

I Want to Work

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



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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**, it 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.

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 **01628 823 524**

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 **01628 823 524**

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).

Please note that the information in this booklet is a guide only, and is not intended as a substitute for individual guidance from appropriate agencies. While we have made every effort to ensure this information is accurate at the time of going to press, please be aware that details may change. We strongly recommend you seek advice according to your individual circumstances, as we cannot be held responsible for any consequences arising from reliance on the information in this booklet.

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Foreword

Dame Carol Black
DBE CBE MD PRCP MACPF MedSci
Expert Advisor on Health and Work
to the Department of Health, England

As a rheumatologist by background I have a great understanding of the problems faced by people with rheumatoid arthritis in the workplace. I was therefore particularly pleased to be asked to write this foreword.

Work is an important part of life and helps people keep hold of their self-confidence and sense of purpose. Supporting people with long-term health conditions can also have a positive, long-term impact on an organisation's productivity.

Employers are learning that retaining and supporting people through many common conditions can be a more sensitive and cost effective way of retaining staff, rather than absorbing the substantial costs of redundancy and recruitment that will apply if they lose staff who have long-term health conditions.

There is a wealth of innovation and excellent work being done. As National Director for Health and Work I am keen to support all the people who are working hard to achieve our common goals. Improving health and well-being in the context of life and work is a priority for the Government, along with achieving the related goals of



Photo: Katy Blackwood

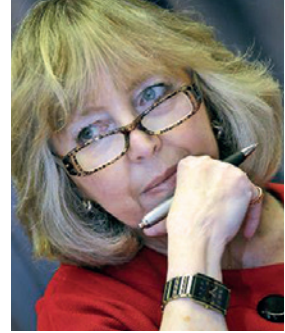
reducing health inequalities and offering improved opportunities for every person of working age.

I am delighted that NRAS have produced this booklet about rheumatoid arthritis and the effect it can have on working lives. The workplace is a key venue for the early intervention and treatment of ill health should it occur. In the modern workplace it is important that jobs are adaptable and flexible to facilitate keeping people at work or returning to work more quickly following a period of illness.

This booklet provides a practical and definitive source of guidance and information to help employees deal with the long-term implications of working with rheumatoid arthritis.

About this booklet

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



If you have rheumatoid arthritis and you want help to remain in work or to return to work, then this booklet is for you. In it you'll find up-to-date and accurate advice and information, to make sure you can find the help you need to stay in your job. If you're worried about your career following a recent diagnosis of RA, you can find more information about what kind of support you are entitled to. This booklet also discusses the options of re-training or moving to different types of job within an organisation. These can be worth thinking through if you're feeling that you may have difficulties continuing in your current role, due to physical limitations for example.

Rheumatoid arthritis is still a poorly understood condition. Treatments have improved a great deal. Today people who are diagnosed with RA have far more effective treatments than they did in the past – much better than they did 25-30 years ago, when I was diagnosed. The Goal is now to diagnose RA at an early stage and treat quickly with far more effective medication. With understanding and support from

employers and healthcare teams, it is possible for most people with RA to remain in work for as long as they wish.

However, this does not always happen. NRAS have carried out major surveys on employment and the impact RA has on peoples' working lives in 2007 and 2010 and most recently in 2017. The findings suggest that still far too many people are having to give up work early due to their RA.

The findings also shed light on some of the less obvious costs of rheumatoid arthritis. For people in employment, the picture is often one of slowed career progression, changes in employment to accommodate their rheumatoid arthritis and uncertainty about the future, as they face the possible loss of income and pension contributions. It was also clear that when people experience problems at work, it can have a major impact on their social life and their relationships with their partners and families. The NRAS booklet *Emotions, Relationships and Sexuality* explores the impact of RA and is available online or by calling NRAS.



What is encouraging, however, is that many of the barriers people experience in the workplace are not impossible to overcome. Our findings suggest that several factors are important in helping people to remain at work. These include: awareness and understanding from employers; help with travel arrangements; help with specific adaptations or equipment; and urgent access to rheumatology teams when people need help. We have taken this message to government.

We hope that this booklet will be helpful for employees, health professionals and organisations who advocate for the rights of people with long-term conditions.

I am grateful to all the individuals, health professionals, organisations and NRAS members who have made such valuable contributions to this booklet.

How can Rheumatoid Arthritis affect my employment?

The effects of rheumatoid arthritis are different for everyone, some people are more severely affected than others. You may find it more difficult to cope with work at some times than at others, because of your changing symptoms.

The most common symptoms that can affect whether you can continue to do your job normally are:

- Problems with mobility or functioning as a result of damage and
- Inflammation in the joints
- Early morning stiffness
- Pain
- Fatigue

How you manage your symptoms can depend on the type of work you do and it also depends on having good medication to control your arthritis, effective pain control and the right support from your rheumatology team. Some people with mild or well controlled RA can continue working normally with very few problems, but most people face some challenges in the workplace at some point. In our most recent survey almost 20% of respondents had to leave or retire from work as a direct result of their health issues of which RA was the most

significant. However since the first survey in 2007 the percentage of those in employment had risen from 55% to 63% which is encouraging.

All three surveys showed similarities in the problems people faced in the workplace and that contributed to them leaving or changing their work. They include:

- Taking time off when they were having a flare or unwell
- Getting to and from work
- A lack of understanding from their employer
- Employers' reluctance to make adjustments
- A lack of understanding from their colleagues
- Physical limitations to being able to carry out the work tasks
- Fatigue affecting the ability to work to full capacity

The good news is that many of the problems can be overcome. With the right support from their employer, rheumatology team and patient support groups, many people find that problems in the workplace can be successfully managed so that they can remain in their job. Some manual jobs may be

more difficult to manage, particularly if they require heavy physical work, standing or lifting. It may be necessary to consider other options, such as changing your duties, having additional training or seeking an alternative type of work.



Tip: take time to make decisions

Remember: it can be difficult in the early days, when you are experiencing symptoms, you may not have a definite diagnosis and you've not yet started on treatment.

It can take some time (several weeks or even months) for treatment with disease modifying anti-rheumatic drugs (e.g. methotrexate, sulfasalazine, leflunomide) to take effect. However, once your treatment takes effect and your disease is better controlled, you should notice an improvement. So don't rush to make decisions about the future during that early period.

At the beginning it was difficult lifting and carrying things. Even to pick and carry a ream of paper for the photocopier was a task. Once I started treatment things began to improve and now I'm back to 95% compared with how I was before diagnosis.

Rosanna
Information Officer

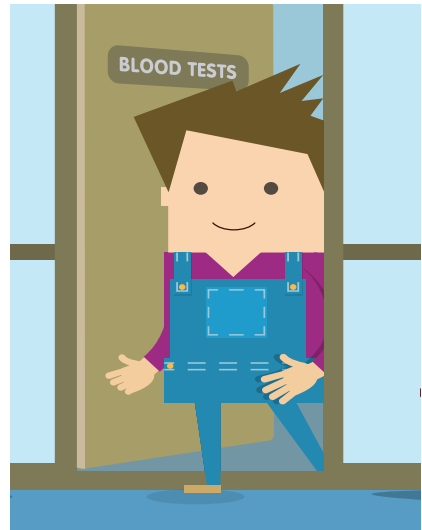


What are the benefits of employment?

Staying in work is likely to be one of the most important goals for you and your family. And according to Dr Patrick Kiely, consultant physician and rheumatologist, it is not an unrealistic one. 'For many patients with newly diagnosed or established RA, today's treatments can suppress the activity of your disease so successfully that you feel well, you have energy and you can continue to work', he explains.

Work isn't only about the money. Of course it is better financially if you can stay in work, but there are other important benefits in working. Research has shown that people who are able to work are more likely to have:

- Better self-esteem – leading to
- Less depression
- Less pain
- Less isolation, because of their social interaction with colleagues or workmates



I suppose I could have just accepted that with RA I would stop work, go on the dole and put a sticker in the car. As it turns out the only time I take off now is for blood tests or hospital appointments. The biggest bonus is that I thoroughly enjoy the work. I've become wrapped up in it, and that makes all the difference.

Stephen
Full-Time Sheet Metal Worker



Helping people to stay at work

Dr Bruce Kirkham
Consultant Rheumatologist

Alyssa Macedo
Specialist Occupational Therapist, at Guy's and
St Thomas' NHS Foundation Trust

Our research for the Trust's specialist RA Centre clinic shows that for many people, staying in work is both possible and worthwhile.

'Over the past few years, we've been investigating trends in work life and the overall health of our employed RA patients. In 2005, we surveyed 700 RA patients, and 82% of our employed RA patients felt that having their job helped them manage their condition. When we investigated work life further, we found two things. First, we found that working tends to help in keeping our patients active, motivated and connected with society. But second, we found 50% of them struggle to remain in work. So we then did an initial study with over 30 RA patients who felt they were at some risk of stopping work in the future, because of disability. We set out to investigate if we could keep them in work. Our findings show that we could keep our patients securely employed if they had focused medical care that takes account of their needs at work, and occupational therapy to help prevent and address specific problems. We also found that being securely employed increased people's overall quality of life and job satisfaction, and reduced their pain. We plan to assess if these advantages can be translated to a wider population from other centres in the near future.'

Other recent studies have also shown that work is an overall contributor to health and wellbeing. It seems clear that participation in paid work is good for you! For most adults, it's a major part of their life, part of their identity and it contributes to their overall health.'

The main benefit of work is that I have something else to focus on other than the pain and discomfort. There is no time to mope around feeling sorry for myself so I just get on with it. I have a daily goal of getting through the working day and getting my job done well. Working has helped boost my self esteem a great deal. I truly believe that if I wasn't working, my RA would have progressed faster and I would be in a worse state than I am now.

Ms A.T.
IT Analyst, aged 34



Whom should I tell that I have RA and when?

There is no 'one size fits all' answer: you will need to make a judgement about the best time to tell your employer. Your decision will of course be influenced by the type of work you do and whether, or how much, your RA affects your ability to do the job.

If you're currently employed

It is particularly important to consider telling your employer if you think you may need some help to continue to do your job to a reasonable standard, now or in the future. This may help avoid the possibility of your employer treating any future problems with your work as a disciplinary issue. You are protected against unlawful discrimination on the grounds of disability from the first day of your employment, as long as your employer knows or can be reasonably expected to know about your condition. It is not lawful to be treated less favourably than a non-disabled employee by your employer, unless the employer is able to lawfully justify this less favourable treatment. [Justification will depend on the circumstances of the individual and the employer.] There is no qualifying period for discrimination, unlike other employment rights (for example, the right not to be unfairly dismissed where there is a two year service requirement). So it is generally good practice not to delay telling your employer.

Large employers normally have their own human resources (HR) department and many have access to an occupational health practitioner. They may ask you to have an assessment so that they can fully understand your ability to do your work and provide appropriate support. When you are offered an assessment it is normally in your best interests to do this. It is important that the HR Department works with your line manager so that he/she knows about the process – and ideally is supportive of it – or you may find there is a difference between corporate promises and the 'real world' of the business day to day.

Smaller companies often do not have a professional HR person or use occupational health resources, and may not be familiar with working with employees with a disability. However, such companies are perhaps more likely to treat you as an individual. It is important to tell them what you can do now and explain how your RA may impact on your role.



I had only just been diagnosed with RA when my new boss started with us. She was very unsympathetic to the condition. Added to this she didn't know me very well and thought I was very short-tempered and miserable. I was in a state of shock at the time and found it hard to convey my feelings.

Peter
Building Control Officer

It may be a good idea to give your manager a copy of the NRAS Employer's Guide so that they better understand the impact of RA on the individual and the employer's legal responsibilities.

You may wish to tell colleagues about your RA. Again this is a decision only you can make, but it may be in your interests. If you've had adjustments made to your job, telling colleagues can help them to understand your abilities and have an appreciation of what living with RA is like, including the impact of pain. However, you can ask your employer to keep the information confidential, if you prefer. If you do not tell your employer about your condition, you are not necessarily protected if your employer is found to not know about your disability in a discrimination case. Figures relating to employers who did not understand the disease have increased since 2007. Small businesses may be less likely to have internal HR departments and less likely to understand the requirements of the Equality Act 2010.

NRAS has published a guide for employers, with information about RA and how they can support employees who have RA.⁵

If you're applying for a job

As a general rule, you should be upfront with a prospective employer about the fact that you have RA. However, it is not a requirement and some people choose to wait and see how the recruitment process goes before deciding whether to tell them or not. Many organisations have previously used health screening processes as part of their recruitment process, but, as part of recent changes in the Equality Act, employers should, generally, not ask candidates to complete any health questionnaire, attend a medical, or ask any questions relating to the employee's health until they have made a formal job offer. Employers may still ask candidates if they have any disabilities that would require reasonable adjustments being made



to the recruitment process. Employers may also ask specific questions to establish whether or not an applicant will be able to carry out an “intrinsic” (or absolutely fundamental) function of the work, however, such questions should be clearly relevant to candidates. If, after a job offer has been made, you are asked specifically about your health, you must of course answer truthfully, and discussions at this point in the process should include reasonable adjustments that may be made to enable you to do the role. If you voluntarily disclose information about your health or disability before the employer has made any job offer, the employer should still not get involved in a conversation with you which is outside the exceptions set out above.

If your RA means that you will need reasonable adjustments to enable you to do the job you have applied for, you should discuss this with the employer before you start work. This is particularly important if there are health and safety considerations. (This could range from your RA affecting your ability to leave a building easily in case of fire, to doors with knobs which are difficult to turn) In practice it is very rare for employers not to be able to make adjustments to comply with health and safety legislation and only rarely should this be a barrier to you continuing in your job. For more details on available funding for adjustments see page 26.

What can I do to cope better at work?

Everyone copes with the effects of their RA in different ways. It's worth thinking about how to make full use of available help. There are some practical things you can do yourself and there is help available in the workplace.



Practical tips

- It helps to be proactive. Find out as much as you can about your rheumatoid arthritis. The more you understand your condition, the more you will feel in control about the decisions you take.
- Give information leaflets about RA to your employer and ask them to read them.
- Remember that your rheumatology team is there to provide support.

If your condition changes or you feel it is not well controlled, **ask for help quickly**. Don't just put up with it – most RA can be kept under reasonable control with effective treatment.

- Ask your nurse or physiotherapist about different methods of pain control. Sue Oliver, nurse consultant, suggests: *'Think of it in two stages. **Step up** when the pain is beginning to be difficult to control: review your **pain control** strategies and increase*

*medication according to your doctor's instructions. **Step down** when the pain is well controlled: review how to reduce your pain control medications gradually, and adjust your additional strategies, e.g. Reduce your resting time as long as the pain remains controlled.'*

For more details contact NRAS to ask for a copy of managing the pain of RA article or visit the website.

- A **physiotherapist** can help with pain management and simple exercises, such as stretching and keeping mobile at work.
- A **podiatrist** can help with problems with your feet or ankles. They can give advice and treatment to help reduce your pain. It can make all the difference at work to have comfortable feet.

For more information visit the foot health area of the NRAS website.

- An **occupational therapist/physiotherapist** usually takes the lead on workplace issues. They can help with: joint care; ergonomic advice (that is, advice on the interaction between people and environment); advice on gadgets and splints. They can also carry out workplace assessments. For more details of how they can help, see page 17.
- If your company has its own **occupational health adviser** you may prefer to approach them first. Their role is to support the health of employees at work. They can be very helpful in getting your employer to understand the impact that RA may have in your work, and in particular that RA symptoms can fluctuate.

Self management

Two of the main challenges to remaining in work are pain and fatigue. Learning how to cope with these is one of the best investments of your time you can make.

There are effective self-management strategies that you can learn and use, including joint protection, pacing, sleep management, exercise, relaxation and stress management. If you can learn these early and use them sufficiently in your daily life, you will see the benefit. Research shows that these strategies help to prevent or slow down problems in the future, if people change their habits and use them enough. This means you can stay in work for longer.

NRAS Groups

NRAS has many local groups for people with RA. While these are not self-management courses, they do help to improve your ability to self-manage as they provide opportunity to increase your knowledge of RA and how to manage it and give you the chance to share experiences with others and help each other cope. To find out if there is a group near you email groups@nras.org.uk or call **01628 823524** or visit www.nras.org.uk/groups

Am I covered by the Equality Act 2010?

The Equality Act (EA) 2010 replaced the Disability Discrimination Act 1995 with effect from 1 October 2010. Under the EA, disabled persons are protected against discrimination when applying for employment, during employment and when their employment is terminated. The EA also imposes a duty on employers to make reasonable adjustments.

Many people with RA and other long-term conditions do not think of themselves as disabled. The NRAS 2007 survey, for example, showed that 52% of people who qualified as disabled under the EA and had rights not to be treated unfairly because of their disability or health condition did not consider themselves to be disabled. However you have protection under the EA if you can demonstrate that you are disabled according to its definition – a person who has a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities.

In the context of people who have been diagnosed with RA, this test can be broken down into four elements as follows:

- **Does the individual have a physical or mental impairment?**
RA is almost always likely to fall within the definition of a physical impairment and, therefore, will satisfy this element of the test.
- **Does that impairment have an adverse effect on the individual's ability to carry out day to day activities?**
Day to day activities are those which are carried out by most people on a fairly regular or frequent basis, for example walking, carrying normal objects, reading and taking part in normal social interaction. They can also encompass activities relevant to working life. Depending on the aggressiveness of the condition, most people with RA are likely to be able to satisfy this definition.
- **Is that effect substantial?**
This is the more difficult element of the definition to satisfy and will require an analysis of what the individual cannot do or can only do with difficulty as a result of the condition. What is key is how the role would be performed by a non-disabled individual, not how well a disabled individual is able to do the task – with or without medication. Importantly with this context, the effect is considered ignoring



the effects of any medication or treatment. Where a person suffers from RA as a progressive condition (one which is likely to change and develop over time), they will be able to satisfy this definition if they can show that although the effect that the RA has on their ability to carry out day to day tasks at the moment is not substantial, this effect is likely to become substantial in the future as their condition develops. How well an individual copes and adapts to their RA does not lessen their legal protection.

- Is that effect long-term? Long-term is defined as having lasted at least 12 months, or being likely to last 12 months or for the rest of the affected person's life. As RA is a long-term condition, people with RA are likely to be able to satisfy this element of the definition.

Protection against discrimination

Under the Equality Act, an employer may not unlawfully discriminate against a disabled person. There are various types of discrimination – see the EHRC Worker's Guidance for more details. In particular, your employer must not treat you less favourably because you have RA than a comparable employee without such a disability, for example, in opportunities for promotion and training, or indeed termination of employment.

There is also a new requirement under the Equality Act for employers to not treat a disabled person unfavourably because of something arising from their disability where this cannot be justified. Disability related sickness is an example of this. If you need to take leave because of your RA, it is

good practice for your employer to distinguish between such 'disability leave' and general sick leave. Your employer may then discount some or all of the disability leave when considering any disciplinary issues, performance measures or selection criteria for promotion or redundancy. This is why it is important for your employer to be aware of your disability. However, you will be subject to the company's normal sick pay policy. An employer does not have to pay more sick pay to a disabled person (although they can choose to).

It is also discrimination if an employer does not make a 'reasonable adjustment' where a disabled worker would be at a substantial disadvantage compared with their non-disabled colleagues. This is covered in more detail in the following section.

'Reasonable adjustments'

If you meet the Equality Act's definition of disabled you can discuss with your employer how reasonable adjustments can be made to your job, equipment or workplace to help you, including the provision of auxiliary aids. The purpose of making reasonable adjustments is to overcome any substantial disadvantage caused by a person's disability and thus enable them to continue working, or return to work if currently on long-term sick absence. An employer's obligation to make reasonable adjustments is an on-going one, so it should be reviewed if your condition changes.

Possible reasonable adjustments in the context of people suffering from RA could include:

- Making adjustments to premises, eg easier door opening
- Allowing the individual to be absent during working hours for assessment or treatment
- Acquiring or modifying equipment
- Modifying the work area
- Allocating some of the disabled person's duties to another person
- Altering hours of work or training
- Assigning to a different place of work or transferring to fulfil an existing vacancy

For more details about adjustments see '*What kind of changes can be made at work?*' on page 22.

The duty of providing reasonable adjustments falls on the employer where a disabled employee is placed at a substantial disadvantage to other non-disabled colleagues because of the way in which business is done, the physical features of the workplace and also the lack of auxiliary aids or services. Anything that is more than minor or trivial is a substantial disadvantage.

When deciding whether an adjustment is reasonable an employer can consider:

How effective the change will be in avoiding the disadvantage you would otherwise

- Experience
- Its practicality
- The cost
- The organisation's resources and size
- The availability of financial support.

For example, it would be reasonable to expect all employers to provide ramps, rails and simple ergonomic equipment for computers and telephones or minor adaptations to machinery. However, if a building has awkward stairs, it may not be physically possible to install a stair lift without extensive additional building work, which might then be considered unreasonable or placing a disproportionate burden on the employer.

Some larger companies with a large workforce may be able to afford to allocate another employee to provide assistance as necessary, whereas a small company with only a few employees may not be financially able to do so.

As a matter of good practice, it is advisable for employers to consult with employees regarding the steps taken to ascertain which adjustments should be made and to agree any proposed adjustments. This is likely to include seeking advice from the individual's GP and/or an occupational health adviser. Be proactive and seek a letter of support from your therapist.

If you cannot reach an agreement on reasonable adjustments and you feel that your employer is being unreasonable, you should raise the matter as a formal grievance. If this does not improve matters you should get some further advice before taking any further action. Your local Citizens Advice Bureau or ACAS (see page 34 for address) should be able to give you advice.

When should I get help with my job?

It's best to seek help at an early stage. Many people put off getting help about work until there is a crisis or they are forced to take more sick leave. Once people go on extended sick leave, they are more likely to lose their job within a few years. Making changes to how you do your job sooner rather than later may keep you in work for longer. It may well also be cheaper as your employer can put changes in place before the problem becomes more costly.

Where do I start? Who can help?

- **Occupational therapists** specialise in enabling people with illness or disabilities to perform work, leisure, daily activities and social roles more easily. They can provide both physical and psychological interventions (e.g. stress management) and information. They can also help with balancing lifestyles and assess the impact of your RA across all aspects of your daily life, to help reduce pain and fatigue in non-work activities too. This helps you to get a good work/life balance and therefore helps you to continue working.
- **Occupational health physiotherapists** also specialise in work problems.
- **Occupational health nurses** specialise in work-related health issues

Any of these professionals can provide workplace advice and/or job analysis and assessments. Assessments can be

carried out by visiting you at work or by a structured interview.

If the therapist can **visit you at your workplace**, they can see your physical environment and what you do. They can evaluate job tasks and advise how you might simplify or modify them to reduce the effort needed. They may suggest changes or adaptations to equipment; 'assistive technology' (meaning gadgets to help you in using equipment); other devices such as splints; changes to your work environment; and changes in how you perform the job. The therapist can analyse how fast you do things, your movements, the positions you're in, and the order of your tasks. Based on this, they can recommend changes to these to make your work easier.

Therapists can also: discuss issues with colleagues and employers sensitively; advise you on how to negotiate with employers about adjustments; help you to think through how you liaise with others at work; and provide advice to help them appreciate your difficulties.

If you do not want or need a workplace visit the therapist can use a **structured interview assessment** to help identify the problems you have or may have in doing your job. These might be, for example, problems with: transport; access within the workplace;

a specific ability or task you need to do the job; your physical and social working conditions. They can help you to prioritise these, come up with acceptable solutions and draw up action plans to make the changes you need.

What kind of changes can be made at work?

Therapists may suggest:

Ways to help relieve pain at work, including:

- exercise programmes to stretch your joints and relieve pain between tasks, e.g. hand exercises
- splints to relieve pain in the wrists and increase the strength of your grip, changes to your footwear, including insoles in your shoes to reduce lower limb pain.
- use of heat or ice packs in the workplace to reduce pain and inflammation
- regular taking of analgesia – including as a preventative measure

Changes to equipment, including:

- adapted computer equipment, such as ergonomic keyboards, an ergonomic mouse and voice-activated software
- better ergonomic seating
- better positioning of office equipment and furniture to reduce strain on joints
- equipment to help with driving to and from work, for example adapted controls, specialist car seats, blue badge

Changes to the physical environment, including:

- ramps, rails, changes to door handles, automatic opening doors
- stairlifts to improve access, parking space nearby, change in working location to
- reduce distance walked or to avoid stairs

Training in new skills, including:

- how to keep the correct posture and protect your joints by using different movement patterns
- how to conserve energy by pacing yourself, so that you reduce pain and fatigue and increase your endurance training in communication skills, to help you negotiate support from your colleagues and employer

Alterations to your hours, including:

- reduced hours, more flexible hours
- working from home for part of the time
- a temporary restriction from shift or night work

'I'm still working full time and enjoying my job'

Jane, a full time teacher, describes her work assessment and the adjustments it led to.

'The visit was a turning point in my life as an RA sufferer. With the adjustments that followed I could continue to support my family as a single parent and achieve a measure of success in the workplace.'

A year after I was diagnosed, a rheumatology nurse carried out an initial work assessment. She recommended that my classroom was relocated, because to reach it I had to climb three flights of stairs about five times a day. The school cooperated and moved my classroom to a more suitable location. I now only have to climb one flight of stairs to the staff room and my classroom is on the same floor.

I had a further assessment about four years later, with a clinical specialist occupational therapist. We filled in a questionnaire, and she inspected all the rooms I used. We met the headmistress and she explained carefully but firmly what my needs were and the adjustments I would need. She explained that these could largely be funded by the Employment Service Scheme, Access to Work.

I now have a suitable chair for my office and classroom, a new computer and screen with voice-activated software, a roller ball mouse, more suitable smaller keyboard and an arm rest I use with the computer. The adjustments are very helpful. I'm still teaching full-time, and enjoying my job.'

How do I find an occupational therapist?

Your local rheumatology department may have an occupational therapist (OT) in the team or in a separate unit in the hospital. You can ask to be referred to OT.

Some NHS therapy services have occupational therapists and physiotherapists who specialise in work assessment. You can ask your GP to refer you to a local occupational therapy or physiotherapy department to find out if they have this kind of service or can refer you on to another department elsewhere.

If these services are not available locally, the following are organisations of specialist practitioners:

- The Royal College of Occupational Therapists www.rcot.co.uk has specialist sections for OTs specialising in Work, Rheumatology, and Independent practice. They can provide work (vocational) assessment and rehabilitation. A list of independent practitioners can be obtained from www.rcotss-ip.org.uk
- The Chartered Society of Physiotherapists www.csp.org.uk Visit the Physio2U section to find a private physiotherapist.

- The Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) www.acpohe.org.uk. The website has a directory of private practitioners in their Physio Near You section.
- Access to Work adviser.

What is a Disability Employment Adviser?

A Disability Employment Adviser provides specialist support to people who are recently disabled or whose disability or health condition has deteriorated and who need help in finding a job or gaining new skills. They can also tell you about programmes and grants to help you back into work such as the Work Choice programme (see page 32).

What occupational therapy can offer

Nicola Briggs, occupational therapist, talks about the services at Queen's Hospital, Burton

'Very rarely do we have to recommend to anyone that they stop their paid or voluntary work. The team here is aware of what work means to people – not just the financial aspect but the social side, the daily routine and the confidence or sense of achievement work may give.

Some individuals are referred here because they're already having difficulties with their work, and didn't know someone could help. For other people, we identify potential difficulties because we're already working with them. Problems can come up with the layout of someone's desk or workstation, fatigue, handling small or heavy tools, or completing specific tasks.

Discussions or assessment may take place within the workplace. We offer advice, specific to each person, about their job and any potential difficulties. There are some things that people can implement themselves, while other recommendations may need input from the occupational health team, the human resources department or managers at work. We can liaise with all of these if people want. We can also liaise with the local Access to Work team who may be able to provide funding for equipment.

There are different options people can consider, including planning and pacing their day, adapting job tasks and altering the hours they work – either in total or their starting time. If people want to change their job but are unsure how or which job to do, we can refer them to a Disability Employment Adviser, who can help match their skills and needs to a type of job.

It's important to us to help people stay in their jobs – because it's so important to them.'

The DEA can also put you in touch with the **Access to Work scheme (AtW)** (this is called the Disablement Advisory Service in Northern Ireland). This scheme provides practical support to disabled people, people with long-term health conditions and their employers, to help overcome work-related obstacles resulting from a disability or health condition. An AtW adviser can give advice on what is available. They may be able to act on an existing report from a therapist, or they may need to arrange for an assessment to determine how much and what type of help you need.

Support and financial help is available for:

- Special aids and equipment
- Support workers
- Travel to and from work, where extra costs are incurred in travelling to and from work because of a disability
- Adaptations to premises and equipment.

Access to Work can pay up to 100% of the approved costs if you are:

- Unemployed and starting a new job
- Self-employed
- Working for an employer and have been in the job for less than six weeks
- Setting up your own business through the new enterprise allowance scheme
- Starting work experience

Whatever your employment status, Access to Work will also pay up to 100% of the approved costs of help with:

- Support workers
- Fares to work
- Communicator support at interview

Access to Work pays a proportion of the costs of support if all of the following apply to you:

- Employers with less than 10 staff – access to work can pay 100% of the approved costs
- Employers with 10 to 49 staff – access to work can pay 100% of the approved costs
- Employers with 50 to 249 staff – employer will have to pay the first £500 and access to work can then pay 80% of the approved costs up to £10,000
- Large employers with 250 or more staff – employer will have to pay the first £1,000 and access to work can then pay 80% of the approved costs up to £10,000
- Access to work would normally cover all additional costs over £10,000

Access to Work funding is available for up to three years. At the end of this period your needs will be reviewed to assess if continued or further funding is required. As long as you need the funding, you should continue to get it. Grants are now capped at £40,800 per year.

Other sources of help

Some private companies also provide workplace assessments. Therapists may be self-employed or employed by health insurance companies, private health companies, or rehabilitation case management companies, some of which specialise in musculoskeletal conditions.

To identify private occupational therapists and occupational health physiotherapists, you can search online at the following sites.

For occupational therapists: The Royal College of Occupational Therapists Specialist Section in Independent Practice

www.rcotss-ip.org.uk

For physiotherapists: Association of Chartered Physiotherapists in Occupational Health and Ergonomics (ACPOHE) at **www.acpohe.org.uk**. Their professional body is the Chartered Society of Physiotherapy **www.csp.org.uk**

Commercial Occupational Health Providers Association COHPA will assist and advise on suitability of different providers in your area **0333 772 0401** | email **manager@cohpa.org**

The Chartered Institute of Ergonomics and Human Factors also lists some therapists and other ergonomics professionals at **www.ergonomics.org.uk**

Some consultancies specialise in problems of workers with disabilities, and others provide general ergonomic workplace advice for preventing injuries-in-the-workplace injury. Look

at the detailed information about their specialist services, e.g. on the internet.

Rehabilitation case management companies may provide a range of services covering physical, psychological and social issues. Some specialise in employment-related services (e.g. ergonomic and worksite assessments, stress awareness, promoting wellbeing, rehabilitation, and planning for a return to work). Practitioners who are members of the Case Management Society UK adhere to the Society's code of practice and standards. To find a practitioner and identify the company they work for search **www.cmsuk.org**, select the Case Management tab on the Home page and then click on 'Find a case manager'.

A new qualification in the UK has recently developed as Vocational Rehabilitation (VR) Counsellor; this is for therapists or other professionals who have completed a certified/ accredited VR training course. The UK Rehabilitation Council's "*Rehabilitation Standards*" and "*Choosing a Rehabilitation Provider*" (2009) may help you identify good quality private providers (**www.rehabcouncil.org.uk**).

National charity AbilityNet provides advice on computing and disability. They help people with a wide range of disabling or limiting conditions to continue using computers. They provide an advice and information service and individual assessments to help people find the right solution. For more information call **0800 048 7642**, or visit **www.abilitynet.org.uk**

Am I entitled to time off for medical appointments?

The Equality Act obliges employers to make reasonable adjustments, one example of which is to allow a person 'to be absent during working or training hours for rehabilitation, assessment or treatment'. The EHRC Code also lists regular hospital appointments as a consequence of disability for which, if unfavourable treatment results, can be classed as discrimination. There is no automatic right to be paid for time attending such appointments, though again many organisations do pay it.

If you take sick leave because of your RA, it is good practice for your employer to discount some or all of these absences when considering any disciplinary issues, performance measures or selection criteria for promotion or redundancy. This is because sickness caused by disability does place those with a disability at a substantial disadvantage compared to those without a disability. However, you will be subject to the company's normal sick pay policy. An employer does not have to pay more sick pay to a disabled person (although they can choose to do so).



I do get paid sick leave and am allowed time to go to hospital appointments, although I do feel they still don't really understand.

Sue
Shop Worker



Should I consider a different type of work?

Some jobs can be particularly difficult to cope with when you have RA, such as jobs that involve heavy manual work and lifting.

Before you make any decision about stopping work, talk to your rheumatology team to find out if they think your disease is adequately controlled. If they feel it is, this can help you to think about the next steps. You might want to discuss the possibility of retraining or transferring to another

job within the company – if this is a possibility. You can consider asking for help from your employer, employer's Occupational Health Service, HR team, NHS Health at Work Network (contracted OH services) or your Disability Employment Adviser.

Changing to a new job

Gill, an administrator, explains how she did it.

'I was offered a three-month trial for another job, very different from what I was used to. My employers gave me full support for this change of direction by opening up training opportunities, mentoring and career coaching. They also offered me designated parking and upgraded existing equipment and minor physical features of the building. My request to work variable hours, including avoiding rush hour travel and splitting my rest and lunch break really helped me by reducing fatigue.

Believe in yourself! The adjustments allow you to integrate, and put the emphasis on what you can do not what you can't.'

What can I do if my employer treats me unfairly?

If you feel you are being treated unfairly because of your RA you should first discuss this informally with your manager. If you cannot resolve your concerns informally then you can formally register your grievance following the company's grievance procedure.

If you belong to a trade union your representative can support and advise you. If the grievance procedure does not lead to an acceptable solution, as a last resort you may have the option to take a case of discrimination through an employment tribunal. You may wish to contact the Equality Advisory and Support Service (EASS) or ACAS for advice.

Before you submit a tribunal claim you should be aware that the disability discrimination questionnaire is no longer in use, but you can use similar questions to help you during the Tribunal process. Please also be aware you will have to pay a fee when you pursue a Tribunal claim. 10a You may be eligible to get money off your tribunal fees if you meet certain criteria regarding income, benefits or savings. In addition legal fees are not covered under Legal Aid. You can represent yourself at hearings, or explore a no win no fee option with a legal firm. Legal fees can also be covered by some household insurance policies.

Please note legal costs are not generally awarded by tribunals, even when the claim is successful.

Useful organisations

Advisory Conciliation and Arbitration Service (ACAS)
www.acas.org.uk (online help) or telephone 0300 123 1100

Citizens Advice Bureau (CAB)
www.citizensadvice.org.uk or telephone local CAB office

Specialist legal advice can help to find a speedy and satisfactory resolution to your concerns and help to avoid tribunal proceedings. (See useful addresses on pages 34-39)

The Equality and Human Rights Commission (EHRC) publish excellent resources for finding out about your employment rights. For more information visit **www.equalityhumanrights.com**

Fighting for a settlement

David, a bank employee, explains why he went to a tribunal, and what the outcome was.

'I wasn't dismissed, but I took early retirement on ill health grounds. I didn't really have a choice. A new manager took over and started to give me low bonuses and poor reviews. He made no offer to alleviate my working situation or make any modifications because of my RA. He fumed that he was fed up with me telling him how RA affected me – he had previously thrown RA pamphlets I gave him straight in the bin in front of me. He said if I couldn't do the job I should resign.

After agreeing to leave, I made a complaint about the way I had been treated. A senior HR manager came to my house and tried to talk me out of it. In the end HR would not proceed with the complaint.

I then took my complaint to a tribunal and solicitors were involved on both sides. A number of HR managers rang me over some months, saying that I would definitely lose the case. They said it was pointless to continue and it would cost me a lot of money.

However, the day before the tribunal, the company rang, and said they were willing to settle financially out of court and also give me a full written apology. I took the offer as I was just worn out by this time!'



Now my RA is under control... I would like to return to work. Where should I start?

The Disability Employment Adviser (DEA) at your local Jobcentre (see page 20 for how to find them) can help you with retraining, seeking appropriate work and practical support to get back into work. They can give you details of suitable vacancies and explain more about the range of programmes available to help you. You may need to consider whether part-time work might be more suitable and could consider looking for a job share or flexible hours.

The type of help you can get through your DEA includes:

- **Employment assessment** to help you find out how your disability or
- Health condition affects the type of work or training you want to do
- Help and advice on looking for a job
- Advice and information about training information on the **Work Choice** scheme. Work Choice can help you get and keep a job if you're disabled and find it hard to work. It's voluntary - you don't have to do it. (Other schemes are available in Northern Ireland – Go to www.nidirect.gov.uk and click on 'People with disabilities' then 'Employment support for people with a disability or health condition' and 'Work schemes and programmes')

The type of help you get depends on what you need - it's different for everyone. For example, you might get help with:

- Training
- Building your confidence
- Finding a job that suits you
- Interview coaching
- Developing your skills

You'll have an interview to see what support you need when you join **Work Choice**. See over for more details.

How Work Choice works

Work Choice is delivered by different providers across the country. They offer 3 levels of help.

Level of help	What you get	How long it lasts
Work Entry Support	Advice on work and personal skills to help you find a job	Up to 6 months
In-Work Support	Help to start work and stay in your job	Up to 2 years
Longer-term In-Work Support	Help to get on in your job and work without support	Long-term

Work Entry Support can be extended by 3 or 6 months in exceptional circumstances and when there is a clear prospect of a job.

- When you're looking for work, look for the 'positive about disabled people' symbol (with 2 ticks) on adverts and application forms. The symbol means the employer is committed to employing disabled people. If a job advert displays the symbol, you'll be guaranteed an interview if you meet the basic conditions for the job.

Other sources of help and advice

- Your occupational therapist
- **Remploy**, a specialist employment services group, provides a range of services (including online support) to help people get the right job. www.remploy.co.uk or telephone **0300 456 8110**
- **Shaw Trust**, a national charity that provides training and work opportunities for people who are disadvantaged in the labour market due to disability, ill health or other social circumstances. www.shaw-trust.org.uk or telephone **0300 30 33 111** or information on Work Choice – Please note you will need to be referred to the Shaw Trust from your local Jobcentre Plus.
- There may be a **local scheme or charity** that can help. Ask at your local Citizens Advice Bureau or Jobcentre Plus
- If you are on long-term sick leave meet with your manager, HR or occupational health nurse to discuss your return to work

Can I apply for any state benefits while I am working?

If you are working you may be able to top up your income with **Working Tax Credit** although this benefit is gradually being replaced by **Universal Credit (UC)** which is a new means-tested benefit payable to people of working age who are on a low income. Over the next few years **UC** will replace the following benefits:- **Child Tax Credit, Housing Benefit, Income-related Employment and Support Allowance, Income-based Jobseeker's Allowance, Income Support and Working Tax Credit**. You can check to see when UC will be rolled out in your area by visiting the Gov.UK website or by contacting your local Citizens Advice Bureau.

If you are out of work or working part-time and are looking for work you may be able to claim **Jobseeker's Allowance**. If you are getting a benefit because you are considered to be incapable of work, such as **Employment Support Allowance**, you may still be able to do some limited 'permitted work'.

Whether you are in or out of work, you may be able to claim **Personal Independence Payment** to cover the extra costs that result from your condition. If you are aged 65 or over, then **Attendance Allowance** may be claimed instead. If you have a carer, he/she may be able to claim **Carer's Allowance**.

For details, see *Benefits and Rheumatoid Arthritis – a simple guide to benefits for people with RA*, available free from NRAS.

About Personal Independence Payment

The Personal Independence Payment (PIP) is an important new benefit for people with rheumatoid arthritis. It is not paid simply because you have rheumatoid arthritis but because of the effect that the symptoms have on your daily life and mobility.

PIP is a non-means-tested benefit which means that you can still claim this if you are working. Payments are not affected by any earnings or savings that you may have, nor treated as income for other benefits which are means-tested such as Employment and Support Allowance, Housing Benefit and tax credits.

You can claim PIP if you meet certain basic qualifying condition and the disability conditions (you can read more about this in our self help guide on PIP or on the NRAS website). You must have met the disability conditions for a qualifying period of at least three months and be likely to continue to meet them for a period of nine months in the future. To be entitled to PIP you must be aged 16- 64. If you are over 65 then you may be able claim Attendance Allowance.

Organisations that can help

AbilityNet

National charity and provider of advice on computing and disability.

www.abilitynet.org.uk

Freephone 0800 048 7642

ACAS

ACAS provides up to date information, independent advice and can help employers and employees to solve problems and improve performance.

www.acas.org.uk

0300 123 1100

Monday to Friday – 8am until 6pm

Access to Work

If you're disabled or have a physical or mental health condition that makes it hard for you to do your job, you can get extra help from Access to Work. You should talk to your employer about reasonable adjustments before you apply for Access to Work.

You can apply by calling the Access to Work helpline. Make sure you have all the necessary details with you when you call.

www.gov.uk/access-to-work

Access to Work helpline: **0800 121 7479**

There's a different system for Northern Ireland: Go to **www.nidirect.gov.uk** and click on 'People with disabilities' then 'Employment support for people with a disability or health condition' and 'Work schemes and programmes'

Advicenow

An independent not-for-profit website providing accurate up to date information on rights and legal issues in the form of factsheets which can be downloaded from their website.

www.advicenow.org.uk

Association of Chartered Physiotherapists in Occupational Health and Ergonomics

A proactive group, promoting best practice in the field of occupational health physiotherapy. Can help you to find a physiotherapist near you with their online search facility.

www.acpohe.org.uk

Benefit Enquiries

If you are looking for help with disability benefits then please look at the relevant numbers alongside or visit the GOV.UK website.

www.gov.uk/disability-benefits-helpline

Disability Living Allowance (DLA)

Born on or before 08/04/1948: **0800 731 0122**

Born after 08/04/1948: **0800 121 4600**

Attendance Allowance helpline

0800 731 0122

PIP helpline

0800 121 4433

Chartered Society of Physiotherapy

Can help you to find a chartered physiotherapist that offers private services.

www.csp.org.uk and select **Physio2u** on the home page

020 7306 6666

Citizens Advice Bureau

The Citizens Advice service helps people resolve their legal, money and other problems by providing free, independent and confidential advice, and by influencing policymakers.

Telephone your local CAB office

www.citizensadvice.org.uk

Commercial Occupational Health Providers Association

COHPA will assist and advise on suitability of different providers in your area.

manager@cohpa.org

0333 772 0401

Civil Legal Aid

A government funded legal aid service available to those who qualify for legal aid. Can provide legal advice about discrimination issues at work.

www.gov.uk/civil-legal-advice

0345 345 4345

Monday to Friday – 9am until 8pm

Saturday – 9am until 12.30pm

Disability Law Service

Provides legal representation for the London area and legal advice for England and Wales.

www.dls.org.uk

020 7791 9800

Monday to Friday – 10am until 5pm (closed from 1pm to 2pm)

Disability Rights UK

Aim to provide high quality information to those living with a disability, including factsheets on work and benefits and contact details for many other useful organisations.

www.disabilityrightsuk.org

General enquiries: **0330 995 0400** (NB this is not an advice line)

The Equality Advice and Support Service

Aims to provide bespoke advice to those facing discrimination issues via their helpline.

www.equalityadvisoryservice.com

Helpline **0808 800 0082**

Monday to Friday – 9am until 7pm

Saturday – 10am until 2pm

The Equality and Human Rights Commission (EHRC)

The EHRC has a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine “protected” grounds – including disability. Their website includes information pages on work and work issues.

www.equalityhumanrights.com

Employment Tribunals

The Employment Tribunals are judicial bodies established to resolve disputes between employers and employees over employment rights. This website provides information about the tribunal's procedures and gives guidance on how you make or respond to a claim.

www.gov.uk/employment-tribunals

0300 123 1024

or ACAS **0300 123 1100**

Monday to Friday – 8am until 6pm

GOV.UK

The best place to find out about government services and information.

www.gov.uk

Institute of Ergonomics and Human Factors

Advice on how to choose and where to find an ergonomist.

www.ergonomics.org.uk

0773 689 3350

Looking for work if you are disabled

Details of local Jobcentres and information about the Disability Employment Adviser are available from the following website:

www.gov.uk/looking-for-work-if-disabled

Law Centres Network

Support a national network of Law Centres that work with some of the most vulnerable and disadvantaged people in society. You can find details of your local Law Centre using the search facility on their website or by calling the general enquiry number.

www.lawcentres.org.uk

0203 637 1330

Remploy

A specialist employment services group, provides a range of services to help people get the right job.

www.remploym.co.uk

0300 456 8110

Royal College of Occupational Therapists

Includes OTs in Independent Practice (OTIP). OTIP has online information about private OT services and can help you find an occupational therapist specialising in work problems near you.

www.rcotss-ip.org.uk

'Click on 'Find a occupational therapist'' and select 'Work/Vocational Support' from the category list.'

020 7450 2330

Shaw Trust

A national charity that provides training and work opportunities for people who are disadvantaged in the labour market due to disability, ill health or other social circumstances.

www.shaw-trust.org.uk

General enquiries: **0300 30 33 111**

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Other NRAS publications



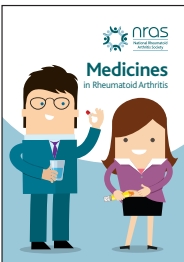
New2RA

New2RA is for people who are newly or relatively newly diagnosed and contains the information you need to help you make sense of and understand what RA is and what you have been told by your rheumatology team.



Living Better with RA

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



Medicines in Rheumatoid Arthritis

We believe it is essential that people living with RA understand why certain medicines are used, when they are used and how they work to manage the condition.



Fatigue Matters

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



The impact of RA on Emotions, Relationships and Sexuality

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



An Employer's Guide to Rheumatoid Arthritis

If you're an employer of someone who has rheumatoid arthritis, we hope you find this booklet useful.



Benefits and Rheumatoid Arthritis

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



RA & Personal Independence Payment

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

For all other NRAS publications, see www.nras.org.uk/publications

To obtain copies of any of our other booklets, or more copies of this one, please call **01628 823 524** or email **enquiries@nras.org.uk**. Copies can also be downloaded from our website at **www.nras.org.uk/publications**



I Want to Work

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

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