

Leicester, Leicestershire and Rutland



an information guide for people
with long-term illnesses

Your health, Your way ... arthritis

This booklet is aimed at people with arthritis, a long-term condition. While there is no cure, it can be managed so that it doesn't dominate and control your life and there is plenty that can be done to control the disease and improve your quality of life.

Living with a long-term condition can sometimes be difficult to manage day to day. So it's important you get the right information and the right help at the right time.

If you understand your condition and its treatment, you'll feel more confident. You'll be able to take better care of yourself and manage your condition; you'll be better equipped to make informed choices and decisions about your care

So it's important to have good, reliable information about the local services available to you.

This booklet is aimed to help you, the people around you, including family and friends, in these difficult times. It will guide you in the right direction - show you where you can get local help, support, services and information. It won't give you the answers to all your questions, but it will show you where and how to get those answers.

It is designed to point you in the right direction to find out more about your condition, your treatment, how to live with it and manage it, how to get involved with local support groups if you want to; who to turn to when you need help and support, and who to talk to if you want to discuss things with people who know what you are going through.

Your condition ... What is arthritis?

Arthritis means, simply, inflammation of the joints. The word rheumatism is even more general, and is used to describe aches and pains in joints. Arthritis is not a diagnosis in itself; it is a general term that acknowledges that something is wrong. It often takes time for a doctor to reach a precise diagnosis.

There are more than 200 kinds of arthritis, or musculoskeletal diseases. Some forms of arthritis are rare, while others, such as osteoarthritis, are much more common.

Most people with arthritis will experience pain and have difficulty moving around. Pain, fatigue and stiffness are effects of arthritis that can limit you in a variety of ways. You can take control of these effects and continue to have a good quality of life by 'self managing' your condition.

Inflammation and swelling are also effects of arthritis. Although it's not clear what causes arthritis, there's no cure at present - but there is plenty you can do to manage your condition and lead a full and active life.

Osteoarthritis (OA) used to be considered wear and tear arthritis, but it is now thought there are many more factors than age and use that contribute to the development of OA – including obesity, past injury and genetics.

It usually affects the hands, spine, knees and hips and develops gradually, over time and several different joints can be affected. Osteoarthritis is more common in women.

Pain can vary in severity and can be so mild that many people don't even notice it, or so severe that mobility and quality of life is affected.

Rheumatoid arthritis (RA) is a condition that makes the joints in the body become inflamed. It is the second most common form of arthritis. Inflammation means swelling and heat. An inflamed joint is swollen, reddened and is warm to touch.

Rheumatoid arthritis varies a lot from person to person. Although it can affect almost any joint, hands and feet are usually involved. Knees and shoulders can also be affected and, less commonly, elbows, hips, the neck and other joints. Most people are affected in more than one joint.

Where can I find out more?

Arthritis Care website, the national charity set up to help people with the condition, has everything you initially want to know about arthritis. The charity's web site at **www.arthritiscare.org.uk** covers most of the questions you want to ask about arthritis and its treatments, help, advice, local support and forum groups.

Other information is available from:

Arthritis Research Campaign, **www.arc.org.uk** a site dedicated to investigating arthritis in all its forms.

The National Rheumatoid Arthritis Society at **www.rheumatoid.org.uk** provides support and information for people with rheumatoid arthritis and juvenile idiopathic arthritis, their family, friends and carers.

Your treatment

Although there's no cure, there's plenty that can be done to help relieve the symptoms, change the course of the disease, and reduce pain. Dozens of drugs are used to treat arthritis. They perform different roles from general pain killers to reducing inflammation or damping down the disease itself. You may be prescribed one or a combination of drugs.

Most types of arthritis will be treated by your GP. Your doctor will try to manage your condition with a combination of medicines, physiotherapy, physical exercise, support from care agencies, and changes in your lifestyle.

However, if this doesn't work and your condition deteriorates, your doctor may refer you to a specialist team at hospital - the rheumatology department.

The dedicated rheumatology service at the **University Hospitals of Leicester NHS Trust** provide all aspects of rheumatologic care for patients from assessment to treatment. The health team diagnose and treat diseases and disorders of the joints, muscles, bones and tendons including arthritis and degenerative joint disease.

In-patient care is based at Leicester Royal Infirmary. Out-patient services are at Glenfield Hospital, Leicester General Hospital and Leicester Royal Infirmary and go out to various community hospitals in Leicestershire and Rutland.

The teams work in close liaison with other departments, including the radiology department to aid diagnosis and treatment and have a range of specialist clinics including an early arthritis clinic; a connective tissue disease clinic; back pain clinic; osteoporosis and metabolic bone disease clinic and physiotherapist lead clinic.

More information about the service is available on the website at **www.uhl-tr.nhs.uk** and follow the 'For patients' link at the top of the page.

Living with arthritis

If the doctor has just told you that you have arthritis, it can be both daunting and frightening.

But you are not on your own. As well as your health teams, there are charities, support groups, and even internet blogs and meetings where you can talk to people in the same situation as you.

Arthritis is not a life sentence, but it can be life changing. Simple daily tasks can become difficult and complicated, while managing family life and juggling work can be exhausting.

Self-management means taking control of living with your condition, and is crucial for your emotional and physical well-being.

Learning about arthritis and the support that is available is a simple but powerful step to regain control of your life, even if you have had arthritis for years. It can reduce workplace stresses, or help you get back into work, which has great rewards.

The national arthritis charity 'Arthritis Care' has developed a self-management programme called '**Challenging Arthritis**' which is designed to teach you skills to live life to the full and to help you get the most out of your healthcare team. It allows you to meet other people with your condition.

For details of free self-management courses, contact **Arthritis Care** on **0845 650 4400**.

Developing your own self-care management plan is crucial. The more you know, the better you will be able to manage your arthritis.

Special equipment such as splints and gadgets can help make carrying out simple everyday tasks easier. Your doctor can refer you to an occupational therapist who will advise you on how to make the most efficient use of your joints without causing further damage.

A physiotherapist can help you prepare exercises to keep your muscles strong and retain a good range of movement in your joints.

Most people will want to carry on working and there are many reasons to do so, including increased financial security. Many people with arthritis find that working makes them feel better in health terms too. However, help is available for those who feel unable to carry on working.

Your feelings: Most people feel overwhelmed when they are told that they have long-term illness like arthritis.

People experience many different emotions, which can cause confusion and frequent mood swings. These emotions are part of the process that many people go through in dealing with their illness. You may find it helpful to talk to your GP, a counsellor or a member of your hospital medical team.

YOUR care plan

Your health teams are there to give you support, help and treatment. However you are in control and you can make choices and decisions that affect your condition and it's important that you develop your own personal care plan to help you manage it. Your health team will help you with this, but there are certain things you might want to do as well.

Lifestyle: You may decide to change your lifestyle to help manage and control your condition. Local help is available to support and advise you: -

Giving up smoking: Both NHS Leicester city and NHS Leicestershire County and Rutland have dedicated teams to help you give up smoking through one-to-one advice, clinics, personal advice and nicotine patches and replacements. The City **STOP!** Team can be contacted on **0116 295 4141**, and the County and Rutland team on **0845 045 2828**.

Healthy weight: Eating a balanced diet is key to maintaining a healthy weight. Controlling your weight is often the most effective thing you can do to reduce the symptoms of arthritis. Even a small weight loss can reduce strain on the hips, back, knees and feet if you are too heavy.

Carrying extra weight adds extra pressure on weight bearing joints such as the back, hips, knees, ankles and feet. Losing even a few kilos can make a significant difference. By simply adopting a healthy diet you will find you will probably lose some weight. Your health team will help you plan this as part of your own personal plan.

There is a lot of debate about whether what you eat affects your arthritis. If you notice that certain foods make your symptoms worse, then it makes sense to avoid them. You must ensure that your diet is still balanced, so you may like to take supplements to keep getting the right amounts of vitamins.

The **Leicestershire Nutrition and Dietetic service** has a team of dietitians who work in a variety of clinical specialties and can help you make informed choices about the food you eat. You can access general healthy eating advice and condition specific advice via their website at **www.lnds.nhs.uk**. If appropriate your GP or practice nurse can refer you to a dietician working within your local area.

Keeping Active: Regular physical activity can help and also reduces the risk of other serious conditions, such as heart disease and stroke. Leicester, Leicestershire and Rutland has a wide range of activities available such as gentle aerobics, cycling, salsa, walking and yoga. Every level of fitness is catered for, with help and advice readily available. Each district or borough has its own physical co-ordinator who provides advice on what's available in your area. Whether you are new exerciser; returning after a long time off; or a regular exerciser, all different abilities are catered for.

Your doctor or a physiotherapist can help you to pick an exercise programme to suit you and advise you on the best exercises after assessing your joints and muscles. Consult your GP or health team about what level of activity is best for you in view of your arthritis.

For more details, go to the Leicester-Shire and Rutland Sport website, **www.lrsport.org.uk** or telephone your local co-ordinator on:

Hinckley and Bosworth **tel: 01455 255875**

North West Leicestershire **tel: 01530 454830**

Charnwood **tel: 01509 634836**

Melton **tel: 01664 502389**

Harborough **tel: 01858 821284**

Blaby **tel: 0116 272 7704**

Oadby and Wigston **tel: 0116 257 2672**

Rutland **tel: 01572 720936**

Leicester **tel: 0116 252 7350**

For more details, go to the Leicester-Shire and Rutland Sport website, **www.lrsport.org.uk** or telephone your local co-ordinator on:

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Leicester **tel: 0116 252 7350**

Fit and Active Buddies (FAB) Project – personal trainers and cut price gym sessions to help people lose weight in Braunstone, Beaumont Leys, New Parks and Belgrave. **tel: 0778 538 5911**

Walking: **www.leicester.gov.uk/walking**

City Sport: **www.leicester.gov.uk/sports** for a variety of sport and leisure activities to suit all.

Talking to others: Meeting and talking with other people who are, or have been, in a similar situation can be both reassuring and helpful. Details of local support and help groups listed below can be found by contacting: **Arthritis Care** at Unit 7, Carlton Business & Technology Centre, Station Road, Carlton, Nottingham NG4 3AT **tel: 0115 952 5522**; fax 0115 952 0336; **email: centralengland@arthritiscare.org.uk**

Local groups are:

Ashby de la Zouch: War Memorial Club, North Street, Ashby de la Zouch, fourth Tuesday of each month at 7.30pm.

Community Leicester Arthritis Self Help (CLASH) meets at the Luther King Centre, Longslade Community College, Birstall, every second Wednesday of each month at 7.00pm.

Hydrotherapy - every Monday at 11am at the hydrotherapy pool at Leicester Royal Infirmary.

Young People and Families Group first Sunday of each month from 10.00am-12.00pm at The Peepul Centre, Orchardson Avenue, Leicester, www.leicestershirevillages.com/birstall/clash or **tel: 07954 584 402**

Syston: Church Hall, Lower Street, Syston, first Monday each month at 7.30pm.

Support groups are also listed on the Leicestershire **'Infolinx'** website. Infolinx is a community information website run by the nine county and local councils, detailing more than 5,000 clubs, societies, organisations and self help groups based in the region. It can be reached at infolinx.leics.gov.uk

Need help or advice?

The **Patient Advice and Liaison Service (PALS)** is a free, confidential and individual service where you or your carers can be advised about the NHS or express concerns about either your own or a relative's treatment. It aims to help solve any problems, concerns or questions you have when using health services in the area - a customer care service for your local NHS. PALS:

- Provides advice and support to patients, their families and carers
- Provides information on NHS services and local support groups
- Listens to your concerns, suggestions, queries or compliments
- Gives advice on how to make a complaint
- Helps sort out health concerns on your behalf
- Provides information on how you can get more involved in developing NHS services

You can contact a member of the PALS team in person, by telephone, email or letter. Patients and members of the public can meet PALS staff by arrangement.

NHS Leicester City PALS tel: 0116 295 7011 (Monday to Friday, 9am to 5pm. Outside hours please leave a message and PALS will call you). **email: pals@leicestercity.nhs.uk**

NHS Leicestershire County and Rutland PALS tel: 01455 441971 or **01509 564444**. **email: pals@lcr.nhs.uk**

University Hospitals of Leicester PALS tel: 0116 258 3100.
email: pals@uhl-tr.nhs.uk

Leicestershire Partnership NHS Trust PALS tel: 0116 225 6647.
email: pals@leicspart.nhs.uk

Other organisations that could help:

LEEAP (Leicestershire Ethnic Elderly Advocacy Project) 30 Chandos Street, Leicester **tel: 0116 275 5515**

For city services and support groups: visit www.leicester.gov.uk/socialcare or www.leicester.gov.uk/health

Getting the most from your medicines

Around half of patients with a long-term condition do not take their medicines as prescribed. However, for patients to take real control of their conditions, they need fast and convenient access to medicines, involvement in decisions about those medicines, advice about how to take them and information on any side effects which they may suffer.

Pharmacists have an increasing role as a source of advice for patients and their carers. There are more than 200 pharmacists throughout Leicester city, Leicestershire and Rutland who are available to help with advice and information.

Refer to the NHS Choices website at www.nhs.uk, or talk to **NHS Direct** on **0845 46 47** for details of your nearest pharmacist.

Benefits and financial help

Many people find that facing a long-term illness affects their finances and can cause money problems. Several local organisations offer information and advice about benefits, grants and loans you may be able to obtain.

Another useful source of information is the Government citizens' information website, **www.direct.gov.uk**

Having arthritis can often mean extra expense. You may be able to get state benefits to help with the extra costs or if you can't work.

It's worth checking that you're claiming everything that you are entitled to.

www.entitledto.co.uk or **www.direct.gov.uk/en/Money-TaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/BeginnersGuideToBenefits**

FirstStop Advice is an independent, free service providing information and advice about care and housing in later life provided jointly by Counsel and Care, Elderly Accommodation Counsel, Help the Aged and a private company. The service is provided through a free phone advice line from Monday to Friday 9am-5pm on **0800 377 7070** or online at **www.firststopcareadvice.org.uk** covering issues including care and support, housing, finance and rights.

Benefit Enquiry Line: Confidential advice and information for people with disabilities, carers and reps about social security benefits, **tel: 0800 882200**

Leicester Money Advice: Free debt service which provides money advice and counselling for people who live in the city, **tel: 0116 242 1120**

Age Concern: Offers practical help, advice and information about services for older people. Age Concern Leicester has its own Welfare Rights Officer on **tel: 0116 222 0555**. Other officers can be contacted at:

Leicester, Leicester-Shire and Rutland - **tel: 0116 299 2233**

Lutterworth - **tel: 01455 557116**

Oadby and Wigston - **tel: 0116 288 5203**

Hinckley and Bosworth - **tel: 01455 619519**

The right equipment and social care

You might need special equipment to help you live at home, for example stair rails, jar openers, stair lifts, bath rails or even tap turners. If you are experiencing some form of disability as a result of your condition or its treatment, you may be entitled to help. If you are a hospital inpatient you may be seen by occupational therapists (OT) before you are discharged. The OT will assess you to find out if you need any special equipment or living aids to help you maintain your independence or improve your quality of life.

If you are not an inpatient, you can ask your local social care services department for a care assessment to assess your needs. The social care services offices are:

Blaby, Oadby and Wigston - **tel: 0116 278 7111**

Market Harborough - **tel: 01858 465331**

Charnwood - **tel: 01509 266641**

Melton Mowbray - **tel: 01664 564698**

Hinckley and Bosworth - **tel: 01455 636964**

North West Leicestershire - **tel: 01530 275200**

Rutland County Council - **tel: 01572 722577**

Leicester - **tel: 0116 253 1191**

British Red Cross Disabled Living Centre: The Disabled Living Centre has a permanent display of daily living aids and equipment to promote independence. They offer free, impartial advice, information and assessment to people with disabilities, the elderly, carers and health professionals.

A referral is not required. Assessment is by appointment only.

Monday – Friday 9.00 am – 4.15 pm on **0845 373 0217** or

dlcinfo@redcross.org.uk

British Red Cross Independent Living Products Shop at 113 Clarendon Park Road, Leicester, LE2 3AH stocks extensive range of equipment to improve the quality of life for elderly and disabled people on **0116 244 9049**. Monday – Friday: 9.00am – 5.00pm, Saturday: 9.00am – 4.30pm.

British Red Cross also provides a dial-a-wheelchair service providing manual wheelchairs on short-term loan (up to two months). This service is available from 244 London Road, Leicester, LE2 1RN **tel: 0116 270 0210**. Monday: 10.00am – 4.00pm

The Disabled Living Foundation – www.dlf.org.uk is a national charity that provides free, impartial advice about all types of daily living equipment for disabled adults and children, older people, their carers and families on **0845 130 9177**.

Carers

A carer is someone who, without payment, provides help and support to a relative, friend or neighbour who, because of frailty, illness or disability is unable to manage without help.

CLASP, the carers centre, provides a wide range of support services for carers in Leicester, Leicestershire and Rutland. CLASP is located on the Fourth Floor, Matrix House, Unit 19, Constitution Hill, Leicester LE1 1PL, **www.claspthecarerscentre.org.uk** or **tel: 0116 251 0999**.
email: enquiries@claspthecarerscentre.org.uk

Leicestershire has its own **carers project** which aims to provide carers with a local contact who can supply information, advice and support. The project also runs quarterly forums every year bringing carers together to enjoy each other's company and meet organisations and individuals providing support.

Carers development workers are located around the county and each team offers a variety of practical help, support, information and advice. Contact your local office for further details of the services and help available.

Voluntary Action Blaby District: Sandra Stocks **tel: 0116 272 7669**
email: carers@vabd.org.uk

Voluntary Action Charnwood: Nita Patel **tel: 01509 631783**
email: nita.patel@voluntaryactioncharnwood.org.uk

Voluntary Action Melton: Helen Brocklehurst **tel: 01664 485304**
email: Helenb@voluntaryactionmelton.org.uk

Voluntary Action Rutland: Gill Huddleston **tel: 01572 720052**
email: gill@claspthecarerscentre.org.uk

North West Leicestershire CVS: Sarah Houlton-Ellingworth

tel: 01530 510515 email: sarahhe@nwlcvs.org.uk

Oadby and Wigston Community Action: Sarah Lambrianou

tel: 0116 281 0026 ext.28 email: ksmith@vaow.org.uk

Voluntary Action South Leicestershire runs a carers telephone befriending Service, where carers enjoy a weekly call from a volunteer befriender giving them time to talk to someone confidentially outside the family. If you care for someone and would like more information to help you in your caring role, contact either Jacqui Mowson on **01858 439263** or Diane Claridge on 01858 439262. The carers project is based at Voluntary Action South Leicestershire, The Settling Rooms, St, Mary' Place, Market Harborough, Leicestershire LE16 7DR. **email:jmowson@vasl.org.uk**

Advice

Citizens Advice Bureau: www.citizensadvice.org.uk gives advice on debt, benefits, housing, employment and other legal rights.

Leicester - **tel: 0116 285 2801**

North West Leicestershire - **tel: 01530 454751**

South Leicestershire (Blaby, Lutterworth, Market Harborough) and outreach venues - **0844 848 9009** Debtline - **tel: 0844 248 0040**

Melton - **tel: 01664 484050**

Charnwood (Loughborough) - **tel: 01509 267376**

Hinckley - **tel: 0844 826 9710**

Shepshed - **tel: 01509 506663**

Rutland - **tel: 0845 120 3705**

Mosaic, Shaping Disability Service (Leicester) - tel: 0116 251 5565 Helpline: 0116 262 6900 textdirect: 18001 0116 251 5565.

Voluntary Action Leicester Shire provides information and support for voluntary and community groups and volunteers in Leicester city and various venues across Leicestershire. See their website, **www.valonline.org.uk** for more information or email **helpline@valonline.org.uk** or telephone the helpline on **0116 257 5050**.

Voluntary Action Blaby District - **tel: 0116 272 7669**

Voluntary Action Oadby and Wigston - **tel: 0116 281 0026**

Voluntary Action South Leicestershire - **tel: 01858 432014**

NW Leicestershire CVS - **tel: 01530 510515**

Voluntary Action Charnwood - **tel: 01509 631750**

Voluntary Action Melton - **tel: 01664 483043**

Voluntary Action Hinckley and Bosworth - **tel: 01455 633002**

Shopping

Shopping can be difficult if you find it hard to get around because of your condition. But there are local shopmobility schemes that provide or loan disability equipment to help, such as mobility scooters.

Leicester Shopmobility operates from two locations in the heart of the city:

Highcross Shopping Centre - **tel: 0116 253 2596**;

Haymarket Shopping Centre - **tel: 0116 253 7125**

Further information can be found at www.leicester.gov.uk/shopmobility or for details and contacts of other Shopmobility schemes, visit www.shopmobility.org

Melton Mowbray - **tel: 01664 480677**

Market Harborough - **tel: 01858 410864**

Hinckley - **tel: 07982 302 780**

Fosse Park - **tel: 0116 263 0600**

Coalville - **tel: 07982 706 285**

Loughborough - **tel: 01536 412 886**

Your choice...

You have the right to be treated where and when you choose.

For instance, if you needed hospital treatment, in the majority of cases you can pick the hospital of your choice for your treatment, which is right for you and your family.

Your doctor or health team would discuss the choice with you, so that you have the right information to make the decision that is right for you.

You might want to choose a hospital closer to family or friends, or a big teaching hospital. If you needed treatment, such as an operation, you might want to delay it to avoid a special occasion. But the choice is yours!

You can find out more at:

- Your GP practice
- Libraries
- **www.nhsdirect.nhs.uk**
- **NHS Direct Interactive** on digital satellite TV
- **NHS Direct** on **0845 4647**
- **www.nhs.uk**
- **www.healthspace.nhs.uk**
- **www.chooseandbook.nhs.uk**
- **www.healthcarecommission.org.uk**
- **www.patientopinion.org.uk**

NHS Choices

A wide range of information and advice about your condition and choices about your care and treatment is available on the NHS website, '**NHS Choices**', or from the NHS telephone helpline, '**NHS Direct**'.

'**NHS Choices**' on **www.nhs.uk** is a wide ranging comprehensive guide and directory that gives:

- Medical advice about most conditions
- Services from GPs to gyms, doctors to dentists, midwives to memory problems
- 'All you need to know' guides covering 750 conditions and treatments
- Carers help and advice
- Blogs to talk to the experts and other patients
- Feedback from other patients
- Up to date medical news and views on treatment and research
- Tips and help on keeping you healthy
- Benefits advice
- Links to other medical, charity and support websites
- Comparisons between hospitals to help YOU chose where YOU want to be treated

For those without internet facilities, the same information and more is available from 'NHS Direct' – the 24 hours a day every day of the year helpline. Trained staff are available round the clock to give advice and information on all aspects of health - from instant help with immediate symptoms or problems and where to get treatment; to details of walk in centres, clinics, local organisations, support and help on **0845 46 47**.

This publication has been jointly produced by the four NHS organisations in Leicester, Leicestershire County and Rutland. Printed copies are available by contacting any of the organisations:

- **NHS Leicestershire County and Rutland**

Lakeside House, 4 Smith Way, Grove Park, Enderby,
Leicestershire, LE19 1SS

tel: 0116 295 7689

or **email: communications@lcr.nhs.uk**

- **NHS Leicester City**

St John's House, 30 East Street, Leicester, LE1 6NB

tel: 0116 295 1100/1400

or **email: enquiries@leicestercity.nhs.uk**

- **Leicestershire Partnership NHS Trust**

George Hine House, Gipsy Lane, Leicester, LE5 0TD

tel: 0116 225 6485

or **email: feedback@leicspt.nhs.uk**

- **University Hospitals of Leicester NHS Trust**

University Hospitals of Leicester NHS Trust Headquarters,
Gwendolen House, Gwendolen Road, Leicester LE5 4QF

tel: 0116 258 8963

or **email: communications@uhl-tr.nhs.uk**

For further information or comments, or if you would like to contribute to the production of this document or further publications, please contact any of the above trusts.

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The NHS trusts listed above cannot be held responsible for any information provided by non-NHS organisations detailed in this document