Newly Diagnosed with RA?

Newly Diagnosed with Rheumatoid Arthritis?

A guide to your next steps

November 2014
About National Rheumatoid Arthritis Society

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

- 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, with support from our team of medical advisers.

- NRAS website www.nras.org.uk has a wealth of information about living with RA, treatments and the latest research and developments.

- 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. NRAS can match you to speak to someone also living with RA who understands what you are going through and who will call you at a mutually convenient time. If you’d like to arrange for someone to contact you, call us on the helpline number 0800 298 7650. To meet others with RA check the NRAS website to find out if there is a group near you.

- Help NRAS to help you and others like you. Support our work by joining the society visit www.nras.org.uk or call 0845 458 3969 and speak to the membership team to find out about the host of benefits for NRAS members.

For a comprehensive list of other charities and organisations that may be of help to you, visit the **Useful Links** section in Help for You on the NRAS website. If you don’t have access to the internet, and think you need to contact other organisations, call us and we will provide the information you need.

Contact us at NRAS

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So, you have rheumatoid arthritis...

If you or someone close to you has been diagnosed with rheumatoid arthritis, this booklet is for you.

It has information from doctors, nurses and other people with rheumatoid arthritis, about:

- Being diagnosed
- What rheumatoid arthritis is and how it can affect you
- Care and treatment
- Managing day to day
- Thinking about the future

One short booklet can’t tell you everything there is to know – there’s a lot to learn. It aims to give you an idea of what to expect over the next 12 months or so, and where to find more information or support as you need it.

The symbol means there are suggestions for further information on page [x].

Being diagnosed

Rheumatoid arthritis – called ‘RA’ for short – is different for everyone. Other people may have different symptoms from yours, and it doesn’t follow a single pattern. Symptoms may develop suddenly, almost overnight; or you may become gradually aware of them so that it’s hard to pinpoint exactly when they began.

It can take time for doctors to establish exactly what type of joint problem you have before confirming that it’s rheumatoid arthritis. It can be a difficult disease to diagnose. This is partly because some signs or symptoms of rheumatoid arthritis can have other, more common explanations. For example, swollen and painful joints may be caused by viral infections.
The outlook is much more positive now

Diane Home, Rheumatology Consultant Nurse, explains how advances in treatments have changed things for people diagnosed now.

For people who are diagnosed with RA today, things are much brighter than they were for our parents’ or grandparents’ generation. Treatments have improved enormously, particularly in the last 10-15 years, and research is going on all the time.

We now know far more about what happens in rheumatoid arthritis, how to slow down or prevent damage to your joints by using proven treatments effectively. For example, treatment as early as possible can help to slow down or prevent much of the joint damage that people used to get, when they were diagnosed maybe 15 or 20 years ago.

Rheumatoid arthritis is a long-term condition, but for the vast majority of people this doesn’t mean it has to have a long-term devastating effect on their life. It’s true that it is painful and for some it can be an aggressive disease that is difficult to control. However, advances in treatment have made it possible for most people to have well-controlled rheumatoid arthritis and therefore to enjoy a much better quality of life than was possible in the past.

“My aunt was really bad with RA and in my mind I was afraid I was going to be like her, though I know it’s different now.”
Feelings when you’re diagnosed

“It was a relief to pinpoint what it was. I’d got dark thoughts of what it could have been; this took the weight off my shoulders.”

Being diagnosed with rheumatoid arthritis is often difficult to come to terms with. The news may come as a shock or a relief: some people can’t take it in, while others find it’s actually a help to know what’s wrong and now there is something they can do about it.

Whatever you feel, you don’t have to cope on your own. The important thing is to find the right person to talk to.

- Health professionals are there to give advice and support.
- Family and friends can be a lifeline.
- You can talk to other people with RA who understand what you are going through via the NRAS telephone volunteer scheme or at local NRAS group meetings.

It’s entirely normal to have strong feelings. You may be angry this has happened to you, or want to ignore it. You may just want to be left alone. It’s absolutely normal to get frustrated if you can’t do everything you want to, and it can be hard to start accepting help if you’ve never had to before. Some people feel they ‘ought’ to be managing better, or are worried about the future. However you feel, there is help available.

“I didn’t hear anything else anybody said that afternoon or the next morning. Someone asked me, do you have any questions and I was just numb, couldn’t think of a thing.”

“I know I have had a lot of contact with NRAS and its volunteers lately, and I just can’t believe how amazing & helpful the society is. If only I’d known about it before. The advice & info etc that I’ve received has been invaluable.”
‘It will get easier’

For almost everyone with rheumatoid arthritis, starting a programme of treatment helps to manage the pain, reduce the stiffness and inflammation and get the underlying process of the disease under control. As your rheumatoid arthritis becomes more controlled, you’ll start to feel better.

Hi – I started with rheumatoid arthritis I reckon just over a year ago. Yes the pain and stiffness really knocks you low. Hands alone drove me crazy, I’d rather have had toothache. Now on a small dose of steroids as well as methotrexate. Things have calmed down and I feel 90 per cent better – not nearly so many painkillers.

Sure the first year with rheumatoid arthritis can be the worst, as it takes a while to find the drugs that work for you. Tell your GP, nurse and rheumatologist how it affects you. Don’t miss out anything, even if you’re feeling better at the time.

Now I’ve had my first 10 weeks of feeling great. Be positive – it will get easier when the drugs kick in.

Posted on the NRAS Members’ Forum which can be found in the Members’ Section on our website.

Your family and friends

As well as your health, rheumatoid arthritis may affect your life in many other ways. Relationships with family and friends may change.

It can be difficult for other people to see how RA affects you – it isn’t like a rash that everyone can see. Sometimes people don’t understand a great deal about what RA is. You could encourage your partner or family to read the information you get (including this booklet) and ask them to come to clinic with you if you want; the team will welcome them.

Family and friends can be a vital support, but it may be hard for other people to appreciate how you’re feeling. Pain can be impossible to describe; exhaustion can wear you down.

On any one day you can feel better or worse than the day before, but not look any different. It can help to explain that rheumatoid arthritis is an unpredictable disease: it’s different for everyone and can change day to day.

“I asked relatives to read the information I’d got so that they’d understand. The diagrams helped them see what was going on in my joints so I could explain what was happening. I don’t think people really understand what the pain is like.”

More information about why RA flares up on page 16
If you’re working, you may feel comfortable telling your employer about your diagnosis – or not. It could depend on how much your symptoms are affecting your work. Some people prefer to keep health matters private.

But if you can talk to your employer, it can help. You may be worried about the amount of sick leave you’ve had or may need, but it will probably help to be upfront about it. Think about giving your employer some information about rheumatoid arthritis, to help them understand its effects and how unpredictable it is. NRAS has booklets for both employees and employers about how RA affects people at work which may be helpful to you – please ask for copies.

If you’re making major decisions, for example about reducing your hours, don’t let yourself be rushed. If you’re going through a difficult period or waiting for drug treatments to take effect, remember that things can improve.

““It was hard to tell people at work – but I had to, as the rheumatologist said to expect more time off work. As it turns out, the only time I take off now is for blood tests and hospital appointments.””

At work

“I didn’t want too many people to know at work, at first. I could see in their faces that sometimes people didn’t believe me. It’s difficult because I could get out of bed tomorrow and feel I could run the marathon, and then that afternoon – bang. There’s no predictability to flare-ups. But it’s got better as people understand more; most of my colleagues are very helpful.”
Adapting

“There’s a lot to learn in the first few months. It’s the start of a journey: people say they learn to adjust to what they can and can’t do. It’s natural to rebel against that – particularly if you’ve always thought of yourself as a very active person. If people have always relied on you for certain things, they may have to adjust too. If you’re in pain or exhausted, it may not be possible to do everything you used to. Don’t feel you must. If it’s difficult to get dressed in the morning, a day’s work or getting the garden done can take all the energy you have – a social life as well may be too much to think about. But with treatment, things can get better. And if you have to make changes because of rheumatoid arthritis, you’re still the same person.

“If you feel a bit wonky you have to treat yourself differently. I don’t run anywhere anymore, ever. I know if I carry things it hurts, so I ask someone else to do it.”
When they said rheumatoid arthritis all I heard was arthritis. I thought, I’m not old, how can I have that? I didn’t understand the rheumatoid bit.”

When most people hear the word arthritis, they tend to think of an older person’s disease and ‘wear and tear’ on the joints. They’re probably thinking of osteoarthritis. Rheumatoid arthritis is quite different.

Eight things you need to know about rheumatoid arthritis

1. It’s a lifelong condition.
2. It’s not an ‘older person’s disease’. People can develop it at any age, even as children. For most people symptoms generally begin between 40 and 60 years of age.
3. There is no obvious pattern to the symptoms. Everybody’s disease is different. People get ‘flares’, or periods when their symptoms are much worse, which then subside. You can have periods when the disease is quiet and doesn’t cause you any problems.
4. It doesn’t only affect the joints. It can sometimes affect other parts of the body, for example the eyes and lungs, though not for everyone. Apart from joint pain, stiffness and swelling, some people may have difficulty in sleeping, feel intensely tired and feel like they have bad flu.
5. It’s a type of disease called an ‘auto-immune disease’, which results from a problem with the body’s immune system (see page 11).
6. Left untreated, it is a destructive disease that can cause serious damage to joints, if the inflammation is not controlled.
7. Some people have very little damage to their joints and a few (about 1 in 20) have severe damage in several joints. It is a progressive disease, but how it progresses varies from person to person. Treatment aims to control the disease and reduce the damage.
8. With early diagnosis and the right treatment, most people diagnosed today can expect to lead full lives with their symptoms under control.
‘Cells behaving badly’: RA and your immune system:

Gill Wilson is a Rheumatology Specialist Nurse at the Freeman Hospital, Newcastle. She explains what happens in the body when you have RA.

Rheumatoid arthritis is an auto-immune disease. It’s a case of ‘cells behaving badly’. In an auto-immune disease, cells in your immune system don’t behave as they should.

Our immune system is a complex mechanism of cells and antibodies which protect us from disease and infection. Usually it only attacks things that may be dangerous to our body, such as bacteria.

Inflammation commonly occurs as a healthy response to the body protecting itself from infection.

In rheumatoid arthritis the immune system also attacks tissues of the body, particularly the lining of the joints. As a result the joints become inflamed, painful and swollen.

What causes rheumatoid arthritis?

Doctors know a great deal about what happens in rheumatoid arthritis and how to control it, but they don’t yet know enough about what starts it off in the first place.

It isn’t completely clear why people develop RA, but research so far suggests that a combination of factors is at work. There is a genetic element, though it isn’t necessarily passed on from parent to child. Some genes make it more likely that a person will develop rheumatoid arthritis, but it’s not inevitable. When someone has these genes, something else then has to happen to trigger the disease process. It’s not clear exactly what these ‘triggers’ are but research suggests the following may play a part: cigarette smoking, infection, virus, foodstuffs, stress or injury.

In the past 10 -15 years promising new areas of research have opened up. There are now several ‘biologic treatments’ which include therapies which target different aspects of the body’s immune system which are responsible for inflammation. You can read more about these drugs on page 15. These are expensive drugs prescribed by the hospital doctors according to the guidance issued by NICE (National Institute for Health and Care Excellence). These therapies have given more options to people whose RA doesn’t respond to the drugs which are usually given initially on diagnosis such as methotrexate, sulfasalazine, hydroxychloroquine and leflunomide. There is an enormous amount of work going on to investigate how to target particular parts of the immune system which could lead to further treatments in the future and even possibly a cure.
About your care

How rheumatology services are organised varies, depending on your local Clinical Commissioning Group (CCG). You might have all your appointments at a hospital clinic or it may be ‘shared care’ between the clinic and your GP. Whatever the arrangement, different health professionals with specialist knowledge of RA make up your rheumatology team. You see some of them regularly and may be referred to others when you need them. Teams vary around the UK: they don’t all include every professional.

At clinic visits

**DO**

- Wear clothes that are easy to take off and on.
- Bring your medication list, including any supplements or complementary medicines, so the team knows exactly what you’re taking and the doses.
- Be as clear as you can about how you’ve been, even if you’re having a good day. The clearer the details you can give, the better the team can help. Keeping a diary can help, especially to record daily levels of pain and fatigue.
- Ask questions and don’t worry if you think they sound silly. The doctors and nurses won’t think so and they’re there to help.

**DON’T**

- Worry if you need to go over things again. Ask for written information if you’re given advice.
- Miss an appointment without letting the clinic know – someone else could use that slot.

“I was quite ill when I was diagnosed but two and a half years on I’m OK. The treatment has worked for me, things are under control and I’m almost back to normal.”
Who’s who

“It’s hands and elbows that are the problem – I’ve found the occupational therapist is a lifeline.”

- Your GP or practice nurse is the person you’ll probably see most often.

- Your Consultant Rheumatologist is a specialist doctor who confirms your diagnosis, works out your treatment plan, monitors how it’s working and changes it when needed. He/she supervises your care; you may see him or her, or another doctor on their team. How often you see your rheumatologist depends on how your RA is responding to treatment and how soon your treatment needs to be reviewed.

- Most clinics have a rheumatology specialist nurse or practitioner, who gives advice and support about rheumatoid arthritis management and monitors your drug treatment. In many clinics consultants share patient care with a nurse specialist, who sees patients once they’re diagnosed and getting established on treatment.

Most specialist nurses run telephone advice lines that you can 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. If you have a flare or a problem comes up, you can get advice about how to manage from the nurse.

- A physiotherapist can help you keep mobile, get the best from your joints and strengthen your muscles. He or she can advise on: difficulties with movement; protecting joints from stress or injury; and safe stretching and exercises.

- An occupational therapist can help you adapt and find new ways of carrying out everyday activities. The aim is to take the strain off painful joints and help you feel less tired. He or she can give advice about equipment (including splints for affected joints) and changes at work or at home to protect your joints and make things easier to use.

- A podiatrist can help if rheumatoid arthritis causes problems with your feet or ankles. They can give specialist advice and treatment to help reduce pain when you’re standing or walking, and keep you as mobile as possible. An orthotist can recommend adapted shoe insoles or supports.

- A dietician can help you lose weight 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. If this applies to you, you may find it helpful to discuss it.

Other professionals who could help may include pharmacists, radiologists, counsellors and social workers – though they may not be part of your team. Ask your rheumatologist or nurse specialist if you want more information.
How often will I come to the clinic?
Your rheumatologist or nurse specialist decides how often, depending on how active your RA is, how you are feeling and how your drug treatment is going.

Should I bring anything?
Bring your most up-to-date prescription list and your blood monitoring booklet if you have one. Write yourself a note if there are things you want to remember to ask.

Can I get time off work to come?
Depending on your relationship with your employer, you may feel comfortable explaining what is happening right away or you may need some time to think about telling them. Once your employer knows, time off for hospital appointments is usually considered a ‘reasonable adjustment’ for them to make – see page 27. If you choose not to tell your employer, it’s still important to ask for time off in advance so that you can attend your clinic appointments.

Will I need to get undressed to get examined every time?
Probably not, though you’ll probably be examined, including the joints that are painful. A more thorough examination depends on how well you are and whether the doctor feels it’s necessary.

What are the blood tests for?
Blood tests show the rheumatology team:
- How much inflammation is in your joints – a measure of how active your RA is and how well the treatment is working.
- Warning signs of problems with treatments before they happen. Some drugs can affect the blood count (number of blood cells) or how the liver is working. Occasionally, people have to stop treatment after a blood test. It’s essential to have your blood monitored regularly, and the nurse or rheumatologist will talk to you about the monitoring you need. The clinic may give you a book to keep the results of your blood tests in – if you don’t have one you can ask for a copy.

Will I need an X-ray every time?
No. It’s usual to have hands and feet X-rayed at your first visit to check for signs of early joint damage. You may have X-rays later on to monitor the benefits of treatment. When you first start treatments, you may also have a chest X-ray. Some drugs occasionally affect the lungs, so it is important to know how your lungs are before you start treatment. Other imaging techniques such as ultrasound, CT or MRI scanning may also be used.

How will I pay for my prescriptions?
If you pay for prescriptions you may save money if you buy a pre-payment certificate or ‘season ticket’. You can get free prescriptions if you are over 60, receiving benefits or on a low income.
There's no one standard treatment, because RA is different for everyone. Your rheumatologist or specialist nurse will discuss your treatment with you, and can answer your questions and concerns.
Disease modifying anti-rheumatic drugs: the facts

Your rheumatologist may prescribe one of the many disease modifying anti-rheumatic drugs (DMARDs) that are available. It’s helpful to know:

- Disease modifying drugs take weeks or possibly months to work.
- Some people have no side effects. Others do: they may feel nauseous, have diarrhoea and generally feel worse not better when they start treatment. It can be hard to keep going when you don’t feel well, but stick with it, side effects can diminish over time. Talk to your nurse specialist straight away about side effects: she or he may be able to prescribe something to help.
- Because rheumatoid arthritis is different for everyone, what works for one person won’t necessarily work for another.
- It can take time to find the drug and the dose that works best for you. In the first months, the dose may change often.
- Drugs can be used singly or in combinations (see NRAS website for more information on Combination Therapy).
- If one drug doesn’t work well, there will be other options.

“...My whole body was in pain until they found the right medication for me. To me it’s the best thing since sliced bread. I am just very grateful that I have my life back. RA is not so much an enemy that I fear but a part of me that I have come to respect. There is light at the end of the tunnel.”

We can’t cure it, but we can control it

Dr Patrick Kiely is Consultant Rheumatologist at St Georges’ Hospital, Tooting. He explains how drug treatment can ‘turn down the heat’ and make RA easier to live with.

The disease process in RA is a bit like an oven. When it’s active, the temperature’s on a medium heat, and in time it would burn the food. Sometimes it shoots up to very hot – when you get flares – and then things burn more quickly. In RA we can’t turn the oven off completely, but we can turn down the heat so that it’s hardly cooking at all.

To put it another way: we can’t reprogramme the immune system so that it stops attacking and damaging your joints, but we can calm it down. There are many effective treatments to reduce the immune system’s attack so that it causes less damage to your joints. This is how disease modifying drug treatments reduce your symptoms, over time.

It may take time to find the drug or combination of drugs that work best for you, but there’s a very good chance that modern treatments will make you feel a lot better.
Frequently asked questions

- **How long do I have to take them for? I don’t like the idea of being on medication for the rest of my life.**
  It's a similar situation with other long-term conditions like diabetes or asthma: people can lead normal lives but to do that they have to take medications probably for life. To keep the RA under control, you need to keep on taking the drugs, even when you feel better. The good news is that if you take them early on, they slow down the effects of rheumatoid arthritis and you’re more likely to do better over the long term.

- **This drug’s a cancer drug. Why have I been prescribed it?**
  Some drugs used to treat rheumatoid arthritis are also used to treat other diseases. Methotrexate, for example, is used to treat cancer. Treatments for cancer and RA are both trying to stop the immune system cells attacking your own body. But they’re used in a different way to treat RA, at much lower doses. They’re closely monitored, through your blood and urine tests, to ensure they are safe. Methotrexate has been used safely for people with RA for many years.

- **Isn’t there a natural remedy?**
  It's understandable to want one, but unfortunately there is no evidence that any ‘natural’ or alternative therapies control rheumatoid arthritis effectively. If they did, your healthcare team would certainly have told you.

  Natural remedies can’t affect the disease process but they may help in other ways, for example to help relieve pain. But ‘natural’ isn’t necessarily ‘harmless’: alternative remedies can have side effects too and can interact with your medication. If you plan to take anything, always talk to your rheumatology team before you do.

“I was started on methotrexate after being admitted to hospital, at that point I could hardly walk or lift a cup of coffee, and it has given me my life back. It did not completely eliminate my symptoms but it gave me so much extra quality of life.”
Weigh up the long-term benefits

Some people worry about the side effects of disease modifying anti-rheumatic drugs. Nurse Consultant Susan Oliver, MBE, offers advice and reassurance.

While side effects are a possibility, it’s important to weigh that up against the long-term benefits of treatment. Remember that almost any drug – even a paracetamol – has side effects.

Side effects can be a nuisance, but in most cases they are not harmful and get better once you’re used to the medication. Your nurse or rheumatologist will talk to you about any significant side effects you need to be aware of, and make sure that you know what to do if you experience one. Take time to read all the information about your treatment, including what comes with its packaging.

Four golden rules are:

1. Remember the things you mustn’t do while you’re on treatment.
2. Remember the important things to look out for and report them promptly.
3. Let the team know about any medications you take, including over-the-counter medications from the chemist or alternative treatments. These can all interact with the medicines that have been prescribed for you.
4. Always make sure you have your blood monitoring tests.

If side effects are a real nuisance, talk to your rheumatologist or nurse specialist. If possible you should continue taking your medication until you speak to your rheumatologist/nurse. There are other treatments they can give you to reduce the side effects and help you feel better. In the rare event that you have problems getting in touch with your team – and the side effects are really bothering you - stopping treatment for one or two days until you can get advice will not harm you.

Warning!

Don’t believe all you read on the internet about drug treatments and side effects. There is a huge amount of information – not all of it true or based on any evidence at all, and some of it makes frightening reading. Remember: if there was a miracle cure with no side effects, your rheumatologist would tell you.
Managing and looking after yourself

“I’d love to do loads of jobs that I know I can do. But I might be risking my strength for the week, and I want to go to work on Monday. I’m making that choice.”

Taking control

“The main advice I can give is stay positive and find out as much as possible about the disease.”

Be proactive: find out as much as you can about rheumatoid arthritis. If you feel you understand your condition, you can feel more in control about the decisions you take. Some people find that courses, called expert patient or self-management courses, help them to gain more control of their lives and manage day to day. Other people find that a positive approach is an important part of feeling in control.

You’ll benefit too if you can follow a healthy lifestyle:

- Giving up smoking is one of the most important things you can do – people with rheumatoid arthritis who don’t smoke do better over time.
- Aim for a healthy weight, as this helps to reduce the stresses on your joints.
- A balanced diet with plenty of fruit and vegetables – aim for five portions a day – can help in maintaining your weight.
- Try to get plenty of sleep.

“I just want to thank you NRAS for your excellent website. I have found many interesting articles, which have given me a much better understanding of my condition. Your website is so easy to navigate, which is most important to me, as I am still rather a novice as far as the computer is concerned.”
Pace yourself

“What I have learned over the last few weeks is listen to your body. If it’s telling you it hurts, rest. It took a while for me to understand that, as being so young I find it hard to accept. But listen to what your body is telling you!”

You may not be able to do everything you used to, or as fast as you want to. It’s about learning to do things differently. Some people feel this is ‘giving in’ to RA – but think of it instead as being realistic. To look after yourself you may need to adjust, and recognise when it could help to slow down.

If you’re not used to asking for help it can be hard at first, so give yourself time to get used to it. Find out too about the practical aids and gadgets that can help. Little changes can make a difference, from headphones for the telephone to raised chair seats to electric tin openers. You can ask to see an occupational therapist for an assessment and recommendations that will help you.

“I can’t go sailing any more – I can’t squat down in the boat. But you can live with that, in the scheme of things. I walk, I swim.”

I take life one day at a time

Tracy Parden is a volunteer and part of NRAS’ national support network. She has lived with RA for many years.

I’ve found it helps to think: don’t fight it, work with it. Don’t be too proud to ask for help. Change your expectations and learn to be realistic about what you can do. If I go to the gym I aim to do six minutes on the treadmill. I know it doesn’t sound a lot, but it’s a lot better than doing nothing.

If I have a busy day coming up then I plan for it, try to conserve energy as much as I can. I take life one day at a time.
Pain: what can help?

For many people pain is the worst part of living with rheumatoid arthritis. But there are things you can do.

- Try to keep active, even if you don’t always feel like it. It’s about finding a balance between getting enough rest, and being active enough to keep your muscles strong and your joints mobile without harming them. Swimming can be ideal, because the joints are supported while you exercise. And you don’t have to pay for exercise for it to do you good – walking counts!

- Gentle stretching exercises help to keep you mobile. Making small changes to your daily routine now will add up over time so that you feel the benefits.

- Your drug treatment is an important part of controlling rheumatoid arthritis. If things aren’t settling down and your pain gets worse at any time, call your clinic advice line or specialist nurse.

- Before each clinic appointment, think carefully about describing your pain. Which joints are painful – e.g. one knee, your hands? How would you score the pain you feel? This helps the team know best how to help. Your nurse can advise you on pain relief treatments and on non-drug ways to manage your pain, such as using hot packs.

- Think about stress and fatigue. Pain is complicated, and can be affected by how tired you are or what else you’re worried about: sometimes just understanding what these things are can help you feel better.

More information about pain and exercise on page 26

Sex and relationships

“There’s some good advice about positions, to keep the strain off your joints. I found it really helped.”

You may be coping with changes in your relationship and roles as well as your health. They may be changes you wouldn’t choose: about who does what at home, who’s the main earner, or who’s looking after whom. It can be stressful, and some people find their relationship is affected.

It’s understandable that being unwell can make people feel less confident or desirable, and that having RA can affect how you think of yourself and each other sexually. It isn’t easy to be someone’s married partner or lover, and looking after them, at the same time. And it’s impossible to get away from ‘perfect’ bodies in magazines and on the TV: even though those images aren’t reality, in our image-conscious society they have an effect on how we see ourselves.
Sex and relationships (cont.)

While RA can affect your sex life, the good news is that most problems are not permanent and some 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 communication. 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.

Find a close friend, or someone from the healthcare team, or talk to the NRAS helpline. Getting things out in the open can help them seem less problematic.

Feeling low or depressed

“It helps to talk to someone else who has RA, though I didn’t want to at first.”

Everyone can feel low from time to time, so don’t be too hard on yourself. You may feel you ‘ought’ to be coping fine, but when you’re diagnosed with RA there is a lot to take on board. It can dent your confidence – about work, your relationship or your social life – so give yourself time to accept and adjust.

It can help to talk. It may be to a friend, another person who has rheumatoid arthritis, or your nurse specialist. If you like the idea of meeting others who have “been there, done that” then pop along to an NRAS group if there is one near where you live. For locations of NRAS groups visit www.nras.org.uk/groups or call 0845 458 3969. If you’re not keen to join a group, NRAS can put you in touch with someone you can talk to over the phone who has rheumatoid arthritis and can offer some insight into how they manage their disease on a day to day basis.

Words from a recently diagnosed lady who was helped by an NRAS volunteer:

“It was wonderful to have Kathy at the end of the phone…helped me through some very difficult times when no-one else understood.”

More information about sex and relationships on page 27

More information about support on page 27

More information about someone to talk to on page 27
About the future

“It hasn’t changed how I think about the future. I still want to achieve the same things. I want to go on doing my job, have nice holidays.”

“I never wanted children – but being diagnosed has made me think about it all again.”

Will my working life be affected?

Not necessarily, the treatment and management of RA today is much different from 20 years ago. Early effective treatment and the wide range of drug options available mean that work is still very much on the agenda for most people with RA. When you are newly diagnosed that may seem hard to believe but, with the correct medication, support and time, things will begin to look quite different.

If needed there is lots of help available to ensure that you can continue working. There are a wide range of professionals who can help you if you are finding your job difficult and there is protection provided by the Equality Act which protects many people with long-term health conditions, including RA. Employers cannot treat a person less favourably than anyone else because of their physical limitations, and the law requires them to make reasonable adjustments for people covered by the Act. These can include: changing your tasks or work patterns; special equipment; time off for appointments; or help with travelling to work.

Will my RA have a long-term effect on me physically?

People diagnosed today are far less likely to sustain damage to their joints than used to be the case, because of early and more effective treatment. Treatment early on can prevent much of the damage to joints that people used to get. While a minority of people are severely affected by RA, for the vast majority early treatment means they will be able to lead a full life.

Will my ability to have children be affected?

No. If you’re thinking about having children, discuss it as early as possible with your rheumatologist. The team will want you to be as well as possible while you’re trying for a family and will advise you on how to manage the condition and drugs you must avoid. RA can affect fertility if it’s poorly controlled, and so can the drugs used to treat it. There are some drugs that women and men need to stop taking for varying periods of time depending on the drug before trying to conceive, as they can affect the developing baby.
Can we have children? (cont.)

There’s no reason why women with RA shouldn’t have a normal pregnancy if their disease is well controlled. Many women find that their symptoms improve during pregnancy, though they tend to return or flare up in the weeks after giving birth. So planning ahead and getting help arranged for when the baby arrives is important.

“Because of the toxic medication I was taking, getting pregnant could never have been a “happy accident” and required careful planning with my Rheumatologist. Once I eventually became pregnant, the Obstetricians kept a close eye on my symptoms and medication, ensuring that everything progressed normally and I was as comfortable as possible. When my baby was born and the RA flared up again I found ways of coping and relied on my family for a couple of weeks. Now my RA is stable and I am back on my original medication, enjoying being an active mother of a very lively toddler!”

Getting used to the ups and downs

Thinking about the future can become easier if you feel you understand your disease better. Everyone has to get used to RA’s ups and downs – and how you adjust, and how long it takes, is unique to you.

Talk to your healthcare team, find out all you can, and come back to your own questions when you need to. Above all: give yourself time.

NRAS is here to help

We’re here to support you every step of the way. If you have any questions about your RA or how to cope with the change: call us. Every day we take calls from people recently diagnosed with rheumatoid arthritis – you’re not alone.

If we can’t answer your question immediately, we’ll look into it and get back to you. We’re supported by a UK-wide team of specialist advisors that includes doctors, nurses and other health professionals. And don’t forget the NRAS Members’ forum, Facebook and Health Unlocked if you want to connect with others online or visit an NRAS group or arrange a call from one of the NRAS telephone volunteers.

“Now I have the NRAS helpline number in my mobile phone – and so do my friends.”
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 advice 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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For more information about ...

Blood tests
See NRAS website www.nras.org.uk and search Laboratory tests used in the diagnosis and monitoring of rheumatoid arthritis.

Drug treatments (Pg 15)
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.

NRAS can put you in touch by phone with someone who’s taken disease modifying drugs and whose RA is now well controlled. Call the freephone helpline on 0800 298 7650.

Exercise (Pg 21)
Keep moving, a booklet including a poster from Arthritis Research UK, has details of stretches and exercise.

NRAS has information about exercise on their website. Look in the Living with RA, Lifestyle section of the website!

Self management (Pg 19)
Self Management UK run self management programmes to help you manage your long-term health condition better by yourself. They give you the tools, skills and support you need to improve your wellbeing. For more information please visit selfmanagementuk.org or ask a member of your rheumatology team about available courses.

The RA self management programme is now available in some areas of the UK. Please contact NRAS for more details and to find out if there is a course near you - 0845 458 3969

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

Fatigue
Fatigue: Beyond Tiredness is available to download from the NRAS website.

Fatigue and arthritis, information booklet available from Arthritis Research UK.

Living with rheumatoid arthritis
Managing Well: Living with rheumatoid arthritis - an NRAS booklet.

Emotions, Relationships and Sexuality – an NRAS publication.

www.healthtalkonline.org (select Bones and Joints) features videos of patients’ personal experiences of living with RA.

Article by GP Dr. Mark Devlin
Getting the most from the initial consultations with your GP available on NRAS website and in hard copy.

Pain (Pg 21)
For more information on pain, visit the NRAS website.

Pain and Arthritis, a booklet from ARUK.
Living with long term chronic pain, a guide to self management – an ARUK publication.

The Pain Society has a range of publications for patients on this topic.
See www.britishpainsociety.org for more information or call 0207 269 7840.

Prescriptions
For details about Prescription Prepayment Certificates (PPC), prices and how to apply, ask your pharmacist or GP surgery for form FP95, or you can order online at www.nhsbsa.nhs.uk or by phone 0300 330 1341 or 0191 279 0563.
Pregnancy (Pg 24)
Pregnancy and Arthritis, a booklet from Arthritis Research UK.

Research
See NRAS website for research/drug updates.
If you are interested in being involved in a clinical trial then visit www.ukctg.nihr.ac.uk.

Rheumatology department
Meet the rheumatology team – an Arthritis Research UK booklet available to order or download.

Sex and relationships (Pg 22)
Emotions, Relationships and Sexuality – an NRAS publication.
Sex and Arthritis, a booklet from Arthritis Research UK.

Someone to talk to (Pg 6/22)
As well as the NRAS helpline, www.nras.org.uk has a members’ forum where NRAS members can communicate with each other. Likewise NRAS HealthUnlocked blogging site can connect you to people across the world as can NRAS Facebook. To arrange a call from one of the NRAS telephone volunteers call the freephone helpline 0800 298 7650 or email helpline@nras.org.uk.

Support (Pg22)
NRAS helpline, 0800 298 7650.
Ask about NRAS local groups 0845 458 3969.
Your hospital advice line or helpline.
Ask at your clinic if they have a network of buddy or support groups. Try the hospital notice board for information, or ask your local health centre if they know of any groups.

What is rheumatoid arthritis?
What is RA – article written by Professor David GI Scott, NRAS Chief Medical Advisor and Ailsa Bosworth, NRAS Chief Executive - available on the website or by calling NRAS.
Rheumatoid Arthritis, an information booklet published by Arthritis Research UK.

Work (Pg 8/14/23)
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!
To speak to someone about discrimination at work visit the Equality Advice and Support Service – www.equalityadvisoryservice.com 0808 800 0082.

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
Switchboard: 020 7380 6500
Helpline: Freephone 0808 800 4050 (10 am – 4pm weekdays)
Email: Helplines@arthritiscare.org.uk
www.arthritiscare.org.uk
Contact us...

General: 0845 458 3969
01628 823 524
Email: enquiries@nras.org.uk

Follow us...

Join the NRAS Facebook page
www.facebook.com/nationalrheumatoidarthritisociety
& be part of the NRAS community

Follow us on Twitter
Twitter@NRAS_UK

To see what is happening on Helpline
follow them
Twitter@helpline_NRAS

For up to date membership
information follow
Twitter@members_NRAS

National Rheumatoid Arthritis Society
Ground Floor, 4 The Switchback
Gardner Road, Maidenhead,
Berkshire SL6 7RJ