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 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 you can also email: helpline@nras.org.uk

The NRAS website, www.nras.org.uk, contains a wealth of information about all aspects of living with RA, including treatments, the latest research and developments, as well as full details of other 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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New to RA
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 in excess of 400,000 adults in the UK. Three times as many women as men are affected, and it can strike at any age.

In excess of 400,000 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 they’ll 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 (see below). 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’ and find out more about managing your CVD risk by following the ‘Love Your Heart’ online programme at www.nras.org.uk/loveyourheart

**Symptoms of rheumatoid arthritis**

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 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.

**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 mean any of your relatives have RA, or that they will develop it in the future, 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 the foreign invaders like viruses.

So far, researchers have found that stress seems to play a key role, as does 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 his or her suspicions of RA, and include a measure of inflammation (an ‘ESR’

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
or ‘CRP’ test) as well as tests of your immune system (e.g. ‘Rheumatoid Factor’ and ‘Anti-CCP’ test). However, it is 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. NICE (National Institute for Health and Care Excellence) guidelines say that when a case of RA is suspected this should be treated as a ‘Health Associated Medical Emergency’ and that urgent referral to a specialist is required. You may find the leaflet produced by NHS England and the British Medical Association on what to expect when you get referred to see a specialist helpful.

For more information on getting a referral to see a specialist and what to expect, go to: [www.nras.org.uk/the-inflammatory-arthritis-patient-information-pathway](http://www.nras.org.uk/the-inflammatory-arthritis-patient-information-pathway)
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 one 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, a health history and family health history. It can be a little like putting a jigsaw together to get the full picture.

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.

A multidisciplinary team for RA includes:

- 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 at the back of this booklet or on your mobile phone.

- **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.

  www.nras.org.uk/exercise-videos

- **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.

- **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).
 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 www.nras.org.uk/footohealth

- **A Pharmacist.** As someone with RA, you will probably come into contact with several different types of pharmacists. 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-skeletal 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.

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’. You can have both antibodies in your blood, neither of them or be positive for one but not the other! Those who have rheumatoid factor (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/seropositive-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.

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.
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 stress 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

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Analgesics</strong> also known as painkillers</td>
<td>Paracetamol</td>
<td>To help control pain</td>
</tr>
<tr>
<td></td>
<td>Co-Dyramol (Paracetamol and Dihydrocodeine)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Co-Codamol (Paracetamol and Codeine Phosphate)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tramadol (strong painkiller and mild opioid)</td>
<td></td>
</tr>
<tr>
<td><strong>Non steroidal anti-inflammatory drugs (NSAIDs)</strong></td>
<td>Ibuprofen</td>
<td>To ease pain and stiffness by reducing inflammation but NSAIDs do not prevent future damage</td>
</tr>
<tr>
<td></td>
<td>Meloxicam</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Diclofenac</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Naproxen*</td>
<td></td>
</tr>
<tr>
<td><strong>Corticosteroids</strong> also known as steroids</td>
<td>Prednisolone</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>Methylprednisolone</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>Triamcinolone-acetonide</td>
<td>Can be injected into or around inflamed joints</td>
</tr>
<tr>
<td></td>
<td>Triamcinolone-hexacetonide</td>
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</tbody>
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*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>
<thead>
<tr>
<th>DMARD name</th>
<th>What you need to know:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methotrexate (MTX)</td>
<td>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. <strong>When you take methotrexate, you should also take a Folic Acid supplement</strong> 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.</td>
</tr>
<tr>
<td>DMARD name</td>
<td>What you need to know:</td>
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<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Methotrexate (MTX)</td>
<td>Methotrexate should be taken <strong>once a week</strong>, 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.</td>
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<td></td>
<td>The dosage you’re prescribed will vary considerably, depending on the severity of your disease.</td>
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<td></td>
<td>Take a look at the short animation about methotrexate <a href="http://www.nras.org.uk/methotrexate">www.nras.org.uk/methotrexate</a> as well as other informative videos on different aspects of taking methotrexate.</td>
</tr>
<tr>
<td>Sulfasalazine (SSZ)</td>
<td>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.</td>
</tr>
<tr>
<td>Leflunomide (LFL)</td>
<td>Tablets taken daily – This drug can be given as part of disease modifying drugs taken in combination.</td>
</tr>
<tr>
<td>Hydroxychloroquine (HDX)</td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>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.</td>
</tr>
<tr>
<td></td>
<td>For 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.</td>
</tr>
<tr>
<td>Ciclosporin</td>
<td>Rarely used now but sometimes as an add-on treatment to one or more of the above. See the NRAS booklet <em>Medicines in Rheumatoid Arthritis</em> for more information.</td>
</tr>
<tr>
<td>Azathioprine</td>
<td>Rarely used now since the continuing development of more effective, targeted treatments. See the NRAS booklet <em>Medicines in Rheumatoid Arthritis</em> for more information.</td>
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</table>

See over the page for general information on biologics, biosimilars and other innovative treatments.
Biologic & Biosimilar 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 and biosimilars.

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. Your RA specialist doctor or nurse can tell you more about why these drugs are not appropriate for everyone with RA.

**JAK inhibitors** (Janus Kinase Inhibitors) are a new class of drug that can be taken orally for the treatment of rheumatoid arthritis. JAK inhibitors are innovative new medicines and are different to biologics. 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?

There is lots of exciting research going on into finding new treatments for RA. Promising new biologic and non-biologic drugs are already in the final

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*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
phases of clinical trials, and some are about to come to market.

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

Over the past 20 years, 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 epidemiological study 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, more than 25,000 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 the new oral therapies that were approved in the UK in 2018 – the ‘small molecule’ JAK inhibitors.

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 (if you’re under 16 or over 60, on one of a number of benefits, or have a specific exemption). Your GP or pharmacist will be able to advise you on whether or not you have to pay for your 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. 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.

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.

<table>
<thead>
<tr>
<th>What blood tests measure and why</th>
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<tbody>
<tr>
<td><strong>Haemoglobin</strong></td>
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<tr>
<td><strong>White cell count</strong>: the number of white cells in your body. There are different types of white blood cells, including neutrophils.</td>
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<tr>
<td><strong>Liver function tests (LFTs)</strong>: alkaline phosphatase, ALT, LDH</td>
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<tr>
<td><strong>Renal function test (U&amp;E)</strong>: urea and creatinine.</td>
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<tr>
<td><strong>ESR (erythrocyte sedimentation rate)</strong>: the level of inflammation</td>
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<tr>
<td><strong>CRP (C-reactive protein)</strong>: a protein produced by the liver during times of inflammation</td>
</tr>
<tr>
<td><strong>Cholesterol</strong></td>
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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 Disease Activity Score. It assesses your joints, blood test results — C-reactive protein (CRP) and 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.

Take a look at the NRAS Know your DAS booklet and also find out about the NRAS DAS App, which can help you track your own DAS on your phone or tablet. Find out how to download the app at www.nras.org.uk/knowyourdas

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

# DAS28- Self Assessment

You can find out more about DAS 28 from www.nras.org.uk/disease-activity-score-das, where there is a patient guide to Know your DAS.
**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.
Managing Flares and Pain

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 you might need to consider switching to another medication.

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) can 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.
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.

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!
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, diagnosed in 2003
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
Honorary Consultant in Rheumatology Senior Research Fellow, NIHR Clinical Trials Unit

Drug Adherence Tips from people with RA:

- 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.

The ‘Know your DAS’ app mentioned earlier has a handy treatment reminder section, which you can set up to help you remember which drugs to take and when they’re due. www.nrmas.org.uk/knowyourdas
Self-Management Techniques

Love Your Heart

In February 2018, we launched Love Your Heart, an engaging and interactive video programme that aims to educate people with RA about heart disease and atherosclerosis. It is part of our commitment, as enshrined in the current NRAS Strategic Plan, to enable more people with RA and JIA to self-manage their condition and to improve the ability of health and care providers to support them in doing so.

Love Your Heart explains, in simple terms, why people with RA are at increased risk of cardiovascular disease. The programme allows you to calculate your own risk factors. You can then access tools to help you reduce that risk and achieve a healthier lifestyle, thereby reducing risk of premature death from heart disease.

The programme has in-built evaluation questionnaires to enable NRAS to measure (anonymously) intended behaviour change and, six months after completion of the programme, actual behaviour change and the benefits derived. The results will be published in due course.

Love Your Heart is a ground-breaking contribution to the wide-ranging resources provided by NRAS to enable people with RA to better manage their health and optimise their outcomes. It also gives health professionals further high-quality resources to which they can signpost their patients.

Within a month of launch, over 650 people had signed up to the Love Your Heart programme. To join them, visit www.nras.org.uk/love-your-heart

As a newly diagnosed person, it’s so 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, diagnosed in 2007
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.
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

and reduce 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. You could start by borrowing a relaxation CD from your local library.

You may also find the www.reframera.co.uk website useful to find out more about mindfulness and much more. The RefRAme campaign is supported by NRAS.

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.

Talk to your GP or specialist nurse if you continue to suffer from poor sleep, as they will be able to help. Also see the NRAS leaflet on Sleep Hygiene, which you can download from the publication area of the NRAS website, or order from enquiries@nras.org.uk

Diet
Just like the medicines and the disease itself, it varies between people what foods and diet can influence their response to treatment. Keeping a food diary is a great idea to help identify what works best for you. Getting advice from a dietitian may help you. Diet alone cannot control your disease.

I read that pineapple and turmeric are natural anti-inflammatories, so I still make sure I eat as much of them as possible.

Mark
Aged 33, diagnosed in 2010
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

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 and therefore some find them helpful.

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 you might find it useful to read how this can interfere with RA medication.


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. See more about this at www.drugs.com/drug-interactions/st-john-s-wort.html

**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, diagnosed in 2008

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, diagnosed in 2002
I tried some well-known supplements, but they did not make any difference.

Ralph
Aged 51, diagnosed in 2008

I have used acupuncture in the past to manage my pain. I found it really beneficial.

Lucy
Aged 29, diagnosed in 2007

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 to 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.

Take a look at the Love Your Heart video programme which includes information and support on smoking cessation.

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 NRAS 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.

**Apni Jung अपनी जंग**

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

One of the aims of the NRAS Strategic Plan 2016-2019 was to make NRAS services more visible, relevant and accessible in order to offer the greatest support to all, especially those who need us most. As a result, we are targeting populations who are known to have poorer outcomes, starting with the UK’s South Asian communities.

**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.

In spring 2018, we launched a new 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. [www.nras.org.uk/apni-jung-अपनी-जंग](http://www.nras.org.uk/apni-jung-अपनी-जंग). The video includes contributions, all in Hindi, from one of our young volunteers, a consultant rheumatologist and a researcher.

We will continue to develop the Apni Jung area of our website to provide relevant, accessible information for the South Asian communities in the UK and elsewhere as part of our continuing commitment to the development of accessible information.

[www.nras.org.uk/about-apni-jung](http://www.nras.org.uk/about-apni-jung)
Don’t suffer in silence. Speak to your RA specialist nurse, contact NRAS or talk to your friends and family.

Ralph
Aged 51, diagnosed in 2008

Not long after I was diagnosed, my parents encouraged me to write a diary detailing how I was feeling physically and mentally. It helped me put the negative thoughts that were constantly in my head down on paper, so I could forget about them and move on.

This coping mechanism was just as important as talking about my RA anxiety and pain to my family, especially when I was away from home at University.

Sasha
Aged 22, diagnosed in 2014

NRAS is working exclusively in the UK in partnership with Daman, an innovative Danish digital healthcare company, to maximise the potential for this app in the UK for people with RA and families of children and young people with Juvenile Idiopathic Arthritis (JIA).

RheumaBuddy is free and enables users to record, manage and discuss their symptoms. 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

Rheumabuddy

In late 2017, NRAS launched RheumaBuddy a new digital self-management app that can be used on mobile phones and tablets. Many people have already downloaded and are using this useful app to keep tabs on their RA.
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.

As a consequence of the findings in our report Work Matters, as well as listening to the issues on work raised in calls to our helpline, it is our intention to create new resources on our website for working people and those not currently working but who want to get back into the workplace. Visit www.nras.org.uk/work for more information.

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, diagnosed in 1982
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.

You might find it helpful to read the NRAS Emotions, Relationships & Sexuality booklet, which looks at how RA can make you feel and ways to cope with this. If you are in a relationship, you can share the booklet with your partner too.

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

Take a look at the Behind the Smile videos at www.nras.org.uk/behindthesmile that might help when talking to your family, health professionals, colleagues etc.

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, diagnosed in 2014
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 Know your DAS – DAS 28 (Disease Activity Score)

This is a measurement of how your disease is progressing. The lower the score the more in control your disease is. It involves your nurse or clinician examining 28 joints to test how swollen and tender they are, adding to this your blood results and how your RA is currently affecting you, on a score of 1 to 10, to calculate a composite score called DAS.

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. You can now measure your own DAS with the DAS app available to download onto your phone or tablet.
2 Regular blood monitoring

Regular blood tests are extremely important when you have RA. They help your multidisciplinary team to assess your general health, show your level of inflammation, indicate whether medications are having an effect on your normal blood system and reveal how well the main organs in your body are working. They are also an important early indicator of any changes in your disease activity.

You may have all your blood monitoring carried out at your GP surgery, or at your local hospital, or there may be a mixture of both. The frequency and relevance of blood monitoring will be explained to you by your Specialist Nurse or Consultant.

If you’re nervous or anxious about having regular blood tests, tell the phlebotomist (specialist blood taker) or GP practice. They will understand and should be able to reassure you, perhaps by teaching you some distraction techniques.

For more information about regular blood monitoring see www.nras.org.uk/laboratory-tests

3 Support to help you quit smoking

We know that having RA puts people at increased risk of heart disease. Smoking further increases this risk. Evidence also shows that RA treatments are less effective in people who continue to smoke. See page 31 for more information.

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

4 Annual holistic review

All people living with RA should be offered an annual holistic review. This not only assesses whether, and how much, your disease has progressed, but also gives you the opportunity to talk about any issues you might have and what you may need. You’ll be able to discuss how RA is affecting both your emotional and mental health and how it’s impacting your family and working life.

5 Access to the multidisciplinary team

Everyone with RA should have the opportunity to see any of the specialist professionals listed on page 13. You can use these appointments as a way of learning more about your condition and to help you manage it. Don’t be afraid to ask any questions you might have.

6 Learn how to self-manage

It’s really important that you understand your own symptoms and have a say in the way your RA is treated. To help you manage it, you should be offered the chance to attend self-management education sessions, where you’ll get good quality, approved information and be able to draw up an individual care plan.

7 Access to a specialist nurse led helpline

You should have access to a nurse-led helpline whenever you need it, for instance if you’re experiencing side effects from drugs, or having a flare-up of symptoms. Make a note of your nurse advice line telephone number in the back of this booklet for handy reference.
8 Clear signposting to patient organisations

Ask your doctor or specialist nurse about patient organisations that provide comprehensive services for people with RA, such as a helpline, peer to peer support, information booklets, online forums and educational opportunities.

9 Exercise

Research shows that taking regular exercise is very important for people with RA and plays a key role in controlling symptoms, including fatigue, pain and referred pain (where pain appears in a different part of the body to the source of the pain). Ask to be referred to a physiotherapist, who can help design a tailored exercise programme for you. It’s also important to maintain a healthy lifestyle by eating a nutritious diet and by trying to remain at a constant healthy weight.

10 Pregnancy

If you or your partner are thinking about, or planning, to start a family, it’s important to ask for information and support from your specialist team. Both men and women with RA who are trying to conceive will need to be very closely monitored, and drug regimens might need to be controlled or altered. You can ask your team for care and support at every stage of a pregnancy, from pre-conception to post-natal.

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

- 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.

- Have your blood fats (cholesterol) measured annually
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.

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 distant 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.

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, diagnosed 1992
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.

JIA Explained and Managing JIA in Schools

Two booklets for parents and young people addressing the issues of living with JIA.
The impact of RA on Emotions, Relationships and Sexuality

This booklet tackles emotions, relationships and sexuality, and how these very personal and intimate issues are affected by being diagnosed with and living with rheumatoid arthritis.

RA & Benefits

This guide will make it easier for you to understand how to find out more about benefits that may be relevant for you and your family.

RA & Personal Independence Payment

A self-help guide to claiming Personal Independence Payment for adults with rheumatoid 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.

When an Employee has 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.

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

<table>
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<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td><strong>Adherence</strong></td>
<td>Taking your medication at the times and in the doses prescribed by your doctor</td>
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<tr>
<td><strong>Complementary therapy</strong></td>
<td>Refers to treatments used in addition to or as an alternative to those prescribed by your doctor. Examples would include acupuncture or vitamin supplements. 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</td>
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<tr>
<td><strong>CRP</strong></td>
<td>C-reactive protein is produced by the liver and can be measured in the blood as a marker for inflammation</td>
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<td><strong>Disease activity score or DAS 28</strong></td>
<td>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</td>
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<tr>
<td><strong>ESR</strong></td>
<td>Erythrocyte (red blood cells) sedimentation rate is a measurement of inflammation in the blood</td>
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<tr>
<td><strong>Inflammation</strong></td>
<td>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</td>
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<tr>
<td><strong>Molecule</strong></td>
<td>A group of atoms bonded together, representing the smallest fundamental unit of a chemical compound that can take part in a chemical reaction</td>
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<tr>
<td><strong>Remission</strong></td>
<td>To be symptom-free</td>
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NATIONAL RHEUMATOID ARTHRITIS SOCIETY

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
Pharmacist telephone number
NRAS freephone number

0800 298 7650

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

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References

For a full list of all the references used in compiling this booklet (such as articles in medical journals), please call NRAS on 01628 823524.

For general enquiries, call: 0845 458 3969/01628 823524 or email enquiries@nras.org.uk

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:

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[www.nras.org.uk/join](http://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.*
New2RA
A self-help guide for people newly diagnosed with rheumatoid arthritis

First published April 2018
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