National Rheumatoid Arthritis Society

New2RA

A self-help guide for people newly diagnosed with rheumatoid arthritis

ABOUT US

The National Rheumatoid Arthritis Society (NRAS) is the only patient-led charity in the UK focusing specifically on **rheumatoid arthritis (RA)** and **juvenile idiopathic arthritis (JIA)**, including adult JIA. We provide information and support services for those affected by RA and JIA, their families, friends, carers and health professionals

CONNECT WITH NRAS

Our freephone helpline can be contacted by phone on **0800 298 7650** or by email at **helpline@nras.org.uk**. Our trained helpline staff, supported by an advisory board of medical and healthcare professionals, are there to answer your questions on all aspects of living with RA and JIA.

NEW2RA RIGHT START

Ask your healthcare team to refer you to the New2RA Right Start service, where you can speak to friendly, empathetic, expert staff, get tailored, evidence-based support and benefit from peer support. For more information, go to: **www.nras.org.uk/resource/rightstart**

NRAS AND JIA WEBSITES

Our websites offer a wealth of information about RA and JIA and their treatment, the latest research and developments, as well as lifestyle and supported self-management resources.

www.nras.org.uk

www.jia.org.uk

OUR BOOKLETS

NRAS produces a wide range of information booklets about RA and JIA. These can be downloaded or ordered through the website or by email at **enquiries@nras.org.uk**. If you don't have access to the internet, just call us on **01628 823524**.

JOIN US

To find out how to support the work of the charity by becoming a Member of NRAS, visit **www.nras.org.uk/join** or call our Membership team on **01628 823524**.

CREDITS

This booklet has been written with input at every stage from NRAS Members, with grateful thanks for their time, frankness and constructive comments. Thank you also to all the health professionals who have contributed to this booklet.

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New2RA

What to expect from this booklet

We've designed this booklet specifically for you: someone who has been diagnosed with RA within the last couple of years, and who wants to learn more about RA and what this means for you. You probably have many questions about your condition and how it will affect you. We hope we can help to answer some of them, such as:

- What is RA?
- How did I get it?
- How will it be treated?
- Will I get better?
- Who will be involved in my care?
- What can I do to help myself?
- What might the future hold for me?

Dealing with an RA diagnosis can be scary and confusing. You may not yet be sure what you want (or need) to know, or feel ready to ask about it. So please don't feel you have to read everything at once, if you don't feel ready to. But we hope that, at the very least, this booklet will reassure you that there is a lot of support out there, and if you do have any questions, you'll know where to go to find some answers.

I can remember the day I was diagnosed with RA so well. My son was just over a month old. At first I was relieved it wasn't something more sinister, as my symptoms had come on so suddenly. One day I was fine, the next I woke up feeling like a truck had reversed over me several times. Everything hurt so much that I couldn't move, and just the weight of my duvet on top of me felt unbearable. I had no idea what was going on, and I was terrified.

As I left the hospital after diagnosis I felt utterly bewildered. I had so many questions. Where had this come from? I was only 31 years old – wasn't arthritis an old person's disease? Why me? Had I done something wrong? What was going to happen to me? Would I ever be me again?

I had practical worries too. How was I going to look after my children? Could I do the housework? Would I ever be able to go back to work after my maternity leave?

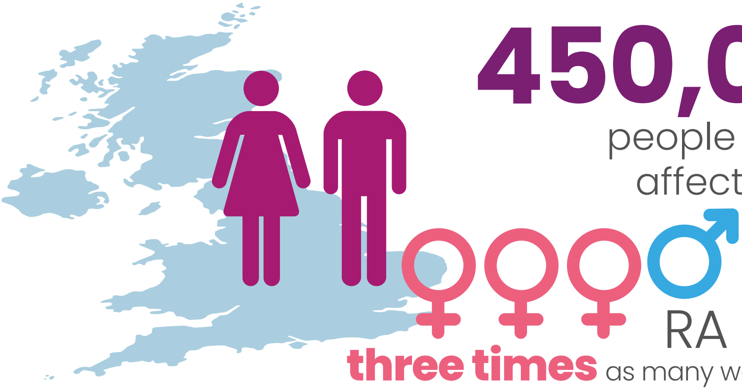
Luckily, I found NRAS online. With the support of my rheumatologist and armed with the information NRAS provided, I started treatment, and it wasn't long before I began to feel like me again.

Life is different, but it goes on. And do you know what? In some ways, my life is actually better, as being diagnosed with RA has made me re-evaluate my priorities. I am back at work, but part time, and now I make time for myself and for my family. I eat well, exercise and pace myself. My RA is well-controlled and life is good.

Julie
Aged 40, who has lived with RA for 9 years

What is rheumatoid arthritis?

RA is the most common form of inflammatory arthritis. It affects over 450,000 adults in the UK. Three times as many women as men are affected, and it can strike at any age.



Over **450,000** people in the UK affected by RA

RA affects **three times** as many women as men (up to the age of 60, after which this ratio evens out)

You might not have heard the term 'rheumatoid arthritis' until a rheumatologist told you that you have the condition. Or, perhaps, you have heard of it, but you still aren't entirely sure what it means.

It's called rheumatoid arthritis because 'rheumatoid' – rather unhelpfully - means 'relating to rheumatism' (which is pain in the joints, muscles and soft tissue), and 'arthritis' means 'a disease causing painful inflammation and stiffness of the joints'.

RA is very different from osteoarthritis (OA), which is the condition that most people think about when they hear the word 'arthritis'. OA is usually caused by wear and tear to the joints, often linked with ageing or sports/occupational joint damage.

> *While rheumatoid arthritis is the medical term for the condition, if you really want people to sit up and take notice, why not call it rheumatoid disease instead? That way people have to ask what it means!*

RA is an autoimmune condition, which means that it occurs when your immune system mistakenly attacks your own body. Nobody is sure exactly why this happens. In RA, the main result is inflammation (pain and swelling) within the joints. However, the disease can impact on the whole body, leading to symptoms including fatigue (extreme tiredness) and – when the disease is particularly active – making you feel like you have the flu.

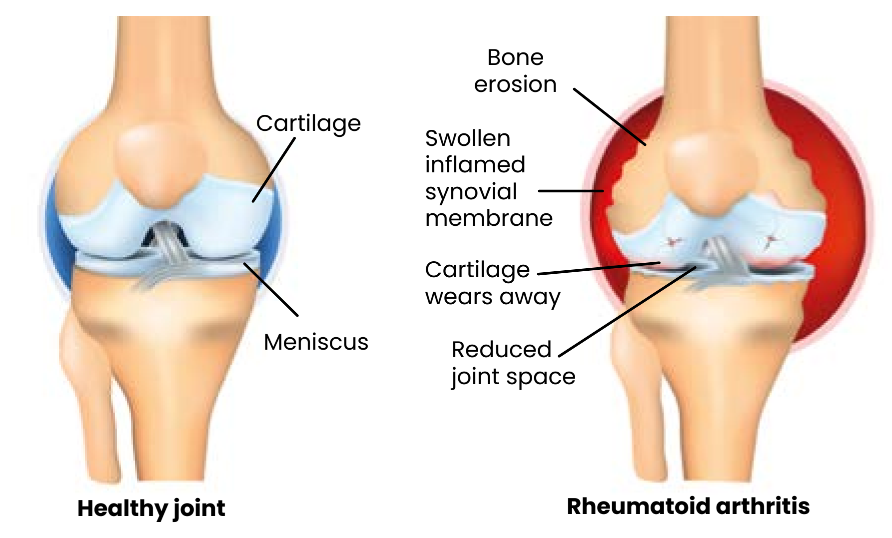
Sometimes (although it's less common today, thanks to better treatments), inflammation can develop in places other than the joints, such as the eyes, skin or lungs. People with RA are also at greater risk of cardiovascular disease (CVD). You can read more about this in the NRAS booklet 'Living Better with RA'.

Unlike osteoarthritis (OA), RA is a symmetrical arthritis, which means that if you have it in any joints in your left fingers, knuckles or wrist, you will usually also have it in the same joints in your right hand, and that if it affects your right knee, it will probably affect your left knee as well. Interestingly, it doesn't usually affect the spine, with the exception of the top neck joints.

Symptoms of rheumatoid arthritis

How and why did I get RA?

The short answer is: nobody knows. There is a great deal of research being carried out to try to identify the causes of RA. What we do know is that it's not your fault, and there's probably not much you could have done to prevent it.



We also know that some people are more likely to develop RA because they have a genetic predisposition to the condition. That doesn't necessarily mean that you are expected to have a family member with RA, or that you should be concerned that someone else in your family might develop the condition, just that there are genes in your family that make it more likely. In fact, the chances of the child of someone with RA also developing the disease is only around 1-3%!

But genes aren't the whole story. Some people have no family history of RA or other autoimmune diseases, and still develop the condition. There is evidence that, regardless of your genes, certain environmental triggers can "switch on" your immune system to make it start 'misbehaving' and attacking your body, instead of what the immune system is designed to do i.e. attacking foreign invaders, like viruses.

So far, researchers have found that stress seems to play a key role, as can smoking and changes in hormone levels due to childbirth or the menopause. For some, RA may be triggered by an infection or virus.

How RA is diagnosed

Your GP may suspect a diagnosis of RA based upon your symptoms plus the presence of swelling and pain when they examine your joints. Blood tests are routinely done to help confirm their suspicions of RA, and include a measure of inflammation (an 'ESR' or 'CRP' test) as well as tests of your immune system (e.g. 'Rheumatoid Factor' and 'Anti-CCP' test). However, it is

My RA started with an acute attack just six weeks after the birth of my fourth child. My first symptom was excruciating pain. It was a very difficult time, as I had a newborn and three other young children to look after but, with the help of my wonderful husband, family and friends, I managed to stay positive.

Being told you have RA can be a depressing diagnosis, especially at first. It doesn't help that arthritis is often associated with being old, or that the pain is generally invisible to others. But things have got a lot better since I was diagnosed. Today, there are some amazing treatments available, with many more options than in the past.

My advice to others who are newly-diagnosed is: don't be fearful. Try not to read too much on the internet and always stick to trusted sources like the NRAS website. I am now in my late 50s and doing very well. I'm very much looking forward to the birth of my first grandchild. I plan to be a very involved granny and not let my RA hold me back from enjoying this new phase of my life.

Jane
Aged 58, diagnosed at age 36 in 1995

only a rheumatologist or a GP with a special interest in rheumatology who can give a firm diagnosis of RA. This is because RA is a complex condition that presents in different ways in different people and sometimes the symptoms can be similar to, or mistaken for, quite a number of other conditions. Getting a referral to a rheumatology specialist in a timely manner is essential.

For more information on this and other topics, visit **www.nras.org.uk/smile** to learn more about 'Smile', our free self-management e-learning courses.

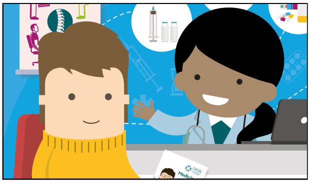
Getting a diagnosis

In addition to the various blood tests, x-rays or ultrasound scans of the joints are often organised (usually the hands and feet, as this is where RA is most easily seen on scans). No single, individual test is absolutely diagnostic, and many people will have negative blood tests or scans, especially early on in the illness. It is therefore important that people with suspected RA are assessed by a rheumatologist who will be able to make a diagnosis by taking all the tests into consideration, combined with a physical examination and health/family history. It can be a little like putting a jigsaw together to get the full picture.

6 stages of the RA patient journey

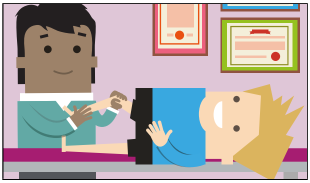
1: Recognising symptoms

2: First visit to GP



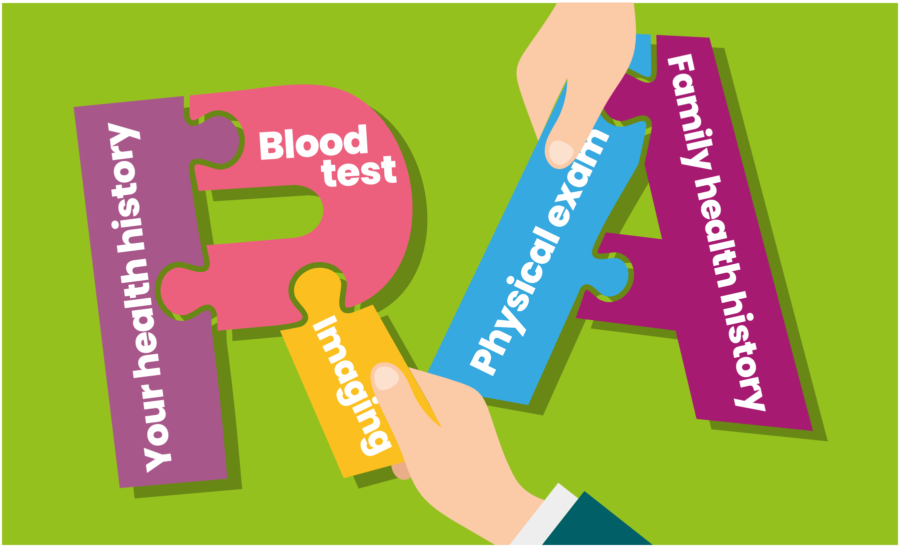
3: Specialist referral

4: Tests, treatments and information



5: Ongoing care

6: Long-term management



Who will be involved in my RA care?

Once you have a diagnosis, several different health professionals – known as a multidisciplinary team (MDT) – will be involved in working with you to help get your RA under control and your life back on track.

Who is included in the MDT will vary from hospital to hospital, but can include:

- **A consultant rheumatologist** is a doctor who specialises in the care of people with rheumatoid arthritis and other rheumatological conditions. It is their task to diagnose you and to help you decide which treatments are most suitable for you. They will also help introduce you to the wider multidisciplinary team, as well as communicating with your GP about your progress
- **A rheumatology specialist nurse or nurse practitioner** is a nurse who will give you advice and support about managing your RA, and will monitor your drug treatment. In many clinics consultants share patient care with a nurse specialist. Some nurses are also qualified to administer steroid injections as part of flare management as well as trained to prescribe medicines. Once you've been diagnosed, the nurse will see you and help to get you established on your treatment pathway. Most rheumatology departments have a nurse-led telephone advice line that you can contact between appointments, especially if you have a flare (a worsening of the disease process) or a problem with your medications.

Make sure you get the telephone number of the advice line and keep a note of it.

- **A rheumatology specialist physiotherapist** helps people affected by arthritis to improve their movement using special exercises and therapy, and by giving education and advice. Your physiotherapist will be involved in working with you on improving your fitness, flexibility and day to day function, i.e. keeping you moving. Usually, they will have more input when you are newly diagnosed. After that, it's likely you may only have occasional reviews with direct access once you are happier self-managing your home exercise / fitness programme. If exercising seems beyond you at the moment don't worry! Why not take a look at the section on the NRAS website that shows simple exercises you can build up at your own level at home (not a scrap of lycra in sight!). Please note, not all hospitals will be able to give you access to a specialist physiotherapist automatically

*For more information on meeting the team and other topics, visit **www.nras.org.uk/smile** to learn more about 'Smile', our free self-management e-learning courses.*

- **An occupational therapist** will work with you to help you find new or better ways to carry out everyday activities, if your RA is making some things difficult. They can give you advice about equipment that will help take the strain off your painful joints, as well as offering tips and techniques to protect your joints e.g. how to lift things in a different way.

www.nras.org.uk/exercise-videos

- **A podiatrist (or chiropodist)** can help with specialist advice and treatments if your RA causes you pain and/or problems with your feet and/or ankles. This can impact on activities involving standing or walking, and it's the podiatrist's job to help keep you as mobile as possible. They may assist by fitting and providing insoles (orthoses) and footwear. Podiatrists may also prescribe medication, administer steroid injections and perform minor foot surgery, as well as offering education and guidance about more general foot care matters. There is much more on foot health, including a video of a foot health programme run by a podiatrist, on our website at **nras.org.uk/resource/ra-foot-health**

- **A pharmacist**. As someone with RA, you will probably come into contact with several different types of pharmacist. A community pharmacist (a local high street pharmacist) will fulfil your prescriptions and may also be able to offer you an annual Medicine Use Review (MUR). A hospital-based pharmacist will specialise in the biologic/biosimilar medications that your consultant may prescribe if conventional DMARDs (disease modifying anti-rheumatic drugs) don't get your disease under control. If you have medications delivered directly to your home, a homecare delivery company pharmacist will check your prescription before your drugs are dispatched to you

- **A general practitioner (GP)**. Usually the first port of call when initial symptoms occur. A GP will refer you to a rheumatology service if they suspect inflammatory arthritis. Following diagnosis, they will help with work issues if fit notes (statements of fitness to work) are required, prescribe some medications and offer support.

  Under a shared-care agreement, GPs will prescribe and arrange blood monitoring for some of the drugs recommended by rheumatologists. They will also act as advocates for patients with RA, coordinating care and corresponding with all other professionals. GPs should offer annual RA reviews and detect and manage other conditions commonly related to RA, such as cardiovascular disease, hypertension, low mood etc
- A **GP** with a Special Interest in Rheumatology (GPwSI) works in the community, often in an interface musculoskeletal (MSK) service. MSK means anything to do with the joints and muscles. GPwSIs take referrals from primary care colleagues/GPs and will diagnose and treat a number of MSK conditions such as frozen shoulder, carpal tunnel syndrome, ligament strain etc. These days, a large proportion of rheumatology care is delivered in the community by GPwSIs working as part of the multidisciplinary team.

  Your GP practice may also have the following:

  Clinical pharmacist: can help with reviewing patients' medication and helping with adherence. They can prescribe for long-term conditions and deal with medication for patients recently discharged from hospital.

  Advanced Nurse practitioner (ANPs): registered nurses who have done extra training to be able to examine, assess, diagnose and treat patients. Like GPs, they can prescribe medication and make referrals to secondary care

  Social prescriber: connecting patients with relevant organisations and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing.

Other professionals, who may not be part of your regular multidisciplinary team, but who are also available to help include:

- **A talking therapist** e.g. a counsellor. Dealing with a diagnosis of RA can be difficult, and some people feel anxious or experience periods of low mood or feel depressed. A clinical/health/counselling psychologist specialising in helping with physical health conditions can support you in adjusting to your condition, and help you if you suffer from low mood and/or anxiety. They often have practical ideas for helping you find self-management strategies that work for you and your family

> *I have reflected on that day I was diagnosed… I attended the hospital alone, thinking it was just another appointment… I felt that my consultant behaved as though I understood what was wrong with me and she was just confirming it. … My wish is that following the diagnosis that immediately there would be a counselling session…*
>
> **Chris**
> **Aged 46, diagnosed in 2014**

- **A dietitian** is an expert in human nutrition and the regulation of diet. Some people with RA may find it helpful to see a dietitian if they struggle to maintain a healthy weight and diet. Many conditions including RA are exacerbated by obesity and some foods can be triggers for inflammation. A dietitian can advise you on how to alter your diet based on your medical condition and individual requirements

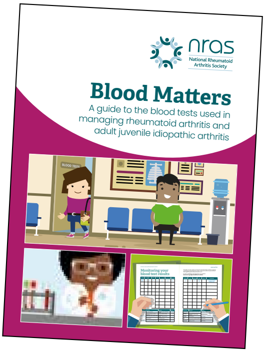
Remember, YOU are at the centre of your multidisciplinary team.

*It can be difficult to access talking therapies through your rheumatology team or GP in a time frame that works for you but it is worth asking.

How will my RA be treated?

Treatment and therapy

RA is not one disease which affects everybody in the same way – there are different sub-types. Blood tests which look for antibodies found more commonly in the blood of people with RA will identify which sub-type you have. The blood tests which are used are called 'rheumatoid factor' (RF) and 'anti-CCP antibodies' (ACPA). You can have both antibodies in your blood, neither of them or be positive for one but not the other! Those who have RF are described as 'seropositive' and those who do not have RF are described as being 'seronegative'. Whether or not you are positive for anti-CCP auto antibodies as well adds to the clinical information which will help clinicians to determine treatment and dosage. (For more information, see our article: **www.nras.org.uk/resource/seropositive-and-seronegative**). Unfortunately, these tests are not perfect, and false positive or false negative results are possible, making things more complicated and requiring the expertise of rheumatologists to make a firm diagnosis. For more information on blood tests for the diagnosis and treatment of RA, see our *Blood Matters* booklet.



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Blood Matters

A guide to the blood tests used in managing rheumatoid arthritis and adult juvenile idiopathic arthritis

While a specific drug or therapy might help control one person's RA, it might not work for someone else with a different form of RA. Required drug dosages also vary from person to person, depending on the severity of symptoms. Often it's a matter of time, as well as trial and error, before the right treatment can be found for you. Try not to get disheartened if the first drug you try doesn't work, there are other medicines to try. Eventually, there will be a tailored treatment that works for you.

How should a treatment help you?

- An effective treatment should reduce inflammation and its side effects: pain, swelling, stiffness and fatigue
- It should protect your body from the risk of damage to joints and bones caused by uncontrolled inflammation
- It should protect other organs in your body that might be affected by uncontrolled inflammation, such as heart, lungs, eyes
- It should allow you to maintain the ability to lead a normal life, with minimal impact on your relationships, family, home, work and leisure time.

Below, we discuss some of the treatments you may be prescribed for your RA. For more detailed information on all the various medications currently available, you can request a free copy of the NRAS Medicines Booklet ***Medicines in Rheumatoid Arthritis.***

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Medicines
in Rheumatoid Arthritis

BMA
Patient information awards
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Managing pain

Pain is an extremely personal and individual experience, with a plethora of effects on both physical and mental health. It involves not only the nerves at the site of the pain, but also the nerve pathways leading to the brain, and special pain pathways within the brain itself. Put simply, pain is a complex issue.

If you're in pain for any length of time, whatever the underlying cause, it can make you feel low or depressed, and interfere with your sleep. The stresses associated with RA-related job issues or relationship or family problems don't help either. Feeling stressed and anxious impacts on how we cope with pain, sometimes making it feel worse.

The best way to ease the pain of RA is by effective and continuing control of the disease process, using the various medicines available.

Taking simple over-the-counter (OTC) painkillers and combined pain remedies can bring immediate relief from pain. You may also find OTC or prescription non-steroidal anti-inflammatories (NSAIDs) - or in some situations, steroid preparations – helpful, as they give relief by reducing swelling and inflammation.

Table 1 – Pain and Anti-Inflammatory drugs

Type	Examples	Purpose
Analgesics also known as **painkillers**	**Paracetamol** **Co-Dydramol** (Paracetamol and Dihydrocodeine) **Co-Codamol** (Paracetamol and Codeine Phosphate) **Tramadol** (strong painkiller and mild opioid)	To help control pain
Non steroidal anti-inflammatory drugs (NSAIDs)	**Ibuprofen** **Meloxicam** **Diclofenac** **Naproxen***	To ease pain and stiffness by reducing inflammation but NSAIDs do not prevent future damage
Corticosteroids also known as **steroids**	**Prednisolone**	Reduces inflammation, thereby relieving pain. Usually prescribed as tablets. Can be given as a course of tablets during a severe episode of RA or when diagnosed to control pain and inflammation until disease modifying drugs kick in.
	Methylprednisolone	Can be injected into muscle or joints. Is given as an intramuscular (into muscle) or intra-articular (into joint) injection for the same reasons outlined above.
	Triamcinolone-acetonide **Triamcinolone-hexacetonide**	Can be injected into or around inflamed joints

*The following NSAIDs, celecoxib and etoricoxib, called COX 2s (cyclo-oxyganase-2) inhibitors are used occasionally, usually when standard NSAIDs are not appropriate, with the knowledge that they can have an impact on the cardiovascular system.

Drugs used in RA treatment

Disease Modifying Anti-Rheumatic Drugs (DMARDs)

This class of drugs works by dampening down the immune system's response. Unlike painkillers, they don't take effect immediately – it can sometimes take up to 12 weeks for them to begin to work properly.

They may be prescribed individually or in combination. Sometimes a stepped approach is used to allow your body time to adjust to the medication and gradually build up to the optimum dosage to get your RA under control. One or more of these medications is what everyone, when first diagnosed, will start on. The earlier in the course of RA that a DMARD is started, the better the long-term outcome. Up to 60% of people will find their disease can be well managed using standard DMARDs. However, for more aggressive and complex disease, there are more treatments which we will come to shortly. DMARDs may be prescribed individually or in combination. Despite the concern that many patients would naturally have that using two or more drugs is going to cause more side effects, in fact there is good evidence that this is not the case.

Table 2 – Standard Disease Modifying anti-Rheumatic Drugs (DMARDS)

DMARD name	What you need to know:
Methotrexate (MTX)	Methotrexate (MTX) was introduced in 1947. Because it slows down the growth of rapidly dividing cells it was used in high doses to treat people with leukaemia and other forms of cancer. It is used in people with inflammatory arthritis in much lower doses and since the 1980s has demonstrated good efficacy and safety in managing RA. MTX is now regarded as the "gold standard" and it is generally agreed that it should be used early in the course of RA. There is also evidence that its use will reduce the risk of developing cardiovascular disease in people with RA. Side effects, as with any medication, can take time to manage and for some, switching from tablets to injections of methotrexate can help reduce a common side effect, nausea. When you take methotrexate, you should also take a Folic Acid supplement as methotrexate depletes levels of folic acid in your body. Taking this supplement can also help to reduce the impact of some side effects, including upset to your stomach/digestive system, mouth ulcers and hair loss (which, though uncommon and usually slight, can be a side effect of the drug). It's important to note that not everyone experiences all (or any) of these side effects.

Table 2 – Standard Disease Modifying anti-Rheumatic Drugs (DMARDS)

DMARD name	What you need to know:
Methotrexate (MTX)	Methotrexate should be taken once a week, ideally on the same day each week. You can either take it as tablets or as a subcutaneous (under the skin) injection via a pre-filled syringe or pen device. The dosage you're prescribed will vary considerably, depending on the severity of your disease. Take a look at the short animation about methotrexate **www.nras.org.uk/methotrexate** as well as other informative videos on different aspects of taking methotrexate.
Sulfasalazine (SSZ)	Tablets daily – This drug can be given as part of disease modifying drugs taken in combination, usually gradually increasing in the first three weeks until the maximum daily dose is achieved.
Leflunomide (LEF)	Tablets taken daily – This drug can be given as part of disease modifying drugs taken in combination.
Hydroxychloroquine (HCQ)	Tablets taken daily – This drug can be given as part of disease modifying drugs taken in combination or can be given as mono-therapy in people with mild disease. HDX can, in rare cases, affect the eyes. The Royal College of Ophthalmologists recommend that at baseline (or within first 12 months of treatment) a full ophthalmology (not optician) assessment is conducted including 'OCT' (which is like a mini CT scan of the retina). Then, for most patients, no further assessment will be needed until after five years of therapy and thereafter annual reviews should be conducted. Patients with increased risk of eye complications (those with pre-existing retinal problems, those with kidney damage, those on higher than usual doses, or those also taking tamoxifen) should start annual screening immediately, rather than at five years.
Ciclosporin	Rarely used now but sometimes as an add-on treatment to one or more of the above. See the NRAS booklet ***Medicines in Rheumatoid Arthritis*** for more information.
Azathioprine	Rarely used now since the continuing development of more effective, targeted treatments. See the NRAS booklet ***Medicines in Rheumatoid Arthritis*** for more information.

> *I didn't realise that it's common to have to try several different treatments before finding one that works for you. When the first few didn't work for me, I felt like my life was over, and thought I was going to end up in a wheelchair. But I did find the right treatment for me and now I am in work, fully productive and the disease is well managed.*
>
> **Andrew**
> **Aged 57, diagnosed in 2002**

Advanced Therapies

Rheumatoid arthritis (RA) is usually treated with one or more of the many disease modifying anti-rheumatic drugs (DMARDs) that are available (as outlined in the previous pages).

But some people's disease does not respond adequately to the conventional DMARDs, and they need an alternative. For them, the next step may be to progress to medications known as biologics, biosimilars and JAK inhibitors.

Biologic therapies are medicines developed to target specific abnormal immune response pathways. (A fuller explanation is available in the *Medicines in Rheumatoid Arthritis* booklet.)

Biosimilar medicines are newer and work in the same way as biologics. To date, some of the original biologics have come off patent, so now other pharmaceutical companies are able to make their own versions of the original biologic therapies. There is the potential for each originator biologic to have several biosimilar versions of that drug.

There is guidance set down by the National Institute for Health & Care Excellence (NICE) that stipulates the eligibility criteria to be able to access a biologic or biosimilar drug. More detailed information on this guidance can be found in our booklet, ***Medicines in RA***.

JAK inhibitors (Janus Kinase Inhibitors) are a different class of drug that works differently to biologics and biosimilars. Biologics are large molecule drugs that have to be injected or infused, whereas JAK inhibitors are small molecule drugs (therefore can be taken orally) which interrupt the signalling pathway from inside the cells involved in the inflammatory process.

Are there any new treatments in the pipeline?

Exciting research is ongoing to find new medications and ways to treat the condition. RA is a complex disease that presents differently in different people, therefore new modes of action in medication are still being discovered and developed.

For more information on all these medicines and treatments take a look at the NRAS ***Medicines in Rheumatoid Arthritis*** booklet.

What happens if I experience side effects or have an adverse reaction to a treatment?

If you do experience any side effects or reactions that you are worried about, your first port of call should be your GP or rheumatology team. In addition, you can report directly to the Yellow Card scheme, which is run by the Medicines and Healthcare Product Regulatory Agency (MHRA). This scheme collates and reviews reports of suspected adverse reactions for all licensed and unlicensed drugs.

yellowcard.mhra.gov.uk

You can use the Yellow Card app to report any side effects quickly and easily, even if you're on the move.

Measuring the long-term safety of biologic therapies

BSRBR
The British Society for Rheumatology Biologics Registers

Over recent decades, biologic therapies for rheumatoid arthritis (RA) have become a mainstay of the treatment of RA. But how safe are they? To answer that question, a UK-wide register of people receiving biologic therapies was established in 2001.

The British Society for Rheumatology Biologics Register for Rheumatoid Arthritis (BSRBR-RA) was set up to assess the long-term risk of serious side effects from biologic therapies. This population study into the health of those with inflammatory arthritis is a unique collaboration between the BSR, The University of Manchester and the pharmaceutical industry. Data from this study has provided doctors and patients with reassurance regarding the longer-term safety of these drugs.

The register has also proved to be a valuable resource for policymakers such as the National Institute for Health and Care Excellence (NICE), and some believe that this has led to greater patient access to biologic drugs.

Over the intervening years, over 30,000 people in the UK have contributed to the register, which is hosted by The University of Manchester.

In recent years, the BSRBR-RA has started to recruit patients who are starting biosimilars for the treatment of their RA. Although biosimilars have been prescribed for other conditions in the UK since the 1990s, they have only been approved to treat RA since 2015, increasing the number of treatments available on the NHS.

As previously mentioned, as biosimilars are not identical to the original biologics from which they derive, the BSRBR-RA study has been extended to follow patients receiving these new drugs. The study will also follow patients taking JAK inhibitors, which were approved for use in the UK in 2018.

For more information about the register, visit **www.bsrbr.org**

Your Prescriptions

If you live in Northern Ireland, Scotland or Wales, you'll get free prescriptions for all your medicines. In England, however, you may have to pay unless you have an exemption certificate. To find out whether you are entitled to free prescriptions, go to: **www.nhs.uk/nhs-services/prescriptions-and-pharmacies/who-can-get-free-prescriptions**

You won't be charged for any medication that is dispensed to you directly, without you having to fill a prescription; for example if you are in hospital as an in-patient, attend an NHS walk-in centre or are administered medication by your GP or hospital team in person (such as injections into a joint).

For regular prescriptions issued by the GP, especially if you have to obtain more than 12 prescribed items in a year, you can save money by getting a Pre-Payment Certificate. These can be paid annually or monthly. For more information, go to: **www.nhs.uk/nhs-services/prescriptions-and-pharmacies/save-money-with-a-prescription-prepayment-certificate-ppc**.

If you're taking regular medication for RA, it's likely that you'll 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, which can collect the prescriptions for you and dispense them. 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. They can help if you are concerned about your medications or the instructions for taking 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 an annual ***Medicines Use Review*** with your pharmacist if, for example, you are taking multiple drugs (for example, if you're also taking drugs for another condition other than RA).

How will I know if my treatment is working?

As we mentioned earlier, it can take several weeks for your disease to start to respond to the medication you're prescribed. In the meantime, you may also be given extra pain relief and steroids to “bridge” the therapy. Once you’re established on particular treatment, you will be monitored to make sure the regime is working. One very good indicator of this is, of course, the way you feel, but even if you feel better your disease may still be active. That’s why regular blood tests are so important.

Below is a table with an overview of some of the common blood tests used in RA. More detailed information can be found in our booklet, *Blood Matters*.

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	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. 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.

Other ways of monitoring and measuring of disease activity

DAS 28

DAS stands for **D**isease **A**ctivity **S**core. It assesses your joints, blood test results – C-reactive protein (CRP) or erythrocyte sedimentation rate (ESR) – and also your own view of how you have been feeling over the past week. The reason it's called DAS 28 is because it assesses 28 specific joints for tenderness and/or swelling. While other joints can be affected by RA, research has shown that these 28 give the best indication of how active your disease is. All these results are then added up to give you a personal score result.

The National Institute for Health and Care Excellence (NICE) RA Guidelines recommend that, following diagnosis, DAS 28 assessments are performed monthly until your disease is under control.

If you don't know your DAS, ask your healthcare team about this at your next appointment.

Knowing your disease activity is really helpful and can reassure you that if you see your score decreasing your treatment and therapy is working. Equally important, an increased DAS may mean that you need an adjustment to dosage or even a change in medication. Keeping an eye on your own disease activity will help you have informed and balanced interactions with your clinical team. A true DAS28 score will include results from monitoring 28 joints but also take into account blood test results. However, just examining your own joints on a fairly regular basis can be hugely beneficial for you and your treating physician as it can demonstrate what's been happening in between appointments.

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**	Active disease that may require change in medication
More than **5.1**	Very active disease that requires careful monitoring and adjustment to medication

The University of Manchester has been working on developing useful tools for remote monitoring patients with RA and there is a simple, easy to follow video available to demonstrate how to examine your own joints. This is part of a wider study called 'REMORA', REmote MOnitoring of Rheumatoid Arthritis. The study aims to develop, test and evaluate a system for tracking daily symptoms in people living with RA, where data are collected using a smartphone app and integrated into NHS electronic patient records. However anyone can access the demonstration video on Youtube at: **youtu.be/SBSJKMYNOaw** and the chart and table for tracking your self-examinations can be downloaded from the patient resources on the study's webpage **https://sites.manchester.ac.uk/remora**

X-rays

X-rays show if there are changes to the bones and their positions, but they are not as good at revealing problems with surrounding tissues or swelling. That's why you won't have many of them. You might have an occasional chest X-ray to look at your lungs if, for example, you have new symptoms or are about to start a treatment (e.g. methotrexate) and the team needs to see how your lungs look before commencing.

RA is a generalized disorder which can affect virtually any organ of the body due to the inflammatory process. Although most patients are aware of its effects on the joints, fewer may recognise its potential for causing lung disease, hence the requirement to check the lungs.

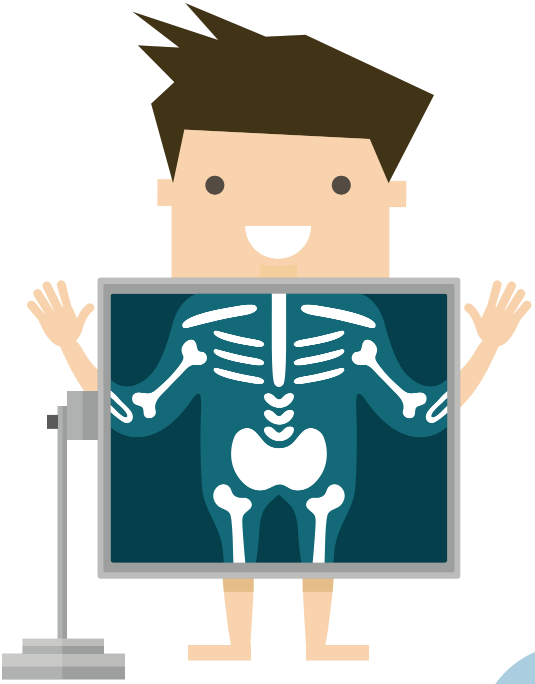
Ultrasound

Ultrasound images are much better than X-rays at revealing inflammation in certain joints. That's why ultrasound is increasingly being used as a tool in the diagnostic process, particularly in the early stages of RA, to detect inflammation that may not be visible as swelling or redness. Ultrasound can also detect early damage to the bones, such as erosions (the eating away of the surface of the bone) caused by the inflamed synovial membrane between the joints. If left unchecked and untreated this is how RA causes long-term disability and deformity.

Health Assessment Questionnaire (HAQ)

The HAQ is a questionnaire that asks how easily you feel you can complete a range of tasks, to determine how well you are functioning physically. Questions include how easily you find dressing and personal grooming, preparing food or opening packages, walking certain distances or climbing stairs etc. Sometimes you may be asked to complete this yourself in the clinic waiting room or sometimes you will complete it with your specialist nurse.

There are other questionnaires in use by rheumatology teams within the NHS. It is important to complete these, if asked, as this data helps health professionals to understand more about how you are feeling and responding to treatment.



Drug Adherence Tips from people with RA:

Managing Pain, Flares and Fatigue

What is a flare?

A "flare" is defined as a worsening of the disease process, which is experienced in a similar way to when your symptoms first started. You might think that your disease seems to be under control and then, suddenly, your joints become inflamed and painful, and you might also feel unwell and/or fatigued.

The cause and duration of flares varies. Some people say that stress is a trigger for their flares. Sometimes flares occur after infections, such as viruses. But there might not be any obvious reason. Doctors believe flares can be related to natural (but poorly understood) fluctuations in the immunological processes that drive inflammation. They can be relatively short-lived, or so severe you can hardly get out of bed. A flare might be confined to one or two specific joints, or it could affect your whole body.

One of the hardest things to cope with when you have RA is the unpredictability of flares. They can be frustrating, bewildering and painful. You may get better at identifying the early signs of a flare. Sometimes, you can tell you're going to have one because you notice symptoms getting worse over a few days. Fatigue can also be a warning sign – feeling like you're 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 warning signs at all. RA flares really don't play fair and can strike at the most inconvenient times.

Coping with flares

Sometimes, simple self-management techniques and a few days' rest are enough, and you won'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 medicines. It could be that your dosage needs to be changed or that a change of medication might be needed.

Some good general strategies for coping with a flare include:

- Get some rest and relaxation early on
- Use cool packs on hot swollen joints. If you don't have a cool pack, a bag of frozen peas can be equally effective. Protect your skin by wrapping them in a tea towel or similar
- Protect your joints e.g. carry items on your forearms rather than holding them with your hands
- Wear comfortable, well-fitting shoes. If your feet are one of the main problems, ask to see a podiatrist
- 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 that you're not feeling well, and allow them to help you.

If you're having a flare, your General Practitioner (GP) may be able to help and will liaise with your hospital healthcare team, if necessary.

Managing pain

Learning how to manage pain involves employing a range of different strategies. While drugs are important, non-drug treatments such as using heat and cold, relaxation and distraction techniques can also make a big difference. It's about finding what works for you.

It helps to keep as active as you can, so you 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 better about yourself by releasing the body's natural painkillers, endorphins. For more information about exercises that you can do at home see: **www.nras.org.uk/exercise**

Managing fatigue

Living with RA, you'll know that fatigue isn't just tiredness. It's much more than that. It can feel like wading through mud or running into a brick wall.

Fatigue is a very common symptom, and there is a great deal you can do to help prevent and reduce your fatigue. Above all, it's important that your RA is well controlled. If you're feeling more fatigued than usual and it's getting hard to manage, don't ignore it! Talk to your rheumatology team, and ask for help rather than trying to struggle on alone until your next appointment.

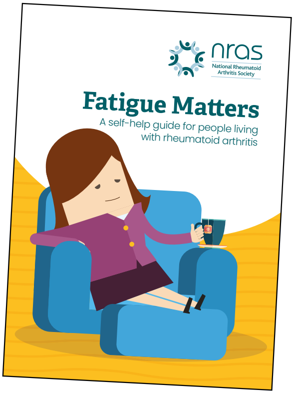
> Don't beat yourself up just because you can't do it right now. Tomorrow is another day!

There are many different techniques and tips that can help you cope with fatigue. You may need to experiment until you find the ones that work best for you. As fatigue and pain can be connected, the advice on managing pain in this booklet and other NRAS publications such as *Medicines in Rheumatoid Arthritis* may also help to reduce fatigue.

These are some of the fatigue-busting tips that people with RA say they have found helpful:

- Make sure you take plenty of rest and give yourself time for relaxation
- Pace your activities, and plan ahead for what you want and need 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, all of which make everyday activities less taxing. An occupational therapist can help and make suggestions
- Ask other people with RA for their tips, for example, via our online forum, NRAS HealthUnlocked, which can be accessed through the NRAS website.

Take a look at the NRAS ***Fatigue Matters*** booklet.



nras
National Rheumatoid Arthritis Society

Fatigue Matters

A self-help guide for people living with rheumatoid arthritis

> Little things help to make life easier, when I'm fatigued. Getting dressed can be tricky but I find coats with slippy linings are so much easier to get on and off!

For more information on managing pain and flares and other topics, visit **www.nras.org.uk/smile** to learn more about 'Smile', our free self-management e-learning courses.

What else can I do to help myself?

Ensure you take your medicines as prescribed.

Adherence – the technical term for 'sticking with your drug regimen' – that is taking your medicines as prescribed – is often easier said than done, and you're far from alone if you find it difficult. Research shows that, for chronic disease in general, patients take their treatments only half of the time and, for patients with RA, that figure varies between 30% and 80%. There are many reasons for this: people may forget; they may fear side effects or experience side effects which are unpleasant; or they might just feel better so think they don't need to take their medicine any more. And sometimes, people simply get fed up having to think constantly about their RA, especially if they have to take daily medication in addition to adopting lifestyle changes like diet or exercise. Adhering to a regimen of any kind takes psychological stamina.

These days, people are increasingly involved in their own disease management and in decisions about their care, but that doesn't mean adherence is any less important. Drugs only work properly if they're taken exactly as prescribed. If you struggle to take your medications, or don't understand why you need to take them even when you begin to feel better, it is worth being open and honest with your doctor or specialist nurse or pharmacist. They won't judge you, but they will be able to explain exactly how your medicines work and the risks you take by not continuing to follow the therapy as prescribed. They should also be able to give you advice on how to stick to your prescribed regimen.

> *My RA began in my thumbs. The rheumatologist talked about medication, but I thought this seemed too much for "only" sore thumbs and I didn't like taking drugs, so I said I would try fish oil instead. I wish now that I'd started to tackle the RA with medication at that time, as it might have reduced the painful effects that later developed.*
>
> **Robin**
> **Aged 55**

> *The evidence is unequivocal: the success of RA therapy hinges on adherence. Patients who don't take their treatment run the risk of flares of disease (worsening of symptoms), as well as continuing pain and stiffness, joint damage and disability.*
>
> **Dr Cathy Swales**
> **Director of Clinical Studies, University of Oxford Medical School**

I use my phone to send me a reminder.

I remember when to take my drugs because M is for Monday – that's Methotrexate day – and F, for Friday, means Folic Acid day.

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.

Self-Management Techniques

SMILE-RA

SMILE-RA is a unique e-learning programme, free to register, and helps people with RA to learn about all aspects of their disease, its treatments and how to live well with it. Being able to self-manage your disease effectively between rheumatology appointments is critical to getting the best outcomes for you, especially in a changing healthcare landscape where you may see your team less often than pre-pandemic. In modular format, you can choose the modules of most interest to you at any particular time. Your family can watch it with you, which helps them better understand how to support you.

In a survey, 88% of users found it easy to use, and 72% stated that SMILE-RA has increased their understanding of the importance of self-management. The programme has helped 2,300+ people at time of publication of this resource and is a great resource for those living with or caring for someone with RA.

Each module is on a particular theme or subject and and most take between 20 – 30 mins to complete. There is an accessible and intuitive interface making it easy to use and navigate. After registering and completing the Foundation module, which includes baseline evaluation questions, you can direct your learning experience and revisit modules to refresh your knowledge.

For more information and to register for SMILE, go to:

www.nras.org.uk/SMILE

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National Rheumatoid Arthritis Society
E-Learning
Smile-RA
Self-Management
Individualised Learning Environment

> *SMILE-RA is an extremely helpful and worthwhile tool - easy to navigate, user-friendly, and with a wealth of important information for those newly diagnosed.*
>
> **Feedback from SMILE user**

Heat Therapy

Heat, whether dry or moist, can help if you have a painful muscle or a sore joint. If you're applying dry heat – such as a hot water bottle, electric heat pad or jelly pad, make sure you protect your skin with a towel. Helpful moist heat techniques include: taking a hot shower or bath; placing the affected limb in a basin or bowl of hot water; or applying a damp towel that's been heated in a microwave.

Cold Therapy

Cooling an inflamed (red hot, swollen) joint can also provide relief. You can use almost any clean, cold item. Try dipping your hands or feet in a bowl of cold water that has ice cubes in it. Or use a bag of frozen broad beans as a mouldable ice pack (wrap it in a towel so you don't get ice burn). You can also use a jelly pack or a damp towel that's been kept in the fridge.

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 before trying it.

TENS works by delivering small electrical pulses to the body through electrodes placed on the skin. It is thought to interrupt pain signals being sent to the brain.

Relaxation/Meditation

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 for a long time, you can become tense without realising it. You can become mentally and emotionally tense, with the result that you find yourself trapped in a 'cycle of pain'. Learning relaxation techniques can help to break this cycle and reduce

> *I've found that, in addition to taking my RA meds, making dietary changes has really helped me. I have mostly cut out wheat, gluten, dairy and sugary foods and drinks, which have helped me to lose quite a bit of weight. I also undergo a lot of intensive physiotherapy at least twice a week, which helps to keep my joints mobile and my joint pain to a minimum. Doing yoga and some simple exercises in the mornings and evenings also helps to reduce the stiffness of my joints.*
>
> **Anoushka**
> **Aged 28, diagnosed in 2012**

pain. It takes practice, but once you've learned a technique, you can use it anywhere. There is a lot of information available on relaxation, mindfulness (a particular technique to help you relax) and meditation. There are many YouTube videos and apps, such as ***Headspace*** to help you get started.

Get 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 called 'sleep hygiene') can help. The way to do this involves:

- 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
- Choosing not to nap during the day
- Avoiding caffeine, nicotine and alcohol late at night
- Not eating a heavy meal late at night.
- Avoid screen time before bed. The blue light that emits from devices (including TVs) suppresses the natural production of melatonin – the hormone you need to feel sleepy.

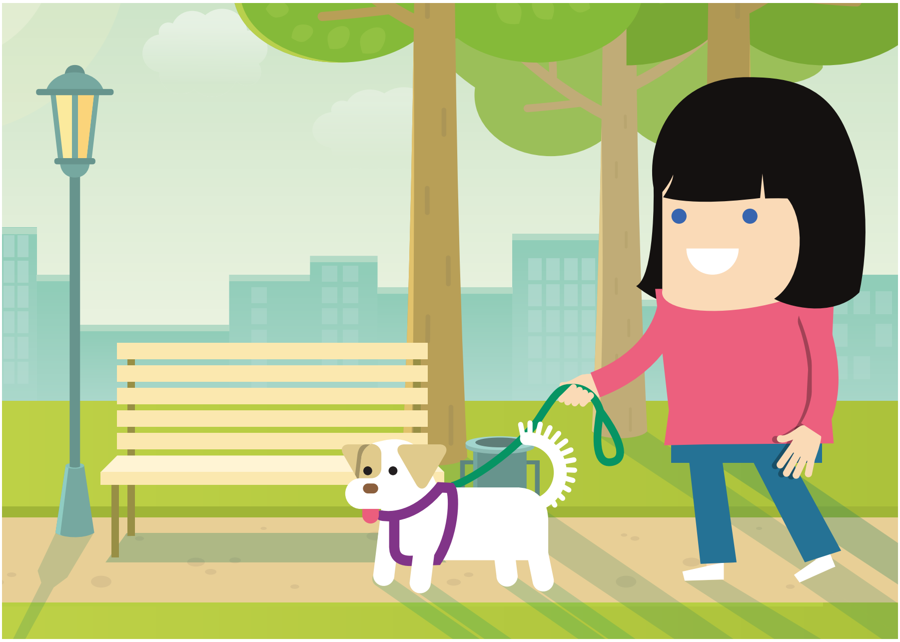
Talk to your GP or specialist nurse if you continue to suffer from poor sleep, as they will be able to help. For more information on sleep, visit:

www.nras.org.uk/sleep

Diet

Just like the medicines and the disease itself, the foods and diet that may help your symptoms varies from person to person.

Some foods come up more often as either improving or worsening RA symptoms. A Mediterranean diet, for example is commonly considered helpful. Keeping a food diary is a great idea to help identify what works best for you. More information on diet can be found on the NRAS website: **www.nras.org.uk/diet**



Exercise

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

So, for people with RA, physical activity is important in managing their condition 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; **www.nras.org.uk/exercise** and the SMILE module on importance of exercise; **www.nras.org.uk/smile**

Everyone is different: What may work for one person with RA may not suit another. A physiotherapist will be able to offer you advice and design an exercise programme personalised to you.

Don't underestimate the importance of doing an activity you enjoy – walking, dancing, swimming etc. as you are much more likely to continue doing it! Also, exercising with someone else (a family member or friend) can be more enjoyable and help with motivation.

Think 'I Can', not 'I Can't'

Some people find that 'positive thinking' helps them to cope better. But this approach may not suit everyone. If you are feeling down about your RA you shouldn't feel bad or blame yourself.

If you do want to give it a go, the trick is to try making small changes to the way you think by focusing on the things you can do, rather than those you can't. 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

Getting immersed in an activity that interests you can help you to stop focusing on your pain, which can reduce the level of pain you feel. This is called diversion. You can also use distraction techniques to take your mind off your pain. For example, if going upstairs causes you difficulty, try naming a different country with each step you take. You'll find yourself concentrating on the activity, rather than how much it hurts to climb.

Complementary Therapies

There is no scientific evidence that alternative or complementary therapies have any effect on the disease process or progression in RA. However some complementary therapies can help to relieve symptoms in some people.

Always remember that 'natural' doesn't necessarily mean 'harmless'. Some alternative remedies have side effects and can interact in harmful ways with medication. Even if you choose to take complementary therapies, it's not advisable to take them instead of the treatments prescribed to you by your healthcare team.

For example, grapefruit may seem to be entirely healthy, but it has been shown to interfere with many medications, in some cases increasing the amount of medication in your blood, which can have serious consequences.

St John's Wort is also a good example of a commonly taken complementary therapy which is not as benign as it may seem, as it is known to interact with a very large number of medications.

> *However difficult your symptoms, don't forget to plan activities that make you happy, whether you do them on your own or with family and friends.*
>
> **Ralph**
> **Aged 51**

If you are considering any complementary or alternative therapy, discuss it with your rheumatology team first to make sure that it will not interact with your usual medication.

> *I scoured the internet looking for alternatives. There are plenty of sites that tell you to eat X and you will be "cured". Don't fall for it.*
>
> **Andrew**
> **Aged 57**

> *I tried some well-known supplements, but they did not make any difference.*
>
> **Ralph**
> **Aged 51**

> *I have used acupuncture in the past to manage my pain. I found it really beneficial.*
>
> **Lucy**
> **Aged 29**

Giving Up Smoking

Giving up smoking is good general advice for everyone, but for people with RA it is particularly important. There is clear evidence that smoking can make your symptoms far worse and medications considerably less effective. One of the environmental factors to developing RA is smoking. This risk relates to both the number of cigarettes smoked per day and the number of years someone has smoked, but importantly even moderate intensity smoking (such as smoking 6 to 9 cigarettes a day) can cause significant risk and this risk remains for many years (up to 19 years) after stopping smoking.

Cigarette smoking is associated with the production of rheumatoid factor and with positive anti-CCP antibodies; these are both specific and sensitive antibodies associated with developing RA. Smoking is associated with more severe RA such as more active disease, more joint damage (which can lead to deformity and loss of function), or disease outside the joints, such as nodules and inflammation of the blood vessels.

Evidence shows those who smoke require more treatment with DMARDs, suggesting that smoking weakens the effectiveness of DMARDs and/or makes the disease more active. Indeed, the British Society for Rheumatology Biologics Register for RA (BSRBR-RA) which collects data on patients who are on biologic, biosimilar and novel therapy medications (JAKs) showed that, when analysing data on 3000 patients, smokers were less likely to respond to some biologic therapies. Studies suggest that rates of RA remission may also be lower in smokers compared to non-smokers.

Additionally, patients with RA are at an increased risk of heart disease and strokes. Smoking only compounds this risk, putting people with RA at an even greater risk of heart disease.

These are all good reasons to seek help in stopping smoking as it isn't easy to do on your own. Your GP or practice nurse may be able to refer you to local services to help you quit smoking, as may other members of your rheumatology team. Your local pharmacist should also have details.

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

Talk About It

Your RA symptoms may be invisible, especially in the early stages. People with RA don't look sick, which makes it hard for colleagues, friends and family to understand what you're feeling. That's why it's important to talk about it. You may need to explain – both at work and at home - what RA is, how it affects you and what you need to better manage your RA.

Opening up or finding the words to explain can be hard, but the NRAS Helpline Team can help you with this. As well as providing information about every aspect of RA, we can put you in touch with a trained Volunteer who understands what you're going through and can talk to you on the phone. Sharing their experience with you can help get things in perspective and give you some real practical tips and techniques to getting your RA under control.

You can contact the NRAS helpline team on **0800 298 7650**
or by email
helpline@nras.org.uk

Apni Jung अपनी जंग

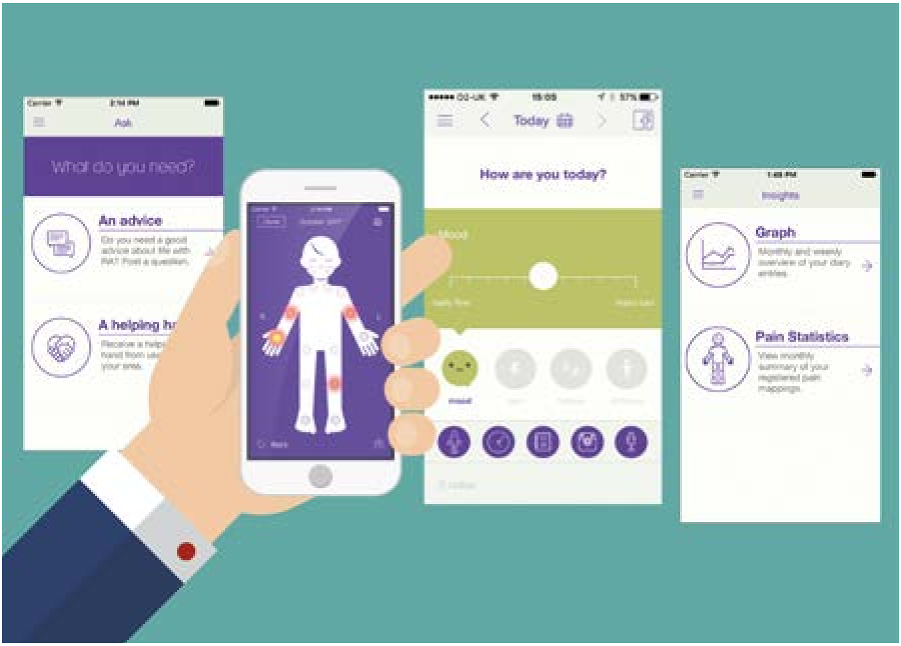
'Apni Jung' means 'our fight' in Hindi. It is also the name of the area on the NRAS website – Apni Jung: our fight against RA – which makes information about RA and its treatment available in Hindi.

Apni Jung offers a range of materials in Hindi, including videos, downloadable podcasts and pages of written information. Some of the information is also available in Punjabi and Urdu.

This includes a video for Hindi-speakers that looks at what is involved in moving from standard treatment with a disease-modifying anti-rheumatic drug (DMARD) to a biologic drug. **nras.org.uk/2018/04/26/apni-jung**.
The video includes contributions, all in Hindi, from one of our young volunteers, a consultant rheumatologist and a researcher.

www.nras.org.uk/apnijung

Rheumabuddy



RheumaBuddy app

RheumaBuddy is an app NRAS have worked on in collaboration with the Danish company Daman. The app is free and enables users to record, manage and discuss their symptoms with their healthcare professionals. Similarly, it can be used as a resource by the parent of a child with JIA to understand their child's arthritis, and record levels of pain and photographs of flare-ups.

RheumaBuddy offers an easy way to record symptoms such as pain, fatigue, low mood and stiffness, while also helping to identify things that can trigger a flare. With this insight, the app can help you to prevent or minimise future flares and provide you with a bank of personal data to share with a doctor, rheumatologist or other healthcare professional. This can be particularly helpful when there may be several months or longer between appointments (for patients with stable disease), making it hard to recall periods when pain, fatigue or other symptoms or side effects have been difficult to manage.

For more information or to download the app, visit **www.nras.org.uk/rheumabuddy**

NRAS New2RA RightStart service

NRAS run a service for newly diagnosed patients, known as **RightStart**. The aim of this service is to support people newly diagnosed with RA to understand their diagnosis and how it may affect them. Getting the right, supportive start can help people to make adjustments to behaviour, lifestyle and health beliefs and understand why self-management is important and how to make those important first steps to managing their disease effectively.

Referral (by a health professional) is particularly effective at the beginning of someone's journey with RA and we are pleased to offer the **NRAS New2RA Right Start Service**.

Step 1

Referral to the Right Start Service begins with an online referral from a health professional at **www.nras.org.uk/rightstart**

Step 2

On receipt of the on-line referral, a member of the NRAS team will get in touch with the person and arrange a call with our trained helpline team. We will try to contact the person being referred up to 3 times.

Step 3

Following the above call, the helpline team will send further information to the individual, tailored to their conversation and that person's individual needs and interests.

Step 4

During the helpline call, if the person chooses, we can match them to a trained peer support volunteer with RA and arrange a phonecall with them.

Step 5

Should you want it, a follow up call can also be arranged with the helpline team, around 6 weeks after the initial call, to see if we can be of further assistance.

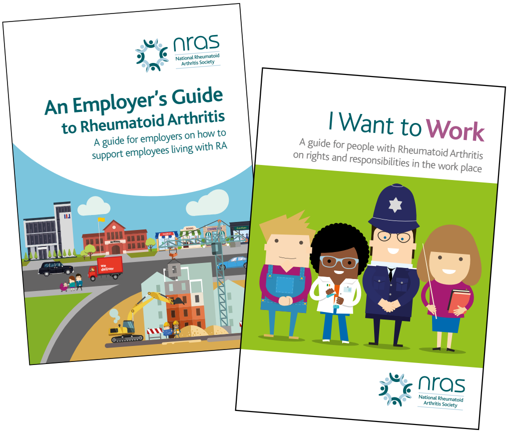
What Does the Future Hold for Me?

Impact on Work/Career

While RA can be challenging, it's important to remember that most people with the condition can, and do, carry on working. You may need to make some changes or adjustments over time. For some, part-time work may be an option, or you may be able to work shorter hours or even alternate days. Adaptations and adjustments to working conditions and equipment can also make an enormous difference.

There is support available to help you stay in work. NRAS can help with information about every aspect of working with RA, from how to talk to your employers/ colleagues, to your legal rights.

For more information about work and RA, order or download our work booklets, one for you and one to give to your employer, on the NRAS website.



nras
National Rheumatoid Arthritis Society

An Employer's Guide to Rheumatoid Arthritis

A guide for employers on how to support employees living with RA

I Want to Work

A guide for people with Rheumatoid Arthritis on rights and responsibilities in the work place

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Planning for a Family

If you are a woman of child-bearing age, or a man who could father a child, it's important that you ensure you take adequate contraceptive precautions while on RA medications. There are certain drugs that it is advisable not to take while trying to conceive or during pregnancy and while breastfeeding. They may require time to clear from your system before it's safe to start trying to conceive.

If you think you may wish to start a family in the future, do discuss this with your rheumatology nurse or consultant.

> *RA has impacted my life but has not defined it.*
> *By adapting and finding different ways of doing things, I have been able to have a family, a career and lead a very full life.*
>
> **Amanda**
> **Aged 40**

Impact on Family

Remember those who love you are also living with your RA, so keep them in the loop as to what is happening with your disease and include them in your RA journey.

> *As a newly diagnosed person, it's important to take each day as it comes and to listen to your body and its needs. Too many times I have pushed on through excruciating pain and later regretted it.*
>
> **Lucy**
> **Aged 29**

> *I also wish I'd believed my doctors and my family more when they told me that I would be able to live a normal life again. You have to trust the people around you who care for you that things will get better. Doctors won't stop until the right drug is found for you, so you can live a happy, fulfilling life.*
>
> **Sasha**
> **Aged 22**

> *Dad doesn't go to the doctor often; he'd rather live with the pain. So you're worrying all the time. I'd phone every evening to see if he was any better, and mum would say no. If you'd speak to him, he'd say "I'm fine" but he wasn't.*
>
> **Maria**
> **Adult daughter of parent with RA**

10 Healthcare Essentials for those living with RA

Every person diagnosed with RA deserves and should expect a minimum level of healthcare.

According to guidance from the NHS, NICE (National Institute for Health and Care Excellence), SMC (Scottish Medicines Consortium) and the British Society for Rheumatology, these are the 10 essential checks and services you are entitled to, or may benefit from knowing about. If you don't think you are getting all the care you need, take this checklist to your rheumatology healthcare team and discuss it with them.

1 Check your DAS (Disease Activity Score)

NICE guidelines recommend that a DAS assessment should be carried out at least twice a year, but you should expect to have your DAS measured at every consultation, especially when newly diagnosed.

2 Regular blood monitoring

Depending on the drug treatment prescribed, frequency of blood tests required may vary, but will commonly include ESR, CRP (inflammatory markers), liver function tests, FBC (Full Blood Count) and blood chemistry (monitoring effects on the kidney and liver). Ask your consultant or specialist if you are unsure about the frequency or relevance of blood monitoring. (Refer to the NRAS website for more information). It's also helpful to know whether you are Rheumatoid Factor positive or negative and Anti-CCP positive or negative as this may influence drug choices at some point in your treatment pathway.

3 Get support to quit smoking if you are a smoker

Having RA puts people at increased risk of heart disease, and smoking further increases this risk. Evidence shows that RA treatment and therapy is less effective in people who continue to smoke.

4 Annual Holistic Review

People living with RA should be offered an annual holistic review which not only assesses disease progression but also gives you the opportunity to talk about your individual needs, any risk of conditions over and above your RA, and discuss the impact RA is having on your family and working life as well as your own emotional and mental health.

5 Access to the multidisciplinary team

To help manage your RA, you should have the opportunity to see specialist professionals including a rheumatologist, specialist nurse,

Physiotherapist, occupational therapist, podiatrist, dietician and psychologist if required. Use every meeting with a member of the team as an educational opportunity and don't be afraid to ask any questions you may have. Keep asking questions until you are satisfied, you understand.

6 Learn how to self-manage

To help you understand and manage your RA, its treatment, drugs and symptoms, you should be offered, and have the opportunity to access self-management education, be given good quality approved information and have an individual care plan.

7 Access to a specialist nurse-led helpline

You should have access to a nurse-led helpline when you need it, for instance, when experiencing side effects to medications or for help if you flare.

8 Clear signposting to patient organisations

Ask your rheumatology healthcare professionals about patient organisations that can offer comprehensive services including a helpline, peer to peer support, information booklets, online forums, educational opportunities and resources to help you self-manage.

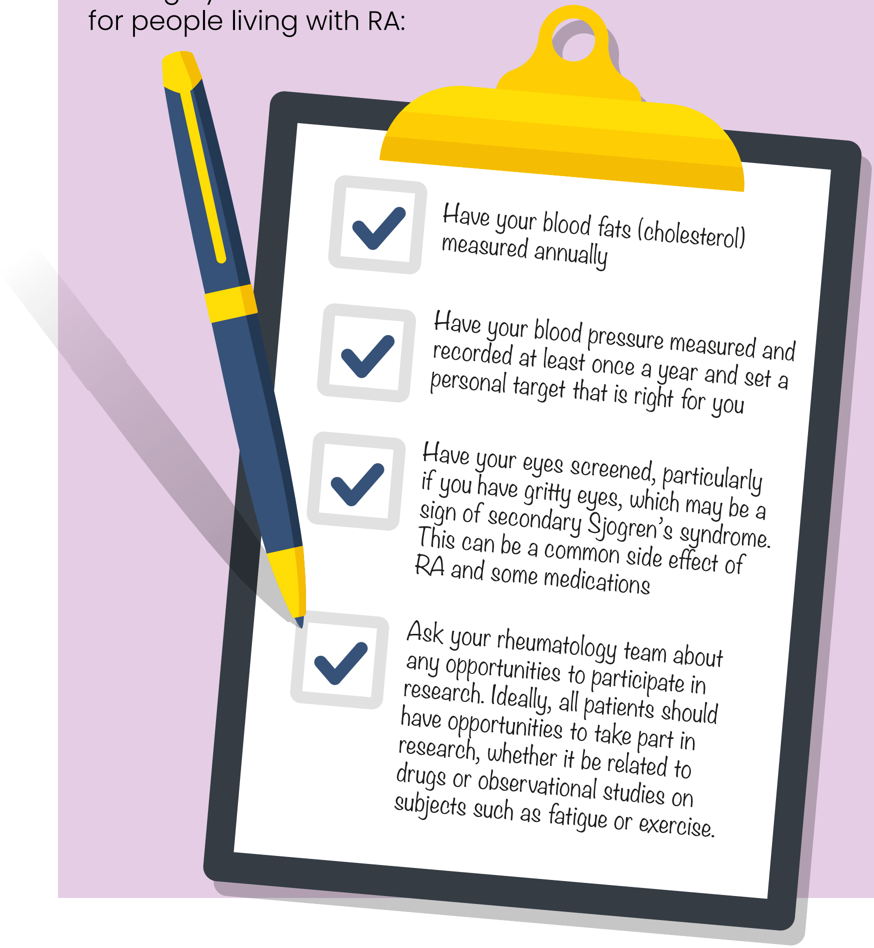
9 Exercise

Ask your physiotherapist about an individual exercise programme designed for you. Exercise is essential and plays a key role in controlling the symptoms of RA, including fatigue and pain. It's also important to maintain a generally healthy lifestyle, including healthy diet and appropriate weight.

10 Pregnancy

Get information and specialist care if you are planning to have a baby Your RA will need to be more tightly controlled and monitored during family planning for both prospective mothers and fathers. You should expect care and support from specialist healthcare professionals at every stage, from preconception to postnatal care.

In addition, the following are highly recommended for people living with RA:



- ☑ Have your blood fats (cholesterol) measured annually
- ☑ Have your blood pressure measured and recorded at least once a year and set a personal target that is right for you
- ☑ Have your eyes screened, particularly if you have gritty eyes, which may be a sign of secondary Sjogren's syndrome. This can be a common side effect of RA and some medications
- ☑ Ask your rheumatology team about any opportunities to participate in research. Ideally, all patients should have opportunities to take part in research, whether it be related to drugs or observational studies on subjects such as fatigue or exercise.

Finally...

As we stated at the beginning of this booklet, being diagnosed with RA can be really scary. You may feel that everything will come to an end, or that your life is no longer going in the direction you wanted it to. It can be hard to go from seeing yourself as a well person to accepting that you have a medical condition.

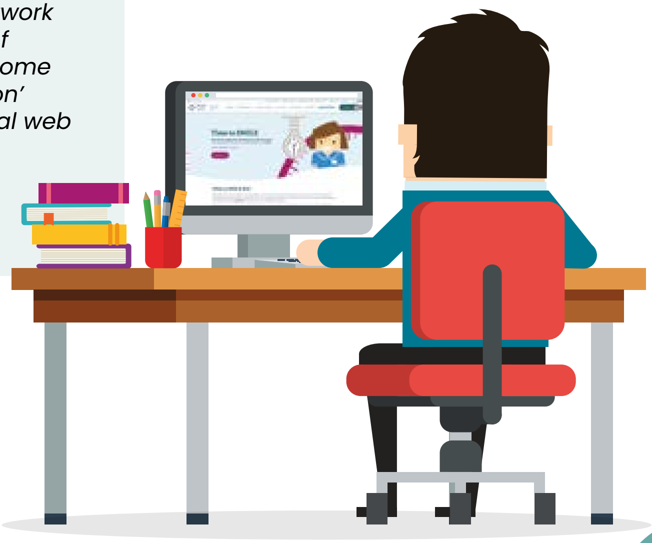
These feelings are perfectly natural. There is nothing wrong with acknowledging them. If you need to have a good old cry, then do so. Or if you feel really angry and want to scream and shout, do it.

Don't bottle it all up but once you've done that reach out for the help that is there for you.

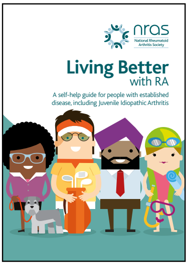
> *I wish NRAS had existed when I first learnt about my rheumatoid arthritis. It is a great support network and a useful source of information – unlike some of the 'fake information' you get from a general web search.*
>
> **Lorraine**
> **Aged 47**

While nobody can predict the future, please feel reassured that being diagnosed with RA now is not the devastating news it once was. The future can be very bright. Knowledge of RA and how to treat it has improved hugely, and more and more people are achieving remission every day. With masses of research underway, the landscape can only get better. One day, in the not too distance future we are hopeful that there will be a cure but in the meantime a lot can be done to manage your disease. Even though the disease remains incurable for now, a lot can be done to manage your disease and it doesn't mean that you can't or won't live a full and active life.

We really hope that, whatever your concerns, this booklet has helped to reassure you and answered some of your questions.

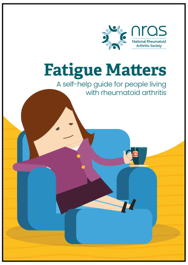


Other NRAS publications



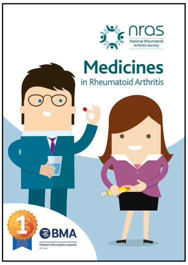
Living Better with RA

Living Better with RA is a self-help guide for people with established disease, including adults with Juvenile Idiopathic Arthritis.



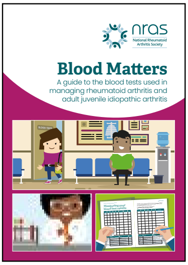
Fatigue Matters

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



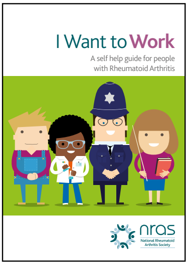
Medicines in Rheumatoid Arthritis

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.



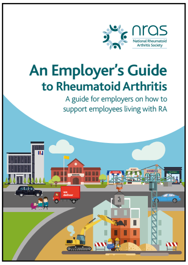
Blood Matters

A guide to the blood tests used in managing rheumatoid arthritis and adult juvenile idiopathic arthritis.



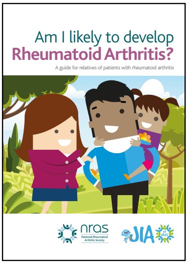
I Want to Work

In this booklet you will find up-to-date and accurate advice and information, to make sure you can find the help you need to stay in your job.



An Employer's Guide to Rheumatoid Arthritis

This booklet can be given to your line manager or HR department to help them understand your RA and what they can do to help you in the workplace.



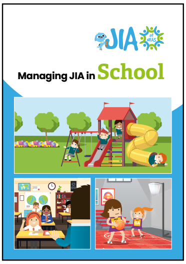
Am I likely to develop RA?

A guide for relatives of those living with RA. This PDF booklet was developed by a group of European patients and physicians funded by a grant from the European Union Health Programme.

JIA Explained

JIA Explained has been created with the shared expertise and knowledge from parents, health care professionals and JIA-at-NRAS staff.

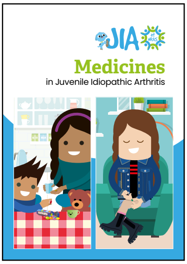
We hope that it provides you with the right amount of information and sign-posting to support you and your child or young person coping with JIA.



Managing JIA in School

Attending school is a huge part of a child's life. It provides structure and stability, as well as helping children develop crucial social, emotional and behavioural skills.

Managing JIA in School is a guide for everyone who works in an educational setting and for parents/carers who have education-related questions.



Medicines in Juvenile Idiopathic Arthritis

The focus of the booklet is on the medicines that are used to treat JIA, but it also contains information about what you can expect at every stage from diagnosis to ongoing long-term care. As you will learn, medicines are only one part of treatment.

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 **01628 823524** or email **enquiries@nras.org.uk**. Copies can also be downloaded from our website at **www.nras.org.uk/publications**

Join us

For information about becoming a Member of NRAS, visit:

www.nras.org.uk/become-a-member

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

To become a member, go to

www.nras.org.uk/become-a-member

If you have any further questions, you can contact us on

01628 823 524

New2RA

A self-help guide for people newly diagnosed with rheumatoid arthritis

First published April 2018. Reprinted and updated July 2023.

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