Managing well: Living with RA

Managing well
Living with Rheumatoid Arthritis

A self help guide for people with established disease

March 2016
Help and information from NRAS

NRAS is the only patient-led charity in the UK specifically for people with rheumatoid arthritis, their families and carers, providing information, support, advocacy and campaigning.

- The NRAS freephone helpline 0800 298 7650 is open from 9.30am to 4.30pm Monday to Friday. Our trained helpline staff are there to answer your questions on all aspects of living with RA, supported by a team of medical and healthcare professionals.

- Our website www.nras.org.uk has a wealth of information about living with RA, treatments, the latest research and developments, and an online members’ forum. It also has a full list of useful charities and organisations. If you don’t have access to the internet, and think you need to contact other organisations, call us and we’ll provide the information you need.

- If you’d like to talk on the phone to another person who has RA, we can put you in touch with one of our trained telephone support volunteers. We can match you as closely as possible with one of our volunteers who will then call you to discuss whatever aspect of living with RA is your main concern. If you’d like to arrange a telephone support call please first call us on the helpline number: 0800 298 7650 and we will discuss your requirements.

- Local NRAS groups meet regularly around the country. 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

Contact us at NRAS

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NRAS is a private company limited by guarantee.
Registered in England and Wales No 7127101
Charity Nos 1134859 SC039721
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Acknowledgements

This booklet has been written with input at every stage from NRAS members, including people who are experienced in self management of rheumatoid arthritis. It draws on individual interviews, focus group discussions about its scope and content, reviews of drafts and feedback on designs. Our thanks to everyone for their time, frankness and constructive comments, and to the NRAS staff, Members and Volunteers who feature on the cover.

With thanks also to health professionals Maggie Carr, Lynne Goodacre, Liz Hale, Susan Oliver, Dorothy Pattison, Tony Redmond, Sarah Ryan, David G I Scott and Peter Taylor, and to focus group members Carolyn Calcutt, Carolyn Carter, Sue Carter, Rosemary Cleaver, Jill Hibbitt, Lynn Mattai, Ann Montgomery, Manjit Notta, Diana Skingle, Mary Spacey, Sue Thwaite and Sally Underwood.

Edited by Kate Wilkinson, www.helpcommunicate.co.uk

Design and print by AIT Marketing Associates. www.ait-uk.com
Managing life with rheumatoid arthritis...

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

It combines information from doctors, nurses, healthcare professionals and people with rheumatoid arthritis, about:

- Self management: what it is and how it helps.
- Making the most of your care and treatment.
- Evidence about some of the latest drugs ie Enbrel, Humira etc.
- Monitoring and why it’s important.
- Managing pain and flares.
- Keeping well, including having a healthy diet and managing fatigue.
- Reducing your risk of complications, and what to be aware of.
- Talking about RA with friends, family and at work.

RA is a complex disease, and there is far more information about it than can fit in one booklet. There are also details of where to find more information on different aspects of self management.

Self management and how it helps

Maggie Carr is Consultant Nurse in Rheumatology at Ashford and St Peters Hospitals NHS Trust. She explains what self management is, and how it can help.

‘The Department of Health defines self management as “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition”. In practice, it’s about being able to manage your RA, your treatments and day-to-day life in the best possible and most realistic way.

When you have a condition like RA, you’re already managing it in lots of ways, and there are also specific skills you can learn to gain more confidence and knowledge. Your rheumatology specialist nurse and other members of the team can help with information about your condition, treatment and medication. They can offer support, particularly when things change or when you have a flare-up, helping them, their family and friends to understand.
For successful self management, you need a good partnership with your healthcare team. It will help you to control the impact of RA on your life and get the best from the support and resources available. Make sure you know who to contact for help when you need it.

A number of courses have been developed across the world to support people living with long-term conditions like RA. Evidence about these programmes shows that these courses have real benefits: they give people more confidence to manage their condition, more energy and better quality of life.’

What are self management skills?
- Setting goals and making action plans.
- Solving problems.
- Managing emotions.
- Managing your relationships with family, friends and colleagues.
- Getting the best out of your medications.
- Communicating with health and social care professionals.
- Shared decision making.
- Pacing daily activities - managing fatigue, sleep, pain, anger and depression.
- Understanding the importance of exercise, keeping active and eating a healthy diet.

From About EPP CIC, Improving the lives of people with long-term conditions www.expertpatients.co.uk

NRAS/smuk self management programme
NRAS has always promoted the benefits of proactive self-management and has developed a self-management programme specifically for people with RA, working in partnership with self-management uk who used to be the Expert Patients Programme. Two people run each programme: a health professional in rheumatology (usually a specialist nurse or other allied health professional such as specialist OT or physio), and a person living with rheumatoid arthritis.

The programme has been commissioned in some parts of England and Scotland and results being achieved are very good and proving to be sustainable over 6 months. Longer evaluation is being carried out.

For more details and information about the programme’s cost and availability, please contact Nicola Freemantle at NRAS.

Where to find self management support
- smuk runs self-management courses for people with any long-term condition(s) both face to face and on-line. You can find out more by visiting their website: www.smuk.org.uk
- Arthritis Care run a number of courses for people with all forms of arthritis. You can find out more by visiting their website: www.arthritiscare.org.uk
- NRAS has approximately 50 local groups for people with RA. While these are not self-management courses, they do help to improve your ability to self-manage as they provide opportunity to increase your knowledge of RA and how to manage it and give you the chance to share experiences with others and help each other cope.
Making the most of your care and treatment

When you live with RA you can become accustomed to living with pain. You can end up feeling that this is what life is going to be like, from now on. But you really don’t have to settle for it: there is always something that can be done.

‘Treat to Target’ means the team work with the patient to focus on an individual treatment plan (target) that aims for a DAS 28 score of 2.6 or lower. This approach is more effective if the patient and the team work together with the shared vision of getting the lowest DAS score for that person (see page 22 for more information on the DAS28).

If you’re experiencing constant pain, ask for help from your rheumatology team. It may be that your disease is not adequately controlled and you may need a change of medication. Raise this at your next appointment if that’s coming up soon; otherwise call your hospital or clinic helpline. (For more about helplines, see Understanding the NHS system on page 13).

Getting what you need from appointments

“It’s important to develop a therapeutic relationship with your team, sharing in the decision making about your treatment and care to ensure you get the most out of your consultations.”

It helps enormously to have a good understanding with the people in your rheumatology team. You need peace of mind to be able to get on with your life, and this comes from having a team you can trust. You can self manage much better when you know you can rely on people for care, ongoing support and swift help when you’re finding things difficult. It takes time and effort to develop good relationships, but they are important. When it’s hard to find the right words, or when you’re talking about personal matters, it helps if the person you are talking to understands something about you and your life.

Appointments often seem very brief, and when your disease is controlled they are needed less often. This makes it all the more important to get the most out of appointments, to help you to manage your condition.

“I used to say “Oh, I’m not too bad” – and you shouldn’t do that.”
Do:

- **Prepare** for your appointment. Think through what you want to get out of the appointment and write your questions down, with the important ones at the top of the list. Use the list to make sure you don’t forget anything, or ask the nurse or doctor to go through it with you.

- **Be honest, not brave.** You may be so used to telling friends and family you’re OK that it’s hard to be honest with health professionals about your pain or concerns. But your team needs to know the real picture.

- **Be precise.** Some people find it helps to keep a diary of how they are and what they can do each day or week. There’s more information about this on page 24.

- **Think about taking your own records with you** – it can save time, so that you don’t spend most of the appointment going through your medical history. You may want to take: a list of your medications; your blood monitoring results; details of operations or drugs you’ve had in the past. A summary is best as time is limited and you need to be realistic about the amount of notes that you can use.

- **Always ask if you don’t understand.** It’s fine to keep on asking until you’re happy that you understand the explanation.

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

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

**Understanding who’s who**

If you can get to know who’s who and how the health system works in your area, you’re better placed to get the support you need.

The chart on page 8 is a quick reminder of the various health professionals who may make up your rheumatology team, and others who can help. Multi-disciplinary teams vary from hospital to hospital, so it is worth finding out from your specialist nurse who makes up the team in your area and how you can access them. If you don’t have a specialist nurse, talk to your consultant about who is available.

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

<table>
<thead>
<tr>
<th>The team</th>
<th>You may have access to all or some of the following in order to manage your RA</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Your GP</strong></td>
<td>The first port of call when you develop symptoms.</td>
</tr>
<tr>
<td><strong>Consultant Rheumatologist</strong></td>
<td>Makes the initial diagnosis and plans your treatment, monitoring how it is working and making changes when needed.</td>
</tr>
<tr>
<td><strong>Rheumatology Nurse Specialist</strong></td>
<td>Help with practical advice on living with RA. The majority of Rheumatology departments have one.</td>
</tr>
<tr>
<td><strong>Voluntary Organisation</strong></td>
<td>Organisations such as NRAS, Arthritis Research UK &amp; Arthritis Care offer support and information.</td>
</tr>
<tr>
<td><strong>Physiotherapist</strong></td>
<td>Can help you to maintain strength &amp; function of the joints &amp; muscles.</td>
</tr>
<tr>
<td><strong>Occupational Therapist</strong></td>
<td>Can help you to find new ways of doing everyday activities, including work. Can also make splints for affected joints.</td>
</tr>
<tr>
<td><strong>Pharmacist</strong></td>
<td>Based either in the hospital or the community the pharmacist can be an invaluable source of support and information about your medications.</td>
</tr>
<tr>
<td><strong>YOU, the patient</strong></td>
<td>(The most important member of the team).</td>
</tr>
<tr>
<td><strong>Podiatrist</strong></td>
<td>Specialises in problems caused to the feet and ankles by your RA, often working with an Orthotist who may be called upon to make insoles for your footwear to help improve your walking pattern.</td>
</tr>
<tr>
<td><strong>Phlebotomist</strong></td>
<td>Take blood to be tested for analysis to help in diagnosis and assessment.</td>
</tr>
<tr>
<td><strong>Radiographer</strong></td>
<td>X-rays and other imaging techniques such as ultrasound and MRI scans are commonly used in diagnosis and assessment.</td>
</tr>
<tr>
<td><strong>Social Worker</strong></td>
<td>Can help with housing, benefits &amp; care at home.</td>
</tr>
<tr>
<td><strong>Dietitian</strong></td>
<td>Can help you to maintain a healthy diet and keep to a healthy weight level.</td>
</tr>
<tr>
<td><strong>Psychologist or counsellor</strong></td>
<td>May be called on to help you with the emotional adjustment to living with RA.</td>
</tr>
<tr>
<td><strong>Orthopaedic Surgeon</strong></td>
<td>Specialises in operating on bones &amp; joints.</td>
</tr>
</tbody>
</table>
**GP or Practice Nurse**
This may well be the person you see most often. Some practices have a GP (family doctor) with a special clinical interest in rheumatology, known as a GPwSI. These are GPs who have had specialist training in rheumatology and offer additional services such as joint injections. They work in Primary Care and usually have good links with the specialist rheumatology team. At the moment there are not many GPwSIs so there may not be one in your local practice, but it is worth finding out.

**Consultant Rheumatologist**
He or she works out your treatment plan, monitors how it’s working and changes it when needed. He or she supervises your care and you see him or her for regular reviews. How often these take place depends on how well your RA is controlled, and how frequently your treatment needs to be reviewed. When you are newly diagnosed, your consultant (or one of their team) should see you frequently to measure how well you are responding to treatment. Once your disease is well controlled this is less often, perhaps every six to nine months. However, at least once a year you should have a full review that covers your treatment and all aspects of living with RA.

**Rheumatology Specialist Nurse**
Most clinics have a specialist nurse or practitioner who advises on rheumatoid arthritis management and monitors your drug treatment. The nurse has a pivotal role in the team, responsible for co-ordinating patient care and providing the first point of contact. She or he also works to help you with any specific anxieties or concerns you have about your treatment and how it may affect you personally.

Increasingly, consultants share patient care with nurse specialists, who may run their own clinics. Most specialist nurses also provide telephone advice lines so that you can make contact between visits. Make sure you get information about whether there’s an advice line at your clinic, when it’s open and when to expect a reply.

There may be a range of services at a nurse-led clinic. Nurses or practitioners can assess your joints, monitor your drug treatment and review blood tests. Some nurses can also prescribe and change your medication and give steroid injections for swollen joints.

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

A physiotherapist helps you to keep mobile and exercise in the right way to keep your muscles strong and flexible. Many people see a physiotherapist soon after being diagnosed. They can advise on joint protection, managing flares, pacing activities, managing fatigue and pain relief. You may also need to see a physiotherapist at other times for particular symptoms such as difficulties with movement. Whether this is short-term or longer-term treatment, the physiotherapist works closely with you and other members of the team.

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

He or she can then help you by:

- Teaching you how to stretch your joints safely, to increase their range of movement.

- Teaching you exercises to strengthen muscles and correct imbalances between different muscle groups.

- Advising you how to improve your walking pattern (gait), if it’s altered because of changes in how your joints are moving. They may also recommend insoles and walking aids.

- Referring you to other health professionals such as podiatrists and orthotists if you need more complex appliances.
Occupational Therapist
An occupational therapist, or OT, can help you improve or maintain your ability to do everyday activities. He or she works with you to find out what you’re finding difficult and ways to reduce the problems. This might be by:

- Changing how you do things – helping you to use your time and energy effectively or finding ways to save energy. You might break activities down into smaller parts or do less at any one time.

- Helping you to reduce the impact of RA on your daily activities. This could mean teaching you about looking after your joints during everyday activities or about ways to manage pain and fatigue.

- Offering you support in making changes, for example with individual counselling or group programmes.

- Adapting your home or workplace to make activities easier. For example, the right piece of equipment or a structural alteration can make all the difference. OTs can also liaise with employers to ensure that appropriate adaptations are provided through statutory services, where possible.

- Treating symptoms such as painful hands. This can involve making splints for affected joints and showing you how to wear them, and (often working with a physiotherapist) showing you hand and arm exercises that help you make the best use of your hands.

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

The Podiatry Rheumatic Care Association (PRCA) have published Standards of Care for people with Musculooskeletal Foot Health problems. Copies of the standards are available online at www.prcassoc.org.uk/standards-project and there is section specifically for people with inflammatory arthritis. NRAS also has a dedicated area on Foot Health in the Living with RA section of the website www.nras.org.uk.
**Pharmacist**
The pharmacist may be based in your local health centre in the community or in the hospital, and can be a valuable source of support and information. He or she can help if you are concerned about your medications or the instructions about your treatment, or if you need to check whether you can take other medications or over-the-counter treatments at the same time.

**Dietitian**
A dietitian can help you to lose weight if this is an issue for you, and provide healthy eating advice. Being overweight adds to the strain on already inflamed joints and can lead to further damage. For some people, diet also appears to have an influence on the way their joints feel although there is no evidence that particular diets influence the progress of RA. If you have a particular sensitivity to a food, it is possible that this might affect your symptoms but this cannot be generalised to everyone with RA. If this applies to you, you may find it helpful to discuss it.

**Counsellor**
There may be times when you need additional help with the emotional impact of living with RA. While a very few rheumatology teams can refer you directly to a clinical, health or counselling psychologist, your GP may be able to refer you to a local service. Different types of treatments include problem-solving therapy, cognitive behavioural therapy and other forms of counselling.

* We appreciate that it may not be possible for everyone to access these services so would suggest that you discuss your needs with your team to find out about possible referral or, if these services are not available, to find out what other resources are open to you, including good website and other accredited information.
Understanding the NHS system

“You need to be what’s called an ‘intelligent customer’ and be proactive. I keep copies of everything. And you need to understand the mechanics of how services interact.”

It helps you to stay in control and manage your disease better if you know what the services are in your area, how they relate to each other, and how you can get urgent help about a flare or medication. Some points to remember:

- Services vary hugely from area to area, so don’t assume that things will be the same if you move to a new hospital. For example, if you live in an area where there is shared care, your blood monitoring can be done by your GP. If this isn’t the case in a new area, you may have to go to the hospital for monitoring which may be some distance away.

- Don’t assume that different services communicate with each other or that they’ll all have all your notes. It may seem logical but it’s not always how things work! It can be a real help to keep your own records and take them with you. It can also be helpful to have a list of your current medications to save you having to remember them which you can hand to your health professionals.

- Keep copies of your blood results, and know what is normal for you. There is more information about understanding blood results on page 23.

- If you have other conditions as well as RA, it is most important to be aware of how different drug treatments may interact. If you are seeing another consultant for another condition, you can ask the two consultants to talk directly to each other, to make sure you’re getting the most appropriate treatments for both conditions. This can be difficult and you may need to persist.

- Don’t wait until your next scheduled appointment if you need help sooner – you can ask for it to be brought forward.

- Make sure you know who to contact for urgent help: you need the number of the helpline at the hospital and your GP’s number including the emergency number for out of hours.
If you’re not happy with the care you’ve been offered

“Sometimes you’ve got to push it in the NHS, you can’t just sit back.”

If you are in pain or you feel your disease is not well controlled, don’t think you must just accept it. You can always be looking for progress. This is not always easy if you have to be challenging or insistent with your healthcare team. Remember:

- Don’t feel guilty about needing time to explain how you’ve been and to discuss options. It is not your fault that you have RA!
- You have the right to ask for a second opinion.
- The NHS has a Patient Advice and Liaison Service, known as PALS, which represents patient views. Your PALS local office may be able to help you resolve things informally.
- If all else fails, hospitals have a formal complaints procedure. You can write to the Chief Executive of the hospital or ask for a complaints form. PALS can also give you information about NHS complaints procedures and how to make a complaint.

Personality clashes?

It is important to have a good relationship with members of your healthcare team, but personality clashes can and do occur. They make good communication extremely difficult. If you don’t get on with your consultant or your GP, it can cause genuine anxiety and emotional distress. This is unhelpful in the management of your disease and it can get in the way of your ability to self manage effectively. Under these circumstances it may be better to change to another team in another hospital in the area. A first step may be to discuss the problem with your GP, who may be able to suggest other consultants or rheumatology units.

If a change is not feasible, it is worth being straight with your specialist about the problem. You can say something like: ‘Look, I think we may have got off on the wrong foot. I feel I would be more comfortable seeing another consultant within the team, if you would be good enough to refer me to someone else.’ (You may want to take someone with you for added confidence.) Most consultants are happy to refer patients with RA to one of their colleagues. It is often helpful in any case to have a second opinion and these ‘internal referrals’ are not that uncommon. It may also be worth discussing any such problem with your nurse practitioner.
An important part of self management is understanding your own medication: which drugs you are taking and why, the benefits and side effects and what your monitoring means. There is more information about monitoring on page 23.

The table below briefly describes the different types of drugs used in the treatment of rheumatoid arthritis. Most people take a combination of these types. You may also take other types of drugs, for example to help manage the side effects of disease modifying drugs, or of course for another condition altogether.

### Drugs at a glance - Used to treat the symptoms of RA

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
<th>Purpose</th>
</tr>
</thead>
</table>
| Analgesics, also known as painkillers     | E.g. Paracetamol, Co-codamol, Tramadol  
May be prescription only or bought over-the-counter (OTC) | Help to control pain.  
There are different types that work in different ways. Some people respond better to one medication than another. If the first drug you're offered doesn't work when taken as prescribed, ask your doctor or nurse if you could try something else.  
There's more information about taking painkillers effectively on page 42. |
| Non-steroidal anti-inflammatory drugs, or NSAIDs | E.g. Ibuprofen, Naproxen, Aspirin, Celecoxib  
May be prescription only or bought over-the-counter | Reduce inflammation. Can work quickly. They inhibit chemicals involved in inflammation.  
(Read more about the use of anti-inflammatory drugs on page 17.) |
## Drugs at a glance - Used to treat the impact of the disease

<table>
<thead>
<tr>
<th>Type</th>
<th>Examples</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Corticosteroids, also called steroids</strong></td>
<td>E.g. Prednisolone, Depo-medrone</td>
<td>Reduce inflammation. Can be injected into inflamed joints, into muscle, given intravenously or taken as tablets. If you take steroids over a long period (more than three months) or at a high dose (more than 7.5mg daily) you should ask your doctor about additional medication to protect your bones.</td>
</tr>
<tr>
<td><strong>Disease modifying anti-rheumatic drugs, or DMARDs</strong></td>
<td>E.g. Methotrexate, Sulfasalazine, Leflunomide, Hydroxychloroquine</td>
<td>Reduce joint inflammation and damage by ‘damping down’ the immune system in different ways. Can take time to work. A way of controlling the disease over the long term.</td>
</tr>
<tr>
<td><strong>Biologics</strong></td>
<td>E.g. Anti-TNF drugs: etanercept, adalimumab, infliximab, certolizumab pegol and golimumab, as well as other biologics such as rituximab, abatacept and tocilizumab</td>
<td>More recently developed protein-based DMARDs. They work by targeting specific chemical messengers or cells that activate inflammation in the body. Some are delivered by a drip, in hospital and others by self-administered injection/ pen under the skin, in the way diabetics give themselves insulin.</td>
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</tbody>
</table>

The table above gives the generic names of the drugs. You may also know them by proprietary or brand names. For example, Ibuprofen is marketed as Nurofen and Brufen; Maxtrex is a branded Methotrexate tablet; Remicade is the brand name for infliximab.

For information on how drugs interact with vaccines, please contact the NRAS Helpline and ask for information sheet no. WS61 entitled ‘Immunisation for people with RA’. You could also consult the Department of Health Green Book for further help.
Making decisions about treatment

“It’s my decision but I want the doctor’s advice. I need them to explain about the side effects.”

A recent Government initiative aims to improve health care outcomes by involving patients more fully in their own care, using what has been called a Shared or Informed Decision Making process. The Government’s vision is for patients and clinicians to reach decisions about treatment together, with a shared understanding of the condition, the options available, and the risks and benefits of each of those. When you’re making decisions with your healthcare team about drug treatments, make sure you are fully informed about your options. You might want to discuss:

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

A note about anti-inflammatory drugs

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

Recent recommendations advise that another tablet should be prescribed with NSAIDs or COX-2 to protect your stomach, often referred to as a PPI (Proton pump inhibitor) which work to reduce the amount of acid produced by your stomach. There are potentially additional risks if you have a severe heart problem, high blood pressure, impaired kidney function or have risks related to bleeding from your gut, such as a previous stomach ulcer or are on medication such as warfarin or aspirin.

When COX-2 drugs were introduced it was hoped that they would provide equal anti-inflammatory effect as conventional NSAIDs but with lower risk of gastrointestinal bleeding. Whereas this has generally proved to be the case some COX-2 drugs including rofecoxib (Vioxx) had to be withdrawn because of an increased risk of heart attack. However conventional NSAIDs including diclofenac and ibuprofen (but probably not naproxen) have also been associated with a slightly increased risk of heart attack, particularly when high doses are used. Large scale studies of two widely used COX-2 drugs, celecoxib and etoricoxib, have not shown an increased risk of heart attack as compared with conventional NSAIDs and they are used widely.

For the majority of people with RA, the very considerable benefits of NSAIDs in terms of symptom relief greatly outweigh the possibility of side effects, but for people at increased risk of either stomach bleeding or heart attack the benefits have to be weighed against possible risks. It is best to discuss with your doctor or nurse whether this type of drug is appropriate for you and if so, which one.
Medication can be a source of concern for many people, and there is good, detailed written information available about all the drugs used in the treatment of RA.

Biologics: Frequently asked questions

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

  They cannot be taken by mouth and are given either by a drip or by self-administered injections/pen under the skin in the way diabetics give themselves insulin. If they are given by drip this is done during visits to the hospital. Time intervals between visits vary from once every one to two months, to just two infusions a fortnight apart and repeated after many months as required. If they are given by subcutaneous injections, a nurse teaches you or a carer to administer the injections at home. The frequency of injections may vary, from twice weekly to once every two or more weeks, dependant on which drug you are taking.

  Biologics work by targeting specific chemicals or cells in the body’s immune system response. Anti-TNF drugs work by blocking the activity of TNF, a chemical messenger (a cytokine). Blocking the TNF results in many biological effects which tend to reduce or stop different aspects of inflammation. Other biologic therapies target other areas of the immune system that are involved in the processes of inflammation. These include various other cytokines such as IL-6 and cells such as B and T lymphocytes. Biologics have significant benefit for most but unfortunately they do not work for everyone.

- **Anti-TNF drugs are:**
  - adalimumab (brand name Humira),
  - infliximab (Remicade),
  - etanercept (Enbrel),
  - certolizumab pegol (Cimzia) and golimumab (Simponi).

  The drug rituximab (brand name Mabthera) is also a biologic, but acts on B cells.

  *Drugs which target the T-cells – abatacept (Orencia).*

  *Drugs which target the interleukin (IL) proteins – tocilizumab (RoActemra)*

  For more details about the biologic drugs which are available please see our patient guide to biologics – ‘Biologics ...the story so far’

  Others are in development.

- **Can I get biologics?**
  National Institute for Health and Care Excellence (NICE) has set strict criteria for who is eligible to receive biologics funded by the NHS in England and Wales. (In Scotland, the equivalent of NICE is the Scottish Medicines Consortium (SMC) who may have different criteria). You meet the NICE criteria if:

  - You have failed to respond to or have had unacceptable side effects with at least two DMARDs, one of which is methotrexate, over a minimum period of six months.

  - You have a Disease Activity Score, also known as a DAS 28 score, of higher than 5.1 on two separate occasions, at least one month apart. The DAS is a widely-used test of how active your RA is – there is more information about this on page 22.
In some circumstances your doctor may decide you need biologic treatment even though you do not meet the criteria, and a special report has to be completed to request funding from your local health authority. Your doctor or nurse will discuss this if it applies to you.

**My local health authority won’t fund my treatment. What can I do?**

Clinical Commissioning Groups (CCG) in England, and the Health Boards in Wales, have a legal requirement to fund your treatment if you meet the criteria stipulated by NICE. However, in Scotland the Health Boards follow the treatment criteria stipulated by the SMC, which is not mandatory (although the SMC does follow NICE Guidance for Multiple Technology Appraisals). For information about how to challenge your treatment decision contact NRAS (also see the section about NICE on this page for further information and NICE guidance on the prescribing of biologics issued in July 2010).

**What if my biologic therapy does not work for me?**

For some people a first biologic (an anti-TNF, tocilizumab or abatacept) may not work for them and so NICE has issued guidance in which it suggests, based on the evidence available, the most suitable sequence of treatment. If a patient fails on a first biologic they would normally be prescribed rituximab and methotrexate unless there is some medical reason to avoid these drugs, or if rituximab or methotrexate has to be withdrawn because of a side effect, in these circumstances patients would be offered access to a second anti-TNF, abatacept or tocilizumab.

**Can I access a biologic which hasn’t been passed by NICE for use in the NHS (England and Wales)?**

If your doctor thinks that another drug which has not been passed by NICE is more suitable for you then he/she can apply to the CCG to try to obtain the drug on a named patient basis.

**Where can I find more information?**

The situation is changing as new drugs come onto the market and NICE and others begin to appraise them. The NRAS helpline team keeps up to date and can send you written information on all the issues. Call and ask for a copy of our patient information booklet entitled ‘Biologics – the story so far’. If you have a specific medical query, it is best to ask your own rheumatology team if possible.

The NRAS helpline has access to a national network of Medical Advisors who may also answer medical queries. You can also speak to NRAS volunteers who have RA and are benefiting from biologic therapies: this can be reassuring if you’re about to start treatment.

NICE also produce patient information leaflets about these drugs and their use.
Keeping RA under tight control

The benefits of ‘tight control’ in the management of rheumatoid arthritis are now widely accepted. Peter Taylor, Norman Collisson, Professor of Musculoskeletal Sciences, Kennedy Institute of Rheumatology, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, University of Oxford, explains.

‘The faster we can switch off the inflammation in RA, at every stage of the disease, the better the patient does. Even if you were diagnosed many years ago, the more the inflammation can be suppressed now, the better you will do. What matters is to keep the total amount of inflammation you experience, over time, as low as possible. That’s the aim of tight control, and it can benefit everyone with RA.

So what does it mean, in practice? Because RA is different for everyone it’s not easy to generalise. Every person will discuss their individual treatment with their healthcare team. But the principles are that you have regular monitoring and that treatment is stepped up when there is still evidence of ongoing disease activity. How often monitoring takes place depends on how active your disease is. If you’re in remission or near remission – that is, with low disease activity while you’re on medication – this may be every six to eight months. If your disease is more active then you may be assessed more often, and your treatment escalated until the inflammation settles down.

Tight control can involve using disease modifying drugs in combination as well as singly. We now know that in the majority of cases, combination therapy achieves tight control with few additional side effects or complications. If conventional DMARD treatments do not improve joint inflammation adequately, there may be a case for a biologic treatment. This is a different type of medication that cannot be taken as a tablet and is therefore given by injection. If a biologic treatment is to be used, the first type of biologic to try is generally an “anti-TNF”.

For some people, if their inflammation is reduced rather than completely normalised, combination therapy does mean a slightly higher risk of infections. While this is still a low risk overall, combination therapy may therefore not be appropriate for absolutely everyone: it may be more important for some individuals to minimise their risk of infection. Each person’s treatment involves balancing a range of factors. But overall, tight control with escalation of treatment leads to better outcomes – and this is increasingly the guiding principle of treatment.’

Research and developing drug treatments

Not everyone with RA benefits from every drug: anti-TNFs, for example, work for about 60% to 70% of people. Similarly, other biologic therapies such as rituximab, abatacept and tocilizumab, work well for some people with RA, but not for others. This is one of the reasons why it is good to have a range of different drugs to test out.

Although the development of biologic drugs has been a breakthrough in the management of RA, it is not possible to achieve remission for everyone. For this reason, it is important to undertake research to find more drug treatments for RA. There are new biologic drugs being tested and also new, oral synthetic (non-biologic) DMARDs being tested with promising results so far. Research and development is likely to continue into the use of existing and new DMARDs in combinations to understand how to achieve the best treatment responses. There is also a great deal of research being done which is designed to determine how we can predict which of the many choices of treatments available now, with even more likely in the future, will be exactly the best approach for any given individual with RA.
Monitoring how you are

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

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

General health

In assessments, the team asks about your overall health and any changes. These could be related to your RA, an unrecognised side effect of medications, or entirely unrelated. Some changes to your health might have implications for your treatment: for example, problems with the kidneys or liver (which would show up in your blood test results) mean that some drug dosages may need to be reduced to bring your blood results back to the normal range.

Make sure you discuss with the team:

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

Physical function

Any changes in your ability to carry out everyday activities help the team to assess whether the treatment you are having for your RA is working. If there are changes, the team will try and reduce the problems, for example by referring you to an OT or providing treatment for the problem joints. They may also look at your pain relief, physiotherapy or reviewing your medications.
Make sure you discuss with the team:

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

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

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

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

**Health Assessment Questionnaire (HAQ)**
The HAQ is a questionnaire which asks how easily you can complete a range of tasks. You score them according to whether you can do them with: no difficulty; some difficulty; much difficulty; or not at all.

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

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

The National Institute for Health and Care Excellence RA Guidelines recommend that after diagnosis, DAS 28 scores are done monthly until the disease is under control. The DAS 28 is one of the assessments you have if you are being considered for biologic treatments. If you don’t know your DAS score, ask the team about this at your next appointment.
<table>
<thead>
<tr>
<th>DAS score</th>
<th>Suggests</th>
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<tbody>
<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>
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Call NRAS for an information booklet and/or DVD on DAS28 or visit the website.

**Blood monitoring**

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

### What blood tests measure and why

<table>
<thead>
<tr>
<th>What tests measure and why</th>
<th>Why</th>
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<tbody>
<tr>
<td>Haemoglobin</td>
<td>To find out if you are anaemic</td>
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<tr>
<td>White cell count: the number of white cells in your body.</td>
<td>White blood cells are involved in fighting infections. Some drugs can affect how your body produces them</td>
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<tr>
<td>Liver function tests (LFTs): alkaline phosphatase, ALT, LDH</td>
<td>To find out how well the liver is working. Some drugs can affect the liver function</td>
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<tr>
<td>Renal function test (U&amp;E): urea and creatinine</td>
<td>To find out how well the kidneys are working</td>
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<tr>
<td>ESR (erythrocyte sedimentation rate): the level of inflammation</td>
<td>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</td>
</tr>
<tr>
<td>CRP (C-reactive protein): a protein produced by the liver during times of inflammation</td>
<td>To assess the level of inflammation. It is said to be a more sensitive test than ESR. Again, it is not specific to RA</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>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</td>
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</table>
Blood results can reveal trends. For example, if your CRP levels show a downward trend it means your inflammation is reducing, probably due to medication. Other trends may highlight a problem. For example, if your haemoglobin levels show a downward trend it may mean your RA is poorly controlled or medications you’re taking are affecting the production of blood cells.

“I had an A4 sheet with the normal levels for blood tests, but now I’ve learnt what they are.”

It’s important to get to know your own levels: what’s normal for you may not be for others. Always ask your doctor or practitioner to explain the results to you when you see them. Get to know the important ones that help you know how your rheumatoid arthritis is: the ESR and CRP levels. Ask which levels you should watch that may indicate any problems with your medications. Look at the trends: how do the last few results compare? are they going up or down? If you see a trend, ask the team what it means.

“I know that what’s normal for me is out of the ‘normal’ range.”

Quality of life

Your healthcare team uses standard measures of disease activity and physical function, and at times you may also be asked to complete a questionnaire about how RA affects other aspects of your life, such as your mood and your relationships with other people: the things that make up how we perceive our quality of life.

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

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

Keeping your own records

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

It helps to have your own records, though don’t feel you have to spend all your time keeping notes: it is a balance. You need enough information to be safe and get the best out of your treatment. Find a way of recording key facts that works for you and keep all the information in one place. Then it’s easy to find when you go to clinic and easy for the doctor or practitioner who’s looking through it.
Many people keep a **diary** of what they do, how they feel and any problems. They find it helps them understand the pattern of their RA. Be as honest as you can, and aim to quantify things and be as precise as possible. For example:

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

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

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

The most common form of shared care is having **blood monitoring tests** done by your GP between visits to your specialist. It is helpful to keep records of these tests and take them for your specialist to see at clinic appointments, as well as for your own information. Other examples of shared care involve a **change of treatment** by your GP between hospital appointments or even giving you a steroid injection to treat a flare. If you have a steroid injection between appointments, it is important to tell your rheumatology team about it when you visit them.

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

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

A healthy diet

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

The NICE RA Guidelines suggest that it may be beneficial for joints and for cardiac health to follow a Mediterranean style diet: eat more bread, fruit, vegetables and fish; eat less meat; and replace butter and cheese with products based on vegetable and plant oils.

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

- Eat a balanced and varied diet.

- Keep to a healthy weight, and exercise regularly if you can. If you take little or no exercise you’re more likely to gain weight, and it’s far more difficult to lose it than not to put it on in the first place. If you cannot take regular exercise, try keeping a diet diary for a week or two to spot where you can cut out unnecessary snacks.

- Eat less animal fat, and change to olive oil or rapeseed oil where possible. Use olive-oil based margarine.

- Eat oily fish two or three times a week: oily fish include mackerel, sardines, herring, salmon, trout and fresh tuna (not tinned tuna). Oily fish contain omega-3 fats (called eicosapentaenoic acid and docosahexaenoic acid, known as EPA and DHA) which can exert a mild anti-inflammatory effect.

- Eat plenty of fruit and vegetables. Aim for at least five a day, of different colours, to get a variety of vitamins and minerals.

- Remember that calcium is important for people with RA, for maintaining strong bones and reducing the risk of osteoporosis. Semi-skimmed and skimmed milk have as much if not more calcium than whole milk. Soya milk on its own contains no calcium so if you use soya milk or alternatives, look for ‘calcium enriched’ products.
There is good, detailed information available on diet and lifestyle. If you are making major changes it would be sensible to have your diet assessed by a registered dietitian, and you can ask your GP or the rheumatology team about a referral.

Pacing yourself

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

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

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

Don’t wait until your symptoms become severe before you move, rest or change an activity. If you do, you reach the point at which you have overdone it – whether ‘it’ is watching the TV (getting too stiff) or something more active. The key to pacing is to move or stop before the problem begins, rather than let your symptoms tell you when to rest and when to re-start an activity.

“I set myself goals and plan round them. I knew I’d be busy today, so yesterday I had a very quiet day to enable me to manage today.”
Coping with fatigue

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

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

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

People find that different techniques and tips help to cope with fatigue, and you may need to experiment to find what works best for you. Fatigue and pain can be connected, and the advice on managing pain (see page 42) can also reduce fatigue. Many people find that some or all of the following help:

- Get a good night’s sleep.
- Rest and relaxation.
- Pace your activities, and plan ahead for what you want to do.
- Follow a healthy diet and make sure you drink enough fluids.
- Find easy-to-use gadgets, from electric tin-openers to long-handled back brushes in the bath. An occupational therapist can help and make suggestions.
- Find everyday tips from other people with RA.

More information about fatigue on page 42

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

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

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

It helps to keep as active as you can, to maintain your joints’ movement and strength and to reduce stiffness. Exercise also looks after your heart and can make you feel good about yourself by releasing the body’s natural painkillers, endorphins.

Understanding and managing pain

Pain is personal and specific to you. The unpleasant sensations are part of it, but how you make sense of pain and how you think about it influence what you feel. How you cope also depends on previous experiences, your beliefs about pain, how happy, sad or tired you are and how you feel about yourself.

It may help to understand in more detail the mechanisms of how your body registers and interprets pain. Self management courses include information on this and there are some excellent publications that explain how pain works.

Using painkillers effectively

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

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

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

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

Flares

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

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

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

If you are having regular flares it may be time to review your DMARDs. Your symptoms and blood tests will help the team to assess whether your disease is becoming less controlled or whether you’re experiencing more pain for other reasons.
Some general strategies for coping with a flare:

- Get rest and relaxation early on.
- Use cool packs.
- Use aids, for example a stick if your knee is a problem.
- Wear the right shoes.
- Do gentle exercises, to help relieve the stiffness that makes pain worse.
- Take your pain medication regularly and at the right dose.
- Use hot baths or showers to relieve early morning stiffness and pain.
- Let people around you know, so they can understand why you’re not coping as you usually do.

Techniques that can help to manage pain

“I’ve found that different things help: those heat pads you put in the microwave, meditation, tubigrips on the wrists…”

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

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

TENS
Some people find that a TENS machine (Transcutaneous Electrical Nerve Stimulators) is effective for pain relief. The NICE Guidelines on RA suggest that you ask your physiotherapist about TENS.
Relaxation
Relaxation is not just ‘taking it easy’. It means learning how to let
go of physical muscle tension and emotional stress, relaxing both
your body and mind. When you’re in pain over a long time, you can
become tense without realising it. You can become mentally and
emotionally tense, and it’s easy to be trapped in a ‘cycle of pain’.
Relaxation can break this cycle and help to reduce pain. It takes
practice, but once you’ve learned the technique you can use it
anywhere.

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

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. The following tips can
help you to improve the quality of your sleep, and therefore reduce
muscle tension and pain:

- Create the environment: a comfortable bed (maybe use a
  mattress topper), a warm room and no noise.

- Establish a regular sleep pattern. Going to bed at the same time every night trains
  your body to sleep and allows your mind to build up an association between bed and
  sleep. Try not to sleep too much during the day.

- If you are struggling to cope, have a short proper break during the day. Make sure
  you are really relaxed and set an alarm clock so you don’t disrupt your sleep
  pattern completely. A short break, properly relaxed during the day may help you cope
  with pain.

- Avoid stimulants. Don’t have alcohol, caffeine, tea, chocolate, cocoa, nicotine
  or spicy food late at night. They’re all likely to keep you awake.

- Use your bed only for sleep: don’t work or eat in bed. It helps your mind
  build up a strong association between bed and sleep.
Think can, not can’t

“Take up something new – like pilates or yoga”

How you feel also affects your physical symptoms, including pain. If you feel low it can cause you to feel more pain. Try and train your mind to think positively. Instead of thinking ‘I’ll never get to sleep’, try telling yourself ‘at least I’m resting my body!’ Focus on the things you can do rather than what you can’t. Try not to avoid doing things because of your pain, so that it doesn’t dominate your life.

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

Complementary therapies
There is no evidence that alternative or complementary therapies have any effect on the disease process in RA, but some may help to relieve pain. However, remember that ‘natural’ doesn’t necessarily mean ‘harmless’: some alternative remedies have side effects and can interact in harmful ways with medication.
If you are considering any complementary or alternative therapy, discuss it with your rheumatology team first.
Complications are relatively infrequent in rheumatoid arthritis, and they are all reduced when RA is well controlled. But some do occur, and most can be effectively managed. Make sure you have regular monitoring and assessment from your healthcare team, learn what to look out for, and do what you can to reduce the risks.

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

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

Staying aware

David G I Scott is Consultant Rheumatologist at Norfolk and Norwich University Hospital and NRAS’ Chief Medical Advisor. Here he describes the risks and complications to be aware of, and what you can do to reduce them.

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

There are quite simple things you can do to reduce this risk: don’t smoke, take regular exercise and maintain a healthy weight. Also ask your doctor for regular blood pressure and cholesterol checks – these are usually advised once a year.
Some more specific complications can result from RA’s inflammatory process. These are sometimes described as “extra-articular manifestations”, meaning they are problems that occur outside the joint. A key process that drives RA is inflammation of the joint lining, but other tissues in the body have very similar structures which can also become inflamed. These include the lining of tendons (causing tenosynovitis) but also the lining of the lung and heart. So pleurisy and pericarditis, though fortunately uncommon, are recognised complications of rheumatoid arthritis. They can develop in patients who are particularly ill early on in the disease process.

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

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

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

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

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

Everyone feels low in mood sometimes and people with rheumatoid arthritis are no different from anyone else in this respect. But it’s also true that people with RA are more likely than the general population to experience depression. Some people worry about the label, ‘depression’, but it’s widely acknowledged that people with long-term conditions can experience it. Your rheumatology team will not be surprised if you talk to them about it and will not judge you in any way. And of course if you don’t want to tell friends and colleagues, you don’t have to.

“People don’t know that depression can be part of rheumatoid, and culturally it’s difficult to mention that.”

Recognising the signs

Liz Hale is a Chartered Health Psychologist in the Department of Rheumatology at Russells Hall Hospital, Dudley. She suggests how you can recognise signs of depression, and explains what treatments can help.

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

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

Important signs

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

“For me it goes with fatigue. When I feel it coming on I try to give myself an easier time and plan some positive things like lunch with friends or a trip to the theatre.”
‘People with depression often have negative thoughts about themselves and the future. There may be self-criticism, low self-esteem and low self-confidence. They may see other people as critical or mean, or they may focus too much on negative events. They can be unwilling to try things that might help, and in the worst cases a person may think about suicide as a possible way out.

If you recognise these symptoms, or family or friends have said you are behaving differently, think about talking to your GP. You can receive help and you do not have to face this alone. You can also contact your rheumatology helpline if you have one, your local crisis intervention team (their number is in the phone book, usually under Community Mental Health), NRAS, the Samaritans or someone else you trust.

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

NICE guidelines (see CG91 Depression with chronic physical health problems¹) state that for mild depression you should not usually be offered anti-depressants as the first choice of treatment, unless there are good reasons to think you’ll benefit.

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

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

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

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

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

¹ Guidelines can be viewed on www.guidance.org.uk/CG91/NICEGuidance
“It’s important to still see you as you, and to see a career path ahead of you. RA isn’t everything. I’m trying to make it ‘by the way.’”

It takes time to accept that you have RA, to learn how to manage and adapt. While it seems all-consuming at times, it’s important to think about the rest of your life, too: your work, your family and friends. RA changes things, but it doesn’t have to define everything about you.

Talking about your RA

“I don’t say I have arthritis, because they’ll say, oh yes my granny has that. I say I have rheumatoid.”

Because RA can be invisible, especially in the early stages, it’s important to talk about it. If you don’t look sick, it can be hard for colleagues, friends and family to understand what you are feeling. You may need to explain things, at work and at home, that you didn’t need to talk about before you had RA.

Family

“To the kids I’m just mum. Though my daughter went through a bit of a funny patch with aches and pains. I had to sit her down and say, ‘what do you see me not doing?’”

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

Relationships

You may be coping with changes in your roles within a relationship as well as in your health. These can be significant changes that neither of you expected: who’s the main earner, who looks after whom, who does what at home. It can affect how you think of yourself and how you think of each other. It isn’t easy to be someone’s married partner or lover and look after them at the same time.
RA can affect your sex life, though the good news is that most problems are not permanent and simple things can help. On the practical side, solutions include finding ways round difficult or more painful positions, getting used to the idea of ‘planning ahead’ for sex when your energy levels are better, and lubrications for women to help with dryness. On the emotional side, the important thing is communicating about it. If you’re going through a bad patch, give yourselves time to adjust and try to talk about what is happening. Not talking, and not having intimate contact can start a ‘downward spiral’ where either one in a couple can become more reluctant to initiate sex.

**Decision times**

“We’re planning for a baby, and it means coming off the drugs to conceive. My boyfriend also needs help in what we’ve got to come.”

Partners need support too. This is particularly true at ‘decision times’ when RA is a factor: you may be thinking through major events as a couple such as starting a family, or one of you changing your work patterns or hours. It’s important to take your time, and find reliable information to help you. Some people also find it helps to talk to another person in a similar situation.

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

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

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

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

More information about Work on page 43
Keep a note of the phone numbers you need

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
NRAS freephone number 0800 298 7650

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

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**Complementary Therapies (Pg 33)**
Arthritis Research UK (ARUK) booklet: *Complementary and Alternative Medicine for Arthritis*. Copies of the two reports on this topic are also available from ARUK:
- Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia.
- Practitioner-based complementary and alternative therapies for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia.

[www.arthritisresearchuk.org](http://www.arthritisresearchuk.org)

**Diet (Pg 27)**
Information available on the NRAS website. ARUK booklet *Diet and Arthritis*.

**Drug treatments (Pg 5/16/18)**
NRAS information on drug treatments used in RA on the website.

*Biologics… The story so far* – an NRAS patient guide to biologics currently available in the UK, how and when to access them and FAQs.

ARUK publish leaflets on standard and biologic DMARDs used to treat RA.

**self-management uk**
The Chronic Disease Self-Management Programme is for people living with any long-term chronic condition. Find out more at www.smuk.org.uk or ask your GP.

Arthritis Care runs self-management courses for people with all forms of arthritis.

NRAS provides a self-management programme specifically for people with RA. For details of cost and availability please contact Nicola Freemantle at NRAS.

**Fatigue (Pg 5/28)**
NRAS publish a leaflet *Fatigue: Beyond Tiredness*. There are also lots of useful tips on the NRAS members’ online forum and on the HealthUnlocked NRAS forum. If you are not an NRAS member and would like to join, please click on 'Join' on [www.nras.org.uk](http://www.nras.org.uk) or call us on 0845 458 3969.

ARUK booklet *Fatigue and Arthritis*.

**Pregnancy (Pg 39)**
The NRAS website and helpline have information.

Arthritis Research UK also publishes a booklet on *Pregnancy and Arthritis*.

**Pain (Pg 5/15/29)**
NRAS website has for more information on pain.

*Pain and Arthritis*, a booklet from ARUK.

The Pain Society has a range of publications for patients on this topic.

See [www.britishpainsociety.org](http://www.britishpainsociety.org) for more information or call 0207 269 7840.

**Sex and relationships (Pg 39)**
NRAS website for more information on this topic.

NRAS booklet *Emotions, Relationships and Sexuality*.

*Sex and Arthritis*, a booklet from ARUK.

**Sleep (Pg 5/32)**
NRAS and the ARUK both produce information on this topic. Also visit [www.sleepcouncil.org.uk](http://www.sleepcouncil.org.uk)

**Patient Groups (Pg 5)**
For a list of NRAS groups and where they are, visit the NRAS website or call 0845 458 3969.

**Talking about your RA (Pg 38)**
NRAS booklet on *Emotions, Relationships and Sexuality*.

NRAS report – *Family Matters*.

ARUK booklet *Sex and Arthritis* also covers relationship issues.

**Understanding the NHS system (Pg 13/14)**
The Patient Advice and Liaison Service (PALS) provide patients with information and help in understanding the NHS and its services and help with complaints procedures. Find your local office on the NHS Choices website.

The Patients Association has a range of helpful information available from their website [www.patients-association.com](http://www.patients-association.com) or by calling their helpline 0845 608 4455.
Work (Pg 40)

NRAS has two guides on RA and work: I want to work: a self-help guide for people with rheumatoid arthritis and When an employee has rheumatoid arthritis: an employer’s guide.

Work and Arthritis, a booklet from ARUK.

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


Other useful organisations

Arthritis Research UK
Copeman House
St Mary’s Gate, Chesterfield,
Derbyshire S41 7TD
Tel 0300 790 0400
www.arthritisresearchuk.org

Arthritis Care
Floor 4, Linen Court,
10 East Road, London N1 6AD
Tel (switchboard): 020 7380 6500
Helpline: Freephone 0808 800 4050,
10am – 4pm weekdays
email: helplines@arthritiscare.org.uk
www.arthritiscare.org.uk