I want to work ...

Employment and rheumatoid arthritis. A national picture.
Introduction

From Ailsa Bosworth, Chief Executive, NRAS

Employment is a critical issue for so many people with rheumatoid arthritis. At NRAS, every week people with rheumatoid arthritis ask us for support because they are concerned about their employment. Some are worried about taking time off because of their rheumatoid arthritis; others are having difficulty getting the support they need at work.

Often when people call us they are facing a crisis. They fear they will lose their job or they are worried about whether they will be able to continue working with the symptoms they are experiencing. They want to know what the future might hold, and whether it is realistic to hope they can maintain their career. Many are extremely concerned about the financial burden that results from a change in jobs or losing a job, sometimes at the peak of their careers.

The costs of not working or working reduced hours are high: not only for individuals and their families, but for the economy as a whole. There is now a considerable amount of evidence about this, in addition to the anecdotal evidence we at NRAS and others have collected from the people we support. Traditionally, the costs of health and social care, the personal costs to individuals and the costs to economic productivity have been considered separately – but we now need to challenge this.

In this, our fifth national survey, we have aimed to bring together several aspects of employment and rheumatoid arthritis. We wanted to present, from the patients' perspectives, the first national picture of the impact of rheumatoid arthritis on working lives. We asked for people's views about the barriers to remaining in work, and what support they felt could help. The survey is not exhaustive, as the subject is huge and complex; rather we have focused on specific areas and made suggestions for further investigation. Our findings suggest that large numbers of people with rheumatoid arthritis give up work or retire early as a direct result of their condition – over a quarter of the respondents in our survey. They also shed light on some of the less visible costs of rheumatoid arthritis: for those in employment, the picture is often one of slowed career progression, changes in employment to accommodate RA and uncertainty about the future. The findings also showed that problems experienced at work had a significant impact on people's social lives and their relationships with their partners and families.

What is encouraging, however, is that many of the barriers people experience in the workplace are not insuperable. Our findings suggest that awareness and understanding from employers, help with travel arrangements and specific adaptations or equipment can all play an important role. They also point to other critical factors: greater government support, prompt access to the rheumatology team and effective pain control.

We hope that these results will be helpful for government, employers, health professionals, people with rheumatoid arthritis and organisations who advocate for the rights of people with long-term health conditions.

When I was diagnosed in my early 30s, I was very ill and frequently in and out of hospital. But I was supported by a wonderful boss for whom I had worked since the age of 20. Without his help, particularly during the most difficult years following diagnosis, I would not have been able to continue in my job. He could see beyond the ‘long term condition’ that limited my physical usefulness but not my brain!

Unfortunately, not all employers are like my old boss. But I hope that this survey will help, together with the further publications about employment NRAS is producing during 2007. Our aims are to enable government, employers and health professionals to understand the difficulties people with RA face in the workplace, and to work together to help them remain in work, if that is their choice, for as long as possible.
2 Background to this survey

2.1 Employment: the costs of rheumatoid arthritis

There are around 387,000 people in the UK with rheumatoid arthritis, and every year around 12,000 people are diagnosed. While for a minority of people their disease is less severe and remains well controlled, others experience disabling pain, stiffness and reduced joint function, which have a huge impact on their quality of life and that of their families. One of the most significant impacts for people is the effect of the condition on their working life.

Rheumatoid arthritis represents a huge cost to the UK economy, both in terms of health costs and because of lost working days. The total costs in the UK, including indirect costs and work related disability, have been estimated at between £3.8 billion and £4.75 billion each year. The government’s Welfare Reform Bill, introduced into Parliament in July 2006, recognises the costs to the economy of RA and other health conditions. It is aiming to reform incapacity benefit and to tackle the barriers faced by disabled people and people with long-term health conditions. Specifically it aims to move ‘towards the aim of 80 per cent of the working age population in employment’. While it is recognised by government that health services have an important contribution to make to this agenda, we are at the same time in a climate of increasing pressure on the NHS. Rheumatology health professionals are currently feeling uncertain about the future. Many professionals who work with NRAS tell us that they have seen reductions in service provision, redundancies amongst specialist nurses and allied health professionals, and the failure to renew consultant posts: these factors create a difficult time for health professionals and have a negative impact on patient care. The role of occupational therapists in recent years has also been constrained by a focus on delivering the basic services.

We hope that this survey will provide timely and valuable information for:

- Individuals with RA, about others’ experiences in the workplace.
- Employers, about the kind of problems people experience in the workplace. We hope the case studies will be of particular interest.
- Health professionals, about how the disease impacts on individuals in relation to their work and the crucial need for people to be able to rely on rapid access to expert help when needed.
- Policy makers, about the vital contribution of healthcare services as well as employment support by both employers and government all working together, to enable people with rheumatoid arthritis to continue working.

2.2 The survey and its methodology

The survey was designed by the NRAS team together with an independent market research company specialising in healthcare. Questions were developed from issues raised by NRAS members and calls to the NRAS helpline. This is a huge subject and there are many areas that deserve exploration in greater depth than was possible in this survey. We focussed on questions to provide data that would give a picture of the effect RA has on employment, from patients’ perspectives, while at the same time keeping the survey questionnaire to a manageable size for completion.

We submitted the questionnaire design for review to: three consultant rheumatologists; a rheumatology nurse specialist; and a panel of NRAS members with RA. Amendments were made in the light of their comments. We distributed the final questionnaires during November 2006 in three ways, aiming to reach a broad base of respondents:

- We sent a mailing to all NRAS members (approximately 1,100), of which 572 were returned.
- We sent 10 copies of the survey to Allied Health Professionals at each of 150 hospitals. Not all were able to participate, however. We received 172 completed questionnaires.
- We posted the questionnaire on the NRAS website, accessible to non-members. Respondents were required to download the survey and return the completed forms by post. This may have acted as a disincentive to respond (as compared to an interactive questionnaire), we received 38 responses by this method.

In total, 782 respondents self-completed the survey, answering one of two questionnaires according to their employment status. Questionnaires were returned in confidence to an independent data analysis company. They supplied final data to us in a software programme which we were able to interrogate, enabling the flexible examination and presentation of the data. In this report we have presented tables and graphs to highlight the most significant points.

Several of the questions included an option for respondents to give free comments. We have included a small, representative sample of these comments throughout the report.
Sarah was diagnosed with RA in 1994. Now aged 40, she works full time as an accountant.

“When I was diagnosed I was signed off work for three months and then the consultant’s advice was that I could go back for mornings only. After six weeks I was back full time again, because I was bored and I didn’t want to admit there was anything wrong. I think I was in denial. Every time I had a flare I would be in hospital again for a couple of weeks. I had worked for the company for nearly four years so I had a good relationship with them and they were responsive. Perhaps because I was so evidently ill it was accepted. My experience was that the personnel department knew the law and wanted to do that right thing.

I’ve changed jobs six times since then, for career progression, and I did experience some problems. So I didn’t tell people about having RA until late in the interview stages. I wanted them to get to know me first. I also have multiple sclerosis; I was diagnosed in 2002. I think I work harder than other people to compensate; sometimes I try too hard and do too much.

I have had some difficulties with colleagues. The trouble with rheumatoid arthritis is that you can’t always see it. I can’t explain how bad I feel, or how I’ll be fine one day and not the next. I’ve had comments like, “I don’t know if you’ll be able to do this, you may not be well enough.” So I’d say, “You play rugby at the weekend and we don’t worry that you might not be able to do it because you might break a leg.” Comments like that can be upsetting, even if you’re a direct person like I am. You’ve got to stick up for yourself and remember it’s not your fault you’ve got RA.

In many ways I’m lucky. It took a while to find the right drug, but my RA is now controlled enough for me to work. I have the kind of job where I can take things home and I can delegate to other people. We have a very good personnel department and I think that’s important. My boss has been happy to make concessions.

“I’ve changed my hours to come in at 9.30, because of the stiffness in the mornings, and I only take half an hour for lunch. As I’m a supervisor, it’s not reasonable for me to be at home much of the time. But I have one day off a month when my medication arrives, because it has to be refrigerated. I have internet access so that I can work from home then.

I do a lot of mileage for work but I stop every two hours, and I may stay over somewhere instead of driving back the same day. I asked if my company car could be an automatic, and the company signed off on that.

I’d say to other people, don’t be afraid to ask for what you need. You’re not causing trouble; you have to value yourself. If I’d given up work I think I’d have been more ill. It’s been important to me to keep going.”
54.8% of respondents were in employment. Just over a quarter of respondents (25.3%) were in full time employment, 17.8% in part time employment, and 1.9% were employed but on long term sick leave. 4.3% (34 respondents) did not give their employment status; however they all completed the ‘in work’ section of the questionnaire and we therefore felt that it was reasonable to assume that they were employed although we do not know how many were employed full time or part time. Almost half were not currently working: 45.1% were not in paid employment.

Respondents came from a variety of employment backgrounds, as shown in Figure 3.

The distribution of respondents' ages and employment status is shown in Figure 4. Over half the respondents (50.2%) were aged 54 or under, over one third (35.4%) were aged between 55 and 64, and 12.9% were over 65.

Figure 2 Respondents' employment status

Which of the following best describes your job?

Figure 3. Types of employment

Figure 4. Respondents’ age and employment status

Age and employment status

Not employed

Employed

Number of respondents

Age Range

0 50 100 150 200 250

16-24 25-34 35-44 45-54 55-64 65-74 Over 74 Not stated
3.2 Effects of rheumatoid arthritis on employment

The data indicates that RA had a significant impact across all age groups, both on how long people could continue to work and on the type of work they could do.

Stopping work

‘They became frustrated by my stress and requests for support. Eventually, they suspended me on medical grounds and suggested strongly I apply for ill health retirement.’

“I had to take my employer to brink of court under the Disability Discrimination Act to keep my job – I settled out of court after 16 years of loyal service.”

“Have had to take post with fewer responsibilities because of fatigue”

“Changed role to a more sedentary post.”

People’s working lifetimes appear to be significantly curtailed because of RA. Of those people not working, nearly two thirds (229 out of 353, or 64.8%) stated that they were not in employment because they gave up work early as a result of their RA (details at Figure 5). This includes people above and below statutory retirement age. This represents 29.3% of all respondents (229 out of 782).

The impact and costs of early retirement are likely to become more significant in future years, as flexible retirement ages become more common and people have more opportunities to work beyond the age of 65.

Among the 229 people who had given up work or retired early because of their RA:

• over a quarter (28.4%) had had to stop working within one year of diagnosis, and over half (59%) within six years (Figure 6). This includes people above and below statutory retirement age. This represents 29.3% of all respondents (229 out of 782).

• over two thirds of respondents under the age of 55 said that they would like to return to work if they could find a suitable job that would accommodate their RA (56 out of 79, or 70.8%). Over a quarter of those aged between 55 and 64 said the same (30 out of 114, or 26.3%).

Figure 5. Not employed as a result of RA

![Graph showing the number of respondents not employed as a result of RA, grouped by age range.](image)

Impact at work

The survey data indicates that RA has an impact on the type of work people can do, and therefore on their earnings. Among those 429 respondents currently employed:

• 21.2% (91) said they had had to change their occupation to something different because of their RA. Respondents cited a variety of changes, with over three quarters (70 out of 91) referring to changes to their work to allow for changes in their physical abilities.

• While 48.3% of all respondents felt that RA had not had an impact on their career progression, over one third of respondents (37.8%) believed that it had. This varied between respondents’ occupations and roles, perhaps reflecting different expectations of progression in some roles as well as the impact of RA.
The costs
Our survey sheds light on the financial costs both for individuals with RA and for employers, however, in this report we are focussing on presenting the impact of RA on employment from the patients’ perspectives. From the findings of this survey of 782 people, it is clear that RA leads to a significant reduction in productive working years. People are unable to work to their full potential, with a consequent loss of personal income impacting on both themselves and wider society. Individuals are unable to build up their own pension contributions for income in retirement. With many people forced to leave work in their 40s and 50s, employers lose the valuable contributions of skilled and experienced people to their workforce. These consequences are likely to become more significant in the future, as people work for longer and the numbers of older people with chronic disease increase.

The findings indicate that in addition to early retirement, there are further ‘hidden’ costs for those people with RA who do remain in work. People find that their earning potential is affected by a variety of factors, including:

- needing to change occupations to accommodate their RA
- finding that their career progression is hampered
- having to reduce their hours or work part-time.

While more research is needed to quantify these costs, for individuals and for the wider economy, it is clear from these respondents that many people’s personal circumstances are severely adversely affected.

3.3 Barriers to remaining in employment

When asked to consider the potential barriers to remaining in work, only 14% of employed respondents (60 out of 429) felt that their RA had not affected their employment at all or could see no barriers.

The remaining 86% of employed respondents had either already experienced or anticipated experiencing key barriers to remaining in employment. The most significant of these were cited as: pain; physical limitations; fatigue; and having to take time off sick. Respondents in work and respondents not in work were in broad agreement about the factors they perceived as major barriers to staying in work (see Table 1).

Table 1. Perceived barriers to remaining in employment

<table>
<thead>
<tr>
<th>Factors perceived as barriers to remaining in employment</th>
<th>% of respondents identifying this as a major barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain affecting ability to work</td>
<td>62.6 75.5</td>
</tr>
<tr>
<td>Unable to carry out duties because of physical limitations</td>
<td>62.0 64.8</td>
</tr>
<tr>
<td>Fatigue affecting ability to work</td>
<td>59.8 73.0</td>
</tr>
<tr>
<td>Time off sick</td>
<td>32.9 39.2</td>
</tr>
<tr>
<td>Unable to get to, or travel to work</td>
<td>12.7 21.4</td>
</tr>
<tr>
<td>Lack of support and understanding from employer</td>
<td>11.6 16.6</td>
</tr>
<tr>
<td>Need specific adaptations at work to carry out current role</td>
<td>4.2 6.8</td>
</tr>
<tr>
<td>Problems with colleagues</td>
<td>2.3 4.7</td>
</tr>
<tr>
<td>Lack of family support/understanding at home</td>
<td>2.3 3.3</td>
</tr>
</tbody>
</table>

Of respondents who had had to give up work early because of their RA, 13% (30 out of 229) said that their employer had wanted them to leave once they became aware of the respondent having a long term health problem. This is concerning, as it suggests that for a significant minority of people, employers’ attitudes are a major factor in their ability to remain at work.

All respondents, both in employment and not in paid employment, were asked to rank the seriousness of problems they had experienced at work, on a scale of 1 to 5 where 1 meant ‘not at all serious’ and 5 meant ‘very serious’ (see Figure 7 on page 12).

“I was told if I could not carry out my duties exactly as pre-diagnosis she was within her rights to sack me.”

“I worked under a performance pay related scheme. From getting RA in 1996 to leaving in ill health in 2004 it probably cost me £40K over 8 years.”

“It is all very well reducing hours but this affects pay and pension with no way of making up the shortfall.”

“I had a management position and I would have had to step down and take a drop in salary for a sitting-down job.”
The problems that were considered by all respondents to be the most serious (i.e. ranked 4 and 5) were:
- taking time off when they were having a flare or unwell (239, or 31% of all respondents)
- getting to and from work (162 or 21%)
- a lack of understanding or support from their employer (158 or 20%)
- employers’ reluctance to make adjustments (127 or 16%)
- a lack of understanding from colleagues (127 or 16%).

While it is clear that struggling to do your job is often hard work for many people with RA, the findings also suggest that the problems people experience are not insuperable: improved access to health services when needed, more flexible working arrangements, adjustments at work and more awareness from employers and colleagues may all play a role.

### 3.4 Employers’ attitudes and support

Most respondents had told their employer or former employer that they had rheumatoid arthritis: 90.1% (390 out of 429) of those in work, and 67.4% of those not in work (238 out of 353). The majority of respondents informed their employer within one year of being diagnosed (83.9% of all respondents). However, respondents’ assessments of their employers’ awareness and understanding were mixed.

**Awareness and understanding**

It can be difficult for employers to understand the variable nature of the disease, and to the untrained eye there are often no physical changes in a person with RA.

This survey’s findings suggest that there is a real need to address the ‘awareness gap’ amongst employers, both about RA itself and about the needs of people at work who have RA. It is encouraging that, of those who had told their employer of their diagnosis, just under one fifth (17%) felt their employer fully understood RA and a further 27.9% felt that they understood ‘enough’. However, for many people the situation was very different: close to one third (29.5%) felt their employer did not understand enough, while 15.4% – a significant minority – felt their employer had ‘no idea’.

These findings reflect the challenges faced by individuals with RA: as well as accepting their condition themselves, they may face difficulty in communicating it effectively to colleagues and friends.

**Support to help people stay in work**

Respondents had mixed views about how helpful their employers had been in helping them to stay in work. It is encouraging that close to one third of all respondents who had told their employer they had RA (188 out of 628, or 29.9%) described their employer as ‘very helpful’ (rating them 1 on a scale of 1 to 5). However, almost one fifth of all respondents who had told their employer they had RA (117 out of 628, or 18.6%) found them ‘unhelpful’ or ‘very unhelpful’ (ratings 4 and 5).

238 respondents who were not employed had told their former employer of their diagnosis. Of these, 34.5% (82) said they had been offered support to help them make changes to working conditions or equipment to make their work easier.

390 employed respondents had told their employer of their diagnosis. Of these, 50% (195) said they had been offered support to help them make changes to working conditions or equipment to make their work easier. While the difference is not great, this is perhaps a small but welcome indication that the availability of support is increasing.

Only about one fifth of respondents who were in work felt that such support was not needed (92 out of 429, or 21.4%). This suggests that for the majority of people with RA, support from their employer is a significant factor in enabling them to remain at work.

Those 277 respondents who did receive support mentioned several forms. Most frequently mentioned were: special equipment; reduced hours; and flexible working hours (see Table 2 on page 14).

“I think people found it difficult to comprehend how I could cope one week/ day but not the next”

“RA has affected work significantly but employer is very supportive and supplied ergonomic tools to assist.”
“It was very much up to me alone to take the initiative to find solutions to problems – very stressful and worrying.”

The top four factors identified were:

- Increased government priority for schemes to assist people with long term chronic health conditions to remain in work. Over half of all respondents agreed that the government should give higher priority to this issue; perhaps a reflection of the barriers they themselves have encountered.

- Availability of urgent access to rheumatology team when needed (e.g. for flare management). Over half of all respondents (51.7%) identified this: the prompt availability of healthcare was more important to people than any single employment-specific measure, when they assessed what would enable them to remain in employment. This highlights that an integrated approach from government would be the most effective way to reduce the numbers of people unnecessarily out of work because of rheumatoid arthritis. Improved access to clinics will enable people to manage flares better and minimise their time off work.

- Increased flexibility and knowledge of employer. Over 41% of all respondents felt that higher levels of awareness and more flexibility from their employers was important; again indicating that closing the ‘awareness gap’ could help more people to remain productive members of the workforce.

- Better awareness of my rights at work. Many respondents indicated that they had felt unsupported at work and unsure of their rights and their employers’ responsibilities. Almost one third (32.1%) identified this as important.

There was strong support for the suggestion of specific materials to help inform employers about rheumatoid arthritis and the needs of people with RA in the workforce. Over 60% of all respondents, including over two thirds of those currently in employment, felt it would be useful to have a booklet to show to their employer about rheumatoid arthritis and how employers could provide support and meet their obligations under the Disability Discrimination Act.

Table 2. Changes to working conditions

<table>
<thead>
<tr>
<th>Type of support or change to working conditions</th>
<th>number of respondents who received this support</th>
<th>as % of all respondents who had received support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Special equipment/changes to equipment</td>
<td>143</td>
<td>51.6%</td>
</tr>
<tr>
<td>Fewer hours</td>
<td>93</td>
<td>33.6%</td>
</tr>
<tr>
<td>Flexible working hours</td>
<td>90</td>
<td>32.5%</td>
</tr>
<tr>
<td>A change in duties</td>
<td>77</td>
<td>27.8%</td>
</tr>
<tr>
<td>Working from home some of the time</td>
<td>61</td>
<td>22%</td>
</tr>
<tr>
<td>Other adjustments</td>
<td>30</td>
<td>10.8%</td>
</tr>
<tr>
<td>Help with transport</td>
<td>25</td>
<td>9%</td>
</tr>
<tr>
<td>Improved accessibility into the work place or in the work place</td>
<td>21</td>
<td>7.6%</td>
</tr>
</tbody>
</table>

Table 3. Factors identified that would enable people with RA to stay in employment for longer

<table>
<thead>
<tr>
<th>Would any of the following help/have helped you to stay in employment for longer?</th>
<th>% of all respondents who agreed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased government priority for schemes to assist people with long term chronic health conditions to remain in work</td>
<td>54.5%</td>
</tr>
<tr>
<td>Availability of urgent access to rheumatology team when needed (e.g. for flare management)</td>
<td>51.7%</td>
</tr>
<tr>
<td>Increased flexibility &amp; knowledge of employer</td>
<td>41.7%</td>
</tr>
<tr>
<td>Better awareness of my rights at work</td>
<td>32.1%</td>
</tr>
<tr>
<td>Better awareness of schemes to assist disabled people at work</td>
<td>30.9%</td>
</tr>
<tr>
<td>Guaranteed assistance from an occupational health adviser</td>
<td>26.8%</td>
</tr>
<tr>
<td>Good family support at home</td>
<td>25.8%</td>
</tr>
<tr>
<td>Easier access to buildings and better accessibility within the work place</td>
<td>15.6%</td>
</tr>
<tr>
<td>Better assistance getting to and from work</td>
<td>14.2%</td>
</tr>
</tbody>
</table>

NRAS is publishing two booklets in summer 2007 on employment and RA, one for employees and one for employers.
3.5 Social and emotional impacts

Almost half of all respondents (370 or 47.3%) stated that problems experienced at work had had a major impact on their social life. Over a quarter (27.4%) stated that there had been a major impact on their financial health and a similar number felt there had been an impact on their family, partner or relationship (25.6%). This is consistent with the views of other patient groups who have long term conditions, and again raises important issues about health economics and the consequences for society of individuals living with chronic disease.

While the questionnaire did not specifically ask about stress, many respondents referred to the stress that they experienced at work as a result of RA. The range of factors identified is indicative of the far-reaching impact of RA on people’s working lives, and consequently their social and emotional wellbeing.

Respondents were asked whether any problems they had experienced at work because of RA had an impact on other areas of their life. They were asked to rank them on a scale of 1 to 5, where 1 meant ‘no impact at all and 5 meant ‘a major impact’. The problems considered most serious (i.e. ranked 4 and 5) are shown in Figure 8.

Figure 8. Impact of work problems on other areas of life

<table>
<thead>
<tr>
<th>Area</th>
<th>% of all respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family/partner relationships</td>
<td>15.0</td>
</tr>
<tr>
<td>Friendships</td>
<td>10.0</td>
</tr>
<tr>
<td>Social activities</td>
<td>15.0</td>
</tr>
<tr>
<td>Financial problems</td>
<td>15.0</td>
</tr>
</tbody>
</table>

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While the questionnaire did not specifically ask about stress, many respondents referred to the stress that they experienced at work as a result of RA. The range of factors identified is indicative of the far-reaching impact of RA on people’s working lives, and consequently their social and emotional wellbeing.

Real Stories ...

Christine is a former nurse. After being diagnosed with RA in 2000, she changed to a banking career. Aged 48, she has been on long-term sick leave for 7 months.

“I was under a lot of stress in 2000: in charge of a 63-bedded unit at nights and also updating my qualifications at university. Suddenly all my joints went and I was off work for seven months.

There was no way I could go back to nursing; I couldn’t manage the lifting or the stairs. But I needed another job, so I went into banking, looking after corporate customers. The first two or three years were fine. The company was fully aware of my RA and supported me with various things to help: a chair, extra time to do things.

Then I had a series of problems, with my drugs not working so well. I had more time off and a very bad flare. When I went back to work I approached the bank to ask about a different keyboard to reduce the stress on my joints. They arranged for me to have an official assessment under the DDA, but never provided me with the recommended equipment to do my job.

I struggled on, with steroid injections at times, but things went downhill and I went off sick in August 2006.

Personnel were helpful and called me at home to see what they could do. They thought all the adaptations recommended in the assessment had been put in place: a different desk layout, a keyboard overlay, new chair and special mouse. So I’m in dispute with them about that. The assessment is over a year old and now I need a new one as my condition has changed.

Having RA is stressful enough without having to fight your corner. I can’t afford not to work, and I want to work. I needed to sort out more effective treatment in order to get back to work, but the NHS couldn’t give me a consultant appointment for six months. The government may want you to work but they don’t make it easy for you. If the hospital doesn’t give you an appointment you’re stuck, with work eager for you to return.

Finally I went privately and was prescribed a new combination of drugs. It sped things along but I’m still not fit. I had a work medical, and they said they’ll see me again when the new drugs have had time to take effect.

The next appointment is to consider whether I will ever be able to go back, and if not then to pension me.

So now I’m waiting and not sure what will happen. If you get heavy, and stand up for your rights and the Disability Discrimination Act, it would be very difficult to go back after that. It seems to me that you can have the right, or you can have a job. For the past year, work has been an ongoing nightmare.”

“‘They don’t understand the variability of RA. I have missed opportunities, been excluded from same and had to withdraw from work social life.”
4 Conclusions and recommendations

4.1 Survey findings

- For many people, rheumatoid arthritis has a significant impact on their working life. Difficulties arising from this can extend beyond the workplace and contribute to social as well as financial problems.
- People with RA are likely to have their working life cut short, at considerable personal cost. In this survey, nearly two thirds of those not working (64.8%) stated that they had given up work early as a result of their RA. Over half of these (59%) had given up work within 6 years of diagnosis.
- Many respondents reported that they had had to change their occupation because of their RA. Of those respondents in work, 21% had changed their occupation to allow for changes in their physical abilities.
- The most significant barriers to work identified by people with RA, are:
  - pain affecting their ability to work
  - being unable to carry out duties because of physical limitations
  - fatigue
  - having to take time off sick.
- People with RA identified the following as the most important factors that would help them to remain working:
  - increased government priority for schemes to assist people with long term chronic health conditions to remain in work
  - urgent access to rheumatology team when needed
  - increased flexibility and knowledge from their employer
  - better awareness of their rights at work.
- There remains an ‘awareness gap’ amongst some employers that needs to be addressed: over 15% of respondents felt their employer had ‘no idea’ about rheumatoid arthritis.
- Respondents to this survey strongly supported the idea of information they could give their employers, specific to rheumatoid arthritis, which would help them to make employers more aware of the condition.
- Many of the barriers to work identified by this survey’s respondents are not insuperable: with changes and more support, many more people with RA would be enabled to stay in work and contribute to the economy.
- 50% of respondents in employment said that they had been offered some support to help them make changes to working conditions or equipment to make their work easier, while only 21.4% felt that such support was not needed. These results suggest that many employees do not know about their rights to adjustments in the workplace or have not been able to access them. While many employers are supportive, a significant number are not: one fifth of respondents found them unhelpful or very unhelpful.

4.2 The way forward

Integrated government support

The government aim is for 80% of working age citizens to be in employment by 2010. The Department of Work and Pension’s welfare reform strategy acknowledges that only a small proportion of new claimants of incapacity benefit have very severe conditions, and that for a majority of people, effective early support can reduce the impact of health problems on employment.\(^8\) The health service therefore has an important contribution to make for people with long term health conditions if this target of 80% is to be reached. Without access to rheumatology services providing the right care at the right time, many people with RA will continue to face significant problems in the workplace, and some will also face the possibility of having to give up work. Rheumatoid arthritis can start at any age, and giving up work because of a diagnosis of a long-term chronic condition can be traumatic.

- All government agencies need to work together, taking a proactive approach to helping people remain in work if possible and providing support and effective treatment at the right time. This will prevent people from needlessly moving onto benefits.
- There needs to be improved government priority for schemes to assist people with RA to remain in the workplace. Current schemes must work to maximise the opportunities for people with rheumatoid arthritis. The quality of government schemes varies, as we know from talking to the many people who contact NRAS. A consistent approach is needed, drawing on the lessons of pilot schemes.
- Government education and support needs to extend to both large and small employers.

Rapid access to the right services

Over half of all respondents (51.7%) agreed that urgent access to the rheumatology team, for example for managing flares and drug side effects, was an important factor in enabling them to remain at work. This survey also identified pain as the most significant barrier to remaining in work, confirming the findings of a considerable amount of research that pain is a very significant problem for people with RA.\(^9\)

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Nearly 30% of respondents to our survey had given up work because of RA; over a quarter of them within one year of diagnosis. This highlights the importance of prompt treatment and tight management of the disease, particularly in the early stage, in order to improve the long-term health outcomes as well as economic prospects for people with RA.

Unfortunately, current NHS reforms (April 2007) and the responses of NHS Trusts to financial deficits mean that services for people with RA are being adversely affected. Reductions in the number of follow-up appointments and cuts to early RA and rapid-access clinics do not help people who are trying to stay in work. The provision of rapid access services by specialist teams may prove an additional challenge, as a result of increased emphasis on providing care in community settings and less direct access for patients to health professionals with the necessary expertise, who are currently primarily based in secondary care. In addition, there is concern that the capacity of occupational therapists to provide work-related support to employees and employers may be reduced with increasing pressure on services.

There needs to be integrated government support for rheumatology services providing the right care at the right time. Commissioners of services must recognise this vital need, and that not all long term conditions require the same level of resource, if people with RA are to make the most of their potential in employment.

Healthcare professionals in all stages of the patient journey need to have the expertise or resources to provide or refer patients for appropriate prompt pain relief. People with RA probably tolerate higher levels of pain than they need to because they believe it comes with the territory. Patients may need to be more proactive about seeking help with pain relief and health professionals need to be more aware of patients minimising their pain when ‘putting on a brave face’ in clinic.

Further research on the costs of RA

Our survey has indicated that there are significant financial costs for individuals associated with having RA. From these survey results, a health economist has estimated that when a person stops working because of their RA, it represents an average loss of productivity equivalent to £287,544.10

There are also the ‘hidden’ costs to the individual, such as slower career progression or change of occupation. Employers face the significant costs of the loss of experienced staff, recruitment and retraining. When individuals are not enabled to work to their maximum productivity, there are also costs to the economy overall.

Further research is needed on the economic burden of RA, to the individual, employers and the wider economy. Further work is also needed to quantify some of the less visible costs of RA, which include changing jobs, reducing hours and slower or halted career progression.

The National Institute for Health and Clinical Excellence should, when assessing the value of new therapies, include the wider societal costs of work-related disability in their cost effectiveness modelling. It is clear that patients with RA who are treated effectively, at an early stage in the disease, are more likely to remain in work and economically productive.

Education for employers and employees

The fluctuating nature of rheumatoid arthritis and its often invisible symptoms make it particularly difficult for people to understand. As our case studies illustrate (see pages 4, 17 and 22), people with RA can experience problems with colleagues and employers because of this. Some employers’ lack of awareness may be contributing to the lack of support for individuals with RA. Employers may also be influenced by a range of other factors, including how long the person has been an employee, their particular skills and expertise, and whether the employer is able to manage financially with a reduced staff team for some periods.

While the majority of employed respondents (over 90%) had told their employer about their diagnosis, only half had received support or adjustments to their working conditions. Employees may not know about their right to adjustments or may be unable to obtain them; employers may not be complying with their obligations under the Disability Discrimination Act 1995.

There needs to be improved education for people with RA to help them become more aware of their rights in the workplace.

There needs to be improved information available for employers that is specific to RA, in order to encourage employers’ awareness, understanding and flexibility regarding the needs of people with RA. Quite often simple measures can make a big difference, for example: starting work half an hour later; a different computer mouse; or a parking space closer to the building.

As a consequence of the results of this survey NRAS is producing two further booklets on work. One will be targeted at employers to provide information about RA and how they can help support people with RA in the workplace. The second booklet will be targeted at employees and provide information on the support they can expect in the workplace. For more information please contact NRAS or visit the web site www.rheumatoid.org.uk.

10 Calculation of the loss of productivity (LoP) due to RA – see appendix on pages 24 and 25 of this report.
NRAS is the only patient-led charity in the UK specifically for people with rheumatoid arthritis, their families and carers, providing information, support and advocacy.

- The NRAS helpline 0800 298 7650 is open from 9.30am to 4.30pm Monday to Friday. Trained helpline staff can answer questions on all aspects of living with RA, with support from our team of medical advisers.
- NRAS has a national network of support volunteers, available at the end of the phone to chat and listen. To arrange for a volunteer to contact you, call the helpline number above or 0845 458 3969.
- NRAS website www.rheumatoid.org.uk has a wealth of information about living with RA, treatments and the latest research and developments.

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SL6 3RT

5.2 Thank you
Thank you to all NRAS members and others with RA who responded to this survey, and also to all the rheumatology health professionals who made the survey available to their patients.

Our thanks also to Susan Oliver, Nurse Consultant Rheumatology, Chair of the RCN Rheumatology Forum; to the NRAS Members’ Panel and to the rheumatology professionals, who helped with the design and testing of the questionnaire.

Survey carried out by: NRAS in association with Access Research
Data analysis: Weeks Computing
Editorial: Kate Wilkinson
Design and print: AIT Marketing Associates Ltd
Appendix A
Calculation of the loss of productivity (LoP) due to Rheumatoid Arthritis (RA)

We wanted to demonstrate what the survey results might mean to a person with RA and the wider economy from a financial perspective and asked a health economist to look at the data. The following is a broadbrush estimate only and does not form part of the survey results.

NRAS is grateful to: David Collomb PharmD, Health Economics and Outcomes Research Advisor, Abbott and to Alistair Curry MSc, Health Economics and Outcomes Research Manager, Abbott, for working on the survey results and preparing this estimate.

The NRAS fifth Annual Survey was conducted among 782 people through retrospective questionnaires. 429 of them were in employment and 353 not employed, 229 of whom had given up work early due to RA.

The calculation
In order to assess the loss of productivity due to RA, we examined the answers to specific questions given by the 229 people ‘unemployed due to RA’. Results are given by age groups. Note: among these 229, four did not give their age; thus figures below have been established on the 225 remaining.

1. We calculated ages at diagnosis by age groups, from the question: “How many years have you had RA?”

<table>
<thead>
<tr>
<th>Age groups</th>
<th>16-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>Over 74</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample 225</td>
<td>2</td>
<td>6</td>
<td>18</td>
<td>53</td>
<td>114</td>
<td>29</td>
<td>3</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>7</td>
<td>17</td>
<td>27</td>
<td>39</td>
<td>47</td>
<td>55</td>
<td>53</td>
</tr>
</tbody>
</table>

We took the middle age of each age group and calculated the weighted average age at diagnosis by deducting years according to answers. The limitation of this method relies on the interpretation of the “more than 20 years” answer. We have applied a 21 years deduction for this one. Thus we underestimate the average age at diagnosis for each age group.

2. We calculated ages of early retirement from the question: “How many years have you had RA?”

<table>
<thead>
<tr>
<th>Age groups</th>
<th>16-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>Over 74</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample 225</td>
<td>2</td>
<td>6</td>
<td>18</td>
<td>53</td>
<td>114</td>
<td>29</td>
<td>3</td>
</tr>
<tr>
<td>Weighted average number of years between age at diagnosis and retirement</td>
<td>5.5</td>
<td>5.0</td>
<td>4.7</td>
<td>4.7</td>
<td>5.3</td>
<td>4.4</td>
<td>9.0</td>
</tr>
<tr>
<td>Age at Retirement</td>
<td>20.0</td>
<td>22.0</td>
<td>31.7</td>
<td>43.7</td>
<td>52.3</td>
<td>59.4</td>
<td>62.0</td>
</tr>
</tbody>
</table>

We took the average age at diagnosis calculated in Step 1 above, to which we added the corresponding number of years according to the answers in Step 2. We took a conservative option adding 11 years for the answer “more than 10 years”, thus underestimating the length of time between diagnosis and retirement. When the average age of retirement was under 20, we considered those patients would have been working from the age of 20 years.

3. We took annual pay figures from the Annual Survey of Hours and Earnings 2006 (ASHE 2006) from the Office of National Statistics website. We selected the overall figures (that is, including both full time and part time employees).

We used the ASHE 2006 Table 6.7a ‘Analysis by age; Annual pay: Gross’.

We took into account two important pieces of information:
- the difference in normal retirement age between men and women
- the different stages of average annual pay an employee would go through over the years.

The NRAS survey dataset did not include gender data. We therefore assumed a proportion of male and female respondents in line with the proportions of men and women usually recorded as having RA, i.e. 25% men and 75% women.

The results

<table>
<thead>
<tr>
<th>Age groups</th>
<th>16-24</th>
<th>25-34</th>
<th>35-44</th>
<th>45-54</th>
<th>55-64</th>
<th>65-74</th>
<th>Over 74</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>18-21</td>
<td>22-29</td>
<td>30-39</td>
<td>40-49</td>
<td>50-59</td>
<td>Over 60</td>
<td></td>
</tr>
<tr>
<td>Males Annual Pay</td>
<td>£11,025</td>
<td>£21,676</td>
<td>£32,648</td>
<td>£36,856</td>
<td>£32,531</td>
<td>£23,984</td>
<td></td>
</tr>
<tr>
<td>Females Annual Pay</td>
<td>£7,918</td>
<td>£17,171</td>
<td>£20,351</td>
<td>£19,053</td>
<td>£17,730</td>
<td>£11,705</td>
<td></td>
</tr>
<tr>
<td>Total (£)</td>
<td>1,766,672.0</td>
<td>5,195,679.0</td>
<td>12,249,475.5</td>
<td>21,150,268.6</td>
<td>22,820,587.4</td>
<td>1,442,825.1</td>
<td></td>
</tr>
</tbody>
</table>

Note: results for people over 65 appear because they retired due to RA before they reached the legal age of retirement. They were over 65 at the time the survey was carried out.

Based on the data from this survey:
- on average, a person stopping working due to RA represents a cost to the economy in terms of lost productivity of £287,544 (225 persons used for calculations).

This estimate is a good ‘broad brush estimate’ of the costs of loss of productivity in RA. It suggests a massive loss to individuals’ personal income and to the productivity of the economy overall.