phrases which are often used by NHS staff and in NHS information, but which mean little to you as a patient. Your healthcare professionals should always take time to explain these terms to you, but the following gives you a summary of some of the most useful terminology.

NHS and social care

Primary care: includes the health services which you use in your community and which provide continuity of care over time – outside hospital – and are delivered by a wide range of health professionals, including your GP, nurses, dentists, pharmacists, physiotherapists and many more. This is where most care takes place.

Secondary care: is usually provided in a hospital setting, following referral by a GP or – as an emergency – following an injury or sudden illness. Procedures and treatments are carried out which need the kind of specialist skills, support and equipment that a hospital team provides. For people with musculoskeletal conditions or injuries, secondary care often involves contact with the orthopaedic surgery or rheumatology team.

Social care: describes the wide range of services that support people in their daily lives. It includes a range of practical services such as home care, day centres, residential and nursing homes, and supported entry into work. Some of these services are organised and paid for by the local authorities, and some by individuals themselves.

Primary care trusts (PCTs): the local NHS organisations responsible for assessing the health and healthcare needs of their populations, then planning and securing the right primary care, secondary care and other services to meet these needs.

Health and social-care professionals

This list only mentions a selection of the people who may be involved in your care. It does not cover GPs, nurses and the many other professionals who also play important roles in musculoskeletal services.

Chiropodist and podiatrist: assess, diagnose and treat foot problems. They give professional advice on preventing foot problems and on caring for feet properly.

Chiropractor: concerned with assessing, treating and preventing disorders of the musculoskeletal system, and the effects of these disorders on other body systems. There is an emphasis on manual treatments, including spinal manipulation.

Clinical radiologist: specialist doctor who carries out the more complex investigations and is responsible for analysing images of the body. A clinical radiologist also performs procedures under imaging guidance to obtain samples for pathology and for treating some conditions.

Occupational therapist: assesses, rehabilitates and treats people using purposeful activity – such as getting dressed or cooking a meal – to prevent disability and promote a person's health and independence.

Orthopaedic surgeon: a specialist doctor trained in diagnosing and treating musculoskeletal conditions affecting bones, joints and soft tissues (for example osteoarthritis). They also treat injuries such as broken bones. They are mostly based in hospital trauma and orthopaedics units, and carry out major and minor operations.

Orthotist: designs and fits orthoses (for example splints, callipers or braces) which provide support to part of a patient's body to compensate for paralysed muscles, to provide relief from pain, or to prevent physical problems from getting worse.

Osteopath: focuses on treating and preventing musculoskeletal disorders. Osteopaths aim to help the body heal without using drugs or surgery. Treatment is based on mobilising and manipulative techniques.

Paediatrician: a doctor who specialises in treating children. A paediatrician may be based in either a community or a hospital setting. Different paediatricians may take a special interest in different aspects of children's health, including musculoskeletal problems.

Phlebotomist: a person trained in taking blood specimens from patients.

Physiotherapist: assesses and treats people with physical problems – caused by accident, ageing, disease or disability – using physical approaches to reduce symptoms.

Practitioner with a special interest: a relatively new term being used in the NHS to describe the growing group of GPs, nurses, physiotherapists and other health professionals who are improving their skills in particular areas – such as musculoskeletal conditions. This often allows them to give patients more specialised care in the community. Other titles such as ‘nurse practitioner’ or ‘extended scope physiotherapist’ are used to describe professionals who have significantly improved their skills and responsibilities.

Prosthetist: provides care and advice on rehabilitation for patients who have lost or who were born without a limb, fitting the best possible artificial replacement.

Radiographer (diagnostic): a professional who produces high-quality images on film (like x-rays) and other recording media to diagnose a patient’s condition.

Rheumatologist: a specialist doctor trained in diagnosing and treating arthritis and other rheumatic diseases, some of which cause general illness as well as affecting bones and joints. They are mostly based in hospital rheumatology units. They will establish your diagnosis and identify a suitable treatment plan for you. You will probably see the rheumatologist regularly to monitor your disease.

Social worker: a professional trained to discuss with people and their families their sometimes complex, emotional, mental or physical needs, and to find them support and care services as appropriate.

With the exception of phlebotomists, the above professionals are regulated by the appropriate governing body, either the Health Professions Council, the General Medical Council, the General Chiropractic Council or the General Osteopathic Council. All regulators have strong and effective legal powers designed to maintain the standards the public have a right to expect of professionals.



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ARTHRITIS CARE

*Empowering
people with arthritis.*

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London NW1 2HD

Freephone helpline: 0808 800 4050
(weekdays 10am–4pm)

Helplines@arthritiscare.org.uk
www.arthritiscare.org.uk

Charity number: 206563