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Fatigue Matters

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Fatigue Matters: A Self-Help Guide for People Living with Rheumatoid Arthritis

About Us

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

Ask Us

Call our freephone helpline on **0800 298 7650**, 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. If you'd like to talk to someone else with RA, our staff can match you with one of our trained Volunteers, who will then call you back at a mutually convenient time to discuss whatever aspect of living with RA most concerns you. To be put in touch with a Volunteer who has RA, please call the helpline to make the arrangements.

Our website www.nras.org.uk has a wealth of information about all aspects of living with RA, treatments, the latest research and developments, as well as full details of other useful organisations that can help. The NRAS online forum www.healthunlocked.com/nras is a safe space where you can get peer support and blog about your experiences. If you don't have access to the internet and want information sent to you in the post, please call us on **0845 458 3969**.

Meet Us

Local NRAS groups meet regularly around the country. To find out if there is a group near you, visit www.nras.org.uk/groups, email groups@nras.org.uk or call **0845 458 3969**.

Join Us

To find out how to join NRAS and support the work we do, thereby helping us to help even more people, please get in touch (see inside back cover of this booklet for full contact details).

Fatigue Matters Contents

Note: Bold coloured text indicates terms found in the glossary.

National Rheumatoid Arthritis Society

Introduction

Ailsa Bosworth MBE
Chief Executive, National Rheumatoid Arthritis Society (NRAS)

In 2014 we conducted a UK-wide survey on fatigue which drew over 2000 completed responses. We believe this is the first time that so many people with RA have been surveyed about their experiences of chronic fatigue – including their views about levels of public awareness of the symptom, the effectiveness of existing management approaches, and the impact of chronic fatigue on their quality of life and work outcomes.

The respondents ranked chronic fatigue as the least understood symptom of RA by the public. Nine out of ten respondents said they suffered with chronic fatigue, of which nearly two thirds said onset appeared before diagnosis. Equally troubling, the majority of respondents said they experienced chronic fatigue on three or more days during the previous week and that this lasted for several hours at a time. Over three-quarters of respondents said fatigue had a high or medium-level impact. Two-thirds of all respondents said their healthcare professional never or rarely asked them about their fatigue.

The impact of fatigue on work was also very significant, with just under three-quarters of working-age people with RA who were not in work, saying that fatigue had contributed to their unemployment. These findings caused us to commit to developing this new publication devoted to the subject of fatigue.

We collaborated with King's College Hospital to provide a work placement/internship for one of their Health Psychology students to work with us on the framework for this booklet in early 2017. I am extremely grateful to Dr Katie Druce for contributing her great insight and experience on the subject of fatigue to this booklet. Our Editor, Colin Richardson has done a brilliant job of editing all this work to create this informative and insightful resource, and thanks also go to Dr. Katie Hackett for peer reviewing the booklet.

We know that healthcare professionals find it difficult to 'treat' fatigue as there is no magic pill or instant resolution to fatigue. As a consequence, and maybe because health professionals like to be able to provide solutions, it isn't always discussed at clinic appointments.

This means that patients often feel a bit isolated in their battle with this debilitating symptom. We therefore hope that health professionals will find this booklet a very useful resource to give to their patients. All at NRAS sincerely hope that you find this new and comprehensive booklet useful in gaining better control over the problems you may be experiencing with fatigue in your daily life.

Fatigue Matters

Foreword

Dr Katie Druce, PhD
Post-doctoral Research Associate, Arthritis Research UK Centre for Epidemiology, University of Manchester

I am delighted to provide the foreword for *Fatigue Matters*. People with rheumatic diseases, such as RA, tell us that fatigue is one of their most important and distressing symptoms. They also tell us that managing fatigue is problematic. Flares or fluctuations may occur out of the blue, for no obvious reason, and effective treatment options to manage fatigue are limited. It is for these reasons that we often hear from people with RA that they try to manage their fatigue by themselves. However, they often feel like they are undertaking a constant battle of trial and error.

The problem is that fatigue is complex. There is no one-size-fits-all experience of fatigue and many things may cause a symptom flare. The management of fatigue is also difficult because it is invisible to others and therefore hard to relate to. As a researcher into fatigue, I often hear people say that their healthcare providers, friends, and family members don’t care about their fatigue. But I really believe the truth is that they don’t really understand it. Most of us know what it feels like to be tired, but few of us can understand the overwhelming feeling of physical and mental exhaustion reported by people with RA. Even as a researcher in this area, I am constantly surprised by the descriptions of fatigue that I hear:

- “It’s like walking through treacle”
- “I feel like I’ve got a backpack full of stones on my back”
- “I feel absolutely fine and then suddenly – BAM! – it hits me and I feel like I’ve got a full suit of armour and chainmail on.”

That’s why one of the most important themes in this booklet is to talk about fatigue. Whether you are someone with RA, a healthcare provider, friend, or family member, I urge you to talk more about fatigue. As someone with fatigue, this is particularly important because people can’t support you to manage your fatigue unless they understand your experience of it. If you don’t yet feel ready to talk about your fatigue, there’s plenty of other help and advice in this booklet, including the importance of sleep, exercise, and forward-planning.

In creating this booklet, NRAS has done a wonderful job of collating a number of resources, which I hope will help improve the management of fatigue. Whether you are someone with

RA, a healthcare provider, or someone who knows a friend or family member with the condition, I hope that this booklet can help you.

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What is fatigue?

Most people with RA experience fatigue, one of the most common and distressing symptoms of RA.

> I feel totally exhausted; like a tap suddenly opens and all my energy (what little I have) disappears in an instant. It can last hours, days, weeks, or months. I feel like I have limbs of lead, and even completing the smallest of tasks leaves me totally drained. It also leaves me feeling tired emotionally. My fatigue makes me feel helpless, and unable to complete everyday tasks. One of the worst effects is how it affects my thinking. I feel unable to cope in social situations with strangers. It is a blight on every aspect of my life.

All quotes from the 2014 NRAS survey: *Invisible disease: Rheumatoid arthritis and chronic fatigue*

Fatigue can have a severe impact on the quality of life of those affected. A survey conducted by NRAS (*Invisible Disease: Rheumatoid Arthritis and Chronic Fatigue, 2014*) found that 89 per cent of those surveyed experienced chronic fatigue, of whom getting on for half (40 per cent) said their fatigue was persistent and severe. Fatigue can come on at any time of the day without warning. It can last from a few hours to several days at a time. For some, it can persist for weeks or months. It tends to be worse during a flare.

Fatigue is so much more than ordinary tiredness. It is much more debilitating and all-encompassing than that. Fatigue is to tiredness as 'flu is to the common cold.

Fatigue Matters

- Fatigue affects the great majority of people with RA.
- Fatigue is a major but hidden symptom of RA.
- Fatigue is an overwhelming feeling of exhaustion, both physical and mental.
- Fatigue can come on at any time, without warning. It can last for a few hours or days but may persist for weeks or months.

Individual experiences of fatigue vary – it is not the same for everyone. These are some of the ways people experience it:

- Fatigue can be an overwhelming feeling of exhaustion, both physical and mental. You may feel completely drained of energy. You may just want to lie down and never get up again.
- Your limbs may feel heavy. Walking may feel like wading through treacle while wearing concrete boots. It may feel as though you have a heavy load on your back.

Fatigue is a 'hidden symptom' of RA

There is no agreed medical definition of fatigue and no easy way to measure it. People who experience it often find that others may not be very understanding of what it is nor of its effects. Unless you tell them, other people may not be aware that you have fatigue. The NRAS survey mentioned above (*Invisible Disease, 2014*) found that only 31 per cent – less than a third – of the general public identified fatigue as a symptom of rheumatoid arthritis (RA). It can be frustrating having to explain all the time to people who don't understand that you are not just tired. It is easy to feel that others think you are malingering or making it up. You may even start to believe it yourself. But when you do start to talk about it, you will find that people become more understanding and you will have to explain yourself less and less. And you will begin to find ways of coping with and tackling fatigue that work best for you.

- You may find it hard to think or concentrate or perform the simplest of tasks. Some people talk of ‘brain fog’ descending out of a clear blue sky!

National Rheumatoid Arthritis Society

What causes fatigue?

The causes of fatigue in RA are complex and poorly understood. There is no one reason why most people with RA experience fatigue at one time or another. Rather, there are several overlapping, interwoven, and fluctuating factors at play, which, as we shall see later on, have to be tackled on several fronts. Research indicates that it is principally the effects of having RA that can contribute to fatigue – notably, pain, lack of sleep, low mood, disease activity, disability, inactivity, and social isolation.

Pain

There is a strong link between levels of pain and levels of fatigue. Pain can contribute to fatigue directly or indirectly. However, while effective pain control may reduce fatigue in many people with RA, it is not the solution for everyone. Pain can be very tiring. Being in constant pain is extremely wearing and if you have to modify your movements because of pain and/or disability, you will likely find yourself expending more energy than usual.

Fatigue Matters

- Maintaining a comfortable sleeping environment that’s not too hot, cold, noisy, or bright.
- Not napping during the day.
- Avoiding caffeine, nicotine, and alcohol late and avoiding eating a heavy meal late at night.
- The causes of fatigue in RA are poorly understood.
- There is no one cause of fatigue in RA. Instead, there are many overlapping and interwoven factors that lie behind it.
- Some of the main symptoms of RA, if not properly treated, can contribute to fatigue. Pain is most strongly linked with fatigue.

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

At the same time, fatigue may make coping with the other symptoms of RA more difficult. Poor sleep Inadequate or disturbed sleep makes fatigue worse. Sleep helps the body to recover and repair and to restore energy levels. If you do not sleep properly or for long enough, you will have less energy to deal with the day ahead; you won't feel rested, your joints may feel stiffer and more painful than usual.

Also depress your mood. Therefore, establishing good sleeping habits (sometimes referred to by health professionals as 'sleep hygiene') can help and include:

- Establishing fixed times for going to bed and waking up
- Creating a relaxing bedtime routine
- Only going to bed when you feel tired

Working for a better life for people living with Rheumatoid Arthritis

Sleep Hygiene

- Your sleep environment
- Things to avoid
- Relaxing exercises
- Sleeping positions
- Helpful hints

Contact: T: 0800 298 7650 | www.nras.org.uk

Low Mood

Low mood is also strongly linked with fatigue. Excessive tiredness can be a symptom of depression. And having fatigue may itself cause you to be depressed. In our survey of people with RA (Invisible disease, 2014), almost all those surveyed (90 per cent) said fatigue had caused them to feel down or depressed during the previous week, of whom over a third said they felt very down or depressed. Depression can also make everything seem worse than it is. If you feel depressed, your fatigue may feel more than usually severe and you may feel that there is nothing that can be done about it. This is entirely understandable and you shouldn't blame yourself for feeling like that.

RA and Fatigue

- The disease process itself
- Lack of exercise
- Overdoing it
- Disease activity

There is a link between disease activity and fatigue in RA, but the exact nature of the link isn’t clear and isn’t the same for everyone. For some people, controlling their disease to the point that they are considered to be in remission leads to a big improvement in the severity and duration of their fatigue. It may be that being in remission helps to minimise the other symptoms of RA, which may, in turn, lead to a reduction in fatigue. But for others, remission may have little or no impact on fatigue. In either case, minimising disease activity remains the central aim of the treatment of RA, whatever its impact on reducing fatigue, because of its overall beneficial effect on health in the long-term.

Other Factors

Your level of physical functioning can affect your fatigue. RA can lead to disability, which, in turn, can affect your fatigue. Disability can cause physical activity to be harder and you may find that your activities become restricted. You may find that the changes you have to make to compensate for these restrictions mean that even the most basic tasks require more effort, leading to an increase in fatigue. You may also find that when you decrease your levels of physical activity your muscles become weaker, which means that physical tasks require more effort to complete.

Social Isolation

Social isolation may be linked to fatigue. When you have fatigue, ordinary social activities, such as going to the cinema or visiting family or friends, may be beyond you. You may be too exhausted to contemplate leaving the house. At the same time, the unpredictability of fatigue can make it difficult to plan ahead. You may find yourself cancelling arrangements at the last minute. And because constantly having to explain yourself can be very tiring, your friends may not understand and may not ask you out so often in future. All that means you may have less support than you otherwise might; and you will probably find your mood becoming depressed, too.

Adjusting to Fatigue

It can be difficult to adjust to having fatigue. You may try to push through it and continue with your normal level of activity. However, overdoing it is likely to worsen your fatigue. As we will discuss later on, learning to rest and pace yourself will help you cope better with your fatigue.

Diet and Medication

Eating well is important. A poor diet can make you feel run-down and tired. Some medications can make you feel drowsy. A review of your medications can help identify those that are making you feel sleepy and it may well be possible to find substitutes.

Treatments for Fatigue in RA

It is important to be clear that there are no licensed treatments specifically for fatigue. There is no cure for fatigue. But scientists are working hard to find out more about what causes fatigue in RA. They hope to find effective treatments and even a cure. It is equally important to say that there are plenty of things that can be done to reduce fatigue and to make it easier to manage.

- There is, at present, no cure for fatigue.
- But there are plenty of things that can be done to reduce your fatigue and to help you cope better.
- Emotional support, a medication review, effective pain control, exercise, getting a good night’s sleep, and planning your day to conserve energy can all help.

Emotional Support

There is much evidence that talking about fatigue is good for you. First of all, by talking to others about your fatigue, you can start to get the help and support you need. Secondly, ‘talking therapies’ such as cognitive behavioural therapy (CBT), have been shown to be very effective in tackling fatigue by combating depression and low mood and by helping you develop better coping strategies. Anxiety and stress are also commonly experienced by people with RA – often, hand in hand with depression. Feeling stressed and anxious is very wearing and can worsen your fatigue and your ability to manage it. Any ‘talking therapy’ aimed at tackling depression will also look at ways of combating anxiety and stress.

A Medication Review

Some medications can cause drowsiness, which can make fatigue worse; some may even list fatigue as a known side effect. Ask your clinician, pharmacist or healthcare provider for a review of all the medications you take – not just those you take for your RA – which should identify any that might be contributing to fatigue. It may be possible to find a substitute for any medication that is making you feel sleepy.

Pain Control

Effective pain control can greatly reduce fatigue for many people, though it may not be the answer for everyone. In either case, keeping pain under control is a key element of the treatment of RA. Even if it has no direct effect on your fatigue, minimising pain will improve other symptoms of RA (such as poor sleep) and will make it easier to cope. It is important to note that increased or high levels of pain may indicate that your disease is not being well-controlled. If you think this may be the case, seek a review with your rheumatology team by contacting the rheumatology nurse helpline at your hospital.

Exercise

It may seem to go against common sense to suggest that a way to deal with fatigue is to take some exercise, but it really can help. Most people with RA are affected by a condition known as rheumatoid cachexia, which causes muscle wastage and an increase in body fat. When you lose muscle, it takes more energy to accomplish even the simplest of physical tasks. And an increase in weight will also mean you expend more effort on everyday activities, as well as not being good for your general health. But muscle wasting and an increase in weight will not automatically be reversed when your RA is under control. Exercise will help you recover muscle mass, thereby building up your strength, and decrease body fat, which will bring your weight down. Strengthening your muscles and losing weight will both help to counter fatigue. Exercise can also lift your mood and contribute towards a good night’s sleep, both of which will help alleviate fatigue.

A Good Night’s Sleep

There’s little evidence that tackling poor sleep has a direct effect on fatigue. But sleeping well will make you feel better, which will help you cope better. You will likely have more energy if you have slept well than if you have slept badly. And poor sleep may indicate that other things are wrong, so it should not be ignored.

Planning Ahead and Conserving Your Energy

Although keeping active and taking exercise is an important part of any programme for tackling fatigue, it is also important not to overdo it. Fatigue limits your available energy. Planning ahead can help you make the most of the day. Knowing when to rest and when to be active, when to ask for help and when to delegate tasks to others are all about good self-management and part of any energy conservation programme. Later in this booklet, we have a wealth of tips and ideas for getting the best out of your available energy.

At the same time, people who are in employment may find it much harder to organise their time and incorporate regular rest periods into their day.

Fatigue Matters

Fatigue is a hidden symptom of RA, little understood and too infrequently talked about. The first step in tackling fatigue, therefore, is to talk about it – to your healthcare team and to those close to you. That way you can explain how fatigue affects you and begin to get the help, support, and treatment you need.

> "Talk about it. Fatigue is a hidden symptom of RA, little understood and too infrequently talked about." – *Work Matters, page 32*

Diet and Disease Management

Some people whose disease is in remission find that their fatigue is also greatly reduced. However, keeping your disease under control remains the central aim of the treatment of RA, whatever its direct impact on your fatigue. It limits damage to your joints and helps to minimize symptoms such as pain, inflammation, swelling, and stiffness, which may, in turn, help reduce the severity of your fatigue.

Diet

There is no evidence that diet can directly affect fatigue. However, eating a balanced diet, with regular meals, is generally beneficial. Eating healthily will make you feel better, which will make it easier to cope with your fatigue. Both over-eating and under-eating can have an indirect impact on your fatigue. Keeping up your fluid intake is also important. Dehydration is tiring.

- Ensure a balanced diet with regular meals.
- Keep hydrated with regular cups of tea and glasses of water.
- Consider iron-rich foods to combat anaemia.

Communicating About Fatigue

Talk to your healthcare team about your fatigue so that they are aware of how it affects you. Try not to play down how you feel, even if you’re having a good day. Tell them how you feel on the bad days. Don’t be afraid to ask questions or raise any concerns you have. They are there to help.

If you find it difficult to talk to your healthcare team, consider taking someone with you to your next appointment for moral support. Write down in advance any questions you particularly want to ask and take the list with you.

Tracking Fatigue

You may find it useful to keep track of your fatigue, by means of a diary or an app on your mobile phone or tablet. You can then show the results to your consultant, GP, or specialist nurse at your next appointment to give them a clear picture of how fatigue affects you over time.

Explaining Fatigue to Others

Talk to your family, partners, friends, and employer(s) to explain how fatigue affects you and what you need from them when it strikes. Some people find it helpful to have a way of describing their fatigue that they can use whenever telling others about it.

For example, some say it’s like having the plug pulled or the battery on their phone running down and having nowhere to charge it up again. Others talk of their energy levels as a fixed daily quantity – say, six chocolate bars a day; if they use up four bars on one task, then they only have two left to accomplish everything else they have to do that day.

The Spoon Theory

Another way of explaining how fatigue affects you is the ‘spoon theory’. A spoon represents a person’s ability to tackle a task. People who don’t have fatigue have an unlimited number of spoons. They don’t even have to think about using them. But if you have fatigue, you only have a limited supply of spoons.

> "Imagine that each imaginary spoon is a spoonful of energy."

Seeking Support

Talk to other people with RA, to find out how they manage their fatigue. The NRAS Helpline can arrange for a trained volunteer with RA to call you to chat about how they cope and what works for them. The Helpline team can also talk through possible ways to manage fatigue and how to explain it to others.

- Call the NRAS Helpline at 0800 298 7650.
- Join NRAS groups around the UK.
- Visit the NRAS online forum, HealthUnlocked, at www.healthunlocked.com/nras.

NRAS has developed a range of free self-management workshops designed to bring people with RA together to share their experiences and to help them better manage their RA.

Hospital trusts in your area commission them (i.e., provide the funding to put them on). To date, they have been funded in only a very few areas as the reality is that the NHS is so financially strapped that we are really struggling to get these programmes funded in more areas. We know that courses can be life-changing, and our experience is that patients and clinicians are interested in them. Those who have run them or attended them understand their value to people with RA and the long-term benefits to the health system.

For more information, please email enquiries@nras.org.uk or call 0845 458 3969.

Talk to a Counsellor, Life Coach, Therapist, or Psychologist

As we have already said, almost everyone with RA-related fatigue suffers from low mood or depression at some point. At the same time, depression can make your fatigue worse. Being depressed is nothing to be ashamed of. Recognising that you may be depressed is the first step to getting help and support, which in turn may help reduce your fatigue. The evidence shows that ‘talking therapies’, such as cognitive behavioural therapy (CBT), delivered by a trained counsellor or psychologist, are very effective in combating depression and reducing fatigue. If you experience depression, ask your GP, specialist nurse or consultant about the available therapies in your locality and ask for a referral.

- Talk about how fatigue affects you – to your healthcare team and to those close to you.
- Don’t be afraid to ask for help.
- Pace yourself, plan ahead, and accept that there will be days where you do less.
- Don’t overdo it or try to do too much. Be kind to yourself. Rest when you need to.
- Try to keep as active as you can. Gently increase the amount of exercise you take.

Pace Yourself

Fatigue limits your available energy. Understanding how your fatigue affects you will help you plan your day and pace yourself, so that you can make the most of your energy supply. Tracking your fatigue with a diary or with an app on your mobile phone or tablet is a good way to start recognising the patterns: to see when fatigue is likely to affect you and how long it is likely to last; to recognise how a busy day or a bad night’s sleep can make things worse; to get a feeling for when are the best times to rest and the best times to be active.

You can use an ordinary paper diary and fill it in as often as you can and in as much detail as you like. We have designed a simplified diary, using letters to mark busy times, rest periods, and episodes of overwhelming fatigue. There is a sample of the diary, with suggestions as to how best to use it, later in this booklet. There is a digital version on our website that you can fill in online and then print off. Or you can print blank versions and fill them in by hand. We have paper copies available on request – to get a copy call us on 0845 458 3969.

Useful Apps

There are also two free apps that can help you keep track of your RA and its symptoms, including fatigue. They work on iPhones or iPads or on any mobile phone or tablet that runs the Android operating system. You can download them by visiting our website (search for ‘app’).

Know your DAS is a free app that is aimed at tracking your DAS28 so that you can see how well your RA is being controlled. DAS28 is a measure of disease activity. The lower the score, the better your RA is being controlled. A DAS28 score of 2.5 or lower means that your disease is in remission, which is the main goal of RA treatment. As well as tracking your DAS28, this app has a simple diary feature that lets you keep an eye on all the main symptoms of RA, including fatigue. The DAS app can also help you remember when to take your medications as prescribed.

RheumaBuddy is a free app for people with RA and JIA. It helps people get a better understanding of what influences the good or the bad days and with this understanding, increase the number of good days. The app is suitable for people over the age of 16 years to use independently. The pain body-map allows you to pinpoint and note specific areas of pain. You can also log sleep, exercise, and hours of work or school. You can also keep a daily record of the severity of your symptoms, including fatigue, and it is possible to chat with other patients and learn from their experiences. The app helps you to gain greater control of your RA or JIA. By getting a better overview and discovering patterns you can figure out what you can do to influence the disease in a more positive direction. The app enables you to share the findings with your rheumatologist.

Planning and Pacing

Whether you use a diary or not, it is helpful to plan ahead and pace yourself. Some people make use of a ‘traffic-light’ system when planning ahead. They assign tasks in their diary or on their calendar a colour – red, amber, or green, according to how tiring they are; red activities being those that take the most out of you, and green the least. Then they aim to ensure they have no more than one red-light activity on any given day and, say, no more than two amber-light activities.

- If you have a busy day tomorrow, try to have a less busy day today, with regular breaks, and plan to have plenty of rest the day after tomorrow. At the same time, make sure that you plan to take some rest breaks during your busy day.
- You may find that you have more energy at certain times of the day than at others, so try to structure your day accordingly.

- Re-evaluate your ‘to do’ list. Do you need to do everything you had planned for the days ahead? Are there things that someone else could do? More than likely, there are things you can put off or strike off the list altogether.
- Break down the tasks you feel you can’t avoid into manageable chunks, taking time out to rest in between. Try to spread big tasks out over the day or even over several days. Little and often may be the best way to approach tasks rather than trying to do everything all in one go.
- See if there are ways in which you could do things more efficiently or in a less strenuous way. If you’re preparing a meal, for example, try to keep everything you need together, close by, so that you don’t have to keep going off to fetch things. There are a number of gadgets that can help around the home – such as devices to help with opening jars with minimal effort. You may also want to consider getting a perching stool that you can rest on while cooking or using the bathroom sink. You’ll still be at more or less the same height as when you’re standing up but you will be supported, which will help you conserve your energy. You may not need to use such aids every day, but they can be helpful to have on hand for less demanding days.

Good days.

The Disabled Living Foundation is a charity that provides impartial advice, information and training on equipment for independent living. Visit their website at www.dlf.org.uk or call their Helpline on 0300 999 0004.

Be kind to yourself. Accept that there may be times when you will be able to do a lot less. Even when your energy levels are high, be careful not to overdo it. Of course, this is all very well if you have complete control over your time. However, if you are in paid employment or you have regular commitments – say, due to the demands of a young family – it may not be so easy. Later on, we look at what you can do at work to better accommodate your fatigue – flexible working hours may be possible, for example.

National Rheumatoid Arthritis Society

If you are not in paid work but have regular demands on your time – child care, for example, or other caring responsibilities – you may need to ask others to help so that you can build some rest periods into your day. Can someone else collect the kids from school today or take the toddler to the nursery in the morning? Can someone do the shopping for you or do a spot of ironing?

Exercise

Taking even a moderate amount of exercise helps to strengthen muscles and build fitness, which will help to make it easier and less tiring to carry out everyday tasks. Exercise can also help you get a good night's sleep. Exercise doesn't have to involve going to the gym and doing a strenuous workout. It can be as simple as going out for a brisk walk or weeding a flowerbed. You could take a cycle ride, go for a swim or take part in an exercise class. Joining an exercise class or taking part in any other kind of organised activity – a walking group, a dance class or a cycle club for example – is also a good way of meeting people and getting out and about.

Take it very gently to begin with. Even if you were used to exercising hard before being diagnosed with RA, it's probably best not to go for the burn every day. Build up gradually. In time, you will find yourself able to do more and more. There will still be days when you just won't be able to do much more than rest. That's fine. But when the energy returns, beware of trying to make up for lost time; don't overdo it. As you exercise more regularly, you will become aware of your limitations as well as your capabilities.

Fatigue Matters

If you do want to join a gym or an exercise class, talk to your healthcare team first. You should be able to talk to a physiotherapist who can give you advice on the kind of exercise that would be suitable for you. They may also be able to point you towards suitable classes where you live. Some leisure centres run classes tailored for people with long-term conditions and/or reduced mobility. It may be worth contacting the centres near to you to see what they have to offer. You could also do an internet search to see what, if any, classes or activities are run locally. Or visit your local library for information. Some local NRAS groups also run exercise groups or may know of local suitable classes. Contact your local NRAS group. They may have details of exercise classes nearby. They may also be able to put you in touch with other people with RA who live locally and who already participate in regular exercise classes or activities. To find out if there is a patient group near you visit www.nras.org.uk/groups, phone 0845 458 3969 or email groups@nras.org.uk. You can also find some useful exercise videos on our website at www.nras.org.uk/exercise-videos.

Sleep and Diet

Eating well, making sure you stay hydrated (by drinking plenty of fluids during the day) and sleeping well will help you to manage your fatigue better. If you are well-rested and well-nourished, you will feel better able to cope with daily tasks. The general dietary advice is to eat a balanced and varied diet, with plenty of fresh fruit and vegetables, and to avoid snacking between meals. As for sleep, try to establish fixed times for going to bed and waking up each day and steer clear of heavy meals and stimulants such as coffee, caffeine or nicotine in the run-up to bedtime. Try to avoid napping during the day as this can make it harder to get a good night's sleep. For more detailed advice, visit our website at www.nras.org.uk, where there is a wealth of information about healthy eating and tackling sleep difficulties. Our booklet *Living Better with RA* also has a lot of information you may find useful. It is available free as a download from our website or by phoning or emailing our offices and asking for a copy to be sent to you. There is much dietary advice given within our new *Love your Heart* interactive online cardiovascular risk-assessment video, and we would recommend that everyone with RA make use of it. See more on our website at www.nras.org.uk/loveyourheart, where you can register and participate. There is further information and advice about tackling sleeplessness and eating well on the NHS Choices website at www.nhs.uk.

Fatigue Diary

This is a sample diary. Paper copies are available to download from the NRAS website and there is also an interactive version on our website that you can fill in and print out. Visit www.nras.org.uk/diary. See also pages 18 to 20 of this booklet.

- **B** - Busy time; doing a lot, few breaks
- **M** - Moderately active
- **R** - Rest; Sitting or lying quietly, reading, watching TV, but not sleeping
- **S** - Sleeping
- **C** - Crash; When fatigue stops you doing anything

NRAS Helpline: 0800 298 7650

Working with Your Healthcare Team

Many people with RA feel that healthcare professionals don’t take fatigue seriously enough. In fact, some people have told us that they’ve been told by their health professional that fatigue is nothing to do with their RA! Wrong. Part of the problem is that there are no approved treatments for fatigue in RA so doctors and rheumatology consultants may feel they have little or nothing to offer. Instead, their focus may be on controlling your disease. For many people, being in remission will minimise all the symptoms of RA, including fatigue. However, for many others, this is not the case. Pain and fatigue can persist even when you are in remission. If that is the case for you, let your healthcare team know. Being in remission is not just about getting your DAS28 score as low as possible; it is also about how you feel. So, if you’re not feeling well, despite all your tests showing your disease is under control, don’t pretend otherwise. When talking to your healthcare team, be honest, not brave. You may be so used to telling friends and family you’re OK, answering every ‘How are you?’ with ‘I’m fine’, that it’s hard to be honest with healthcare professionals about your pain or other concerns. But your team needs to know the real picture so that they can give you the help you need. However good your health team are they are not mind readers so be open with them. You might find it helpful to take a look at our emotive and informative *Behind the Smile* videos on our website at www.nras.org.uk/behind-the-smile.

If you still feel that your doctors or nurses aren’t taking your fatigue seriously, consider keeping a fatigue diary (see pages 18-20 and 24). Take it to your next appointment. You may also want to take someone with you who can also testify to the ways in which fatigue affects you.

- Don’t be afraid to ask for help if fatigue is making life difficult
- Ask for a review of your current treatment plan

All your medications should be reviewed to ensure that none of them are worsening your fatigue. Emotional and psychological support can make a difference in how you experience fatigue. Your doctor should be able to make a suitable referral.

Members of your healthcare team – the specialist nurse, physiotherapist, and occupational therapist – may be able to help you better manage daily living. One of the things your healthcare team can do that may have a direct impact on your fatigue is to carry out a review of your medication to identify any drugs you are taking (including any medications for conditions other than RA) that may be making you feel drowsy. If they haven’t offered you a review, don’t be afraid to ask for one or speak with your pharmacist about a medicine use review (MUR). It may be possible to substitute other medications for those that are causing you to feel tired.

Your healthcare team can also refer you to other healthcare professionals who can help you tackle fatigue:

- **Physiotherapist:** Can help you devise an exercise programme that is suitable for you. They may also be able to refer you to local exercise classes or activities.
- **Counsellor or Psychologist:** Can help you tackle low mood, depression, and/or anxiety. It can be difficult to admit that you need such help and difficult to ask for it. But your GP, consultant, or specialist rheumatology nurse will understand and be sympathetic; you can always take someone with you to an appointment for moral support. It's better to ask rather than wait to be asked. Research suggests that more than three-quarters of people with RA are not asked about social and emotional issues by their healthcare team.
- **Dietitian:** Can help you adopt a healthy diet and maintain a healthy weight.
- **Occupational Therapist (OT):** Can help you improve or maintain your ability to do everyday activities. They work with you to see what you're finding difficult and to find ways to reduce the problems. This might include:
  - Changing how you do things – helping you to use your time and energy effectively or finding ways to save energy. You might break activities down into smaller parts or do less at any one time.
  - Helping you to reduce the impact of RA on your daily activities. This could mean teaching you about looking after your joints during everyday activities or about ways to manage pain and fatigue.
  - Offering you support in making changes, for example with individual counselling or group programmes.
  - Adapting your home or workplace to make activities easier – the right piece of equipment or structural alteration can make all the difference. Occupational Therapists can also liaise with employers to ensure that appropriate adaptations are provided through statutory services, where possible.

There's more on workplace adjustments later on. The National Institute for Health and Care Excellence (NICE) offers guidance to NHS healthcare professionals on the best practice for treating a wide range of conditions, including rheumatoid arthritis. NICE guidance applies to England and Wales and is generally followed in Northern Ireland. In Scotland, the equivalent body is the Scottish Medicines Consortium (SMC).

NRAS contributes at a national level to the NICE (England and Wales) and Scottish Medicines Consortium Health Technology Appraisals for the introduction of new drugs, as well as the standards and guidelines produced by NICE and the Scottish Intercollegiate Guidelines Network (SIGN). While they refer to symptom management, they do not go into detail about managing fatigue, which is one of the reasons we have produced this booklet. The NICE website is at www.nice.org.uk. The SMC website is at www.scottishmedicines.org.uk. NICE does offer advice to healthcare professionals on managing fatigue, but it is not specifically tailored to people with RA – you can find it here.

Fatigue Matters

Family life and relationships: One of the aspects of fatigue that many people with RA find especially difficult to deal with is its impact on their relationships with family and friends.

> I have two wonderful grandchildren who I cannot play with when I'm fatigued. It's horrible. It's difficult to explain to my toddler that I'd rather sit on the sofa than go to the park with her.

In our survey, Invisible Disease, almost half (48 per cent) of those who responded said they felt guilty about the impact of their fatigue on other people. Nearly three-quarters (70 per cent) of respondents reported that fatigue had prevented them from taking part in activities with their family or partner; and over half (54 per cent) reported that fatigue negatively affected their sex life. In our survey in 2013 on emotions, relationships, and sexuality, 63% said they had been less able physically to have sex in the way they would like to. In our 'emotions' survey referred to above, a third (33 per cent) of respondents rarely or never talked to those close to them about how they feel.

- Fatigue can affect your closest relationships and negatively affect your sex life.
- Fatigue may disrupt or limit your involvement in family and social activities.
- Finding ways to talk to those close to you about how fatigue affects you and the support you need can make a big difference.
- Psychological support and counselling can be a great help in tackling these difficulties.

It is never easy to talk about difficult feelings such as guilt or about intimate matters such as sex. You may find yourself avoiding any discussions that you find awkward. And that's entirely understandable. But your husband, wife, partner, or best friend may prefer you to open up. They may wonder why you don't want to go out, for example, and they may think it's something to do with them rather than being the result of fatigue. In return, you may find yourself being angry and irritable or withdrawn and silent, which may make things worse. But if you can find a way to start talking about what you are finding difficult, it can make a big difference to your close relationships.

It can be difficult explaining to young children how you feel and you may find yourself making up stories that you think they will find easier to understand. But children often notice more than you think they do and they may not entirely believe them if you say you can't take them out to play because you've got a headache. They may instead think that things are worse than they are and become worried and upset.

There is no one simple way to limit the negative impact of your fatigue on your close relationships. One way to start is by talking to other people with RA to find out how they manage. Our Helpline (0800 298 7650) may be able to arrange for a trained Volunteer with RA who has faced similar difficulties to call you for a chat. You can also talk things through with Helpline staff. Or you may want to join one of our NRAS groups or chat to people through our online forum, HealthUnlocked – there are more details on page 17. It's sometimes easier to talk to people you are not emotionally involved with. Alternatively, you may prefer to talk to a healthcare professional, such as your GP or specialist rheumatology nurse. They can also refer you to professional sources of support, such as counselling.

It is also a good idea to make sure that friends and family are aware that fatigue may at times make it difficult for you to meet social commitments. If you find yourself cancelling arrangements at the last minute, your friends and/or family may be less likely to include you in future activities. Explain to those close to you that you often have to say ‘no’ because you are often laid low by fatigue, which can come without warning. However, having to say ‘no’ frequently does not mean that you never want to be asked to join in. They will be sure to understand. There may be more days than you would like when you have to stay at home.

Home, but there will still be plenty of occasions when you are up to going out. Just because you can’t go out sometimes, it doesn’t mean you don’t ever want to go out. If you keep any kind of fatigue diary, you may want to show those close to you. It may help you to explain to them how fatigue affects you.

Diary, pages 18-20 and 24-25

Emotions, Relationships & Sexuality

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

Blaste is Flare getting worse!

The impact of rheumatoid arthritis on how we feel and relate to others.

April 2016

NRAS also publishes a very useful booklet, **Emotions, relationships and sexuality**, which draws on the results of our 2013 sex and relationships survey and is full of helpful advice and information. You may also want to look at our **Family Matters survey (2012)**, which looks at how the families of people living with RA are affected. Both publications can be downloaded from our website or you can phone NRAS on 0845 458 3969 and ask to be sent a copy.

If you are concerned about the impact of fatigue or any other aspect of living with RA on your sexual relationships, you (and your partner, if that’s what you both want) could talk to a sex and relationship counsellor. Your GP or nurse may be able to make a referral. Or you could contact the national charity, Relate, who offer help with all aspects of relationships. Visit their website at www.relate.org.uk or call 0300 100 1234.

National Rheumatoid Arthritis Society

Work matters…

Work is important not just for financial reasons but also because it is generally beneficial to health and wellbeing.

> On days when I work, I can do nothing else; I am completely drained. No one knows this but me. Even thinking about telling anyone makes me cry.
>
> *Invisible disease: Rheumatoid arthritis and chronic fatigue (NRAS survey 2014)*

Work is as important to people with RA as it is to anyone else: three-quarters of people with RA are diagnosed when of working age. But RA and its symptoms, especially fatigue, can complicate matters. Fatigue may disrupt your working life. It may make it hard to get a job in the first place and to retain a job when you have one. It can hold you back from promotion. You may find yourself worrying that absences or poor performance due to fatigue could cost you your job.

In our **Invisible Disease survey** of people with RA, almost three-quarters (71 per cent) of those of working age who were unemployed said that fatigue was the reason they did not work. And almost a quarter (24 per cent) of all those surveyed said that they had had to change jobs because of fatigue. The same survey also reported that almost a quarter (23 per cent) of respondents in employment had taken more than 10 days off in the preceding 12 months due to fatigue; for those diagnosed for less than a year, the proportion rose to more than a third (34 per cent). But almost a half (49 per cent) of respondents said their line manager had not discussed or offered any changes to help them better manage their chronic fatigue in the workplace.

Fatigue Matters

- Fatigue may disrupt your working life.
- Take all the breaks you are entitled to at work – get away from the workplace or at least workstation, for lunch if you can. And make sure you get plenty of rest and support outside working hours.
- Talk to your employer and/or work colleagues about the support you need.
- Consider taking this booklet to work, to share with your manager and work-mates.
- You have a right to ask for and your request to be considered for flexible working hours, whether you are disabled or not.
- The law offers protection from discrimination at work because of your disability.
- Unions, professional bodies, and other organisations may be able to support you in any discussions with or challenges to your employer. You are not on your own.

But while fatigue can complicate matters, there is much that can be done to improve your working life. To begin with, here are some tips for helping you cope better with the working week:

- Pace your activities for work as you would at home. If some elements of your work are more physically demanding, see if you can spread this out across the day/week, rather than doing them all in one session.
- Re-examine the way that you work on a regular basis to see if there’s an easier way for you to do the job. For example, are you sometimes performing tasks while standing when you could be sitting?
- If you drive to work, find out whether there’s a car-share scheme in your area. That way, you can try and rest while someone else drives.
- Fresh air helps. Take a 10-minute walk during your lunch break to get the circulation going and to get away from the working environment. It will also give your brain a break.
- Take your lunch break away from your workstation if possible – a change is as good as a rest.
- Talk about the impact of fatigue with family and friends; how it affects you after a day’s work and the support you might need.
- Keep meals during the week simple and nutritious. Get your partner and family to help you.
- When you cook, perhaps at the weekend, make extra and freeze it for use during the working week.
- If you live with someone else, ask them to cook a couple of nights a week.
- Invest in a slow cooker to cook things overnight or during the day so that you come home to it all ready for you.
- Keep any housework during the week to a minimum.

- Get help with shopping or, better still, do it online and get it delivered.
- Get to bed early on the nights (or days, if you do night shifts) before you have to go to work.
- Help the family understand that you may need a lie-in at the weekend.

But it’s not all up to you. Your colleagues should also play their part. Start by talking to them about your RA. It may be that the reason why you have not been offered any support at work is that your employers are not aware that you need any support. It is a good idea to start that conversation, perhaps with your line manager or with the HR department – or, if you work in a small business, with your employer. You should explain how fatigue affects you. You may want to show them your fatigue diary and/or give them a copy of this booklet. You also have a legal right to request flexible working. That means that your start and finish times can be flexible and/or that you can work at home on some days. Your employer must respond to your request in a ‘reasonable manner’ – this would include weighing up the advantages and disadvantages of your application; meeting with you in person to discuss your requirements; and offering you a right to appeal against their decision. If your request is not handled in a reasonable manner, you can take your employer to an industrial tribunal. Your request for flexible working may be turned down if your employer has a good business reason for doing so. The rules on flexible working are the same in England, Scotland, and Wales. They are slightly different in Northern Ireland. For more information, visit www.gov.uk, www.acas.org.uk or, for people in Northern Ireland, www.nidirect.gov.uk.

Apart from offering flexible working, employers can help you by making adjustments in other ways. Such adjustments might include obtaining specialist equipment to help you do your job with less effort; changing the workplace layout to minimise the distances you have to move about during the working day; offering a car parking space and time off for medical assessments and treatment. By law, employers are required to make ‘reasonable adjustments’ for employees with a chronic health condition or disability. An occupational therapist (OT) can assess your workplace and the way in which you carry out your job in order to make recommendations about the adjustments that you require. An OT can also talk to your employer on your behalf about the adjustments, including flexible working, that would help you. Your healthcare team may be able to refer you to an OT or you can seek a consultation with a private OT (who will charge you for their time). There is also a government-funded organisation called Fit for Work that offers support and advice from a team.

The provision of Occupational Therapists (OTs) to employees with a chronic health condition or disability is an important service. Employees can access this service independently, while employers and General Practitioners (GPs) can also refer employees or patients to the scheme to facilitate a return to work after being on sick leave for four weeks or more.

Fatigue Matters

If you live in England or Wales, visit www.fitforwork.org or call the advice line on **0800 032 6235** to find out what support is available. In Scotland, the scheme is no longer taking referrals, but advice can be obtained from their website at fitforworkscotland.scot or their free helpline on **0800 019 2211** (Monday to Friday, 9am to 5pm). Working Health Services Scotland is an NHS service that aims to help employees of small-to-medium enterprises remain in or return to work quickly after a period of absence.

The Access to Work scheme can advise disabled employees about how to get the support they need at work. They may also offer grants to cover some of the costs of making any reasonable adjustments required. Access the scheme online at www.gov.uk/access-to-work or by consulting a Disability Employment Adviser (DEA) at your local JobCentre or Jobs and Benefits Office. A DEA can also advise on returning to work if you have recently become disabled or lost your job due to your disability. More information is available at www.gov.uk and www.nidirect.gov.uk.

For further information, visit the Healthy Working Lives website at www.healthyworkinglives.com or call **0800 019 2211** and select option 3. The Fit for Work scheme does not apply in Northern Ireland.

National Rheumatoid Arthritis Society (NRAS)

In Northern Ireland, The Disability Employment Service (DES) provides support to employers to help them recruit and retain employees with health issues or disabilities. Visit www.nibusinessinfo.co.uk or www.nidirect.gov.uk.

The law protects people with a disability or long-term health condition from discrimination at work, including during the application process. For more information if you live in England, Scotland, or Wales, contact The Equality and Human Rights Commission (EHRC) by visiting www.equalityhumanrights.com or calling **0808 800 0082**. In Northern Ireland, contact The Equality Commission for Northern Ireland at www.equalityni.org or on **028 90 500 600**.

If you are a member of a trade union or professional body, contact them for advice about your rights at work. They can also support you in any dispute with your employer, including providing a representative to accompany you to any meetings about the dispute. If you are not a member of a union, contact the Trades Union Congress (TUC) at www.tuc.org.uk or on **020 7636 4030**. In Northern Ireland, contact the Irish Congress of Trade Unions Northern Ireland Committee at www.ictuni.org or on **028 90 247 940**.

The Advisory, Conciliation and Arbitration Service (ACAS) provides information, advice, training, conciliation, and other services for employers and employees to help prevent or resolve workplace problems. Call **0300 123 1100** or visit www.acas.org.uk.

NRAS is committed to addressing the impact that Rheumatoid Arthritis (RA) can have on work and Juvenile Idiopathic Arthritis (JIA) on education. We have conducted surveys on work in 2007, 2010, and 2017, and are developing new resources for working individuals with RA/JIA. NRAS is an active member of the Fit for Work Coalition, which unites healthcare professionals, policymakers, employers, and patients to enhance the productivity of Britain's workforce by empowering and supporting people, including those with long-term conditions, to remain in or return to work.

NRAS is also part of the Expert Advisory Group to the Work and Health Unit, spanning the Department of Health and the Department of Work and Pensions. We campaign for better workplace support for people with long-term fluctuating conditions, including raising awareness of the invisible symptoms of RA and JIA, such as pain and fatigue, with government agencies responsible for assessments for benefits like Personal Independence Payment (PIP) and Employment and Support Allowance (ESA).

Does Fatigue Affect My Eligibility for Benefits?

There are several benefits you may be eligible for; however, fatigue may play a key role in determining your eligibility for two specific benefits: Personal Independence Payment (PIP) and Employment and Support Allowance (ESA). PIP can be claimed by individuals in or out of work, while ESA is for those with limited capability for work due to disability. PIP and ESA are for people of working age; after retirement, those needing additional help due to illness or disability can claim Attendance Allowance.

To be eligible for either PIP or ESA, a diagnosis of RA alone is insufficient. You must demonstrate that your RA limits your ability to work and/or perform a range of everyday tasks and activities.

These assessments are not adept at considering hidden and fluctuating symptoms such as fatigue. Clearly explain how fatigue affects you. A diary tracking your fatigue and other symptoms is useful evidence to submit with your claim.

The healthcare professional managing your care will be asked about how RA affects you. Ensure they are updated on how all your symptoms, including fatigue, impact your daily tasks. When applying for either benefit, you will complete a detailed questionnaire about your health, focusing on your ability to perform various everyday tasks. It is crucial to include fatigue among your symptoms and explain its impact on your daily activities.

If fatigue affects your cognitive abilities, such as causing 'brain fog,' mention it. The questionnaire does not specifically ask about fatigue, but there are opportunities to provide examples of how fatigue affects you. For instance, the PIP assessment form asks about your ability to mix with other people (question 11), where you can explain how fatigue makes social interactions challenging. Question 14 asks about your ability to move without severe discomfort, where you can mention that fatigue, not just pain and stiffness, can make movement difficult.

In addition to the detailed assessment form, PIP and ESA assessors will request the name of the person managing your treatment (e.g., GP or consultant rheumatologist) to contact them for information about your health. It is advisable to discuss your symptoms with them before submitting your claim form to ensure they are fully informed. They may also offer advice on completing the form. Including a fatigue diary or a comprehensive symptom diary as part of the evidence for your benefit claim is beneficial.

Once your claim is submitted, you will be asked to attend a medical assessment, typically at an assessment center. If travel is not possible, arrangements can be made for the assessment to occur at your home, provided a letter from your healthcare provider is available.

A doctor must explain that you cannot travel before they will agree to a home assessment. The in-person medical assessment tends to focus on your physical capabilities on the day. Such assessments are not good at assessing the impact of hidden and fluctuating symptoms such as fatigue. For example, it may be that you are having a good day when the assessment takes place but on the following day your fatigue is so severe that you cannot function at all. That’s why a diary and as much other evidence about how you are affected over a period of time (such as an app on your mobile phone or tablet) is very helpful and should be taken along to the assessment.

If you are turned down for either benefit or if you think the level of benefit awarded is too low or, in the case of ESA, if you are judged to have some capability for work when you don't think you have any, you can ask for a 'mandatory reconsideration' of the decision. You can ask to be sent copies of all the evidence used in reaching their decision. In return, you should state in clear terms why you are asking them to reconsider: for example, you could say that you believe they have underestimated the extent of your disability and its effect on your ability to carry out everyday tasks. This would be another opportunity to emphasise the impact that fatigue has on you. If the reconsideration does not lead to a change in the original decision, you can then lodge an appeal. It is important to note that many people do win on appeal, so it is well worth pursuing.

How to Claim

For detailed information on PIP and how to apply for it, see our booklet **How to claim Personal Independence Payment (PIP)**. For further information on ESA and a range of other benefits, see our publication **Benefits and rheumatoid arthritis**. There is also information on our website and our Helpline can help answer any questions you might have. The website www.gov.uk has up-to-date information about all benefits and how to apply for them. Your local Citizens Advice office can also offer advice and support – visit www.citizensadvice.org.uk for contact details. If you live in Northern Ireland, visit www.nidirect.gov.uk for information about benefits.

Glossary

- **Anaemia**: A condition where the number of red blood cells in your blood is at a low level. The red blood cells carry oxygen around the body and if they are depleted your muscles and other body tissues won't get enough oxygen. One of the main symptoms of anaemia is tiredness. The main causes include iron deficiency, vitamin B12 deficiency and several diseases, including leukaemia and sickle-cell disease. Anaemia can be diagnosed by means of a blood test. If it is caused by iron or vitamin B12 deficiency, it can be treated with dietary supplements and by increasing the foods in your diet that are rich in iron and vitamin B12.

- **Autoimmune**: Describes a condition where the body's immune system attacks part of the body itself. The immune system is our defence against infection. It is an incredibly complex system that, for most of us, works well. But sometimes, something goes wrong and the immune system mistakes some parts of the body for a damaging invader (a virus, for example) and attacks it. In such cases, a person develops an autoimmune condition, the 'auto' part of the word here meaning 'self'. RA is an autoimmune disease, in which the immune system attacks the lining of the joints. Other autoimmune diseases include multiple sclerosis, in which the protective coating of nerves (myelin) in the brain and spinal cord is progressively attacked and weakened by the immune system, and type 1 diabetes, where the pancreas is attacked. One of the main damaging mechanisms of autoimmune diseases is inflammation.
- **DAS28**: A measure of disease activity in RA. It combines the results of four measures: the number of joints (out of 28 examined) that are swollen; the number of joints (out of the same 28) that are tender; the levels of certain markers of inflammation in your blood; and your own assessment of your overall health. A score greater than 5.1 indicates that your disease is active; less than 3.2 indicates low disease activity; and lower than 2.6 means your disease is in remission.
- **Depression**: A state of low mood. It may be caused by a difficult life event, such as bereavement or illness. It may also be a result of a long series of events, including a difficult childhood. People with a family history of depression have an increased likelihood of developing it themselves. Some medications can cause depression. Depression can be relatively mild and of short duration; it can be severe and long-lasting. It can be associated with feelings of guilt, worthlessness, anxiety (as if something dreadful is about to happen) and a lack of interest in any activities. People with depression tend to become withdrawn and inactive. They may have suicidal thoughts. They may also be irritable, sometimes angry, and can experience insomnia and a lack of sex drive. Too many people seek help for depression very late, partly because of not recognising the early symptoms of depression. Yet depression is not something to be ashamed of; it is a treatable condition that many people experience at some time in their lives. Treatments include 'talking therapies' such as cognitive behavioural therapy (CBT) or psychiatric support. Antidepressant medication may also be offered.
- **Disease activity**: Refers to the severity of your disease. The more active it is, the more damage it is likely to cause to your joints. One of the principal aims of treatment of RA is to keep disease activity as low as possible. Disease activity is measured by the DAS28 tests.

- **Flare (or flare-up)**: When RA disease activity is very high and symptoms are severe. During a flare, you will tend to experience increased joint pain, swelling, fatigue and stiffness. You may also feel increasingly low in mood. Fatigue may be an 'early warning system' for flares, a sign that your disease is becoming more active. Many flares can be self-managed, but if they are occurring frequently, you should contact your healthcare team as soon as possible.
- **Inflammation**: One of the main mechanisms by which the body's immune system deals with infection. If, for example, you get a splinter in your finger, you will soon notice redness and swelling where the skin has been pierced. That is typical of an inflammatory response. A sore throat is another example of inflammation, usually caused by the immune system responding to an infection such as the common cold. In RA, the immune system causes inflammation in the lining of the joints, which can cause damage to the joints themselves. One of the goals of treatment of RA is to minimise inflammation.
- **Juvenile Idiopathic Arthritis (JIA)**: Refers to inflammation in a child's joints that isn't caused by any other condition.
  - **Juvenile**: The child was aged 16 or under when the problem started.
  - **Idiopathic**: The cause is unknown.
  - **Arthritis**: There is inflammation inside the joint, which can be seen through swelling, warmth and reduced movement. There are different types of JIA, some of which can be short term, while others continue into adulthood.
- **Remission**: Derives from a word meaning slackening or weakening. In medical terms it refers to a period when a person's disease has greatly weakened or abated. RA is said to be in remission when a person's DAS28 score is lower than 2.6. It means that disease activity is minimal. For most people that also means that their symptoms are minimal, too. However, for some people some symptoms – pain and fatigue, for example – may persist even when they are in clinical remission. If that is the case for you, let your healthcare team know as there may be things that can be done to make you feel better.
- **Rheumatoid Arthritis (RA)**: An autoimmune condition in which your immune system attacks the lining of your joints (the synovial lining). This causes inflammation, which leads to symptoms such as pain and stiffness. RA is a symmetrical condition, meaning it affects joints on both sides of the body equally.

Arthritis, meaning that it usually affects both sides of the body in a similar pattern, although this is not always the case. It tends to affect the small joints of the hands and feet first – often the knuckle joints in the fingers. It is described as a polyarthritis, meaning that many joints can be inflamed. RA is a systemic disease – it doesn't just affect joints. RA can affect a person's whole system, including organs such as the lungs, heart and eyes. Around

400,000 people in the UK are living with RA, more than two-thirds of whom are women.

Fatigue Matters

Rheumatoid cachexia affects most people with RA. ‘Cachexia’ means weakness and wasting of the body due to chronic illness. In RA, it causes muscle wasting and an increase in body fat. The condition is not automatically reversed when people are in remission. Andrew Lemmey, Professor of Clinical Exercise Physiology, School of Sport, Health and Exercise Sciences at Bangor University, reported in the Winter 2015 issue of NRAS Magazine that ‘we regularly find that two-thirds of our stable RA patients are significantly muscle wasted and 80 per cent are obese’. However, he goes on to say that exercise can reverse muscle loss and weight gain. In a study he and his colleagues conducted, people experienced a doubling of their muscle strength and a significant loss of body fat following a 24-week exercise programme.

National Rheumatoid Arthritis Society

- **Organisations that can help:**
  - NRAS: www.nras.org.uk
  - NHS Choices: www.nhs.uk
  - Disabled Living Foundation: www.dlf.org.uk or call 0300 999 0004
  - Relate: www.relate.org.uk or call 0300 100 1234
  - Access to Work: www.gov.uk/access-to-work
  - ACAS: www.acas.org.uk or call 0300 123 1100
  - Equality and Human Rights Commission: www.equalityhumanrights.com or call 0808 800 0082
  - Fit for Work: www.fitforwork.org or call 0800 032 6235
  - Trades Union Congress (TUC): www.tuc.org.uk or call 020 7636 4030
  - Citizens Advice: www.citizensadvice.org.uk

Other NRAS Publications

- **New2RA:** A self-help guide for people newly diagnosed with rheumatoid arthritis.
- **Living Better with RA:** A self-help guide for people with established disease, including Juvenile Idiopathic Arthritis.
- **Medicines in Rheumatoid Arthritis:** Understanding why certain medicines are used, when they are used, and how they work to manage the condition.

- **Invisible Disease:** Rheumatoid Arthritis and Chronic Fatigue, a survey of 1,954 people with RA.

For all other NRAS publications, see www.nras.org.uk/publications. To obtain copies of any of our other booklets, or more copies of this one, please call 0845 458 3969 or email enquiries@nras.org.uk.

Emotions, Relationships & Sexuality

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

Work Matters

A UK wide survey of adults with Rheumatoid Arthritis and Juvenile Idiopathic Arthritis on the impact of their disease on work.

I Want to Work

A self-help guide for people with Rheumatoid Arthritis to find the help needed to stay in their job.

An Employer’s Guide

When an Employee has Rheumatoid Arthritis: A guide about RA and how it can affect people at work.

Benefits and Rheumatoid Arthritis

A simple guide to the main benefits that could be available to people with rheumatoid arthritis.

How to Claim Personal Independence Payment

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

Your Phone Numbers and Contacts

- Your hospital number
- Your consultant's name
- Telephone number for consultant's secretary
- Your rheumatology specialist nurse
- Pharmacist number
- Your GP's name
- GP surgery telephone number
- GP out-of-hours number
- Medications homecare delivery number
- NRAS freephone number: 0800 298 7650

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

- Name of drug
- Dosage

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

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

Join Us

You can become a Member of NRAS for as little as £20 a year.* You will be helping our work and helping us to provide help and support to all affected by RA. In addition, you will become part of a vibrant and supportive community of people affected by RA. You will also receive a variety of Member benefits, including:

- The NRAS Members’ magazine three times a year
- Monthly email updates
- An invitation to attend our FREE meetings and events

Join us today by calling 0845 458 3969 or by visiting our website at www.nras.org.uk/join. There is an online form you can fill in or you can download a printable application form to complete and send in by post.

Members’ Magazine

Please read & share

Future Support

To build a better future for those with RA and JIA, consider a gift in your Will. Contact us at legacy@nras.org.uk.

*If you pay by direct debit.

NRAS Lottery

Join the NRAS Lottery. Find out how on page 30.

Get in Touch:

- Website: www.nras.org.uk
- Phone: 01628 823 524

Fatigue Matters

Notes 51

Fatigue Matters: A self-help guide for people living with rheumatoid arthritis

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- Email: helpline@nras.org.uk
- Website: www.nras.org.uk

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Join the community:

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- healthunlocked.com/JIA

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