



nras
National Rheumatoid
Arthritis Society

Living Better with RA

A self-help guide for people with established
disease, including Juvenile Idiopathic Arthritis





nras

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Arthritis Society

ABOUT US

The National Rheumatoid Arthritis Society (NRAS), is the only patient-led organisation in the UK specialising in rheumatoid arthritis (RA) and juvenile idiopathic arthritis (JIA). Due to its targeted focus on RA and JIA, NRAS provides truly expert and wide-ranging services to support, educate and campaign for people living with these complex autoimmune conditions, their families and the health professionals who treat them.

ASK US

Call our **freephone helpline on 0800 298 7650**. Our trained helpline staff can provide expert information on many different subjects related to RA and living with RA. We also have a team of medical advisors across the UK, who can provide support to our team as and when needed.

If you'd like to talk to someone else with RA, our helpline staff can match you with one of our Volunteers, who will then call you back to discuss whatever aspect of living with RA most concerns you. To be put in touch with a volunteer who has RA, please call the Helpline first or email helpline@nras.org.uk

Our website www.nras.org.uk has a wealth of information about all aspects of living with RA, treatments, the latest

research and developments, as well as full details of useful charities and organisations.

The website also links you to the NRAS online forum, www.healthunlocked.com/nras, a safe space where you can communicate with others living with RA and share your own experiences.

If you don't have access to the Internet, please call us on **0845 458 3969** and we can send you any information you require by post.

MEET US

If you'd like to meet other people with RA, there are several local NRAS groups around the country, run by NRAS volunteers, which meet up regularly. To find out if there is a group near you, visit www.nras.org.uk/groups or email volunteers@nras.org.uk or call **0845 458 3969**

JOIN US

Joining the Society supports us and allows us to help even more people just like you. To find out how to become an NRAS Member please complete, detach and return the form inside the bookmark of this booklet or call our Membership team on: **01628 823 524**. Alternatively, you can join online at www.nras.org.uk/join

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Introduction

Welcome to this self-help guide, *Living better with Rheumatoid Arthritis*.

Since 2014, NRAS has provided a similar service for children, young people and families living with Juvenile Idiopathic Arthritis (JIA), a good number of whom will take JIA into adulthood. And so, this booklet is also for people with adult JIA, but we will, for the sake of brevity, refer throughout the booklet to RA.

If you're living with rheumatoid arthritis and you'd like to know more about how to manage your disease and stay in control, this booklet is for you.

If you are new to RA, you may also want to read our booklet, *New2RA*. For details of how to obtain any of our other information resources, or to get more copies of this one, please turn to the inside back cover.

What is RA?

Rheumatoid arthritis (RA) is a painful and debilitating auto-immune disease that causes swelling and damage to cartilage and bone around the joints. But RA doesn't just affect the joints – it is a 'systemic' disease that affects the whole body. It is a chronic condition currently without a cure, but there is a lot that can be done to reduce its impact on your life.

RA affects an estimated 400,000 adults in the UK. There are approximately 30,000 new diagnoses each year. RA affects three times as many women as

men, more noticeably in the younger age ranges (i.e. under 60) but the rates do become more similar in men and women as they get older. The onset of RA most commonly occurs between the ages of 40 and 60 years; however all cases are individual and it can affect people of any age over 16.

We don't have any data about how many adults living with JIA there are, as many of these people are re-classified incorrectly as having RA.

For more information about RA visit www.nras.org.uk

What is life with RA like?

People have very different experiences of living with RA and no two people will have the same story. But there is much that we can learn from one another and you will probably find it helpful to meet with and talk to other people with RA. Contact us to find out more.

Know the score

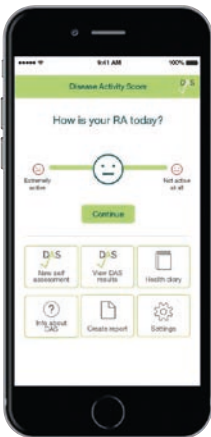
DAS stands for **Disease Activity Score**, and 28 refers to the number of joints that are assessed in compiling the score. The lower the score, the better controlled your disease is. Your score should be regularly reviewed by your healthcare team so that you can see how your treatment is progressing. Knowing your score helps you and your healthcare team set appropriate treatment goals. There's more on this later on in this booklet (see page 37).

A key element of living well with rheumatoid arthritis is the treatment you receive from your healthcare team. They work to a system known as 'Treat to Target'. This means that they work with you on a treatment plan that aims to achieve a target of disease remission, if possible, or as low a disease activity state as possible if remission can't be achieved. The DAS 28 target (in respect of remission) is to **reduce your DAS to 2.6 or lower** (this is the clinical definition of remission).

Keep a note of your DAS score, so that you know how you're doing. How you do that is up to you – there are some ideas later on (see page 37).

We have developed an app for mobile phones and tablets (Apple and Android only) to help you keep track of your DAS score and to assist with other aspects of managing life with RA. The DAS app can be downloaded and installed via our website:

www.nras.org.uk/knowyourdas



Ongoing care

Nowadays, there is a wide range of treatment options to keep your disease under control and to help you live as normal a life as possible. There are drugs that reduce disease activity so as to keep your DAS as low as possible as well as medications that manage the symptoms of RA.

Healthcare specialists in your rheumatology team can help keep your joints and muscles strong. They can sort out any equipment or support aids you may need, offer you emotional support or give advice on healthy eating. Self-management is also a crucial part of your care when you have a long-term condition like RA.

This booklet explains what treatment and support is available. It is full of tips on how you can manage your life with RA and pointers to other sources of information and advice.

And if you can't find the help you need in these pages, don't forget that you can call our Freephone Helpline on **0800 298 7650** (9:30am to 4:30pm, Mondays to Fridays) and speak to one of our trained helpline team, who will be able to find the answers you need and put you in touch with other people living with RA.

Self-management

Self-management is a crucial part of your care when you have a long-term condition like RA.

Active self-management is about using a set of skills that can be learned, rather than just relying on what health experts, such as doctors, can offer us. It's also about approaching the challenges that

living with a health condition like RA brings, in a helpful and constructive way. This booklet aims to help equip you with the basics of self-management.



In practice, self-management is about being able to manage your RA, your treatments and day-to-day life in the best possible and most realistic way to suit your lifestyle. It's not about ignoring or denying a health condition, nor is it about allowing that condition to dominate your life; rather, it offers a much more constructive way of living that has been shown to improve long-term outcomes. What this means in practice is that by having a helpful understanding of the condition, being able to recognise and manage the emotional impact and being able and willing to make adaptations to your lifestyle and the way you approach doing things, you can take back control of your life and get into the driving seat again.

When you have a condition like RA, you're already managing it in lots of ways, but there are also specific skills you can learn, to gain more confidence and knowledge. Becoming a good self-manager takes time and practice; it's rather like learning any other skill, such as driving a car. With the right skills and a positive approach (which NRAS can help you with) you can become an effective self-manager who feels confident to make the decisions and changes which can affect your health in a positive way.

Your rheumatology specialist nurse and other members of your healthcare team can help with information about your condition, treatment and medication. They can offer support, particularly when things change or when you have a flare-up, helping you, your family and friends to understand.



As health professionals, we also work closely with NRAS, who offer a comprehensive and supportive range of services for our patients.

Diane Home

Consultant Nurse in Rheumatology,
West Middlesex University Hospital



There are also a number of courses run by NRAS that commissioners of services and/or hospital trusts can purchase and which would be made available through the hospital, to help you acquire the self-management skills that can really help you make a change for the better, however, in a cash-strapped NHS, few units are able to offer these.

Your healthcare team

A good partnership with your healthcare team, being able to trust and rely on them, is one of the cornerstones of successful self-management. It will help you to control the impact of RA on your life and get the best from the

support and resources available. Make sure you know who to contact for help when you need it – you can write their details in this booklet (see page 68) For more about who's who in your healthcare team, turn to page 13.

What are self-management skills?

Self-management skills help to make day-to-day life with RA more manageable. They include:

- Understanding your disease and the type of RA you have. A blood test called rheumatoid factor (RF) will identify which sub-type you have.

(It will either be positive – known as sero-positive RF – or negative – sero-negative RF – and this result is likely to influence your overall treatment pathway). For more information, see our article: www.nras.org.uk/seropositive-seronegative

- Setting goals and making action plans
- Solving problems
- Managing emotions
- Managing your relationships with family, friends and colleagues
- Getting the best out of your medications
- Communicating effectively with health and social care professionals
- Shared decision making
- Pacing daily activities: managing fatigue, sleep, pain, anger and depression
- Understanding the importance of exercise, keeping active and eating a healthy diet and why, if you smoke, that giving up is so important.

Self-management courses

We have developed a unique supported self-management pathway comprising: **New2RA**, a two-hour workshop for the newly diagnosed; **Living Better with RA**, a 3 hour workshop for those with existing disease; and an established six-week programme called the **RA Self-Management Programme (RASMP)**, which we developed some time ago in partnership with Self Management UK.

RASMP consists of one three-hour session a week for six weeks. It is

delivered by two tutors, one a health professional with clinical experience of working within a rheumatology setting, the other, a lay person who has RA themselves. The course is not for those who are newly diagnosed but is aimed at those who have lived with the disease for at least a year and are finding it difficult to cope.

The above programmes, which are free to attend, have been commissioned (bought) by commissioning groups, health boards or hospital trusts in some parts of England and Scotland and are proving very successful. However, as mentioned previously, we are finding it extremely difficult to get the NHS to commission these programmes given the financial difficulties experienced by the NHS. For more details, please visit our website at www.nras.org.uk, email self-management@nras.org.uk or call **01628 823524**

NRAS local groups, we have many across the UK and we can also signpost to other local groups that offer support, and much more, to those living with RA. Attending a group meeting is not the same as going to a self-management course, but it can certainly help to improve your ability to self-manage, as it provides the opportunity to learn more about RA from expert speakers, share experiences with others and interact with local rheumatology teams and other professionals. For details of groups in your area visit www.nras.org.uk/groups or call **01628 823524**

Care and treatment

Your care and treatment is planned and delivered, in consultation with you, by a multi-disciplinary team of doctors, nurses and other specialists. They are responsible for monitoring and reviewing your treatment and they are there for you whenever you need them.

Nowadays, we know much more about how to manage and control inflammation in RA, even if we don't yet have a cure. So, if things aren't going well at the moment – if, say, you are experiencing constant pain – ask your healthcare team for help. Don't suffer in silence, thinking that you just have to put up with it.

If you can't wait until your next appointment, call your hospital or clinic helpline right away (if you haven't made a note of the relevant number, you should find it on your most recent appointment letter). They should be able to bring your next appointment forward or help in other ways.

Or you could call your GP to see if they can fit you in – many GP practices have a number of walk-in appointments set aside each day for people who require urgent attention.

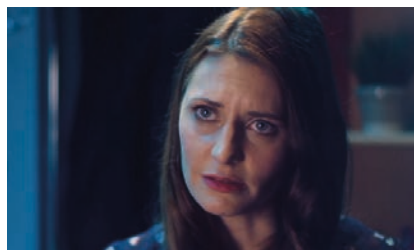
Make sure you know all the numbers to call (ask the receptionist to write them down for you next time you have an appointment), including your GP's out-of-hours number. There's space at the back of this booklet to note them all down so you can keep them handy.

Making the most of appointments

Appointments often seem very brief,

and when your disease is controlled they are needed less often. This makes it all the more important to get the most out of appointments, to help you to manage your condition. Here are some ideas:

- **Prepare** for your appointment. Think through what you want to get out of the appointment and write your questions down, with the important ones at the top of the list. Use the list to make sure you don't forget anything and ask the nurse or doctor to go through it with you
- **Be honest, not brave.** You may be so used to telling friends and family you're OK, answering every 'How are you?' with 'I'm fine', that it's hard to be honest with health professionals about your pain or concerns. But your team needs to know the real picture. Take a look at our moving and informative *Behind the Smile* videos on our website at www.nras.org.uk/behind-the-smile





- **Be precise.** Some people find it helps to keep a diary of how they are and what they can do each day or week
- **Think about taking your own records with you** – it can save time, so that you don't spend most of the appointment going through your medical history. You may want to include a list of your medications (including any over the counter medicines you may be taking for other conditions); your blood monitoring results; details of operations or drugs you've had in the past. A summary is best as time is limited and you need to be realistic about the amount of notes that you can use
- **Always ask if you don't understand.** It's fine to keep on asking until you're happy that you understand the explanation

I used to say 'Oh, I'm not too bad' – and you shouldn't do that.

- **Think about taking a friend or partner** with you, especially if you are making decisions about your care. Many people find it useful to have 'another pair of ears' as there is so much to take in! A friend or partner can take notes, ask questions, and support you after the consultation when you're digesting what has been said and thinking things through.

Your healthcare team

It helps enormously to have a good understanding with the people in your rheumatology team. You need peace of mind to be able to get on with your life, and this comes from having a team you can trust. You can self-manage much better when you know you can rely on people for care, ongoing support and swift help when you're finding things difficult and your own coping skills run out.

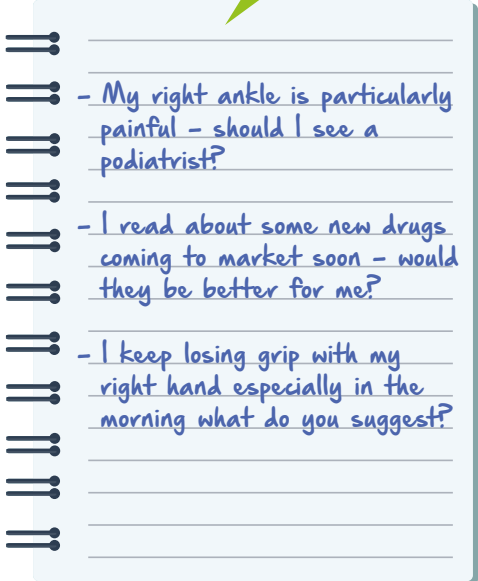
It takes time and effort to develop good relationships with your health professionals, but they are important. When it's hard to find the right words, or when you're talking about personal matters, it helps if the person you are talking to understands something about you and your life.

If you can get to know who's who and how the health system works in your area, you're better placed to get the support you need. In the following pages, we look at the roles of the various health professionals who may make up your multi-disciplinary rheumatology team and others who can help. Multi-disciplinary teams vary from hospital to hospital, so it is worth finding out from your specialist nurse who makes up the team in your area and how you can access them. If you don't have a specialist nurse, talk to your consultant about who is available. You can make a note of your team's contact details at the back of this booklet.

Remember that you can get help from different members of the team whenever you feel you need it: don't think of a referral for treatment as just a 'one-off'. What you need can, over time, change for a variety of reasons, such as: your age; the demands of your work; your family's needs; pregnancy or planning for pregnancy; how active your disease is; and rehabilitation after surgery.



I make a list before an appointment because the time is so precious.

- 
- My right ankle is particularly painful - should I see a podiatrist?
 - I read about some new drugs coming to market soon - would they be better for me?
 - I keep losing grip with my right hand especially in the morning what do you suggest?

Who's who in your healthcare team

Your GP (family doctor)

Your first port of call when symptoms develop.

See page 14

Consultant rheumatologist

Makes the initial diagnosis and leads the team planning and monitoring your treatment and ongoing care.

See page 14

Rheumatology specialist nurse/ nurse practitioner

The link between you and other members of the team. Offers advice and support on all aspects of life with RA. Usually run telephone advice lines, too.

See page 14

Physiotherapist

Helps you maintain the strength and function of your joints and muscles through exercise and movement.

See page 15

Occupational therapist (OT)

Helps you find new ways of doing everyday tasks at home and in the workplace. Can make splints for affected joints.

See page 16

Podiatrist (or chiropodist)

Helps with problems with feet and ankles. Works with an Orthotist to adapt shoes, where needed.

See page 16

Phlebotomist

The person who takes blood samples for testing and analysis.

YOU

The most important
member of the team

Radiographer

Responsible for taking X-rays, MRI scans and ultrasound.

Pharmacist

The person who dispenses your drug prescriptions, can advise on medications and carry out annual medicine use reviews (MUR).

Dietitian

Can help you adopt a healthy diet and maintain a healthy weight.

Psychologist or counsellor

Helps you deal with the emotional aspects of life with RA, including low mood, depression and anxiety.

Voluntary organisation

Organisations such as ourselves (NRAS) and others can help with information, education and support and put you in touch with other people with RA.

Social worker

Helps with benefits, housing and care at home.

Orthopaedic surgeon

A doctor you will only see if you need an operation on your bones or joints or a surgical opinion.

Your GP (family doctor)

Your GP is likely to be the person who first referred you to the rheumatology team at your local hospital. But that is not the end of their involvement in your care. The majority of GPs will continue to be involved in monitoring your treatment and you can call on them whenever you need to discuss how things are going.

Your GP practice may also be involved in the delivery of some of your treatment. You may have your blood samples taken there rather than at the hospital, under a 'shared care agreement'. A shared care agreement is where disease modifying anti-rheumatic drugs (DMARDs) recommended by the hospital-based consultant or another team member on the advice of the consultant, and a treatment plan defined for that particular patient, is communicated to the GP and kept under regular review. The Rheumatology specialist nurse may also make a recommendation as an independent prescriber. DMARD prescribing is initiated by the Consultant led team at diagnosis and whenever a disease modifying drug change is recommended or additional DMARD added to the patient's treatment.

Repeat prescriptions are provided through the GP under a 'shared care' agreement. Shared care arrangements exclude biologic, biosimilar or JAK inhibitor drugs which are always initiated, prescribed and re-prescribed by the hospital-based team. (There's more on drug treatments later on, see page 19.)

Some GP practices employ a specialist known as a GPwSI (GP with a special interest). These are GPs who have had specialist training in rheumatology and offer additional services, such as joint injections. They usually have good links with the rheumatology team in your area. It is worth asking whether there is a GPwSI in your GP practice.

Consultant Rheumatologist

He or she provides a diagnosis, works out your treatment plan, monitors how it's working and changes it when needed. He or she supervises your care and you see your rheumatologist for regular reviews. How often these take place depends on how well your RA is controlled, and how frequently your treatment needs to be reviewed. When you are newly diagnosed, your consultant (or one of their team) should see you frequently to measure how well you are responding to treatment. Once your disease is well controlled you will see them less often, perhaps every six to 12 months. However, at least once a year you should have a full holistic review that covers your treatment and all aspects of living with RA, including checking whether you are at risk of developing other conditions. (People with RA are at greater risk of developing heart disease and osteoporosis, for example – see pages 50 and 57.)

Rheumatology Specialist Nurse/ Nurse Practitioner

Most clinics have a specialist nurse or practitioner who offers patient education about medicines and advises on rheumatoid arthritis management

as well as monitors and sometimes prescribes your drug treatments. The nurse has a pivotal role in the team, responsible for co-ordinating patient care and providing the first point of contact. She or he also works to help you with any specific anxieties or concerns you have about your treatment and how it may affect you personally.

Increasingly, consultants share patient care with nurse specialists, who may run their own clinics. Most specialist nurses also provide telephone advice lines so that you can make contact between visits if needed. Make sure you get information about whether there's an advice line at your clinic, when it's open and when to expect a call back (and write it all down on page 66 of this booklet).

There may be a range of services at a nurse-led clinic. Nurses or practitioners can assess your joints, monitor your drug treatment and review blood tests. Some can also prescribe and change your medication and give intra-muscular steroid injections if you are having a flare.

The nurse specialist can help with self-management, for example by providing information about treatment options, the drugs you have been prescribed and the monitoring process for them, managing flares and managing pain. She or he can also help with the emotional aspects of living with this unpredictable disease, and refer you to other members of the team as needed.

Physiotherapist

A physiotherapist helps you to keep mobile and exercise in the right way to keep your muscles strong and flexible. Many people see a physiotherapist soon after being diagnosed. They can advise on joint protection, managing flares, pacing activities, managing fatigue and pain relief. You may also need to see a physiotherapist at other times for particular symptoms such as difficulties with movement.

If your joints become stiff and you lose some range of movement, it can become difficult or even impossible to carry out some day-to-day activities. At the same time the muscles around joints can become weak. To assess the problem the physiotherapist examines your joints and muscles and sees how you perform specific activities. He or she can then help you by:

- Teaching you how to stretch your joints safely, to increase their range of movement
- Teaching you exercises to strengthen muscles and correct imbalances between different muscle groups
- Advising you how to improve your walking pattern (gait), if it's altered because of changes in how your joints are moving. They may also recommend insoles and walking aids
- Referring you to other health professionals such as podiatrists and orthotists if you need more complex interventions, such as insoles, for example.

Occupational therapist (OT)

An occupational therapist, or OT, can help you improve or maintain your ability to do everyday activities. He or she works with you to find out what you're finding difficult and ways to reduce the problems. This might be by:

- Changing how you do things – helping you to use your time and energy effectively or finding ways to save energy. You might break activities down into smaller parts or do less at any one time
- Helping you to reduce the impact of RA on your daily activities. This could mean teaching you about looking after your joints during everyday activities or about ways to manage pain and fatigue
- Offering you support in making changes, for example with individual counselling or group programmes
- Adapting your home or workplace to make activities easier – the right piece of equipment or structural alteration can make all the difference. OTs can also liaise with employers to ensure that appropriate adaptations are provided through statutory services, where possible
- Treating symptoms, such as painful hands. This can involve making splints for affected joints and showing you how to wear them, and (often working with a physiotherapist) showing you hand and arm exercises that help you make the best use of your hands.

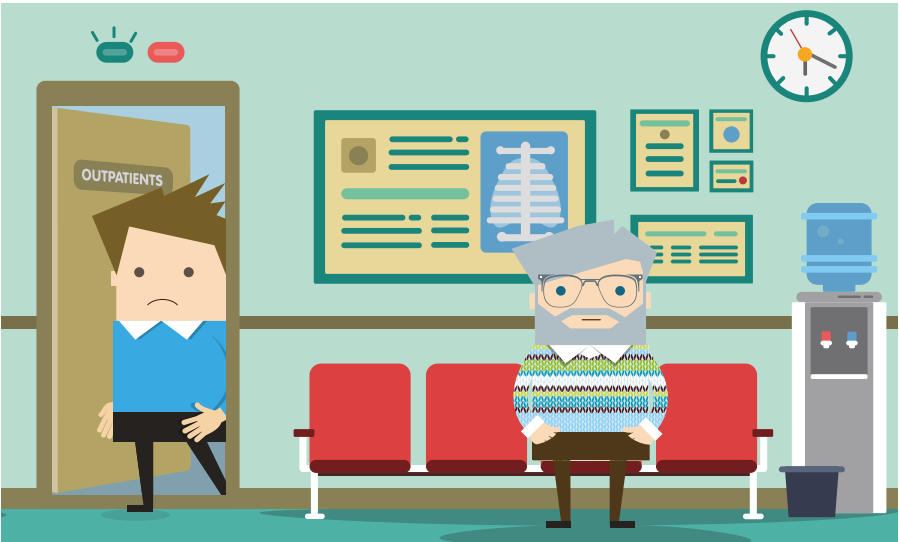
Podiatrist (or chiropodist)

A podiatrist (also known as a chiropodist) is a specialist health professional who can help if rheumatoid arthritis causes problems with your feet or ankles. Feet and ankles can be affected directly, or by problems in other parts of the body such as your back, hips or knees. Podiatrists' advice and treatment can help to reduce pain when you're standing or walking, and to keep you as mobile as possible. Their care for people with RA can include: providing advice about appropriate footwear; advising on and fitting orthoses (special insoles for your shoes); more general foot care such as nail cutting and treating corns; specialist care for feet affected by ulcers or vasculitis (quite a rare condition); and advice on, referral for, or provision of surgery to straighten toes and stabilise badly affected joints.

If you need adaptations to your footwear – such as specialist insoles – in order to help with your walking, you will be referred to an Orthotist.

There is much more on foot health, including a video of a foot health programme run by a podiatrist, on our website at www.nras.org.uk/foot-health-online-course

The Podiatry Rheumatic Care Association (PRCA) has defined a set of 'Standards of Care' for people with musculoskeletal foot health problems. See their website at www.prcassoc.org.uk for more details.



When things aren't working well

If you are in pain or you feel your disease is not well controlled, don't think you must just accept it. Get in touch with your rheumatology team and ask to see someone to talk it over with. Some points to consider:

- Don't feel guilty about needing time to explain how you've been and to discuss options. It is not your fault that you have RA
- You can ask to see your own consultant, rather than another doctor who is a member of his or her team. You may have to wait longer, but you can ask for or make a specific appointment to do this
- If you think you need help from another member of the team, don't wait until it is offered: ask to be referred. Referrals to physiotherapists, occupational therapists, podiatrists or psychologists are not one-offs - you can ask for a re-referral whenever you feel you need to
- If there are problems that you feel are not resolved after you have talked to your team, you might want to write to the head of the rheumatology department or to the hospital and explain the reasons for your dissatisfaction
- You have the right to ask for a second opinion
- In England, the National Health Service (NHS) has a Patient Advice and Liaison Service, known as PALS, which represents patient views. Your PALS local office, usually based in your local hospital, may be able to help you resolve things informally. Equivalent services in Scotland, Northern Ireland and Wales are: Patient Advice Scotland (PASS); the

Patient and Client Council (PCC); and the Community Health Councils (CHCs). Contact details for all are in the Directory at the end of this booklet, page 64

- If all else fails, hospitals have a formal complaints procedure. You can write to the Chief Executive of the hospital or ask for a complaints form. PALS, PASS, the PCC and CHCs can also give you information about NHS complaints procedures and how to make a complaint.

Personality clashes

It is important to have a good relationship with members of your healthcare team, but personality clashes can and do occur. This can make good communication extremely difficult. If you don't get on with your consultant, specialist nurse or GP, it can cause genuine anxiety and emotional distress. This is unhelpful in the management of your disease and it can get in the way of your ability to self-manage effectively.

If this is the case, it may be better to change to another team in another hospital in the area. A first step may be to discuss the problem with your GP, who may be able to suggest other rheumatology units to refer you to.

If your GP is the problem, ask to see another GP in the practice or consider switching to another practice altogether if that is possible in your area. If problems still persist contact your local HealthWatch for advice.

If a change is not feasible, it is worth being straight with your health professional about the problem. You can say something like: *'Look, I think we may have got off on the wrong foot. I feel I would be more comfortable seeing another consultant/nurse/physio within the team, if you would be good enough to refer me to someone else.'* (You may want to take someone with you for added confidence.)

Most doctors and health professionals are happy to refer patients to other colleagues. It is often helpful in any case to have a second opinion and these 'internal referrals' are not that uncommon.

Drug treatments

An important part of self-management is understanding your own medication: which drugs you are taking and why; their benefits and side effects. Taking a variety of tablets at different times of the day isn't always easy, we know, but they will work best if you stick at it. However, if you're finding it difficult, there's always something that can be done to help, as we explain on page 24

There are three main types of drugs used to treat RA:

Symptom-management drugs, which reduce symptoms such as pain and swelling without affecting the underlying disease.

Anti-inflammatory drugs

It is generally recommended that NSAIDs and COX-2s are taken at the lowest effective dose for as short a time as possible. Some people with RA, however, have to take this type of drug regularly for months or even years. Most people find them effective and do not experience problems, but there are potential side effects to consider.

Gastrointestinal (stomach and gut) bleeding is the most likely side-effect. For that reason, another tablet (often referred to as a PPI or proton pump inhibitor) should be prescribed alongside NSAIDs or COX-2 to protect your stomach by reducing the amount of acid it produces.

There are potentially additional risks if you have a severe heart problem, high blood pressure, impaired kidney function or have risks related to bleeding from your gut, such as a previous stomach ulcer or are on medication such as warfarin or aspirin.

Conventional NSAIDs including diclofenac and ibuprofen (but probably not naproxen), have also been associated with a slightly increased risk of heart attack, particularly when high doses are used. Large-scale studies of two widely used COX-2 drugs, celecoxib and etoricoxib, have not shown an increased risk of heart attack as compared with conventional NSAIDs and they are used widely.

For the majority of people with RA, the benefits of NSAIDs in terms of symptom relief greatly outweigh the possibility of side-effects, but for people at increased risk of either stomach bleeding or heart attack the benefits have to be weighed against possible risks. You should discuss with your doctor or nurse whether this type of drug is appropriate for you and, if so, which one.

Standard disease modifying anti-rheumatic drugs (DMARDs), which reduce disease activity, leading to a reduction in symptoms over time. Steroids usually fall into this category and are nowadays mainly used as 'bridging therapy' for people newly diagnosed and waiting for DMARDs to start working and in the management of flares (see page 43).

Biologic or biosimilar disease modifying anti-rheumatic drugs.

You may be eligible for these if you find that conventional DMARDs don't work well for you or if you find the side-effects intolerable and you meet the necessary criteria, which includes having a DAS score of over 5.1. There's more on DAS on page 37 and further information about biologic and biosimilar drugs on page pages 29-31.

If you have been living with RA for any length of time, you are highly likely to be taking some form of disease-modifying treatment. By reducing disease activity, the drugs help protect your joints from damage. Doctors talk of this as 'keeping RA under tight control'. Professor Peter Taylor talks about this in more detail on page 22.

The table on pages 26 to 27 lists the commonly used RA drugs by their generic names. You may also know them by brand names. For example, ibuprofen is marketed as Nurofen and Brufen; and methotrexate is available in tablet form (with different brand names) as well as in injection format with brand names including Metoject and Nordimet, and has recently been re-introduced in the UK in oral liquid form under the brand name Jylamvo (more commonly used in JIA).



For more detailed information on drug treatments for RA, see our publication *Medicines in Rheumatoid Arthritis*.

Making decisions about treatment

The NHS in all parts of the UK aims to improve healthcare outcomes by involving patients more fully in their own care, by following the principles of shared or informed decision-making. The extent to which shared decision-making happens well in practice varies widely.

This means that patients and clinicians reach decisions about treatment together, with a shared understanding of the condition, the options available, and the risks and benefits of each of those. When you're making decisions with your healthcare team about drug treatments, make sure you are fully informed about your options. You might want to discuss:

- Why are you recommending this medicine? What does it do?
- Are there any alternatives?
- How long will it take to work?
 - What benefits can I expect?
 - Will I get worse before I get better?
- What side effects am I likely to get?
 - Will I need other medications to manage any side effects?
- Are there other risks I need to know about?
- What kind of monitoring is needed and why?
 - Is this different from my current monitoring?
- When and how should I take it?
- How long should I need to take it for?
- Will I need to make any changes in my lifestyle?
- Will it affect or be affected by other medicines I take?

Keeping RA under tight control



Professor Peter C Taylor MA PhD FRCP FRCPE

Norman Collisson Professor of Musculoskeletal Sciences, Chief Medical Advisor to NRAS and Fellow of St Peter's College, Oxford, Head of Clinical Sciences, Botnar Research Centre, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, explains:

The faster we can switch off harmful inflammation in RA, at every stage of the disease, the better the outcomes are for patients in terms of quality of life and prevention of joint damage. Even if you were diagnosed many years ago, the more the inflammation can be suppressed now, the better you will do. What matters is to keep the total amount of inflammation you experience over time as low as possible. The ideal goal is for patients to achieve remission, or low disease activity if remission is not possible. That's the aim of tight control and it can benefit everyone with RA, although it gives optimum benefit when started as early as possible in the disease course of RA.

So what does 'tight-control' mean in practice? The principles are that your disease activity is assessed by regular monitoring and that treatment is stepped up when there is still evidence of ongoing disease activity. Clinical assessment ideally needs to be frequent (every one to three months) when treatment is first initiated. If there is no

improvement by, at most, three months after treatment start, or the target has not been reached by six months, therapy should be adjusted. Once the treatment target is achieved, progress check-ups can become less frequent, for example every six to eight months. If your disease remains active or flares after an initial improvement, then you may be assessed more often, and your treatment escalated until it settles down. However, it must be remembered that RA is different for everyone and each person will be invited to discuss their individual treatment plan with their own healthcare team.

Tight control can involve using so-called conventional disease modifying drugs in combination as well as singly. We now know that in the majority of cases, combination therapy achieves tight control with few additional side effects or complications. If conventional disease modifying drugs do not allow the treatment target of either remission or low disease activity to be reached, then you may



be an eligible candidate for a so-called biologic or biosimilar disease modifying drug. However, in part because of the expense of these treatments, in the UK there are eligibility rules to meet before being able to receive treatment with a biologic or biosimilar that are determined by the National Institute for Health and Care Excellence (NICE). And, as with every drug, your rheumatology team will discuss the range of treatment options with you with a view to achieving the best outcomes with the lowest risk of any side effects from drugs. Although it is good to switch off harmful inflammation, it is not desirable to prevent the body from being able to fight infection naturally and to protect us from the environment we live in. But overall, tight control with escalation

of treatment leads to better outcomes and this has become a guiding principle of treatment. If disease remission has been achieved and maintained for a long time, in some cases it may be appropriate to reduce the amount of medication that you are taking. Your rheumatologist will discuss this with you if appropriate. But you should not reduce treatment yourself without consultation, or just because you are feeling better! There is always a risk that this could lead to a flare and your rheumatology team will want to work together with you to ensure that your treatment regimen is the one best suited to your unique needs.

Stopping or missing your medication

You may be finding it difficult taking your various medications all the time and you may be tempted to stop taking, adjust the dosage yourself or miss out some doses. Perhaps the side-effects are unpleasant. Or maybe you find it hard to remember which tablet to take when and find yourself inadvertently missing doses. Or your DAS may be so low that you are wondering whether you really need to keep taking the tablets and/or injections.

But it is important that you keep taking your RA drugs regularly in the way that your doctor prescribed them. If you just stop, you risk future flare-ups, pain, joint damage and disability. We know, from a large body of research, that people who take their prescribed medication regularly, in line with what has been recommended and agreed, have better long-term outcomes, with fewer flares and less disability.

So if you have any difficulties taking your medications or would like to discuss trying to reduce your treatment over time, please talk to your health professionals. Don't worry that they will judge you in any way – they know only too well how hard it can be to keep taking medications regularly for a long time. They will want to do their best to help you.

It may be that there is another medication you can take that won't have unpleasant side-effects, if these are bothering you. Or it may be that you can be assured that any side-

effects will soon wear off. Or it may be that there are things that can be done to counteract any side-effects.

Perhaps you will be able to reduce the dosage of some of the medications you are taking or make other changes to your drug regimen, such as reducing the overall number of tablets you have to take. But these are decisions that should be made in consultation with your healthcare team. Shared decision-making works best when it works both ways.

If you'd like to talk to someone else with RA who is on the same treatment as you, to compare notes, please contact the NRAS helpline team on **0800 298 7650** (Mondays to Fridays, 9:30am to 4:30pm) to arrange a call from one of our trained Volunteers.

Taking other medications

If you are taking other medications for treating other conditions, please let your healthcare team know. And if you are thinking of taking a new medication, including complementary therapies such as St John's Wort, you should mention that, too. Some drugs, including alternative or complementary medications, can interact with each other in harmful ways. Your GP, rheumatology specialist nurse or pharmacist should be able to check for any potentially harmful drug interactions.

Drugs and vaccinations

For information on how drugs interact with vaccines, see our *Immunisation for people with RA* article:

www.nras.org.uk/other-medicines

You can also ask your healthcare team and/or consult the Department of Health Green Book for further help – go to the website **www.gov.uk** and search for 'green book'.

The flu jab

People with RA are among the 'at-risk' population who are recommended and encouraged to have the annual **flu jab**. There's more information about this on our website or by calling our helpline. You can also discuss it with your GP and/or healthcare team.

Prescriptions

Your prescriptions for medication will be free if you live in Northern Ireland, Scotland or Wales.

In England, however, you may have to pay. Any medication that is administered in a hospital, an NHS walk-in centre or by your GP in person (such as injections into a joint) will be free. But you will have to pay for regular prescriptions unless you are under 16 or over 60, are on one of a number of benefits (Income Support, for example) or have a specific exemption. Your GP or pharmacist will be able to advise you whether to pay or not for your prescription.

If you do have to pay and have to get more than 12 prescribed items in a year, you can save money by getting a Pre-Payment Certificate. They currently cost £104 per year, and you can pay in monthly instalments. Visit **www.nhs.uk** or talk to your GP or pharmacist for more information.

You will most likely be in receipt of one or more **repeat prescriptions**. Talk to your hospital healthcare team and/or your GP practice to find out how the system works in your area. Don't assume that prescriptions will automatically be renewed.

Your GP practice may also have links with local pharmacies, who will collect the prescriptions for you and make them up for you and dispense them. You can then collect the medication from the pharmacy or they may be able to deliver them to you.

It's worth getting to know your **pharmacist**, whether they are based in your local health centre or hospital or on the high street. Some healthcare teams include a pharmacist with specialist knowledge of RA prescribing (ask your Rheumatology specialist nurse if that's true in your case). Pharmacists are a valuable source of support and information. He or she can help if you are concerned about your medications or the instructions about your treatment, or if you need to check whether you can take other medications or over-the-counter treatments at the same time.

You can also book a 'Medicines Use Review' with your pharmacist if, for example, you are taking multiple drugs, including, perhaps, drugs for a condition other than RA. You might find this helpful and informative.

The drugs used to treat RA

Symptom management drugs		
Type	Examples	Purpose
Analgesics (also known as painkillers)	Paracetamol Co-codamol Tramadol	Pain control
Non-steroidal anti-inflammatory drugs, or NSAIDs (some newer types are known as COX-2s)	Ibuprofen Naproxen Meloxicam Diclofenac Dexibuprofen Cox 2s * (celecoxib) (*see page 24)	Reduce inflammation
Corticosteroids (also known as steroids)	Prednisolone Depo-medrone	Reduce inflammation
DMARDs (conventional and biologic)		
Type	Examples	Purpose
Standard disease modifying anti-rheumatic drugs, or DMARDs	Methotrexate Sulfasalazine Leflunomide Hydroxychloroquine	Reduce joint inflammation
Biologics & biosimilars For more information about biosimilars, see pages 29 & 30	Anti-TNF drugs , such as: etanercept adalimumab infliximab certolizumab pegol golimumab other biologics such as: rituximab abatacept tocilizumab	Reduce inflammation
JAK inhibitors	Baricitnib Tofacitinib	Reduce inflammation

Symptom management drugs	
Notes	Obtained by
<p>Analgesics come in various types and work in different ways. Some people respond better to one medication than another. If the first drug you're offered doesn't work when taken as prescribed, ask your doctor or nurse if you could try something else.</p> <p>Turn to page 43 for more about using painkillers effectively.</p>	Some can be bought over the counter in a pharmacy; others are prescription-only.
<p>NSAIDs can work quickly. They inhibit chemicals involved in inflammation.</p> <p>Turn to page 24 for more about the use of anti-inflammatory drugs.</p>	Some can be bought over the counter in a pharmacy; others are prescription-only.
<p>If you take steroids over a long period (more than three months) or at a high dose (more than 7.5mg daily), ask your doctor about additional medication to protect your stomach and your bones.</p>	<p>Prescription only.</p> <p>Steroids can be injected into inflamed joints, into muscle, given intravenously or taken as tablets.</p>

DMARDs (conventional and biologic)	
Notes	Obtained by
<p>Standard DMARDs can take time to work. They help to control the disease over the long term. They work by 'damping down' the immune system in different ways.</p>	<p>Prescription only.</p> <p>They may be prescribed singly or in combination.</p>
<p>Biologics & biosimilars are a type of protein-based DMARD that have been developed since the end of the 90s. They work by targeting specific chemical messengers or cells that activate inflammation in the body.</p> <p>They are used particularly when treatment with other drugs is not effective, usually in combination with methotrexate.</p> <p>For more information, turn to page 29.</p>	<p>Prescription only.</p> <p>Some are delivered by a drip, in hospital and others by self-administered injection/pen under the skin, in the way diabetics give themselves insulin.</p>
<p>JAK inhibitors</p> <p>Janus Kinase Inhibitors are a new drug class that can be taken orally for the treatment of rheumatoid arthritis. JAK inhibitors are innovative new medicines that are different to biologics. Biologics are large molecules, whereas JAK inhibitors are small molecules and interrupt the signalling pathway from inside the cell involved in the inflammatory pathway.</p>	<p>Prescription only.</p> <p>Tablets.</p>

Homecare delivery companies

If you are receiving injectable methotrexate and/or an injectable biologic or biosimilar drug, this will usually be delivered by a homecare delivery company. The prescription is sent electronically by the hospital to the homecare delivery company and they then contact you to arrange a suitable date/time to deliver your drugs.

Usually one or two months' worth of injections are delivered at a time, but this may vary between individuals. Many of these delivery companies also provide nurse care to help you when you first start on your injectable drug and a nurse may visit you in your home to teach you how to inject and look after your drugs and the disposal of the empty syringes. They also usually have a helpline you can call if you need help or advice about your medication. If you work, it is possible to arrange to have your drugs delivered to your workplace.

Biologics and biosimilars need to be kept refrigerated at all times so if you don't have access to a fridge where you can store your drugs till you go home, you may be able to have them delivered to a convenient pharmacy that you use where you can arrange to collect them at a time to suit. For more information on homecare delivery services, please call the NRAS enquiry line: **0845 458 3969**

Biologics

How are biologics different from other drugs for RA?

Biologic therapies are protein-based disease-modifying anti-rheumatic drugs (DMARDs) which act on the immune system, targeting specific molecules or cells that play a role in inflammation in RA.

Some biologics block the action of certain chemical messengers in the immune system, notably TNF or interleukin (IL). Others target particular immune cells – B cells or certain T cells.

Biologics have significant benefit for many people, but unfortunately they do not work for everyone. And we don't yet know with any accuracy which type of biologic will be most beneficial to which person, though a lot of research is currently underway to find a better way of matching the drugs to the individual.

Biologics cannot be taken by mouth. Most are taken as self-administered injections/pen under the skin in the way diabetics give themselves insulin. Some, such as infliximab and rituximab are administered in hospital by intravenous infusion (also known as a drip).

For those drugs given as subcutaneous injections, a nurse will teach you or a carer how to administer the injections at home. The frequency of injections may vary, from twice weekly to once every two or more weeks, according to which drug you are taking. Not everyone has access to biologic or biosimilar medicines. There are certain eligibility criteria which have to be met in order to be put on one of these drugs, see below, page 30.

For more details about how biologics work and how they are administered, please see our booklet, *Medicines in Rheumatoid Arthritis*.

Biologic drugs currently available

Type	Drug	Brand name
Anti-TNF drugs	adalimumab*	Humira
	etanercept*	Enbrel
	certolizumab pegol	Cimzia
	golimumab	Simponi
	infliximab*	Remicade
Drugs that target B cells	rituximab*	Mabthera
Drugs that target T cells	abatacept*	Orencia
Drugs that target interleukin (IL) proteins	tocilizumab	RoActemra

Other biologic drugs are in development. Those marked with an * are now or are soon to be off patent, enabling similar versions - biosimilars - to be offered as an alternative choice (see page 31 for more on biosimilars)

Can I get biologics?

Decisions about who is eligible to receive which drugs on the NHS are made in England and Wales by the National Institute for Health and Care Excellence (NICE). In Northern Ireland, the health authorities tend to follow NICE guidance. In Scotland, decisions are made by the Scottish Medicines Consortium (SMC).

You meet the NICE criteria (similar criteria apply in Scotland) for receiving biologics if:

- Your disease has failed to respond adequately or you have had unacceptable side effects with at least two DMARDs, one of which is methotrexate, over a minimum period of six months
- You have a Disease Activity Score, also known as your **DAS 28**, of 5.1 or higher. The DAS 28 is a widely-used test of how active your RA is – there is more information about this on page 37.

In some circumstances your doctor may decide you need biologic treatment even though you do not meet the criteria, and a special report (called an Individual Funding Request) has to be completed to request funding from your local commissioning group or health board. Your doctor or nurse will discuss this if it applies to you.

Clinical Commissioning Groups (CCGs) in England and the Health Boards in Wales have a legal requirement to fund your treatment if you meet the criteria stipulated by NICE. However, in Scotland the Health Boards follow

the treatment criteria stipulated by the SMC, which is not mandatory (although the SMC does generally follow NICE Guidance for Multiple Technology Appraisals – MTAs – when several drugs are appraised simultaneously).

For more information about how to challenge a decision about your RA treatment, email enquiries@nras.org.uk or visit the NICE or SMC websites, details on page 63)

What if my biologic therapy does not work for me?

For some people a first biologic may not work for them and so NICE has issued guidance in which it suggests, based on the evidence available, the most suitable sequence of treatment. The precise order in which these more targeted drugs are used can vary at a local level, and your rheumatology consultant will be able to discuss with you which biologic or biosimilar drug they think would be most appropriate for you.

Can I access a medication which hasn't been approved for use in the NHS?

If your doctor thinks that another drug which has not been passed by NICE or the SMC is more suitable for you, then he/she can apply to prescribe it on a named-patient basis. Also if your doctor wants to prescribe a drug which is outside the standard biologic pathway, this can be done through a process called an Individual Funding Request. There is no guarantee that this will be successful, but it may be worth trying.

Where can I find more information?

The situation is changing as new drugs come onto the market and NICE and the SMC begin to appraise them. Our helpline team can give you up-to-date information. Or visit our website.

If you have a specific medical query, it is best to ask your own rheumatology team in the first instance, if possible.

Our helpline also has access to a national network of Medical Advisors who may be able to help in a general way. They are unable to enter into direct dialogue with patients.

You can also speak to NRAS Volunteers who have RA and are benefiting from such therapies: this can be reassuring if you're about to start treatment and have any concerns.

NICE and the SMC also produce patient information leaflets about biologic drugs and their use. Visit their websites at www.nice.org.uk and www.scottishmedicines.org.uk to download copies.

Biosimilars

Biological medicines are medicines that are made or derived from a biological source and as such are complex, with inherent variability in their structure. As biologic medicines come off patent, other companies are free to make a 'biosimilar'.

A biosimilar medicine is a biological medicine that is highly similar to another biological medicine already licensed for use. It is a biological medicine which has been shown not to have any clinically meaningful

differences from the original medicine in terms of quality, safety and efficacy.

Biosimilar medicines are not considered generic equivalents to their originator biological medicine because the two products are similar but not identical. However, they will have met regulatory requirements in terms of comparative quality, safety and efficacy.

Where NICE has already recommended the originator biological medicine, the same guidance will normally apply to a biosimilar of the originator. Continuing development of biological medicines, including biosimilar medicines, creates increased choice for patients and clinicians, and the increased commercial competition is lowering prices for biologic medicines. The decision to prescribe a biological medicine for an individual patient, whether an originator or biosimilar medicine, rests with the responsible clinician in consultation with the patient. You can find out much more information about biosimilars on our website at www.nras.org.uk/biosimilars

JAK Inhibitors

Janus Kinase Inhibitors are a new drug class that can be taken orally for the treatment of rheumatoid arthritis. This new development could be a positive step for patients who have RA that does not respond to methotrexate (alone or in combination with other DMARDs), patients who's disease has not responded to at least one biologic/ biosimilar and as monotherapy for those for whom methotrexate is contraindicated or not tolerated in one of the above scenarios.

The first Janus Kinase (JAK) inhibitor was approved in the United States in 2012. JAK inhibitors work by hindering the activity of one or more of the Janus Kinase family of enzymes. The enzymes play a role in the cell signaling process involved in the inflammatory and immune responses seen in rheumatoid arthritis. JAK inhibitors are different to biologics. Biologics are large molecules, whereas JAK inhibitors are small molecules and interrupt the signaling pathway from inside the cell involved in the inflammatory pathway. JAK inhibitors have developed into a promising drug class for people with rheumatoid arthritis and currently there are two available in the UK baricitinib and tofacitinib. Others are in the pipeline.

The eligibility criteria to access this class of treatment is also laid down by NICE and the SMC and is the same as the criteria for biologics and biosimilars.

Research and developing drug treatments

Not everyone with RA benefits from every drug: for example, anti-TNFs (the type of biologic or biosimilar that people generally start with if progressing to more targeted therapy) work to a greater or lesser degree for about 60 to 70 per cent of people who are prescribed them. Of those for whom the drug does work, a further proportion will find that the drug gradually stops working as effectively over time, with the result that a different biologic will need to be tried. Similarly, other biologic therapies such as rituximab, abatacept and tocilizumab, work well for some people with RA, but not for others. This is one of the reasons why it is good to have a range of different drugs accessible to try.

Although the development of biologic drugs has been a major breakthrough in the management of RA, it is not possible to achieve remission for everyone. For this reason, it is important to undertake research to find more drug treatments for RA. There are new biologic drugs being tested and also new, oral synthetic (non-biologic) DMARDs that entered the UK market in late 2017 e.g. JAK inhibitors.

Research and development is likely to continue into the use of existing and new biologic/biosimilar and non-biologic DMARDs in combinations to understand how to achieve the best treatment responses. There is also a great deal of research being done which is designed to determine how we can predict which of the many choices of treatments available now, with even more coming in the future, will be exactly the best approach for any given individual with RA.

Drug trials

Scientists test all new drug treatments through a process of clinical trials before they are available for prescription. The trial process takes several years and involves large numbers of people with RA.

You may have thought about taking part in a clinical trial. If so, please visit our website www.nras.org.uk/clinical-trials for details of some of the trials currently recruiting participants. Before signing up, though, do talk it over with family, friends and your healthcare team. There are a number of websites that you can visit to find out which drug trials are currently recruiting participants to find out if you are eligible to take part in a clinical trial. See page 63).

Monitoring how you are

An important part of self-management is working with your healthcare team to monitor your RA. It helps to know what information the team is collecting and why, and how they interpret it to build up a picture of how you are.

The frequency of outpatient appointments varies according to how active your disease is, but it's essential to attend for your regular blood tests and appointments. At assessments the team use a range of measures and tests to review your general health, your physical function and the results of blood tests.

General health

In routine assessments, the team asks about your overall health and any changes you are aware of. These could be related to your RA, an unrecognised side effect of medications, or entirely unrelated.

Some changes to your health might have implications for your treatment: for example, problems with the kidneys or liver (which would show up in your blood test results), mean that some drug dosages may need to be reduced to bring your blood results back to the normal range for you.

Make sure you discuss with the team:

- New medications and complementary therapies you are taking, including for conditions other than your RA
- Changes of treatment since your last appointment
- New problems or symptoms: how long you've had them and what makes them better or worse
- Other medical problems and whether you're seeing other doctors for any care and treatment.

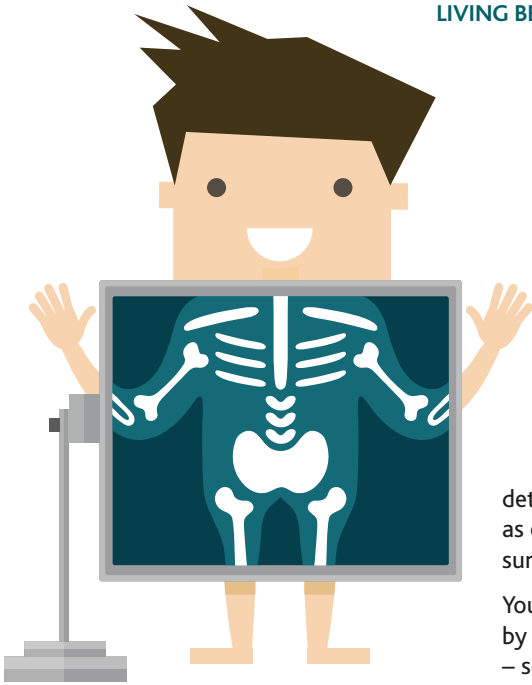
Physical function

Any changes in your ability to carry out everyday activities help the team to assess whether the treatment you are having for your RA is working.

If there are changes, the team will try and reduce the problems, for example by referring you to an OT or providing treatment for the problem joints. They may also look at your pain relief, consider physiotherapy or review your medications.

Make sure you discuss with the team:

- Particular activities at home or at work that are difficult or cause additional pain
- What you can and can't do in the way of normal activities. Sometimes you learn to avoid moving in certain ways because it hurts, and it's easy to forget about a problem when you've found a way round it
- Early morning stiffness and how long it lasts. It's an important indicator of how much inflammation is in your joints
- Any painful or tender joints.



X-rays

X-rays show changes to the bones and their positions but are not so good at showing problems with surrounding tissues or swelling. They are usually kept to a minimum. A chest X-ray is used occasionally to look at the lungs. This may be needed if you have new symptoms or if you're about to start a treatment (e.g. methotrexate) and the team needs to see how your lungs are before you start taking your treatment.

Ultrasound

Ultrasound images show inflammation in certain joints better than X-rays. Ultrasound is increasingly being used as a tool for diagnosis, particularly in the early stages of RA, to detect inflammation which may not be visible as swelling or redness. It can also

detect early damage to the bones such as erosions (the eating away of the surface of the bone).

Your ultrasounds may be carried out by a radiologist or by your consultant – some consultant rheumatologists are trained in performing ultrasounds.

MRI

MRI or Magnetic Resonance Imaging is useful for looking at joints that are less accessible to ultrasound, such as the ankle and knee. MRI can also detect inflammation and erosions earlier than X-rays.

Health Assessment Questionnaire (HAQ)

The HAQ is a questionnaire which asks how easily you can complete a range of tasks to determine how well you are functioning physically. You score them according to whether you can do them with: no difficulty; some difficulty; much difficulty; or not at all.

You tick additional boxes if you use any help to do the tasks: for example, to take a bath you might use a bath seat.

DAS 28

DAS stands for **Disease Activity Score**. The score is arrived at following an assessment of your joints, blood test results – C-reactive protein (CRP) or erythrocyte sedimentation rate (ESR) – and your own view of how you are. It assesses 28 joints for tenderness and/or swelling, which is why it’s called DAS 28. While other joints can be affected, research has shown that these 28 give a good indication of how active your disease is overall. You are asked how you have felt overall with your RA in the last week and mark this on a scale. All these scores are then added up to give you a personal DAS (disease activity score).

The National Institute for Health and Care Excellence (NICE) RA Guidelines recommend that after diagnosis, DAS is done monthly until the disease is under control. The DAS 28 is one of the assessments you have if you are being considered for biologic treatments. If you don’t know your DAS score, ask the team about this at your next appointment.

DAS score	Suggests
Less than 2.6	RA is in remission
2.6 to 3.2	A low level of disease activity
More than 3.2	A higher level, and for some patients a change in treatment may be needed
More than 5.1	A high level of disease activity that requires action. It may mean that you are eligible for biologic therapy



Call the general enquiries number at NRAS (**0845 458 3969**) for an information booklet on DAS or visit the website where you can also find out about and download our DAS App, which can help you to keep track of your DAS, through self-assessment, between appointments.

Blood monitoring

Regular blood tests are extremely important when you have RA. You may have all your blood monitoring carried out at your GP surgery or at your local hospital or a mixture of both.

Which tests you have depends on your medication and also on your rheumatology department. Blood tests help the team to assess your general health, your level of inflammation, whether medications are having an effect on your normal blood system and how well the main organs in your body are working: they are an important early indicator of any changes.

Not everyone gets used to having regular blood tests. The phlebotomist or GP practice nurse – the person who actually takes the blood samples – will understand. Just let them know and they will do their best to keep you calm and to get it done as quickly as possible. You may also want to take someone with you to help distract you.

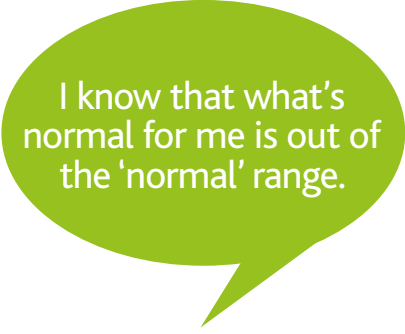
What blood tests measure and why	
Haemoglobin	To find out if you are anaemic.
White cell count: the number of white cells in your body. There are different types of white blood cells, including neutrophils.	White blood cells are involved in fighting infections. Some drugs can affect how your body produces them.
Liver function tests (LFTs): alkaline phosphatase, ALT, LDH	To find out how well the liver is working. Some drugs can affect the liver function.
Renal function test (U&E): urea and creatinine.	To find out how well the kidneys are working.
ESR (erythrocyte sedimentation rate): the level of inflammation	To assess the level of inflammation as an indicator of disease activity. The ESR level can be raised not only because of inflammation but also for other reasons, such as infection. This test is not specific to RA and some people do not have a raised ESR even when their RA is active.
CRP (C-reactive protein): a protein produced by the liver during times of inflammation	To assess the level of inflammation. It is said to be a more sensitive test than ESR. Again, it is not specific to RA.
Cholesterol	<p>Raised cholesterol levels are associated with a higher risk of heart disease. Having RA also increases the risk of heart disease, so it's important to know about raised levels so that action can be taken to reduce them.</p> <p>The test for cholesterol levels is a 'fasting blood test', which means it will be done separately from the other tests. But it is important to keep an eye on your cholesterol levels so that your GP can advise you on ways to lower them if they're too high.</p>

Blood results can reveal trends. For example, if your CRP levels show a downward trend, it means your inflammation is reducing, probably due to medication. Other trends may highlight a problem. For example, if your haemoglobin levels show a downward trend, it may mean your RA is poorly controlled or medications

you're taking are affecting the production of blood cells.

It's important to get to know your own levels: what's normal for you may not be for others. Always ask your doctor or practitioner to explain the results to you when you see them. Get to know the important ones that help you know

how your rheumatoid arthritis is: the ESR and CRP levels. Ask which levels you should watch that may indicate any problems with your medications. Look at the trends: How do the last few results compare? Are they going up or down? If you see a trend, ask the team what it means.



I know that what's normal for me is out of the 'normal' range.

Quality of life

In RA there isn't one single measure that all rheumatologists use to measure quality of life. Your healthcare team uses standard measures of disease activity and physical function, and at times you may also be asked to complete a questionnaire about how RA affects other aspects of your life, such as your mood and your relationships with other people: some of the things that make up how we perceive our quality of life.

Questionnaires can be helpful to the team, but they may not pick up what's most important to you. So it's important to think about what quality of life means to you personally. For example: Can I do the things I want to do? Can I work if I want to? Can I do the gardening, shopping, take the dog for a walk, look after my family?

If you find that your RA is preventing you from doing an increasing number of things, talk to your team about it. It may mean that your treatment needs to be changed to bring your disease under better control, or that you need a referral to another member of the team to resolve some of the problems.

Keeping your own records

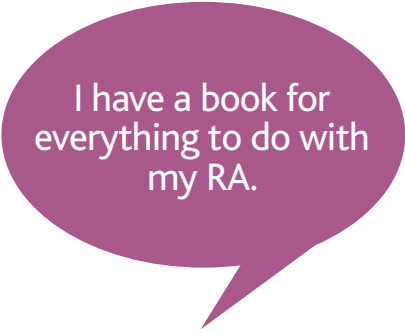
It can be a very helpful to keep your own records of your treatment. You may think that each member of your healthcare team has all your notes or is always in communication with everyone else, but that isn't necessarily so. And if you have to change hospital or GP – for example, if you move house – it can help if you have up-to-date notes with you.

Don't feel you have to spend all your time keeping notes, though: it is a balance. You need enough information to be safe and get the best out of your treatment. Find a way of recording key facts that works for you and keep all the information in one place. Then it's easy to find when you go to clinic and easy for the doctor or practitioner who's looking through it.

Many people keep a **diary** of what they do, how they feel and any problems; they find it helps them understand the pattern of their RA. Others use apps on their mobile phones or tablets to keep track of their health and wellbeing. Take a look at the NRAS **Know your DAS** app and/or the **Rheumabuddy** app.

Be as honest as you can, and aim to quantify things and be as precise as possible. For example:

- Say how long you were stiff for after you woke up – rather than 'stiff this morning.' Say how painful an activity was using a scale of 1-10 – so that you can compare from day to day
- Say which activities you were able to do: for example, getting dressed, making a cup of tea, walking a short distance.



I have a book for everything to do with my RA.

You do not need to record everything in such detail all of the time but, when you are having a difficult time, it can be very helpful.

A **shared care booklet** or **card** can help you keep track of relevant information. Shared care cards are usually given to you by your specialist team. There are different versions, but it is usually a small booklet in which to record your blood results, and sometimes other information such as DAS scores and records of injections.

The most common form of shared care is having **blood monitoring tests** done by your GP between visits to your specialist. It is helpful to keep

records of these tests and take them with you for your specialist to see at clinic appointments, as well as for your own information – although in many locations now, tests done by the GP can be seen by your rheumatology team as they have access to a common IT system. Other examples of shared care involve a **change of treatment** by your GP between hospital appointments or even giving you a steroid injection to treat a flare. If you have a steroid injection between appointments, it is important to tell your rheumatology team about it when you visit them. Often, however, a GP will need to get permission from the rheumatology team before administering steroids.

If you are taking a biologic therapy you should carry an alert card. This has a reminder of any symptoms you need to report to the medical team and space for details of your medication and contact details. Ask your doctor or nurse at your next appointment for a biologic alert card.

If you are taking steroids you should carry a **steroid treatment card**. This has a record of your dosage and indicates how long you have been taking the medication. It notifies health professionals that you need the treatment to be continued. This is important if you become ill or are involved in an accident. You can get a steroid card from the pharmacy when you collect your prescription, and some rheumatology departments also have them.

Feeling not in control makes you feel worse. Taking control by keeping records and notes doesn't, in itself, make a big difference, but it makes you feel like you're in charge.

Patients know best (PKB)

Methods of keeping control of your records and information are changing, and you may have heard items in the news from time to time about the electronic patient record. In England, for example, all GPs are now required to make your Summary Care Record (which gives details of the medicines you are taking and of any allergies or bad reactions to any drugs you may have) available online.

NRAS have been looking at new electronic patient portal systems as this is something which will come in and change the way we manage our health in due course and would be helpful in areas where we have been commissioned to deliver self-management services. As a result, we have formed a partnership with **Patients Know Best**, (PKB).

In a few years from now, everyone will have access to this kind of electronic record and, just like with our mobile phone, we will wonder how we ever managed without it.

Facing challenges

Living with RA brings with it all sorts of challenges. Some days can be worse than others. But there are things you can do to make those days more bearable. Keeping as fit and healthy as you can will also help reduce the bad days and lessen the risk of any complications.

Managing pain and flares

The major challenges of self-management are learning how to cope with the symptoms of pain and with fatigue, as well as managing the unpredictability of flares. Learning how to manage pain involves a range of different strategies. Drugs do a major part of the job, but other methods are important too. These include non-drug treatments such as using heat and cold, relaxation and using techniques such as distraction. It's about finding what works for you.

The more you keep moving the less you seize up. I swear by Tai Chi.

It helps to keep as active as you can, to maintain the full range of movement and strength in your joints and to reduce stiffness. Exercise also looks after your heart and can make you feel good about yourself by releasing the body's natural painkillers, endorphins. There's more about exercise on our website at www.nras.org.uk/exercise

Managing pain

Pain is personal and specific to you. It may help to understand in more detail the mechanisms of how your body registers and interprets pain. Self-management courses include information on this, and there's more about managing pain on our website

and in our booklet *Medicines in Rheumatoid Arthritis*. The Pain Society (contact details at the end of this booklet, see page 62) also has plenty of information on pain management.

The best way to ease the pain of RA is to aim for effective and continuing control of the disease process. This is with management of the disease by the various medicines outlined in this booklet. Immediate relief from pain can be achieved by taking simple painkillers, combined pain remedies. Non-steroidal anti-inflammatories or in some situations, steroid preparations may be prescribed as well to give relief when the swelling and inflammation are excessive.

Using painkillers effectively

If you have pain every day, you need to take your painkillers regularly. Many people reduce their painkillers when their RA is under control, which makes sense. But if your pain flares up or becomes more persistent you should take your painkillers every day, at regular intervals, and not wait until the pain escalates. Find out the maximum dose you can take in a day, and watch out for common side effects such as dizziness or constipation.

I went on a course about using painkillers, and it's made a real difference. The main message was about taking regular medication; don't wait.



Pain medication options include:

- Simple analgesia (Paracetamol) taken regularly at the right dose
- Compound analgesia (analgesia with a mild opioid drug) such as Co-codamol taken regularly at the right dose
- Opioids, such as Tramadol
- Anti-inflammatories such as Ibuprofen or Voltarol gels or tablets (sometimes called NSAIDs and COX-2s). These drugs should only be used for the shortest possible time
- Steroids given either by mouth, injection or infusion.

These are not all suitable for everyone. If your current medications are not helping to control your pain or you're getting side effects, discuss your options with your GP, nurse specialist or rheumatologist.

Pain-management techniques

Heat therapy

Either dry or moist heat can help if a muscle is painful or a joint is sore. Protect your skin from direct dry heat with a towel – you can use: a hot water bottle, electric heat pad or jelly pad. Moist heat can be: a hot shower or bath, a basin or bowl of hot water, or a damp towel heated in a microwave.

Cold therapy

You can get relief from cooling an inflamed (red, hot, swollen) joint, using almost any clean, cold item. Try: a bowl of cold water with ice cubes added for hands or feet; a bag of frozen broad beans as a mouldable ice pack (wrap it in a towel); a jelly pack; or a damp towel, kept in the fridge.

I've found that different things help: those heat pads you put in the microwave, meditation, tubigrips on the wrists...

TENS

Some people find that a TENS machine (Transcutaneous Electrical Nerve Stimulators) is effective for pain relief. The NICE Guidelines on RA suggest that you ask your physiotherapist about TENS.

Relaxation

Relaxation is not just 'taking it easy'. It means learning how to let go of physical muscle tension and emotional stress, relaxing both your body and mind. When you're in pain over a long time, you can become tense without realising it. You can become mentally and emotionally tense, and it's easy to be trapped in a 'cycle of pain'. Relaxation can break this cycle and help to reduce pain. It takes practice, but once you've learned the technique you can use it anywhere.

Different types of relaxation include deep breathing and guided imagery relaxation. No method has been shown to be more helpful than another, so find the one that feels comfortable for you that you can incorporate into your daily routine. You could start by borrowing a relaxation tape from your local library. You may find the RefRAME RA website a useful source of information.

www.reframera.co.uk

A good night's sleep

If your sleep pattern is disturbed this is likely to increase your pain, and leave you tired and lacking in motivation. Establishing good sleeping habits (sometimes referred to by health professionals as 'sleep hygiene') can help and includes:

- establishing fixed times for going to bed and waking up
- creating a relaxing bedtime routine
- only going to bed when you feel tired
- maintaining a comfortable sleeping environment that's not too hot, cold, noisy or bright
- not napping during the day
- avoiding caffeine, nicotine and alcohol late at night
- avoiding eating a heavy meal late at night.

Talk to your GP or specialist nurse if you continue to have poor sleep as they will be able to help. See also the NRAS leaflet on *Sleep Hygiene*.



Think can, not can't

Some people find 'positive thinking' helps them to cope better. But it's an individual thing and may not suit everyone.

If you want to give it a go, try focusing on the things you can do, rather than those you can't. Try not to avoid doing things because of your pain so that it doesn't dominate your life.

Sometimes, small changes to your way of thinking can help. For example, instead of lying awake in bed thinking, 'I'll never get to sleep', you could try telling yourself: 'At least I'm resting my body'.

Diversion and distraction

Divert yourself from your pain with an activity that interests you. Use distraction to get through tasks. It can reduce the pain you feel. For example, if going upstairs causes you difficulty, try naming a different country with each step.

Complementary therapies

There is no evidence that alternative or complementary therapies have any effect on the disease process in RA, but some people find them helpful. However, remember that 'natural' doesn't necessarily mean 'harmless': some alternative remedies have side effects and can interact in harmful ways with medication.

It is not advisable to take complementary therapies instead of the treatments prescribed to you by your healthcare team.

If you are considering any complementary or alternative therapy, discuss it with your rheumatology team first to make sure that it can be taken alongside your prescribed medications.

Take up something new – like pilates or yoga

Managing fatigue

Fatigue isn't just tiredness. Living with RA you know that it can be like wading through mud or running into a brick wall.

But there is a great deal that can help to prevent and reduce fatigue. Above all, it's important that your RA is well controlled. If you're more fatigued than usual and it's getting hard to manage, don't ignore it. Talk to your rheumatology team, rather than struggle on your own until your next appointment.

Little things help to make life easier, for example with clothes. Coats with slippy linings are so much easier to get on and off!



People find that different techniques and tips help to cope with fatigue, and you may need to experiment to find what works best for you. Fatigue and pain can be connected, and the advice on managing pain can also reduce fatigue. Many people find that some or all of the following help:

- Get a good night's sleep (see also page 44)
- Get plenty of rest and relaxation
- Pace your activities and plan ahead for what you want to do
- Follow a healthy diet and make sure you drink enough fluids
- Find easy-to-use gadgets, from electric tin-openers to long-handled back brushes in the bath. An occupational therapist can help and make suggestions

Don't beat yourself up just because you can't do it right now. Tomorrow is another day!

- Find everyday tips from other people with RA – for example, via our online forum, **NRAS HealthUnlocked**, which can be accessed through our website
- Get a copy of the NRAS *Fatigue Matters* booklet.

Managing flares

Whether it's relatively short-lived or so severe you can hardly get out of bed, a flare can be frustrating, bewildering and painful. Along with an increase in joint pain, swelling, fatigue and stiffness, you may feel increasingly low in mood.

A flare can happen at any time, especially after an infection or a period of stress. You may get better at identifying early signs of a flare and sometimes you can tell you're going to have one as symptoms worsen over a few days. Fatigue can also be a warning sign – hitting a 'dead stop' may mean your disease is becoming more active and you need to respond to that. But you may get no early signs at all.

Sometimes, simple self-management techniques and a few days' rest are enough and you don't need additional treatment. But if your symptoms are gradually getting worse, you may need to see one of your healthcare team to discuss treatment options.

If you are having regular flares it may be time to review your RA treatment. Your symptoms and blood tests will help the team to assess whether your disease is becoming less controlled or whether you're experiencing more pain for other reasons.

Some general strategies for coping with a flare include:

- Get rest and relaxation early on
- Use cool packs
- Use aids, for example a stick if your knee is a problem
- Wear the right shoes
- Do gentle exercises, to help relieve the stiffness that makes pain worse
- Take your pain medication regularly and at the right dose
- Use hot baths or showers to relieve early morning stiffness and pain
- Let people around you know, so they can understand why you're not coping as you usually do
- The section on 'pain management' and 'pain management techniques' gives more details on ways to reduce pain when experiencing a flare. Some flares may require more than your own coping strategies can provide, and in these circumstances you may need to seek help from your rheumatology team. It is possible to ask about getting a steroid injection, often referred to as a 'depo' (short for depomedrone) if the pain levels are not responding to increased pain medication that you are taking. Steroid injections given intramuscularly can help to reduce inflammation and pain and the beneficial effects can be fairly swift and last several weeks
- The section on 'managing fatigue' may also provide information which can be helpful in the self-management of flares.

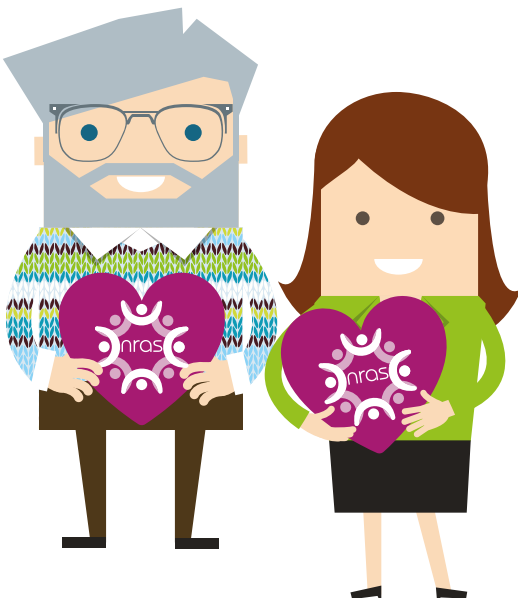
Managing risks and complications

Complications are thankfully much less frequent nowadays than they used to be in RA. Due to better treatments, complications are far less likely when RA is well controlled. But some do occur, and most can be effectively managed. Make sure you have regular monitoring and assessment from your healthcare team, learn what to look out for, and do what you can to reduce the risks.

The most important thing you can do is keep your heart healthy and keep yourself generally well. There is a higher risk of cardiovascular disease associated with RA but this can be significantly reduced: first, by controlling rheumatoid inflammation as completely as possible; and second, by keeping your other risk factors as low as possible – the same as for anyone without RA, and the same advice applies:

- Don't smoke
- Keep active, and find a form of exercise you enjoy
- Keep to a healthy weight
- Have your blood pressure and cholesterol levels checked at regular intervals.

For more on how to maintain a healthy lifestyle, see the next section, **living better**, from page 55 onwards.



'Love your heart'

The sad reality is that it is not unusual to meet someone with RA who does not realise that they are at an increased risk of heart disease, so they are far less likely to address factors such as smoking, weight and diet which are firmly within their control.



As a consequence, NRAS has developed **Love your Heart**, an engaging and interactive online video programme to educate people with RA about heart disease and atherosclerosis (furring-up of the arteries). It explains in simple terms why people with RA are at increased risk. It also enables them to calculate their own personal risk factors and provides the tools to set personal goals to reduce that risk and achieve a healthier lifestyle, thereby reducing the risk of cardiovascular problems.

Find out more about the '**Love your heart**' programme from the NRAS website:
www.nras.org.uk/loveyourheart



David G I Scott

Honorary Professor of Rheumatology Norwich Medical School, Honorary Consultant Rheumatologist Norfolk and Norwich University Hospital, Patron NRAS,

explains how you can reduce the risks of complications from RA

Rheumatoid arthritis is a systemic disease that can affect many parts of the body, with a number of consequences. A lot of research recently has looked at how RA – certainly if it's inadequately controlled – is associated in the long term with an increased risk of cardiovascular disease, much in the same way as diabetes.

There are quite simple (if not always easy to achieve) things you can do to reduce this risk: don't smoke, take regular exercise and maintain a healthy weight. Also ask your doctor for regular blood pressure and cholesterol checks – these are usually advised once a year.

Some more specific complications can result from RA's inflammatory process. These are sometimes described as "extra-articular manifestations", meaning they are problems that occur outside the joint. A key process that drives RA is inflammation of the joint lining, but other tissues in the body have very similar structures which can also become inflamed. These include the lining of tendons (causing tenosynovitis) but also the lining of the lung and heart. So pleurisy and pericarditis, though fortunately uncommon, are recognised complications of rheumatoid arthritis. They can sometimes develop in patients who are particularly ill early on in the disease process.

Some people with RA have rheumatoid nodules. These typically take the form of a lump just below the elbow but nodules can occur elsewhere: the achilles tendon, the hands and more rarely internally. There have been some cases of rheumatoid nodules in the lung where they were initially mistaken for cancer, and also in the heart where they caused the heart to beat at an abnormal rate or in an irregular rhythm. It's important to stress that such complications are very rare, but something your rheumatologist will be aware of if you have nodules elsewhere.

Rheumatoid arthritis can also involve inflammation of blood vessels, or vasculitis. Again problems are rare, but vasculitis can cause problems in the skin and also internally. From the mid-1990s this has become increasingly rare, probably due to better control of the rheumatoid arthritis process, but a few patients – one or two a year here in Norwich – still experience this complication. Typical manifestations are little black lesions around the nail bed, little black spots over nodules and a vasculitic rash. Vasculitis can also involve the nerves, causing problems such as wrist drop and foot drop (sudden weaknesses). Severe vasculitis involving the

nerves or internal organs can be very serious and is treated with strong immunosuppressive drugs.

Other possible complications include Sjögren's Syndrome, an auto-immune condition which causes dry eyes and mouth. This is due to inflammation involving the glands that produce tears and saliva, and it can also cause vaginal dryness.

And finally, there is a link between RA and some other auto-immune diseases. Auto-immune thyroid disease, for example, is more common in patients with RA than the general population, and symptoms of an underactive thyroid include tiredness, dry skin and lethargy. Diagnosis is made on a simple blood test and it is treated with thyroid hormone replacement.

David G I Scott

When I started getting sore, gritty eyes I didn't make the connection. But when I eventually saw an eye specialist he quickly realised I had dry-eye syndrome – Sjogren's syndrome – due to my RA. With hypromellose drops they became much better. I could have avoided 12 months of putting up with sore eyes!

Low mood and depression

Everyone feels low in mood sometimes and people with rheumatoid arthritis are no different from anyone else in this respect. But it's also true that people with RA are more likely than the general population to experience anxiety and/or depression. Some people worry about the label, 'depression', but it's widely acknowledged that people with all kinds of long-term health conditions can experience it.

Your GP or other members of your rheumatology team will not be surprised if you talk to them about it and will not judge you in any way. They may be able to refer you to a counsellor or to your local mental health team. And of course if you don't want to tell friends and colleagues, you don't

have to. Our helpline team, whilst not trained counsellors, are available if you just want to talk – call 0800 298 7650 (9:30am to 4:30pm, Monday to Friday) or can arrange to match you with one of our trained telephone peer support volunteers (who all have RA themselves).

People don't know that depression can be part of RA, and culturally it can be difficult to mention that.



Depression is more than feeling just a bit down.

Liz Hale

Chartered Health Psychologist in the Department of Rheumatology at Russells Hall Hospital, Dudley,

explains how you can tell the difference and what you can do to cope.



Recognising the signs

People sometimes say they feel depressed when actually they mean that they feel a bit low, but there is a difference. So how do you know if this may be depression?

If you feel down, hopeless, or depressed in mood for most of the day, every day, for at least two weeks in the past month, and you have lost interest in activities that you used to enjoy, then you may want to pay attention to the other important signs. Though these signs need to be interpreted in the context of your RA, as someone with active disease may well experience changes in weight, appetite, sleep habits and energy levels.

The important signs to look out for are:

- *A change in appetite or change in weight*
- *Sleeping too much or not sleeping enough, especially if you wake early*
- *Restlessness or feeling slowed down*
- *Fatigue or loss of energy*
- *Feeling guilty or feeling worthless*
- *Being unable to concentrate or being unable to make a decision*
- *Thinking about suicide.*

People with depression often have negative thoughts about themselves and the future. There may be self-criticism, low self-esteem and low self-confidence. They may see other people as critical or mean, or they may focus too much on negative events. They can be unwilling to try things that might help, and in the worst cases a person may think about suicide as a possible way out.

If you recognise that these symptoms have been occurring during the last month, or family or friends have said you are behaving differently, think about talking to your GP. You can receive help and you do not have to face this alone. You can also

For me, depression goes with fatigue. When I feel it coming on I try to give myself an easier time and plan some positive things like lunch with friends or a trip to the theatre.

contact your rheumatology helpline if you have one, your local crisis intervention team (their number is in the phone book, usually under Community Mental Health), the NRAS Helpline, the Samaritans or someone else you trust.

For persistent low mood (subthreshold depression) or mild to moderate depression, psychological treatments such as problem-solving therapy and counselling can be as effective as drug treatments, and you should be offered them.

NICE guidelines (visit www.nice.org.uk and search for 'CG91') state that for mild depression you should not usually be offered anti-depressants as the first choice of treatment, unless there are good reasons to think you'll benefit.

If you are offered them, discuss with your doctor why they are important and how long you'll need to take them.

Anti-depressants can be a very useful part of therapy. Think of them in terms of facing a wall and being given a box to stand on: it will not take the wall down but it will help you to see over it.

If you are offered counselling your GP will refer you to a local service. Counselling varies depending on your needs, but you can expect to see the psychologist for a few weeks for about an hour each time. You'll spend some time getting to know the person you are seeing and agreeing what you will work on. Some forms of counselling, such as cognitive behavioural therapy (CBT), focus on how thoughts, behaviour, emotions and physical symptoms can be linked and on teaching you how to break unhelpful cycles.

You can also access a counsellor or psychologist independently. Some people providing these services work privately, although some take referrals from GPs and insurance companies. You can find a qualified therapist by searching on the British Psychological Society website (www.bps.org.uk) or on the British Association for Counselling and Psychotherapy (www.bacp.co.uk) website. By searching for a therapist from these sources, you can be confident they are qualified to help you. Some counsellors and therapists negotiate fees depending on income, so it is worth asking how much services are likely to cost. The Health Care Professions Council also keeps a register of psychologists trained and qualified to work within the NHS.

A counsellor will also work with you on learning how to make positive plans and set goals. Often, changing your behaviour is one of the first steps to improving your mood. They can also help you with talking to your family, helping to make sure you have emotional support.

The important things to remember are that depression is treatable, and that you can get help.

Living better

Self-management includes learning how to look after yourself and keeping as well as possible. As we saw in the previous section, a healthy lifestyle can reduce the risks of any complications arising. Talking about your RA, maintaining good relationships with those closest to you, working, if you want to, and getting the help you need and are entitled to, these are all aspects of living better with RA.

A healthy diet

A varied and balanced diet helps you to keep to a healthy weight, have the right intake of minerals and vitamins and maintain your energy levels.

You can find out if your weight is at healthy levels by calculating your BMI (body mass index). Your BMI will tell you if you are at a healthy weight for your height. Generally speaking, a BMI between 18 and 25 indicates a healthy weight. There are online calculators to work out your BMI or you can ask someone in your healthcare team to help you work it out – you just need to know your weight and height.

The NICE RA Guidelines (visit www.nice.org.uk and search for 'CG79') suggest that people with RA be 'encouraged' to follow a Mediterranean style diet: eat more bread, fruit, vegetables and fish; eat less meat; and replace butter and cheese with products based on vegetable and plant oils.

There is a huge amount of other dietary advice aimed at people with RA, and much of it is not based on good evidence. There is no good evidence that dietary supplements influence the course of RA – your rheumatologist would certainly tell you if they did – and they can be expensive as well as unproven. In summary, the best advice is as follows:

- Eat a balanced and varied diet
- Keep to a healthy weight, and exercise regularly if you can. If you take little or no exercise you're more likely to gain weight, and it's far more difficult to lose it than not

to put it on in the first place. If you think you are heavier than is ideal for your height (your BMI is over 25), try keeping a diet diary for a week or two to spot where you can cut out unnecessary snacks

- Eat less animal fat, and change to olive oil or rapeseed oil where possible. Use olive-oil based margarine
- Eat oily fish two or three times a week: oily fish include mackerel, sardines, herring, salmon, trout and fresh (not tinned) tuna. Oily fish contain omega-3 fats (called eicosapentaenoic acid and docosahexaenoic acid, known as EPA and DHA) which can exert a mild anti-inflammatory effect. There is some recent evidence that if you don't eat any oily fish, taking fish oil supplements can give cardiovascular benefit
- Eat plenty of fruit and vegetables. Aim for at least five portions a day.

Your GP or rheumatology team should be able to provide detailed information about losing weight and healthy eating, including what a 'portion' of fruit or vegetables is. They may also be able to refer you to a registered **dietitian**, especially if you are considering making major changes to your diet.

There is much dietary advice given within our new **Love your Heart** online cardiovascular risk assessment programme and we would recommend that everyone with RA make use of it. See more details on our website, where you can register and participate in the programme.

www.nras.org.uk/loveyourheart

There is also a lot of useful information and advice on the NHS Choices website at www.nhs.uk

Strong bones

Osteoporosis, or low bone density, increases the risk of broken bones. We all tend to lose bone density as we get older, but people with RA are at greater risk of developing osteoporosis for a number of reasons, including lack of exercise. You can find out more on our website and from the **National Osteoporosis Society** (contact details at the end of this booklet on page 63). There are things that you can do to lower your risk of developing osteoporosis however.

Calcium is important for people with RA, for maintaining strong bones and reducing the risk of osteoporosis. Milk and other dairy products, such as yoghurt and cheese, are high in calcium. Semi-skimmed and skimmed milk have as much if not more calcium than whole milk. Soya milk contains no calcium so if you use soya milk or alternatives, look for 'calcium-enriched' products.

Other calcium-rich foods include green vegetables such as broccoli and curly kale; some fruits, including oranges, apricots and dried figs; canned fish with edible bones, such as pilchards, sardines and salmon; nuts, especially Brazil nuts and almonds; and calcium-set tofu.

In addition to making sure that your diet contains plenty of calcium, you may want to consider taking a supplement containing calcium and vitamin D (which is also important for bone health). Talk to your GP or other members of your healthcare team about what might be best for you.

Weight-bearing exercise, such as walking and running, is good for your bones. Talk to your healthcare team about exercises that would be suitable for you. Also, see our website: www.nras.org.uk/exercise

Exercise

There is a lot of evidence now demonstrating that physical activity is safe and has many benefits for people with RA. We know that physical activity improves RA symptoms and lowers the risk of developing heart disease.

So, physical activity is important in managing your RA and maintaining a healthy lifestyle. Engaging in physical activity (such as walking or swimming) and/or regular movement exercises that can improve your range of motion can enhance your ability to manage day-to-day life. There are many places where you can find information on how to be active.

A good place to start is the NRAS website at www.nras.org.uk/exercise. There you will find information about how to start exercising and the types of exercise that are good for you. Cardiovascular exercise, which raises your heart rate, and strengthening exercises, which improve your muscle tone and helps protect joints, are important contributors to leading a healthy lifestyle with RA.

You can also find out more about how to reduce your risk of cardiovascular disease by doing our interactive online **Love your Heart** programme, where you can hear more about the importance of exercise from Professor George Metsios.

Giving up smoking

Giving up smoking is good general advice for everyone, but for people with RA it is particularly important as there is clear evidence that smoking can make symptoms worse and medications less effective. We now know from research that smoking can be a trigger for developing RA, which most people don't realise.

It's not going to be easy, but if you're a smoker it will be worth the effort. You're not on your own, either. There's plenty of help available. Your GP or practice nurse may be able to refer you to local smoking cessation services, as may other members of your rheumatology team. Your local pharmacist may also have details.

There's also lots of support and advice available through the Smokefree website at www.nhs.uk/smokefree

Pacing yourself

Pacing is about how you maintain a balance between rest and activity during the day and it plays an important part in managing your RA. Rather than pushing yourself until you are forced to stop, you can keep balanced and in control. Pacing is about spreading physically demanding tasks throughout the day or the week and alternating between activities that are more and less physically demanding. You can break down demanding activities into smaller sessions: for example, doing several short sessions of gardening rather than one long one.

I set myself goals and plan round them. I knew I'd be busy today, so yesterday I had a very quiet day to enable me to manage today.

You may feel guilty about resting during the day, but with rest periods you can achieve more in the long run. Rests may be short breaks of a few minutes during an activity but may include a longer rest of at least half an hour. However, this can be more difficult if you work.

Don't wait until your symptoms become severe before you move, rest or change an activity. If you do, you may reach the point at which you have overdone it – whether "it" is watching the TV (getting too stiff from sitting in the one position) or something more active like gardening or shopping.

I work on alternate days – Monday, Wednesday and Friday – so that I don't have to get up the next day.

The key to pacing is to move or stop before the problem begins, rather than let your symptoms tell you when to rest and when to re-start an activity.

I don't say I have arthritis, because they'll say, 'Oh yes, my granny has that'. I say I have rheumatoid.

Talk about it

Because RA can be invisible, especially in the early stages, it's important to talk about it. If you don't look ill, it can be hard for colleagues, friends and family to understand what you are feeling. You may need to explain things, at work and at home, that you didn't need to talk about before you had RA. Because RA can be invisible, especially in the early stages, it's important to talk about it. If you don't look ill, it can be hard for colleagues, friends and family to understand what you are feeling. You may need to explain things, at work and at home, that you didn't need to talk about before you had RA. NRAS has booklets for people who work and have RA and for employers (which you may want to give to your employer or Human Resources department). See our website for more details.

Family

Your family is also living with RA and its unpredictable ups and downs. There are times when you need their help and times when you don't: they may feel they can't win. While it can be difficult if it doesn't come naturally, do try to talk about it. People need to know how you are feeling. Try to give 'I' messages rather than 'you' messages: 'I would like some help...' and 'I'd like to explain...' rather than 'Why can't you' or 'You don't understand...'

Visit our YouTube channel to watch and listen to people with RA and their families talking about how they deal with things. You can find a number of videos at

www.youtube.com/user/NRASociety

With the kids, I'm pretty open about stuff. As soon as they ask questions, I will say, 'I'm just having a bad day' or 'I'm not feeling so great today so can you help Mum a bit more?' They both tend to pick up on it anyway; they're quite in tune with where I am.

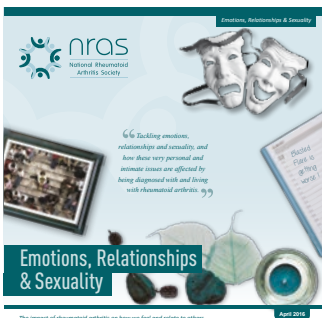
Sex and relationships

You may be coping with changes in your roles within a relationship as well as in your health. These can be significant changes that neither of you expected: who's the main earner, who looks after whom, who does what at home? It can affect how you think of

yourself and how you think of each other. It isn't easy to be someone's married partner or lover and look after them at the same time.

RA can affect your sex life, though the good news is that most problems are not permanent and simple adjustments can make a big difference. On the practical side, solutions include finding ways round difficult or more painful positions, getting used to the idea of 'planning ahead' for sex when your energy levels are better, and lubrications for women to help with dryness. On the emotional side, the important thing is communicating about it with a partner, family or friends.

If you're going through a bad patch, give yourselves time to adjust and try to talk about what is happening. Not talking and not having intimate contact can start a 'downward spiral', where you or your partner may become more reluctant to initiate sex or even to touch or hug each other.



We have a great publication called *Emotions, Relationships and Sexuality*, which covers all these issues and more. As with all our publications, you can

download it from our website or call us and ask for a copy to be sent to you in the post.



Pregnancy

Partners need support too. This is particularly true at 'decision times' when RA is a factor: you may be thinking through major events as a couple such as starting a family. It's important to take your time, and find reliable information to help you and talk to your rheumatologist who will be able to tell you and your partner about medications which you can or can't take when pregnant or trying for a baby.

You can also find information on this and more on pregnancy and parenthood on our website: www.nras.org.uk/pregnancy-and-parenthood

Some people also find it helps to talk to another person in a similar situation. Our booklet, *Medicines in Rheumatoid Arthritis*, also has information on which medications should be avoided when pregnant or trying to conceive (for both male and female partners).



Whatever the decisions you're facing, NRAS can help. As well as information about every aspect of RA, they can put you or your partner in touch with a trained NRAS telephone Volunteer who understands what you're going through and can talk to you on the phone.

We also have two useful publications, *I want to work: a self-help guide for people with rheumatoid arthritis* and *When an employee has rheumatoid arthritis: an employer's guide* that you can download from our website or order by calling **01628 823 524**

Work

While RA is challenging, it's important to remember that most people can and do carry on working, even though they may need to make changes over time. Part-time work may be an option, working shorter hours or even alternate days. Adaptations and adjustments to working practices can also make an enormous difference.

There is support available to help you stay in work. NRAS can help directly with information or signposting to specialist organisations about every aspect of working with RA from talking to your employers to your legal rights.

It's important to still see you as you, and to see a career path ahead of you. RA isn't everything. I'm trying to make it ' by the way.

Help at home

Whether you work or not, you may need help at home. There may be times when you need help with everyday activities like dressing, washing, cooking and cleaning. Or you may need special equipment or adaptations to your house or flat to help you keep living independently at home. In either case, you should contact the social services department of your local council and ask for an assessment by a social worker. Your GP or specialist rheumatology nurse may be able to put you in touch with them. Otherwise, call your council or visit their website.

A social worker may be able to get funding for you to have the adaptations you need. They will also be able to help with getting any benefits you are entitled to or with getting you rehoused somewhere more suitable, if appropriate.

We offer several booklets that contain more information, including a guide to *Personal Independence Payment (PIP)*, the benefit that replaced Disability Living Allowance (DLA). Obtain them through our website or call us and ask for copies to be sent to you.



I was diagnosed at 18 and now, at just turned 40, I still work, and do 30 hours over five days. The shorter hours help me recuperate, even just that half an hour at the end of the day. Plus I miss the traffic so I don't have to sit hunched in the car all rush hour. Work helps me maintain 'normality' – whatever that may be!

Directory: further information

Complementary Therapies (page 46)

Arthritis Research UK (ARUK) offers a booklet, *Complementary and Alternative Medicine for Arthritis*, and two reports on the subject. Call **0300 790 0400** or visit **www.arthritisresearchuk.org**

Diet (page 56)

Information available on the NRAS website and through our online programme, **Love your heart**.

NHS Choices website at **www.nhs.uk**

For more on maintaining strong bones, visit the **National Osteoporosis Society** website at **nos.org.uk** or call their freephone Helpline on **0808 800 0035** (Mon, Weds, Thurs, Fri 9am-5pm; Tues 9am- 7pm)

Drug treatments (page 20)

See our new booklet, *Medicines in Rheumatoid Arthritis*. And visit our website for the latest updates on medications, clinical trials and research.

Guidance on the prescription of RA medications is available at **www.nice.org.uk** and **www.scottishmedicines.org.uk**

Information about clinical trials can be found at all the following websites: **www.findmecure.com**, **www.nhs.uk/conditions/clinical-trials**, **www.ukctg.nihr.ac.uk** and **www.invo.org.uk**

Fatigue (page 45)

NRAS has a guide to dealing with fatigue and there are lots of useful tips on our NRAS HealthUnlocked forum at **healthunlocked.com/nras**

We have a new booklet on fatigue in RA - *Fatigue Matters*.

Pregnancy (page 59)

The NRAS website and helpline have information.

www.nras.org.uk/pregnancy-and-parenthood

Arthritis Research UK (ARUK) also publishes a booklet, *Pregnancy and Arthritis*.

Pain (page 42)

NRAS website has more information on pain, as does our booklet, *Medicines in Rheumatoid Arthritis*.

The Pain Society has a range of publications available. Call **020 7269 7840** or visit **www.britishpainsociety.org**

Sex and relationships (page 58)

Visit the NRAS website for more information or see our booklet, *Emotions, relationships and sexuality*.

Sleep (page 44)

NRAS and the ARUK both produce information on this topic. Also, visit www.sleepcouncil.org.uk or see www.nhs.uk

Talking about your RA (page 58)

The NRAS booklet, *Emotions, Relationships and Sexuality*, and our report, *Family Matters*, have useful information. There are also videos of family discussions about RA on our YouTube channel at www.youtube.com/user/NRASociety. Take a look at www.nras.org.uk/behindthesmile and www.reframera.co.uk

When things aren't working well (page 17)

To find out more about understanding the NHS and for help with making a complaint:

- in **England**: contact the **Patient Advice and Liaison Service (PALS)**. Your local hospital should have details of the nearest service. Or visit the NHS Choices website at www.nhs.uk
- in **Northern Ireland**, contact the **Patient and Client Council** via www.patientclientcouncil.hscni.net or by calling **0800 917 0222**
- in **Scotland**, get in touch with **Patient Advice Scotland (PASS)**. Visit www.patientadvicescotland.org.uk. PASS is run by the Citizens Advice Service. You can find your local Citizens Advice Bureau via www.cas.org.uk or by calling directory enquiries on **192**
- in **Wales**, contact your local **Community Health Council (CHC)**. Visit www.wales.nhs.uk to find contact details for your nearest CHC, ask at your hospital or GP surgery or call **192**

The Patients Association has a range of helpful information on their website at www.patients-association.com. Or call their Helpline on **020 8423 8999**

Work (page 60)

NRAS has two guides: *I want to work: a self-help guide for people with rheumatoid arthritis* and *When an employee has rheumatoid arthritis: an employer's guide*, as well as a report *Work Matters* from our nationwide survey conducted in 2017.

An occupational therapist may be able to give specialist advice about specific problems at work – ask your team.

The Equality and Human Rights Commission has information about your rights at work on their site at www.equalityhumanrights.com. **The Northern Ireland Human Rights Commission** is at www.nihrc.org

To speak to someone about discrimination at work, visit **The Equality Advice and Support Service** site at www.equalityadvisoryservice.com or call **0808 800 0082**. Full references available on request. Call **01628 823 524** or email enquiries@nras.org.uk

Your phone numbers and contacts

Your hospital number

Your consultant's name

Telephone number for consultant's secretary

Your rheumatology specialist nurse

Clinic helpline number

Your GP's name

GP surgery telephone number

GP out-of-hours number

Pharmacist number

Homecare delivery company number

NRAS freephone number

0800 298 7650

It might be helpful to you to record your medication details here:

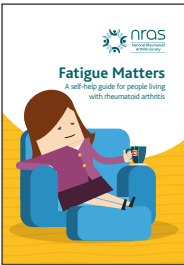
Name of drug	Dosage

Other NRAS publications



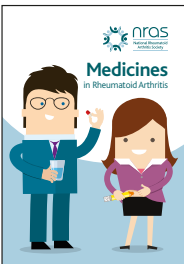
New2RA

New2RA is for people who are newly or relatively newly diagnosed and contains the information you need to help you make sense of and understand what RA is and what you have been told by your rheumatology team.



Fatigue Matters

Advice and resources to help improve the management of fatigue for people with RA.



Medicines in Rheumatoid Arthritis

We believe it is essential that people living with RA understand why certain medicines are used, when they are used and how they work to manage the condition.



JIA Explained and Managing JIA in Schools

Two booklets for parents and young people addressing the issues of living with JIA.

For all other NRAS publications, see www.nras.org.uk/publications

To obtain copies of any of our other booklets, or more copies of this one, please call **0845 458 3969** or email **enquiries@nras.org.uk**. Copies can also be downloaded from our website at **www.nras.org.uk/publications**

Glossary

Adherence	Taking your medication at the times and in the doses prescribed by your doctor
Advocacy	Support and encouragement given by one person, on behalf of, and, for the benefit of, another
Alternative/ Complementary therapy	Refers to treatments used in addition to or as an alternative to those prescribed by your doctor. Examples would include acupuncture or homeopathy. There is no evidence that these treatments can control your disease and it is strongly recommended that you tell your health team if you plan to try any of them
Blood chemistry	The chemical make-up of the blood which can be analysed by various blood tests, such as glucose, iron or protein tests
CRP	C-reactive protein is produced by the liver and can be measured in the blood as a marker for inflammation
Disease activity score or DAS 28	The combined score of a patient's specific 28 joints for swelling and tenderness, a recent blood test for inflammation and both the patient's and the doctor's assessment of how the disease has been over the previous seven days
Escalation	In medical terms, a 'ramping up' of the condition or the treatment
ESR	Erythrocyte (red blood cells) sedimentation rate is a measurement of inflammation in the blood
Fasting blood test	A blood test that measures the levels of cholesterol or other lipids (fats) in your blood requires that you don't eat or drink for 10 to 12 hours beforehand. Typically, you would have no more to eat or drink after, say, nine at night and then have the blood taken at nine the following morning
Holistic	Having regard to the 'whole' needs of a person; the physical, mental, social and spiritual aspects of a person's life
Inflammation	Is a normal protective mechanism of our bodies but in RA, the body's immune system mistakenly attacks the lining of the joints, causing swelling, pain, redness and heat, which are the classic signs of inflammation

Molecule	A group of atoms bonded together, representing the smallest fundamental unit of a chemical compound that can take part in a chemical reaction
Remission	To be symptom-free
Tight control	A plan for treating RA to keep disease activity at the lowest level possible by close monitoring and early treatment of symptoms



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This booklet has been written with input at every stage from NRAS Members, including people who are experienced in the self-management of rheumatoid arthritis.

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NRAS – Changing Minds, Changing Services, Changing Lives
for those living with RA and JIA in the UK

Join us

You can become a Member of NRAS for as little as £20 a year.*

You will be helping our work and helping us to provide help and support to all affected by RA. In addition, you will become part of a vibrant and supportive community of people living with RA. You will also receive a variety of Member benefits, including:

- our NRAS magazine three times a year
- monthly email updates
- an invitation to attend our FREE meetings and events

Join us today by calling

0845 458 3969

or by visiting our website at

www.nras.org.uk/join

There is an online form you can fill in or you can download a printable application form to complete and send in by post. If you are reading the hard copy of this booklet, please tear off the membership form attached to the bookmark, complete it and send it to us.



*if you pay by direct debit.



Living Better with RA

A self-help guide for people with established disease,
including Juvenile Idiopathic Arthritis

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