Family Matters

A major UK wide survey on the impacts on the family of living with rheumatoid arthritis
NRAS is the only user-led charity in the UK specifically for people with rheumatoid arthritis, their families and carers, providing information, support, advocacy and campaigning.

- The NRAS freephone helpline **0800 298 7650** is open from 9.30am to 4.30pm Monday to Friday. Trained helpline staff answer questions on all aspects of living with RA, with support from our medical and allied health professional advisers.

- Our website [www.nras.org.uk](http://www.nras.org.uk) has a wealth of information about living with RA, treatments, the latest research and developments, and an online members’ forum. It also has a full list of links to other useful charities and organisations.

- If you’d like to talk on the phone to another person who has RA, we can put you in touch with one of our trained volunteers – people with RA who understand what you’re going through. They’re available at the end of the phone to chat and listen. To arrange for someone to contact you, call us on **0800 298 7650**.

- Local NRAS groups meet regularly around the country. To find out if there is a group near you, call **0845 458 3969** or visit [www.nras.org.uk/groups](http://www.nras.org.uk/groups)

To help NRAS continue this vital work please support us by:

- Becoming a member
- Participating in or planning a fundraising event
- Donating today – every penny counts.

Published April 2012
Report by Clare Jacklin, Ailsa Bosworth and Kate Wilkinson
Design and print: AIT Associates
From Dr Chris Deighton, BMedSci MD FRCP, Consultant Rheumatologist at Derbyshire Royal Infirmary, and Special Lecturer in Medicine, Nottingham Medical School at Derby

Rheumatoid arthritis has the potential to be devastating for the person affected. The multidisciplinary team tends to focus on the person with the RA, and forget about family and friends around them, and the impact that this disease has on all of them.

This report is an invaluable wake up call to those of us who try to provide high quality services for people with RA. We cannot consider people with RA in isolation, and need to give thought to those around them. The carers have become a lost and hidden tribe. We need to bring them out into the open, and support them, just as we do the person with RA.

The results of the survey and detailed interviews highlight the considerable challenges for carers. We need to make carers an integral part of the multidisciplinary team, and welcome them into all aspects of helping their loved one with RA. They spend much more time with the person with RA than the multidisciplinary team ever does, so it is vital that they are there to help to understand the disease and management, and help the person with RA to manage their own disease. There should be a section in care plans and annual reviews that reminds the multidisciplinary team that carers are important and need to be involved, and not just a tick box exercise, but an ongoing opportunity to keep them at the heart of RA care.

Every interaction with the multidisciplinary team is an opportunity for including carers. They should not have to ask. They should be invited. They are an essential component in high quality care for people with RA.

I welcome this much needed report, and heartily endorse the recommendations.
Forewords

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From Vicky Chamberlain, Chair, Royal College of Nursing (RCN) Rheumatology Forum; Rheumatology Nurse Specialist, Trafford Hospital

On behalf of the RCN Rheumatology Forum I welcome this valuable piece of work. As this report reveals, a diagnosis of RA has a profound impact on the whole family, especially those immediately involved such as partners or children. Nurses undertake many different roles in helping people with RA manage their condition. Encouraging patients to involve their family members in their care, be that at appointments, use of the telephone advice line or even to arrange time to come and discuss any issues with a member of the multidisciplinary team should be part and parcel of what we do.

Friends and family have their worries and concerns with regard to the diagnosis and what the future might hold and, as some of the comments quoted illustrate, need assistance in adapting to changes in both theirs and their family member’s roles. This in itself can cause extra stress within the family and is an aspect of holistic care that is often overlooked and must be considered.

This report is a timely reminder to all of us working with this group of people that holistic care means the whole family not just the person with the diagnosis of RA and therefore, we warmly endorse the recommendations.

From Lindsey Hawley, President of British Health Professionals in Rheumatology (BHPR)

This report powerfully highlights the profound effects that rheumatoid arthritis can have on all aspects of a person’s life and is warmly welcomed by BHPR. Some of the statistics are shocking but it is the people behind these statistics that represent the true extent of the problem and the true cost to families.

It reminds all health professionals to include ‘significant others’ whenever possible but it also demonstrates clearly that there are no easy answers and that each situation requires individual solutions. Carers also need to be given ‘permission’ to acknowledge that their lives too have been affected without feeling guilty, they need to be able to access information and support in a way that is right for them and at the time that the need arises. The recommendations reflect the diversity of approaches that are required.

If even some of the recommendations can be implemented, this report will go a long way to addressing the hidden costs of rheumatoid arthritis and should spur on both government and health professionals to ensure that the disease is recognised and diagnosed early, treated effectively and its impact minimised.

As members of the multidisciplinary team this report challenges us all to start taking small steps right now to recognise the needs of those we rely on most to support our patients in the weeks and months between clinic visits.
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Introduction

Clare Jacklin
NRAS Director of External Affairs

In my role at NRAS I meet many hundreds of people living with RA and their families. It never ceases to amaze me how resilient and stoic people can be when coping with this dreadful disease. I am also struck by how horribly isolated RA can make someone feel, and not just the person with the diagnosis. Many husbands, wives, daughters, mothers, sons and fathers approach me after meetings, with questions and concerns they have never before had the opportunity to voice.

At one meeting, we ran an impromptu workshop for about 20 family members of people with RA, mostly husbands. The anger in the room was noticeable. Many felt frustrated and not listened to. Others felt guilty for feeling the way they did, or for not being able to do more to alleviate the suffering of the person they loved. Many, too, felt a need to shield their partner and hide from them how they were feeling.

From these encounters, as well as from the calls to our helpline from family members, we knew that RA was having a significant impact on loved ones.

We hope that this report has gone some way to giving those family members a voice to share how RA has changed their day to day lives. It has been humbling and a real privilege for NRAS that so many have shared very intimate and personal thoughts with us by participating in this survey. It can’t have been easy. On behalf of everyone involved in this research, I would like sincerely to thank all the survey respondents for sharing their experiences with NRAS. 
2 Executive summary

Our aim is to assist health professionals and all those who support individuals with RA and their families, so that people with RA can enjoy a better quality of life.

2.1 Aims of the research

Section 3 of this report sets out the aims of the research. We wanted to provide data about the impacts of RA on family members of those who have the disease: how RA affects their daily lives, their relationships with partners and with other family members, and their health and wellbeing. We wanted to include personal and emotional issues as well as practical impacts. Our aim is to assist health professionals and all those who support individuals with RA and their families, so that people with RA can enjoy a better quality of life.

2.2 Methodology

Section 4 describes the research methodology. We conducted the research and analysis between October 2011 and March 2012, in three stages.

- We conducted semi-structured telephone interviews, to inform the subject areas for the questionnaire and the types of questions to use.
- We designed, piloted and distributed a questionnaire for two main sample groups: partners living with people who have RA, and adult children of people who have RA. The areas of research included the impacts on their domestic life, finances, leisure time, social life, mental wellbeing, relationship and sex life. We gathered quantitative and qualitative data and identified subjects for follow-up qualitative interviews.
- We conducted semi-structured telephone interviews, to gather further information about the experiences of a sample of family members.

We conducted the research in line with the British Sociological Association’s ethical standards.

2.3 The questionnaire: findings

Section 5 sets out the findings, based on analysis of 392 valid questionnaire responses. 62% were from partners and spouses of a person with RA; 17% from adult children of a parent with RA; 10% from a parent of a son or daughter with RA; and 11% from another relative.
2.3.1 Impacts on partners of people with RA

Impacts on partners are many, interconnected and can be significant. They include:

- **Financial** impacts: 57% reported a negative or very negative effect on their household income.
- Impacts on **domestic life**: 92% reported changes in their responsibilities for household tasks, with 46% reporting significant changes. 82% managed these without paid help or help from family and friends.
- Impacts on their **social life**: 60% agreed that their social life was restricted because of their partner’s RA.
- Impacts on their **mood and mental wellbeing**: 93% reported that their partner’s RA affected their own mood or mental wellbeing, including 22% who said this was often and 13% who said it was most of the time.
- Impacts on their **relationship**: 41% said that they had had difficulties in their relationship as a result of RA, and 67% reported that their sex life had been negatively affected. However, 32% felt that their partner having RA had brought them closer.

68% of respondents with children were concerned about the **impacts on their children**. 63% thought there were negative effects, while 18% also considered there were positive effects.

Few respondents had discussed the impacts on them of their partner’s RA, or had any professional support in coping with them – often because they felt others did not understand RA and they saw little point in talking about it.

When considering support that would be useful, respondents were most positive about: public awareness campaigns (93%); a booklet for family members (81%) and advice on benefits and financial assistance (77%). They would also value health professionals asking about RA’s impact on them as well as on their partner (71%) and giving time for them to ask their own questions about RA, separately (64%).

2.3.2 Impacts on adult children of people with RA

83% of people with a parent with RA reported that this had affected their own life as an adult. Of these, 85% said this was because of their concern about their parent, 44% reported making different choices about their own health or lifestyle and 35% said their parent’s RA had been a factor in their decisions about where to live or work.

Respondents who were under 18 when their parent was diagnosed remembered impacts on their childhood, including: always being aware of their parent having RA (60%); being frightened or anxious on occasions (59%); and being aware that there were some things their family could not do because of their parent’s RA (55%).
2.3.3 Impacts on parents of a son or daughter with RA or JIA

Responses showed wide-ranging and often overwhelming impacts for parents. They include intense anxiety, the stress of uncertainty about the future, and the emotional impacts for the whole family. Giving practical help to their adult children and also to their families can also be demanding. Parents of children with JIA explained particular impacts for other siblings in their family, including coping with feelings of resentment and guilt.

2.4 The interviews: family members’ experiences

Section 6 sets out the findings from the qualitative research. We detail thematic results from eight interviews, with extracts in the interviewees’ own words.

Some concerns were shared by most of the interviewees:

- A lack of public understanding about RA can make it more difficult for them to cope
- They felt that securing effective treatment for their loved one was not straightforward
- They would value more information and support, particularly at an early stage and particularly information that was more relevant to their own situation and circumstances
- Communication within the family was vital – though some hinted that men may be less ready to talk than women.

Four interviewees spoke about their life with a partner who has RA. They described the impacts of increased responsibilities at home, their sadness that RA has restricted their life with their partner, and the difficulty of coping with intense emotions. They explained how concern for their partner could at times make them feel guilty about their own needs and emotions – though it could also make them more ready to do pleasurable things. There were positive experiences, too, of getting support from others outside the family.

Parents explained how their young children felt angry when their parent was unwell, which affected their behaviour, and how older children’s anxiety could be hard to witness as a parent.

Interviewees whose parent has RA explained, from three very different perspectives, the impacts on them of seeing their parent struggling with everyday life, anxieties about their treatment and impacts on their decisions about their own life.
From Dr Chris Deighton, BMedSci MD FRCP, Consultant Rheumatologist at Derbyshire Royal Infirmary, and Special Lecturer in Medicine, Nottingham Medical School at Derby

Rheumatoid arthritis has the potential to be devastating for the person affected. The multidisciplinary team tends to focus on the person with RA, and forget about family and friends around them, and the impact that this disease has on all of them.

This report is an invaluable wake up call to those of us who try to provide high quality services for people with RA. We cannot consider people with RA in isolation, and need to give thought to those around them. The carers have become a lost and hidden tribe. We need to bring them out into the open, and support them, just as we do the person with RA.

The results of the survey and detailed interviews highlight the considerable challenges for carers. We need to make carers an integral part of the multidisciplinary team, and welcome them into all aspects of helping their loved one with RA. They spend much more time with the person with RA than the multidisciplinary team ever does, so it is vital that they are there to help to understand the disease and management, and help the person with RA to manage their own disease. There should be a section in care plans and annual reviews that reminds the multidisciplinary team that carers are important and need to be involved, and not just a tick box exercise, but an ongoing opportunity to keep them at the heart of RA care.

Every interaction with the multidisciplinary team is an opportunity for including carers. They should not have to ask. They should be invited. They are an essential component in high quality care for people with RA.

I welcome this much needed report, and heartily endorse the recommendations.

“I have to carry all the responsibility of bringing in money... that puts a lot of strain on me. We can’t do things together and the laughter has gone.”
NRAS hears every day about the physical, practical and emotional impacts of rheumatoid arthritis (RA) on the families of those who are affected: partners, parents and children; those who see themselves as ‘carers’ and those who may not, although they may do a great deal for their partner or family member with RA. While there is a growing body of research on the effect of RA on the person who has the disease\(^1\), there has been relatively little information available about its impact on family members. This research aims to provide information that will begin to address that gap.

We wanted to present a picture of the impacts of RA on family members of those who have the disease: how RA affects their daily lives, their relationships with partners and with other family members, and their health and wellbeing. Our experience in supporting families has shown us that some of the emotional impacts of having a family member with RA – such as being frustrated or angry about the situation – can be particularly difficult to cope with.

We therefore wanted this research to explore and acknowledge the full impact of RA on families. We wanted it to consider those personal and emotional issues that can be hard to talk about as well as the practical impacts on people’s daily lives and the support they need. We aimed to build this picture by combining significant quantitative data with insights from more in-depth qualitative research.

We have always aimed, as a charity, to support all health professionals working with people affected by RA as well as those affected by the disease. We hope that as more detailed information becomes available about the issues that carers and families are facing, NRAS and health professionals will be in a better position to support individuals with RA and their families, so that they enjoy a better quality of life.

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4 Methodology

We conducted the research between October 2011 and March 2012, using a combination of research methods. We gathered quantitative data using individual self-completed questionnaires, and we gathered qualitative data using one-to-one telephone interviews.

The research project team was:

Clare Jacklin, Director of External Affairs, NRAS
Ailsa Bosworth, Chief Executive, NRAS
Kate Wilkinson, researcher and writer
Sarah Drew, Data Analyst and Research Intern, NRAS
Ruth Grosart, Online & Social Media Coordinator NRAS

4.1 Stage 1: defining the scope of the survey

Our purpose at this stage was to gather information to:

- Inform the questionnaire topics and the style of questions
- Get an early indication of the issues to explore in follow-up qualitative interviews.

We wanted to find out from family members about:

- Day-to-day life with a family member who has RA
- The practical impacts of their family member’s RA
- Demands on them as a result of their family member’s RA
- (If relevant) the impacts of their partner’s RA on their relationship
- What they wanted people to understand about living with a family member who has RA
- Any other issues they wanted to talk about.

Our method was to invite people to volunteer as interviewees, by emailing members of NRAS, including people with RA and their family members. We conducted seven one-to-one telephone interviews in October 2011. The interviews were semi-structured and conducted by one interviewer. They took between 30 and 50 minutes to complete.

The interviewees in our sample were five men and two women, aged between 29 and late 60s. Six were married to and living with a person with RA; they had been married for between 12 and 50 years. Each had two or more children, aged between six and 49. One interviewee was an adult with a parent who has RA. We did not consider it appropriate to interview people under 18 years old, as the conversation could involve potentially sensitive issues and we were not in a position to offer follow-up support.
We compared the interviews and the themes that emerged were:

- The impact of their partner’s RA on their choices about employment
- The financial impacts on the family
- The impact on decisions about where to live
- The impact on roles and responsibilities in the family
- Impacts on parents and parenting roles, for both parents
- Impacts on children of having a parent with RA, both at the time and in their adult life
- Impacts on partners’ social life and leisure time
- Impacts on partners’ physical and mental health and wellbeing
- Impacts on their relationship with their partner who has RA
- Impacts on their sex life.

These themes informed the subject areas for the questionnaire.

We considered other information from the interview process and its significance to the aims of the research. This included: how interviewees contextualised their experiences; how they described impacts and also assessed the seriousness of those impacts; how personal perspectives could vary according to the time elapsed since diagnosis; how ready interviewees were to talk frankly and for how long.

These considerations informed decisions about the types of questions to use.

4.2 Stage 2: the questionnaire

The purpose of this stage was to explore the impacts of having a family member with RA on two main sample groups: partners living with people who have RA, and adult children of people who have RA. We wanted to gather quantitative and qualitative data, and to identify subjects for follow-up qualitative interviews.

Our method was to design and distribute a questionnaire. We designed it in four sections:

- Section A: questions for all respondents to gather data about their characteristics
- Section B: specific questions for partners and spouses
- Section C: specific questions for adult children of a parent with RA
- Section D: an open question for all respondents, about their experiences of having a family member with RA. This was so that we could collect data from any other family member aged 18 and over who wanted to participate in this survey.

We used a combination of question types:

- Multiple choice questions, to gather data from respondents about their lives and circumstances
- Scaled questions, to measure respondents’ subjective views or assessments
- Open-ended questions, to give respondents opportunities to expand on their answers and to express their opinions.

We developed both hard copy and online formats.
We tested both formats with a **pilot** group of seven people, all over 18 and living with a family member who has RA – we wanted to make sure the questionnaire reflected the experiences and concerns of this group. We asked for feedback on: how long it took to complete the questionnaire; whether they found any questions unclear; and whether they felt the questionnaire gave them the opportunity to say what they wanted about the impacts of RA. We revised and finalised the questionnaire after their feedback.

Our **method of analysis** of the questionnaire data consisted of:

- Numerical analysis of responses to multiple choice and scaled questions, to calculate the proportions of respondents answering
- Thematic analysis of respondents’ free text responses to open-ended questions, by categorising responses into themes and sub-themes.

### 4.3 Stage 3: qualitative interviews

Our **method** was as follows. We carried out an interim data analysis of the 242 responses we had received by 2 February 2012, to identify issues. We were confident that the number of responses received by this point was sufficient reliably to indicate key issues. (By 29 February, the closing date, we received a total of 421 completed responses.)

Over one third of these respondents indicated they were willing to be interviewed. We considered their responses and the issues they indicated they wanted to discuss. We selected interviewees who could give a perspective on some or all of the following areas:

- The impact of their partner’s RA on their own mental wellbeing and mood, including their experience of coping with the emotional impacts
- The financial impacts of their partner having RA
- The impacts on their children of a parent having RA
- Their experience of having a parent with RA
- Their experience as a parent of a child with RA.

The sample was not designed to be representative of the survey respondents.

We conducted eight semi-structured telephone interviews between 21 February and 14 March 2012. Questions for each interviewee were based on issues they had identified in their questionnaire responses. Interviews took between 19 and 65 minutes to complete.

Our **method of analysis** was to write up detailed notes, as far as possible in the interviewees’ own words. We reviewed the notes, categorised interviewees’ responses into themes and sub-themes, and compared them.

### 4.4 Ethical standards

We conducted the research in line with the British Sociological Association’s standards2. We took steps to protect participants’ anonymity, privacy and confidentiality. We asked questionnaire respondents for consent to contact them further, and for permission to use quotations anonymously. We erased personal information from our interview notes; we gave interviewees information about how the research would be used and to what purpose. We also gave interviewees opportunities to withdraw any material at any stage of the research process. All the names used in this report have been changed.

2 British Sociological Association (March 2002) Statement of Ethical Practice
www.britsoc.co.uk/about/equality/statement-of-ethical-practice.aspx
accessed on 27 March 2012

The survey was live from 9 January 2012 to 29 February 2012.
It would have helped me to talk to someone in a similar situation.
Robert, 36, is married to Nicky, who has RA. They have two sons: Ben, aged five and Danny, two.

‘Nicky has severe RA, constant flares. No medication even touches the sides, really; we’re trying to get the doctors to put her onto biologics. She’s on methotrexate and it’s not working. Any exertion, even putting a couple of shrubs in the garden, and she’ll pay the price for days afterwards.

‘I’m finding it really, really tiring. Each Monday morning I seem to be more tired after the weekend. I get up at 6.30, get the boys up and ready for school. I leave for work by 8.30 and by then Nicky’s up and she takes them in the car to take Ben to school. I have a management role and I work about 45 hours a week, which I know isn’t the longest hours. When I get home I kick into carer mode, almost; I’m aware that I need to give Nicky time off. You feel as though you have to do everything.

‘It affects your financial situation too, because obviously Nicky isn’t working. She was working in property development and it’s ground to a halt, because of RA.

‘Ben gets really angry with Nicky and is as rude as a five year old can be – to her but not to me. Daddy’s fun; does all the fun things. Nicky wishes she could do more. She can’t do rough and tumble, chasing in the park. She can stand and watch the swings but that’s about it. When she’s around, Ben retreats and reads in his room. I wonder if he’s trying to escape.

‘Some colleagues ask how she is and say oh dear, but it’s all pretty superficial stuff. And I’m quite senior so I have to be upbeat. I’m aware of having to be positive, at work, socially and when I’m with Nicky and the kids. I’m rarely on my own. The 10 or 15 minutes when I walk to work is all I get. And that’s OK, but it’s getting to the point where talking to someone would be good.

‘Our GPs are great but the consultants are harder going and not encouraging. Comments like “we’re not here to tell you it’s going to be OK” – that really upset Nicky. They’re more hard-nosed and factual; I suppose they have to be. Nicky goes to regular blood tests on her own, but I go to the consultant appointments with her. You feel you don’t really exist. They don’t greet you, don’t ask you questions. It’s more like, OK then, you’re the husband, here for moral support.

‘It feels very lonely – no one who isn’t close to the condition would understand. It’s tough. But it’s also how things are. We have two perfect children, and we’re both strong people.’

93% agreed that a public awareness campaign of RA would help
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I welcome this much needed report, and heartily endorse the recommendations.
5 The questionnaire: findings

5.1 About the sample

We received 421 completed responses to the questionnaire. We removed 29 from the analysis because respondents had identified only themselves as having RA, rather than a family member. Analysis is based on 392 valid responses. Values have been rounded to the nearest percentage.

Responses came from every area of the UK, with the largest proportions from the South East of England (22%) and the South West (14%). 64% of respondents were members of NRAS.

The largest group of responses (62%) was from partners and spouses of a person with RA. 17% had a parent with RA, 10% had a son or daughter, and 11% had another relative.

53% of responses overall were from men and 47% from women. The different groups of respondents, however, had very different proportions of men and women, and this is discussed further below.

5.2 Partners of people with RA

242 respondents were currently living with a partner or spouse who had RA.

75% were men and 25% were women. The majority (86%) were married, less than 1% were in a civil partnership and 12% were living together. Assuming that the majority of respondents were in heterosexual relationships, the ratio of male to female partners therefore broadly reflects the ratio of women to men with RA, in the general population.3

98% of respondents gave their ethnicity as white, 1% as Asian, 1% as Black and less than 1% as Mixed.

Respondents in this group were all aged 25 or over and over two thirds (69%) were aged 45 and over. The age group 55 to 64 had the largest proportion of respondents (29%).

The majority were in long-standing relationships: nearly half (47%) had been together (married, in a civil partnership or living together) for more than 21 years and a further quarter (26%) for 11 to 20 years. 90% in total had been together for six years or more.

Respondents’ experiences span a period of more than 21 years. They therefore include experiences of partners having a range of treatments for RA: there have been significant advances in medical knowledge and treatment during this time, including the availability of biologic drugs from the late 1990s.

3 RA affects approximately three times more women than men. www.nras.org.uk/about_rheumatoid_arthritis/what_is_ra/what_is_ra.aspx accessed 20 March 2012
The data suggests that respondents are likely to have been in their current relationship when their partner was diagnosed: only 10% said their partner was diagnosed over 21 years ago and over half (52%) said their partner was diagnosed within the last five years.

Around a third (30%) of respondents in this group had children under the age of 16 living with them.

Over two thirds of respondents were working: 58% of respondents were working full time and 10% part time. Of the respondents who were working part time, 39% said one of their reasons for doing so was to have a better work life balance and 22% said one of the reasons was their partner’s health.

Over one fifth of respondents (22%) were retired, of whom over two thirds (70%) had taken early retirement. 97% of those who had retired early gave more information about their reasons for doing so. 14% said one of the reasons was to look after their partner with RA and 14% said one of the reasons was their own ill health.

Research has shown that RA has significant impacts on the working lives of those who have the condition. The results of this research suggest that RA can also have impacts on partners’ employment choices.

5.2.1 Impacts on their domestic life and financial situation

Respondents gave information about the impact of RA on their family’s income.

57% said that their partner’s RA had a negative or very negative effect on their household income (see Figure 1). Only 10% reported a positive or very positive effect.

Yet over two thirds (69%) said they had never received any information about benefits and financial support. Only 18% said they or their partner were claiming any benefits as a direct result of their partner’s RA.

Figure 1 What effect, if any, does your partner’s RA have on your total family/household income?

<table>
<thead>
<tr>
<th>Effect</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>A very positive effect</td>
<td>4%</td>
</tr>
<tr>
<td>A positive effect</td>
<td>5%</td>
</tr>
<tr>
<td>No effect</td>
<td>24%</td>
</tr>
<tr>
<td>A negative effect</td>
<td>29%</td>
</tr>
<tr>
<td>A very negative effect</td>
<td>33%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5%</td>
</tr>
</tbody>
</table>

4 NRAS (2007)
We asked whether respondents helped their partner with personal care tasks (see Figure 2). A majority helped with getting dressed (33% said ‘occasionally’, 16% said ‘most days’ and 25% ‘if their partner was having a flare’). A majority also helped with washing, showering or having a bath (29% ‘occasionally’, 16% ‘most days’ and 16% ‘if their partner was having a flare’).

44% of respondents had spent over eight hours in the previous week helping with household jobs and personal care, with 20% spending 15 hours or more and 10% spending 35 hours or more.
220 respondents gave information about the extent to which their partner’s RA had changed their responsibilities for domestic tasks (see Figure 3). 46% reported that it had significantly changed their responsibilities for household tasks (such as vacuuming, dusting and laundry), and a further 35% said it had changed their responsibilities on occasion, for example during their partner’s RA flares. Only 8% said it had not changed them at all. 39% reported that their responsibility for food shopping and cooking had significantly changed, and a further 32% that this changed on occasion.

82% said they managed these changes between themselves and their partner, with only a minority relying on paid help (8%) or help from family and friends (6%).

The demands of domestic and personal care tasks on partners can clearly be significant. The majority of respondents are working, so these results suggest that many partners are taking on a number of extra tasks in addition to their employment responsibilities.

5.2.2 Impacts on their children

66 respondents (30%) had children under 16 living with them, and of these, 63 answered further questions.

Over two thirds (68%) said they were concerned or very concerned about the impacts on their children of having a parent with RA (Figure 4). Nearly two thirds (63%) either agreed or strongly agreed with the statement ‘I think having a parent with RA has negative effect(s) on our child(ren)’. Only 10% thought that having a parent with RA did not affect their children at all. A sizeable minority (18%) agreed with the statement ‘I think having a parent with RA has positive effect(s) on our child(ren)’.

Over half (59%) chose to comment further, often in detail. Their concerns included the practical impacts on their children’s lives:

- Children spend less time with their parent because of his or her pain or fatigue
- Their parent is often short-tempered
- Children are unable to do some activities with their parent or as a family
- Children have to take on additional chores that their friends do not.
Respondents also explained the emotional effects they saw, including:

- Children feel left out in comparison to other families
- Children become anxious about their parent
- Children’s behaviour changes.

Those who saw positive effects explained that their children have developed compassion and learned to help; while others commented that they and their children have adapted to cope.

“The RA prevents my wife from spending as much time playing with the children as she would like, she cannot hold them as easily and we can be limited in our outdoor activities.”

“When my husband is experiencing a flare up he has less patience with the children and is often snappy with me... it seems sometimes that he feels guilty if we have planned to do something e.g. go for a walk, and rather than say he doesn’t feel like it or that he’d be better going on a shorter walk, he doesn’t want to let us down so carries on as if everything is fine. Which upsets us as we know he isn’t well.”

“It worries them and upsets them to see their mother suffering. Also at times they are unaware that their mother is unwell, as physically she looks OK. The mental strain that they go through is also something that we have to account for.”

5.2.3 Impacts on leisure activities and social life

212 respondents gave information about this.

A mixed picture emerged about the impacts on respondents’ leisure activities. 27% agreed or strongly agreed that their partner’s RA had not had an impact on their leisure activities. 27% also agreed or strongly agreed with the statement ‘I’ve taken up some new/different leisure activities because of my partner’s RA’. However, 54% agreed or strongly agreed with the statement ‘I’ve given up some activities because of my partner’s RA’.

Respondents’ assessments of changes to their social life suggested a more negative picture overall:

- 26% agreed or strongly agreed that ‘We have lost friends because of my partner’s RA’
- 60% agreed or strongly agreed that ‘My social life is restricted because of my partner’s RA’
- 77% disagreed or strongly disagreed that ‘Our social life has improved as a result of my partner’s RA’.

Despite this, 46% agreed or strongly agreed that ‘I am happy with my social life’, compared to 20% who disagreed or strongly disagreed with that statement. This assessment seems to be at odds with the majority reporting that their social life is restricted: we explored partners’ experiences further in the qualitative interviews (see section 6.3.1).

5 All quotations in this section are from questionnaire responses and used with permission.
5.2.4 Impacts on health and wellbeing

Most respondents described themselves as being in good general health: 19% (of 198 who answered this question) said their health was ‘excellent’, 46% said ‘good’ and 25% said ‘ok’.

11% described their health as poor and gave further information. They mentioned a range of specific health conditions, including: heart disease, cancer, Chronic Obstructive Pulmonary Disease (COPD), Crohn’s Disease, MS, uveitis, pancreatitis and spondylolisthesis.

Some respondents described particular symptoms and explained how their health affected their ability to care for or do activities with their partner. They mentioned: bad back, mobility problems, pain, high blood pressure, poor sight, fatigue, depression. These respondents considered that their own health affected their ability to cope with the impacts of their partner’s RA.

Most respondents reported that their partner’s RA had an impact on their mood or mental wellbeing (Figure 5). Only 7% (of 200 who answered this question) said it never affected them in this way, 57% said it affected them ‘on odd days’, and 35% said it was more frequently: either ‘often’ (22%), ‘most of the time’ (13%) or ‘all of the time’ (just 1%).

Nearly a third (29%) chose to give more information, and their responses made clear the impacts of their partner’s condition. Several themes emerged (in order of most frequently mentioned):

- The severity of their partner’s disease and/or mood has a direct impact on their own
- They are constantly worried or anxious about their partner’s health
- They feel the impact on their lifestyle: they are disappointed or regretful that there are activities they can no longer do, or do together
- They suffer from depression or low mood
- They suffer from stress because of their increased responsibilities, including financial and caring responsibilities
- They feel helpless or frustrated: about the situation, their inability to alleviate their partner’s pain, or the uncertainty day to day
- They feel guilty about their own emotional responses to their situation, such as feeling frustrated, stressed or regretful.

‘My work, social life, leisure etc have all suffered as nothing now matters to me apart from her. Her RA has undoubtedly made me more selfish as I think of others less now, as all my energy and time is taken up with looking after her as well as trying to hold down a full time job. This makes me less happy and more stressed and worried. These emotions then transfer to other walks of life, as her RA is not something I can forget about, even at work or elsewhere.’
‘When the RA is bad, it affects my mood and the way that I cope with things as I have to pick up much of the household work as well as continue working full-time. What affects me more is her mental state when things are not going well with her RA. She becomes depressed and very moody. I have to ensure that the children do not see her like this as it upsets them greatly.’

‘He is constant pain and suffers badly from being tired. I have to carry all the responsibility of bringing in money that puts a lot of strain on me... We can’t do things together and the laughter has gone. I try hard to smile, joke and laugh, but it’s really hard.’

I think the RA symptoms and diagnosis means we value all the well time together more and value each other.”
While some respondents did report that RA had positive effects on their relationship with their partner, the overall picture is of a negative impact (Figure 6):

- 69% disagreed or strongly disagreed that their partner’s RA had had a positive effect on their relationship; while only 14% agreed or strongly agreed.
- 41% agreed or strongly agreed that they had had difficulties in their relationship as a result of RA, compared to 32% who disagreed or strongly disagreed.
- 67% agreed or strongly agreed that their partner’s RA had negatively affected their sex life; only 14% disagreed or strongly disagreed.

Responses were more evenly distributed when respondents assessed whether their partner having RA had brought them closer together. Just under one third (32%) agreed or strongly agreed that it had; 42% were neutral; and 26% disagreed or strongly disagreed.

While relatively few respondents (9%) chose to explain their answers further, over half of those who did, explained how their sex life had been affected – indicating that this is a factor in the impacts of RA on couple’s relationships.

‘We don’t have a sex life anymore, it’s as simple as that.’

‘Constant pain means I am unable to even hold her hand let alone have contact or penetrative sex.’

A partner having RA is likely to have negative impacts on a couple’s relationship, and research suggests that this, in turn, has impacts for other areas of life. Studies have acknowledged, for example, the importance of strong partner relationships for individuals’ health and emotional health, and have considered the impact of family life on a person’s work productivity. The impacts of a partner having RA appear to be many and interconnected: we explored this further in the qualitative interviews (see sections 6.3.1 on page 41 and 6.3.2 on page 43).

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6 Studies have shown a higher divorce rate amongst people with RA than in the general population. www.everydayhealth.com/rheumatoid-arthritis/rheumatoid-arthritis-and-divorce.aspx accessed 4 April 2012.


5.2.5 Talking about the impacts

A partner’s RA can have considerable implications for an individual’s emotional and mental wellbeing. Yet few respondents had discussed these impacts and fewer still had received any professional support in coping with them. Almost two thirds of respondents (66% of 206 giving information) said that they tended not to talk about the impact on them. Most had not talked to friends or family; just 35% said they had. Only 5% said they had talked to their GP or to another health professional, 3% to a counsellor and 1% to somebody else.

13% chose to say more about their answer, nearly half of whom said more about why they did not talk to anyone. The most frequent reason was that they felt people did not understand RA so they saw little point in talking about it. Respondents also explained that no one had ever asked; that it did not feel right because talking would seem like complaining; and that they were unsure if it would help or change things.

‘I have not talked about the impact of her RA on me to anyone since she was diagnosed 5 years ago. Firstly, I would not know where to start and nobody has ever asked me how I deal with things. None of the doctors or health professionals have ever asked me how I cope and nobody at work has any idea how difficult it is for me either. The main reason for not speaking to anyone about it and just bottling all my emotions up is that I don’t feel right telling anyone that it affects me – my wife’s RA after all is far worse than any possible negative effect it has on me, and really I should just be grateful to be healthy. Speaking to someone properly about the impact on me just doesn’t feel right for this reason. That doesn’t mean I don’t want to speak to someone, I just don’t know if it would help, as it wouldn’t make the RA go away.’

‘Support is very limited because the issues are either very personal or because others simply don’t understand just how crippling RA can be.’

66% said that they tended not to talk about the impact their partner’s RA had on them
5.2.6 Support that could help

Using a Likert scale rated “very unhelpful to very helpful” we asked people to rate some possible suggestions made by NRAS to indicate which would be of most benefit to them:

- Advice on and benefits and financial assistance
- Information for children about RA
- Information about sex and relationships when a person has RA
- Public awareness campaigns so that more people understand about RA
- Individual answers to my particular questions
- Opportunities to meet other families where someone has RA
- Telephone helpline for family members/partners
- An NRAS booklet for family members
- Offer meetings for family members.

The three options with the highest positive rankings were:

- Public awareness campaigns so that more people understand about RA: 93% of those who ranked this option said it would be helpful or very helpful
- A booklet for family members: 81% said this would be helpful or very helpful
- Advice on benefits and financial assistance: 77% said this would be helpful or very helpful.

All the options were considered helpful overall: more respondents ranked them as helpful than as unhelpful. Respondents felt less strongly, however, about opportunities to meet other families with RA and about meetings for family members. These options received the highest proportions of neutral rankings (i.e. neither helpful nor unhelpful), 45% and 46% respectively.

The support for public awareness campaigns confirms that the lack of awareness and understanding is keenly felt: respondents indicated that this contributes to difficulties they experience talking about their partner’s RA (see section 5.2.5).
We also asked respondents about what health professionals could do that would be helpful to them (Figure 7).

**What else could health professionals do that would be helpful to you?**

Respondents ranked all three options as helpful overall:

- ‘Ask about RA’s impact on me as well as on my partner’: 71% ranked this as helpful or very helpful.
- ‘Give me time to ask my own questions about RA, separately from my partner: 64% ranked this as helpful or very helpful.
- ‘Offer meetings for families or family support sessions’: 46% ranked this as helpful or very helpful. Respondents felt less strongly about this, however, than the two other options, with 46% also giving it a neutral ranking.

### 5.3 Adult children of a parent with RA

66 respondents answered this section. Of these, 80% were women and 20% were men. This group was more ethnically diverse and younger than the partners’ group.

88% gave their ethnicity as White, 8% as Asian and 5% as Mixed. Over half (56%) were aged 34 or younger. The age group with the largest proportion of respondents was the group aged 18 to 24.

The length of time their parent had been diagnosed with RA varied from less than one year to more than 21 years. 41% said their parent was diagnosed within the last five years, 25% said their parent had been diagnosed for 11 to 20 years, and 18% said over 21 years ago.

Respondents’ experiences and memories of having a parent with RA therefore included experiences of parents having very different treatments for RA. As mentioned earlier in the report there have been significant advances in medical knowledge and treatment during this time, including the availability of biologic therapies, first licensed in the UK in the late 1990s.

Only 20% of respondents said they had received any information, when their parent was diagnosed, about what RA was and what to expect. Of these, most had received the information from their parent.

The majority of the group were adults at the time of their parent’s diagnosis: 54% said they were over 18. 14% were aged between 12 and 17 and 19% were aged between five and 11. Just 8% were under the age of five.
5.3.1 Impacts on their lives as children

35% of respondents, those who were under 18 when their parent was diagnosed, gave information about how they remembered their childhoods (Figure 8). A majority remembered being aware of their parent having RA, and remembered specific impacts:

- 60% agreed or strongly agreed with the statement ‘I was always aware as a child of my mum/dad having RA, while 27% disagreed or strongly disagreed
- 59% disagreed or strongly disagreed with the statement ‘I was never frightened or anxious about mum/dad’s health’ while only 23% agreed or strongly agreed
- 55% agreed with the statement ‘There were some things our family couldn’t do, because of mum/dad’s RA’, while only 23% disagreed or strongly disagreed
- 50% agreed or strongly agreed with the statement ‘I did more to help at home than my friends did because of mum/dad’s RA’ compared to 27% who disagreed or strongly disagreed.

In spite of the impacts they remembered, a majority (57%) agreed or strongly agreed with the statement ‘I never felt any different from other children because of mum/dad’s RA’, compared to 26% who disagreed or strongly disagreed.

Evaluations made in adulthood may not reliably reflect what actually happened in childhood, but they are nevertheless an indicator of how people assess and interpret the impact of childhood experiences.
5.3.2 Impacts on their lives as adults

83% of respondents (52 answered this question) said that having a parent with RA had affected their life as an adult. Of those, 85% said it affected them as they were often concerned about their parent, 44% said they made different choices about their own health or lifestyle and 35% said it had been a factor in their decisions about where to live or work.

33% said that having a parent with RA had affected them in other ways and gave more information. This included:

- They now have RA themselves (10% of all respondents who said that having a parent with RA affected them as an adult)
- They found it emotionally difficult to see their parent ill and struggling (8%)
- There have been impacts on the wider family, including activities and holidays (8%).

‘Mum has had a number of complications over the years and the worry and strain of waiting for constant operations and the recovery and feeling so helpless to be able to do anything that can make a difference for her.’

30% of this group gave information in the free response section of the questionnaire (section D, for all respondents). Their responses indicate that the impacts can vary for each son or daughter, even within a family, however some common themes emerged (given here in the order most frequently mentioned):

- They are concerned and worried about their parent. This includes anxiety about: their parent’s health, the quality of their care and how it is co-ordinated; their parent experiencing difficulties in relation to employment; the stresses in their parent’s relationships with their partner and with other family members
- They feel there is not enough support and information for families
- There is a lack of understanding about RA and its impacts, which makes life difficult for their parent
- They have taken on caring responsibilities
- They feel guilty about choosing to do things for themselves, including having a social life and moving away from the family home
- They have an admiration for their parent’s ability to cope.

‘Although my mum suffered with severe Rheumatoid Arthritis and was in a great deal of pain on a daily basis I feel that many people did not understand just how ill she was and how much determination it took for her to do very basic tasks such as lifting the fork to her mouth when she was eating. Quite often people would tell my mum she looked well and I knew just how much pain she was experiencing and I found it difficult to explain to others what an impact this disease had on my mum and our family. Mum felt exhausted most of the time and I would hear her crying in pain. Watching someone I loved suffer and having no control over her pain left me feeling very sad.’
‘General depressive environment in my family home. My mum’s chronic pain and fatigue means she struggles with general day to day tasks, so my father takes on most of the family responsibility made worse by my brother (26 yrs old) who often lacks the patience and understanding to deal with her condition, i.e. it leads to arguments!

My mum’s RA has always been a factor in my decision making. I’ve recently decided to move back nearer my parents to help her and also relieve some of the pressure my dad takes on.

I think growing up with a parent with chronic health problems has helped me appreciate how lucky I am to have full health and to not take it for granted. I think it has also allowed me to be more compassionate to those who are similarly suffering. However, while I try to help my mum she is often stubborn, feeling that no one can know what it is like unless you have the condition yourself.’

5.4 Parents of a son or daughter with RA or JIA

39 respondents had a son or daughter with RA. Of these, five were parents of a child diagnosed with Juvenile Idiopathic Arthritis (JIA).

19 gave information about their experience in the free response section of the questionnaire (we did not design questions specifically for this group).

5.4.1 Impacts on family life

Respondents emphasised the wide-ranging and often overwhelming effect on their lives as parents. Several themes recurred frequently, including (in the order most frequently mentioned):

- They are intensely worried for their son or daughter. Respondents explained: their anxiety seeing their son or daughter in pain; concerns about their treatment and whether it is effective; worry about their ability to work
- They are giving additional practical help. Respondents described, for example, taking their son or daughter to hospital appointments; caring for their grandchildren; being ‘on call’ for assistance; financial help
- The emotional impacts of RA are on the whole family, not just the person diagnosed. Respondents described how it affects all aspects of their life and is a source of constant strain
- They are concerned about the future: what the longer-term effects of the disease may be and how their son or daughter will cope
- They are under considerable stress, particularly from facing the uncertainty of their son or daughter’s condition and from feeling frustrated or powerless to help.
‘It’s heart breaking seeing someone you love be so poorly (so young – he was only 29 when diagnosed) and you feel so helpless – it literally does affect everything – it was very hard to smile for a long time and there were days where all we seemed to do was cry.’

Parents of children diagnosed with JIA described particular impacts on other children in the family, including coping with feelings of resentment or guilt about the attention their chronically ill sibling received.

‘As my son was only 15 when he was diagnosed with JIA, we were totally unprepared for the emotional impact it had on the whole family. My daughter, the younger of our two children, was also affected as she could no longer behave in the same way that she had previously toward her brother and she felt that she was getting less attention as a result of his illness.

My son is now 24 years old, has graduated from University with a first class Masters degree and is working as an engineer. However, he has had several relapses when his medication has stopped working, has been hospitalised, and has had the stress of not knowing if another drug would help his condition. He has also had to take time off work and although he is no longer living at home, this continues to be a real worry for all of us.’

Three respondents described some positive aspects of their experience: it puts other troubles in perspective, for example, or it makes clear who real friends are.

5.5 Other relatives of a person with RA

43 respondents had another relative who had RA. This is a minority of the overall sample but a sizeable one (11%), and indicates that the effects of the disease are widely felt in families. Other relatives mentioned were: sister, grandparent, cousin, aunt, brother, stepfather, father in law, daughter in law.

Seven respondents gave information about their experience in the free response section of the questionnaire (we did not design questions specifically for this group).

5.5.1 Impacts on the wider family

Their responses make it clear that the emotional and practical impacts of RA are not confined to those who live together; they can also be significant for members of the extended family. The main themes were as follows (given in the order most frequently mentioned):

- They find it upsetting and stressful to see their relative in pain, struggling with daily life and/or low in mood
- They see many impacts on other members of their family as well as on themselves, such as: the strain on their relative’s relationship with their partner; the impacts on their relative’s children; their parent’s distress; other family members’ embarrassment at their relative’s disability
- They either give or used to give practical help, including childcare for their own siblings or their relative’s children.
‘I always stand by my sister’s decisions as I trust she knows her body and how she feels. However, each time she tries a new drug it causes me a huge amount of tension and stress as I always fear that this drug may cause such severe reactions that she might not pull through.

On a practical side I often go with her to the hospital when she has the drug infusions which can take many hours and the parking costs can be very high. As my sister’s RA is very active she is always in pain and often the pain is very severe. This is upsetting as you would long to be able to do anything to relieve it and often I find myself not knowing what to say or do.

I also struggle to know what to say to her children. Recently I was looking after her young daughter. We talk openly about “Mummy being in hospital where the doctors will give her medicine to make her better” and remind her that even though Mummy isn’t at home she still loves her very much. During a conversation my niece said, “but when I touch Mummy I hurt her.” This broke my heart and I tried to explain that it wasn’t her hurting Mummy it was her bones hurt all the time but she didn’t really understand.

My sister also has a teenage son who chats to me about his concerns, everything from the embarrassment of having a disabled Mum in a wheelchair, (He loves his mum dearly and would never say this to her but it doesn’t mean that he doesn’t feel the peer pressure) why does his mum take medicines that make her sicker and not better, the frustration of not being able to do planned activities because mum is in too much pain today.’
When you speak to someone who really knows what it’s about, it makes a difference.
Steve is 24. His mother has RA.

‘Mum was actually diagnosed two years ago but she’d say looking back she probably had it for five years before that. She’s been on biologics for five months now. It’s not a miracle, but she’s so much better than a year ago.

‘I live at home when I’m not away working, so I help practically. I can drive her around when I’m at home. The RA in her neck makes turning difficult. I go with her to hospital appointments. The receptionist at the department where my mum goes for check-ups makes mistakes and gets dates wrong so she isn’t always seen often enough, although the practitioner himself is very good. And then the receptionist tells Mum that she hadn’t appeared for an appointment, which was totally wrong. People shouldn’t be treated that way.

‘The aspects that are most difficult are the basic things, really. Seeing Mum struggling with getting out of the car, helping her over a stile when we’re walking. I see her picking up plates, and she loses grip and thinks she’s going to drop them. The RA affects her shoulders; I hear them cracking. She was always fit, healthy and active. Now I see her getting stressed out and it affects her confidence – it’s not what it was. If she’s going out in the evening, she struggles, even with doing zips up. She cries and gets frustrated.

‘We talk; we speak about it all the time. Sometimes the best thing to do is laugh about it. My dad gets frustrated because he can’t do anything to help. We can still talk, but he’s not comfortable with it.

‘I have made some different choices, about holidays and that. I’ve come home on leave rather than go travelling. I’d have loved to go travelling more, but when you’re back at home with your family you don’t really think about that. I do more at home when I’m there, but they’re things I’m happy to do. I don’t think mum having RA has had more of an impact on me than on my brother or sister, but I notice the basics more, because I’m at home.

‘The worst thing is people not differentiating. There’s a whole lack of awareness about RA. I have to explain to people. I point them to the website to set them straight that it’s not the same as other arthritis. But then, I didn’t know about it or what it was before Mum had it.

‘What’s hard is when you get responses that show people don’t understand. When you speak to someone who really knows what it’s about, it makes a difference.’
The questionnaire data gave measures of the impacts of RA on different aspects of family life; this stage of the research gave insights into how a sample of family members experience, assess and describe those impacts.

All interviewees were willing to give their time and to speak about their personal and family life, often frankly and in depth. Several said explicitly that they were keen to help improve people’s understanding about the impacts of RA, precisely because of their own experience.

We have presented the experiences of two interviewees on pages 18 and 37. The analysis in this section draws on all the interviews, including the two case studies.

6.1 About the sample

We interviewed eight people. They were:

- Aged between 24 and 59
- Four men and four women
- Four partners of a person with RA. Their partners were diagnosed between one and five years ago. Three had children with their partner. The children were aged between seven months and 17 years
- Three adult children of a parent with RA. Their parents were diagnosed two months ago, two years ago and over 40 years ago
- One parent of a daughter with RA.

One interviewee had RA herself.
6.2 Common themes and concerns

While our sample included a range of ages and relationships to the person with RA, nevertheless common themes and concerns recurred across the interviews.

‘I don’t think the kids’ school really take it on board. They are very surprised when you say arthritis, they think it’s something older people get and it just takes you a bit longer to get up out of the armchair.’
Robert, 36, married to Nicky who has RA

‘At the rugby club, I’ve told them I won’t have my wife carrying things for people and I can see them thinking, “Why? she looks fine”’
Vic, 59, married to Olive who has RA

‘The big thing is the frustration – that lack of understanding that there is an impact on you. You’re not the one with aches and pains but it does have an impact on you. You have got to get to terms with it too.’
Vic

‘Olive had been to the doctor but she was only diagnosed because our neighbour, who’s a nurse, saw her while she was having a flare. She listed all the tests and we had to go in and ask for them. Perhaps the doctor’s knowledge wasn’t adequate. Had our neighbour not been a nurse we’d have been six months further down the line’
Vic

‘Nicky feels she’s had to fight all the way for TNF treatment. I helped her write a letter, very desperate, about all the effects on her life – and that got the appointment.’
Robert

‘It’s hard to get the time with the rheumatologist – I was at the appointments but they insisted on talking to him. What could have helped would be an opportunity to ask questions... I wrote the questions down in the end – about NICE, would it be different in a different health area, what if we went private, about the severity of the disease, what’s the likely outcome – so many things we wanted to find out about.’
Sue, 34, married to Tim who has RA

‘My sister works at a hospital so she got my dad an appointment through quite quickly. The GP referred him to the specialist, and she spoke to his secretary, who said, tell him to come in on Monday. Otherwise we might still be waiting... And you need the specialist. I don’t think the GPs know enough about it.’
Maria, whose father aged 74 has RA

However, respondents also had positive experiences of treatment.

‘I think we’re quite fortunate in the way it was dealt with. Kath has friends through a support group and she tells me about experiences they’ve had that weren’t so positive.’
Dave, married for 20 years to Kath, who has RA
Interviewees noted the value of information and support, particularly at an early stage. In particular they wanted information and support that was specifically relevant to their own situation.

‘To be able to meet other people would be an advantage – some kind of support group or network. If someone has RA they don’t want to be trailing out into the city at night. The NRAS message board is good but not a substitute for meeting in person – could we do something with Skype, video technology? to create support groups in that way?’
Vic

‘I was on the NRAS website, saying, Tim, look you can talk to someone, and he was not in a place to accept that. It would have helped me to talk to someone in a similar situation.’
Sue

‘I do get in contact with people via the NRAS website, which is a fantastic resource. There are people on there and I think – that’s me. There’s a guy in London, similar age, his wife has RA, two kids. You do start to think, what have done wrong, to shoulder all this. It reminds you that you’re not alone.’
Robert

‘One thing that I do feel passionately about is that there needs to be a young person’s perspective on RA out there – a balanced but positive source of information that deals specifically with their needs – so different from a child’s or a 50 year old’s needs. I would like everyone to share in my little chat with an orthopaedic surgeon who said when he was a junior doctor (20 years ago), he used to do weekly lists for RA patients and now he sees, maybe, one RA patient a month, if that. That everyone could have sat on the sofa as Lotts and I did in that first summer with a professor in rheumatology who was reassuring and positive – absolutely avoid cigarettes and absolutely – a glass of wine is fine!’
Jane, mother of Lottie, 22, who has RA

‘There’s nowhere to go for advice on benefits, nothing out there on that... It’s not recognised that well, so there aren’t pointers as to where to go. NRAS is always the starting point – but at the beginning it was all in a bit of jumble. There’s nothing like “this is what you might expect, this is what you might be required to do” – I mean for me and for Olive.’
Vic

Interviewees discussed how they and their family communicated about RA and its impacts, and the importance of this. Two interviewees’ comments suggested that their (male) relative was reluctant to talk, and one interviewee suggested directly that men may be less ready to talk than women

‘I keep my personal life private. Olive does have three or four very close friends but my circle is not as close as hers. Perhaps women have closer friends than men, I don’t know. I wouldn’t want to tell other people I know about my personal circumstances.’
Vic

‘I said, you’ve got to talk to me, you’re not going to not talk to me; if we don’t talk to each other we’re not going to get through this. I tease him about it; I’ve made him talk, a bit. Our boys are going to talk when they’re older, have emotions and everything!’
Sue

‘Dad doesn’t go to the doctor often; he’d rather live with the pain. So you’re worrying all the time. I’d phone every evening to see if he was any better, and mum would say no. If you’d speak to him, he’d say “I’m fine” but he wasn’t.’
Maria
6.3 Partners’ experiences

Four interviewees spoke about their life with a partner who has RA.

6.3.1 Impacts on mental wellbeing

‘I went back to work three days a week after having our son Ed. Life was just too hard. I love being a mum and I might have gone part time anyway, but with Tim’s RA as well it was too much. That was a factor.’

Sue

‘Now I do all the housework – we used to share it. Olive does the ironing but I do all the heavy stuff, anything involving lifting. I do the supermarket shopping and sixty to seventy percent of the cooking... If it’s something big, I do it... How do I feel? It’s one of those things. It has to be done. I just do it. I wouldn’t want to swap places. Sometimes it gets on top of you a bit. I might get a bit short-tempered and irritable. But she didn’t ask to have RA, it’s not her fault she has it.’

Vic

‘I’m supposed to be doing more around the house... it was becoming a bit of an issue. I was good at the caring side of things but not about the housework. She didn’t want to have to keep reminding me, and it became a source of friction. I put it down to being a bloke. So we compromise – Kath tries to be a bit more laid back and I try to remember.’

Dave

‘I was always the one who said, we’ve got to get on with it – on the surface, but deep down I suppose I was angry and upset. Kath was in denial for a long time, she didn’t really believe it, she said the consultant may have got it wrong. Whereas I cognitively knew it was right, but deep down I was angry. I still find it upsetting. It frustrates me that we can’t do things together that we’d like. We used to go away for our anniversary, and for the last couple of years we haven’t been able to do that.’

Dave

‘It has had quite an impact on our social life. We don’t go out of an evening as we used to. We were both members of a running club and she can’t go now and we can’t even do the social jogging together that we used to do. Olive used to come to all the rugby club away games but she finds it too tiring now. So I’ll go on my own or make other arrangements.’

Vic

‘I was almost feeling like there was nothing to live for. Now, looking back, that sounds like being a drama queen, but it was like our world had been this wide doorway – we’d travelled a lot together, talked about doing VSO. The wide doorway was now this narrow little gap.’

Sue
They spoke of stresses in their relationship including their sex life.

‘Sex was just not possible, with the RA. It just wasn’t an issue. It was months, we didn’t want to go there. Which is awful, because it wasn’t how we’d been before. And his self-esteem was very low when he went back to work. He’d say, I don’t think I’m doing a very good job. And when it’s like that you don’t think you’ll be good at anything.’

Sue

They described intense and difficult emotions:

‘I knew I wasn’t right. We were in tears every night. I was driving to work, not thinking that I wanted to end it all or anything like that but I remember thinking if I crashed the car then someone would have to come and help me. So I saw a GP who I liked and she said, yes you’re depressed.’

Sue

‘Up until a month ago, my emotions were pretty fried. It’s the uncertainty, the worry. Before RA I used to joke about Kath staying at home and giving up work. I find it very upsetting that she had to give up work; she had a career... But Kath is still Kath. If she’s down, I try to say, in a gentle way, that I prefer it like this to if she’d been killed in a car accident or something. Sometimes she says, though I don’t suppose for a minute that she means it [does not finish sentence]... It’s very tiring, worrying about her all the time.’

Dave

Interviewees also explained how their concern for their partner – their awareness of the physical and emotional impacts of the disease – made it more difficult for them to voice or acknowledge their own needs. Three interviewees described feeling guilty about their own emotions, for example, and a responsibility not to burden others.

‘I do find it frustrating. You can feel a bit sorry for yourself to be honest, and you shouldn’t do. Because it’s not me that has it, is it. She’s not complaining, she’s trying to make the best of it...

Guilty is too strong a word, but you feel a little bit that way. If you go out, you’re thinking, what if this, what if that – it’s on your mind.’

Vic

‘I’d sometimes feel guilty. I would feel lumbered because I was doing everything and it’s hard work. But you shouldn’t feel like that because it’s not you that has it.’

Sue

‘I felt I couldn’t speak even to Tim about some things, especially if he was so low.’

Sue

While all interviewees talked about adjustments and changes to their life, one described the positive impact of being more ready to do pleasurable things:

‘On the flip side, we’re more ready to do things. You think, what’s the point saving for a rainy day. We look at buying things sooner rather than later You never know how things are going to be. We could take the attitude, let’s wait, which might be the wise decision. But if things get worse we may have less opportunity to do things, and you may be needed more in the future.’

Dave
6.3.2 Talking about the impacts

Around two thirds of partners tend not to talk about impacts of their partner’s RA on them (see section 5.2.5 above) and the interviews suggested some factors that may contribute to this. These include: the lack of public awareness about RA, the fact that men may be less inclined to talk than women (see section 6.2) and a sense that their partner’s needs take priority over their own.

‘We try to talk to them [our sons] about it, and that’s aided by the fact that we’ve always talked. Kath sees them when they come in, they have a drink and a biscuit round the kitchen table. And at mealtimes that’s an opportunity to talk.’

Dave

‘I said, you’ve got to talk to me, you’re not going to not talk to me; if we don’t talk to each other we’re not going to get through this.’

Sue

‘If you go out, you’re thinking, what if this, what if that – it’s on your mind... I was going away to a conference and I was worried about going. Olive and I talked about it, and said that’s silly, we’ve got to get on with it.’

Vic

Interviewees spoke about the importance of communication within the family:

I found a local-ish counsellor and there was a waiting list. I started in March and went until June or July, every week. It was difficult financially...

He kept bringing things back to my childhood, and also said I had an anger problem. I didn’t enjoy it or always agree with him but something made me keep on going back. Maybe it was a process I needed to go through. I don’t know.

I stopped going because I felt brighter. I started to feel like me again. I thought, it’s given me enough to feel I can cope. Counselling made me look at things in a different way... it taught me to take breathers, do what I need to do, have a girlie night out, whatever.’

Sue

Interviewees talked about speaking to others outside the family, including a positive experience of counselling:

7 out of 206 people had talked to a counsellor.
6.3.3 Impacts on children

Over two thirds of parents who answered the questionnaire were concerned about the impacts on their children of having a parent with RA. Three interviewees talked about the impacts in their family.

‘Early on Ed had no clue about it but now aged 4 he’s got cross with Tim for going to sleep on the sofa. Tim does have stiff joints but the tiredness is the biggest thing now, and Ed was poking and prodding him – so we’ve tried to explain and he sort of gets the idea. He says, “Have you taken your tablets?” But he’s annoyed and I totally understand; he wants to play. So concerns are starting to creep in. Like, is he feeling he’s missing out, and will it make Tim feel inadequate and feel like he’s not a proper dad.

I do worry about the boys. Not, will they turn on him, but will it frustrate or embarrass them.’

Sue

‘It upsets them to see her in so much pain. We become acutely aware of it when they talk about it to people outside the home. Our youngest was doing a presentation at school about a charity and so he chose to do it about NRAS. And he reduced his friends and the teacher to tears. He had all the slides, wanted to practise the presentation. It’s things Kath and I talk about but it was difficult to hear a 15-year-old saying them’

Dave

‘They want to know, is she going to get any better, will the drugs help. The first anti-TNF she was on caused major inflammation and that was a real dip in her health, so the kids see the medication as a double-edged sword. They know she has to take it but there are the side effects.’

‘They’re very loving, caring individuals. I know with some teenagers they’re never in the house but they’ve always spent time at home... They are experiencing some aspects they may not otherwise have done. With teenagers it varies, even varies with the same person; some have no empathy or compassion, but they were already caring types. They do a bit more around the house maybe, but not too much.’
6.4 Experiences of children with a parent who has RA

Three interviewees talked about having a parent with RA. Their ages, circumstances and personal experiences of their parent’s disease were very different:

- Maria’s father, aged 74, was diagnosed two months ago. She lives with her family about half an hour away from her parents.
- Steve is aged 24. His mother was diagnosed two years ago. He works away, and stays with his parents when he’s home on leave. (Steve’s experience is on page 37)
- Ruth is in her forties. Her mother, now 70, has had RA for over 50 years. Ruth helped to care for her since she was a young child. Ruth lives nearby with her family and was herself diagnosed with RA two years ago.

Parents in this research have expressed concerns about the emotional impacts for their own children today.
Interviewees explained, from these different perspectives, the emotional impacts on them as adults of their concern for their parent, including upset and frustration at seeing their parent struggling with everyday life.

‘The worst thing was the diagnosis... He had 10 weeks of being so ill he could hardly stand up... The doctors won’t speak to you and he didn’t want us to go with him. He’s not that kind of man, to question the doctor – it’s the older generation, isn’t it.’
Maria

‘I was upset that she couldn’t hold the kids when they were babies. Things like feeding them, changing them, there was none of that. I know it really played on her mind.’
Ruth

They spoke of their anxieties about treatment and whether it would continue to be effective:

‘I’ve read up about it and researched it. It’s a life-changing, horrible disease. It’s difficult when you read about biologics and how sometimes they stop working – and you think, is that going to happen? And the steroid injections I read about, when the methotrexate wasn’t working. Though you read some good stories too, about people who’ve started dancing again and things like that.’
Steve

‘I was concerned about mum and dad, and can they ever live a normal life again. That’s changed now because he’s on his medication. I’m hoping he can stay on it. I’ve been reading about it and obviously there are a lot of success stories.’
Maria

‘She had methotrexate and she’s had 10 good years – for her... it made an awful difference... What kills me, now, is if it’s at the hospital and they say about trying something else and she says, “Don’t waste your money on me, keep it for the young women.” And I’m, “But I want to keep you, mummy.”’
Ruth

‘My husband and I put off leaving, really, as long as we could. We live five or 10 minutes in the car from her now. I felt awful guilty.’
Ruth
One interviewee’s parent had had RA for as long as she could remember, over 40 years. She talked about her childhood, caring for her mother and her feelings of concern, guilt and responsibility as she was growing up:

‘I remember helping with my brother and minding him while she got things done. I felt guilty about leaving her.’

‘I’m aware that as a child I was always trying to do something for her. In the bathroom I’d be with her and cleaning the bath afterwards...’

‘When you think about it and look back you see how restricted it was... I do remember not wanting to leave her and go out. It was personal things, so that was me and not my brother. Not my sister – I don’t know why.’

‘I remember times when she seized up. Once she was in hospital for eight weeks, having something done to her knees; once for months. We missed her. My sister went to one grandparent’s, my brother to an auntie. Our dad would come and see us. It felt bad to be split up.’

Ruth

She emphasised that she was happy to be a carer and noted that RA is treated and managed far more effectively today, with more support available.

While children’s circumstances now when they have a parent with RA are unlikely to be similar, parents in this research have expressed concerns about the emotional impacts for their own children today.
7 Conclusions & recommendations

7.1 Conclusions

- When a member of the family has rheumatoid arthritis, there are significant impacts for their partner and for other family members, including the extended family.
- When a person’s partner has RA this is likely to have negative impacts for the person on: their domestic responsibilities; their employment choices and the family finances; their social life; their relationship with their partner including their sex life; and their own emotional wellbeing. These impacts are interconnected and can be severe. A partner’s input is an essential element in the care of a person with RA, and this report shows that there can be a cost to the partner of providing good support, that is not always acknowledged.
- Children with a parent who has RA are likely to be affected by this into their adulthood. The majority in our survey were often concerned about their parent, and almost half said it affected their choices about their own health and lifestyle.
- For parents, the impacts of having a son or daughter with RA or JIA are overwhelming. Respondents in our survey described intense anxiety about their son or daughter and their other children, and stress as a result of the effects on all aspects of their lives.
- The impacts of RA are often hidden or ‘absorbed’ by families. The majority of partners in our survey were working full time and almost half were spending the equivalent of a working day per week or more on domestic tasks and personal care. The majority managed without additional help from outside the family. The majority also said that RA had a negative impact financially on their family.
- The impacts of RA are made more difficult for families by the lack of public awareness about RA, in particular the confusion of RA with osteoarthritis. It is upsetting when their family member’s pain is not acknowledged or understood.
- The majority of partners tend not to talk about the impacts on them. Very few have received any professional support. Many find it difficult to voice their own needs, often because they are aware of their partner’s difficulties and feel that their own are less significant in comparison.
- Family members particularly value support that helps them to feel less isolated: support from people who understand what they are experiencing, or who are in situations similar to their own. They would welcome more appropriate and timely information and support specific to their own circumstances.

7.2 Recommendations

We make these recommendations to clinicians and health professionals:

- Every interaction with the multidisciplinary team is an opportunity for including carers. Take opportunities when they present themselves to ask about patients’ family circumstances, particularly when partners or family members are present at consultations.
- Every care plan and the annual review documentation should include a reference that reminds the multidisciplinary team that carers and family members are important and need to be involved: it is an ongoing opportunity to keep them at the heart of RA care.
Specialist nurses are particularly involved in supporting and educating patients and also co-ordinating their care. They should actively encourage patients to involve their family members in their care right from diagnosis.

All members of the multidisciplinary team have a responsibility to signpost partners and family members to relevant sources of support. These may include NRAS’ helpline and other services, benefits advice services, their GP and counselling services.

We make these recommendations to government and policy makers/Public Health Directors/Commissioners and Health Boards in the devolved nations:

As part of the Long Term Conditions agenda:

- Public awareness of the early signs and symptoms of RA is critically important and urgent action is required. In 2010 the UK Parliament’s Public Accounts Committee recommended the Department of Health carry out a public awareness campaign following its inquiry into the state of RA services. Although this inquiry related to RA services in England, we believe the recommendations are equally applicable to Scotland, Wales and Northern Ireland. More action must be undertaken to raise awareness in the general population to increase the chance of early diagnosis and help to reduce the severity of the burden of disease on patients and their families.

- Actively promote self-management programmes for people with long-term conditions in the NHS bodies they are responsible for. Evidence demonstrates these programmes improve peoples’ ability to manage their condition, generate direct cost savings to the NHS and help reduce familial impacts, by helping patients to better manage their disease.

- Ensure the NHS bodies, which they are responsible for, provide additional information and support to affected families. This information must help families to access appropriate benefits and social care to help them cope with the significant financial and social impacts of the disease.

We make these recommendations to families living with RA

- Talk to each other – keep communicating!
- Give extended family members and friends the opportunity to help, do not wait until things reach crisis point. People feel valued and useful when they are asked to help.
- Realise that as a partner or family member of someone with RA, you are NOT alone. There are lots of people out there who feel just like you.

What will NRAS do?

- Continue working collaboratively with health professionals to promote awareness of the information and support that we can offer to people with RA and their families, and encourage them to signpost family members to our services.
- Contact and support family members directly, on a more regular basis.
- Research smarter and more imaginative ways to provide information and support specifically for partners and family members, in a variety of formats, and fundraise for this as a priority.
- Raise the recommendations to government at every opportunity within our Public Affairs strategy when we talk to policy makers across the UK.
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"I was concerned about mum and dad, and can they ever live a normal life again. That’s changed now because he’s on his medication."
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