Emotions, Relationships & Sexuality

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

The impact of rheumatoid arthritis on how we feel and relate to others
NRAS is the only patient-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 has a wealth of information about living with RA, treatments, the latest research and developments, and an online members’ forum. It also has a 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

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

- becoming a member
- participating in or planning a fundraising event
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NRAS survey 2013

Bibliography
At NRAS, we have wanted to write this booklet for some time now. There has been a major gap when it comes to tackling emotions, relationships and sexuality, and how these very personal and intimate issues are affected by being diagnosed with and living with rheumatoid arthritis.

Our research, including the Family Matters survey published in 2012, confirmed there was a huge need. This was reinforced by the overwhelming response to our 2013 survey, which has informed the development of this booklet. So a huge thank you goes to all those who took part in the survey and the focus groups.

I was diagnosed with RA when I was 31. At that time my ex-husband and I had been trying for a baby for a number of years and were starting to think about IVF treatment when I fell pregnant. My RA quietened down when I was pregnant, but returned with a vengeance six weeks after Anna’s birth. Instead of being confined to one knee it went everywhere.

I remember only too well feeling emotionally out of control. How would having an incurable and incredibly painful disease impact on my future life, my relationship, my ability to work? How would I be able to care for my baby? I was already struggling to pick her up, change her nappy and hold her comfortably. To say that I felt completely isolated in my fears was an understatement. Anna is nearly 31 now. She still gets irrationally upset whenever I have surgery, because she...
remembers as a small child thinking I was going to die every time I went into hospital. I had my first operation when she was nine months old.

I got divorced when Anna was three and a half and some time later got together with my now husband. It might not have happened, because the fact that I had RA was something he thought long and hard about before ‘taking me on’. We have travelled my RA road together and it has made our relationship stronger but there have been many ups and downs along the way. I can relate to all the feelings described in this booklet by those who have bravely shared their most private thoughts.

Things were very different when I was diagnosed. I am relieved and thankful that treatment now is light years ahead of where it was then. With earlier diagnosis and a wider choice of effective drugs, people diagnosed today and in recent years will have less damage to their joints and be able to enjoy a good quality of life, working and doing what they want to do.

But RA is a very individual disease and there are thousands, like me, who have lived with RA for many years and sustained a lot of irreversible damage. We have tried in this booklet to address the widest possible range of concerns for people of all ages living with RA. While you may not experience everything that is raised in this booklet, I sincerely hope that there are elements that bring help and comfort – you are by no means alone.

Ailsa Bosworth
Chief Executive, NRAS
ABOUT THIS BOOKLET

Published April 2013

Living with rheumatoid arthritis means, inevitably, that we make adjustments to our lives and relationships. Some changes happen so slowly that we’re hardly aware of them; others are more abrupt.
It can be reassuring to know that we’re not alone in this, and that others share similar problems. This booklet aims to reflect the many different ways people think and feel about living with this condition – people who have RA and those close to them. Perhaps you’ll recognise something in the experiences and feelings of others here – they’re all from people with RA who contributed to our research.

Feelings describe our emotions or our state of mind: we feel happy, angry, fearful or sad. These states of mind influence how we think and act, during every waking moment and even unconsciously, when we dream. They can alter in an instant or stay with us for hours. Our minds have a profound effect on our bodies, and a condition like RA affects both.

Like most things in life, adapting to RA is a challenge that becomes easier if we know more about it. We can cope more effectively with changes in our lives and relationships if we understand how and why they occur. While we may not be able to control what we feel, we can learn to re-interpret feelings – even difficult or uncomfortable feelings – when we understand more about where they come from. With new information, we can change how we feel.

So this booklet offers information about people’s emotional experiences of RA, and with that, perhaps, an opportunity to think differently about our own experiences. It also offers suggestions and practical tips about understanding and adjusting to life with RA – as individuals, with family and friends, and in intimate and sexual relationships.

If we can understand and accept ourselves, it can make our lives more meaningful and contented, and certainly less stressful. We hope this booklet helps.
“When you have good days and bad days then your reactions to life alternate too... even after four years I'm still learning how to deal with this disease.”
WHY DO WE FEEL THE WAY WE DO?

We are all different and unique. There is no single route to contentment, no right or wrong way to be. The experience of living with a condition like RA is different for everyone. So why is that?
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Psychologists generally agree that we cope differently as adults because of our different experiences as children (see box). And when something happens in your life, such as developing RA or being emotionally involved with someone affected by it, how you think and feel about it is very much influenced by how you thought and felt about yourself already, before it happened.

During our lives we adjust our thoughts and feelings to take in and make sense of new experiences, most of the time without even noticing. But some adjustments might not happen like this, because they seem too difficult and we just don’t know how to make them. So people can find that they have feelings about RA that may seem unreasonable, uncomfortable or difficult to understand.

THERE’S NO ‘RIGHT’ WAY TO FEEL

- 55% of people had felt resentful because of their RA
- 46% had felt embarrassed
- 33% had felt guilty

All the statistics in the booklet are from NRAS’ 2013 survey.
OUR EXPERIENCES AS CHILDREN INFLUENCE HOW WE COPE AS ADULTS

Everything we experience in our early childhood affects who we become as adults: how we think, how we respond to people and events and what we say and do\(^1\) – what psychologists call our behaviours.

Many scientists believe that we are born with some of our personal characteristics (genetic or in-built characteristics), and others are influenced by the care we receive in our early life, for example from our parents. If people have a secure start in life, they stand a better chance of becoming stable and contented adults. If we start out in less than ideal circumstances, we may not feel as able to face what life throws at us later on. Or if we are sheltered from challenges as children, this may also leave us less able to cope later on.

People are born already programmed to form close relationships and this ability is essential to help us to establish meaningful ‘attachments’ to other people throughout our life. And having more positive attachments later on can help to make up for less favourable circumstances in early life.

Our attachments affect how we learn to react to challenges and adapt to change. Ideally we grow away from the people who look after us in our early life and create a new, independent world for ourselves.

\(^1\) See Schore, AN (1994) p540. Details of all the references are in the Bibliography on page 98.
Developing RA is not a failing but it can make people feel ‘different’, and most human beings prefer to belong, to be like everyone else. Many people who have an illness can feel guilty or ashamed about it at times. While this may not seem logical, perhaps it’s not surprising: if we’re taught as children to work hard and improve ourselves, how do we cope with being ‘imperfect’?

Some people feel more doubting about close relationships, particularly within couples. Many people believe that their confidence has suffered as a result of having RA, and in this state of mind it’s hard to be as trusting as they once were. The connection between couples can be a source of security, but it can also leave people feeling vulnerable as they open up their innermost selves to a partner (there’s more about relationships on page 72).

Living with RA can affect a person’s self-esteem too. It isn’t the same for everyone, but many people have concerns about their bodies and how other people feel about them, whether they’re in a relationship or single. We live in a world where everyone is aware of appearances, and we continually see (airbrushed) advertisements that urge us to have perfect bodies and to enhance how we look. A body disfigured by bone damage isn’t likely to fit with society’s idea of what’s desirable – however shallow and superficial that may be. And our bodies have meanings that go far beyond how they look (see page 41). Fortunately for those with RA diagnosed in recent years, visible physical damage is far less likely than it was in the past, because treatments are now so much more effective.

It’s not only about how the world sees us – it’s about how we see ourselves. For many people, much of their self-image has been established over the course of their lives before RA. It’s a different challenge, therefore, if RA strikes someone when they’re young. If RA does alter your appearance, it takes effort and an attitude of self-acceptance to get your confidence back and see yourself differently.
BELIEFS ABOUT ILLNESS AND DIFFICULT TIMES

How people react to being diagnosed with an illness depends on what they understand is happening and what they believe could happen in the future.

Diagnosis is likely to cause a range of physical and emotional reactions. The experience may be shocking. Perhaps you believed arthritis was something that only elderly people can have. You might feel numb, angry, sad and fearful. You might feel relief after all the uncertainty of not knowing what was wrong, or you may feel nothing at all for a while. However people react, the feelings are natural and normal for them. Anyone can feel vulnerable and want support from those closest to them as they start to take in the prospect of life with RA. Or they might want to push others away. There’s no rule book.

Whether we’ve been aware of it or not, we’ve usually had ideas about what our life would be like: a ‘plan’ of some sort. We’d finish our education, start work, fall in love, settle down, do something amazing, and so on. We’re unlikely to have thought about illness as a part of this, unless we had a specific reason to. Being diagnosed with RA comes as a threat to our security and wellbeing.

It takes time to adjust our ‘plan’ to include this new and undesirable fact.

When it comes to managing life with chronic illness (which means long-term illness, not severe), it matters how we’ve learned to cope in general. Some people do seem more resilient – more able to ‘roll with the punches’ – and psychologists have various views about why this is. Adolescence may be important: young adults often feel as if nothing can harm them and it’s a time when they take risks, as if to prove to themselves that they can live forever. This period in our lives may be important for how ‘tough’ we become later on.

To face chronic illness, people draw upon everything they’ve learned about facing hardship. If they’ve come through difficult times in the past, they may expect to be able to survive them again. If they haven’t been able to get through hard times, or they’ve never experienced them, they may find it harder to come to terms with illness.

Fortunately, human beings have an amazing capacity for change – with the right support, time and information.
FACING CHANGES

It’s likely that we’ll get frustrated as RA has an impact on the different areas of our lives, particularly if it affects things that once came naturally to us. At work, with friends and in relationships, it becomes hard to tolerate that we can no longer do what we want or need to do. We may not be able to plan for tomorrow with any confidence, let alone the future, which can make us feel vulnerable. Not only do we feel less physically able, we might not feel as strong emotionally as we did before.

At times we might not be able to continue with all the tasks and responsibilities we’re used to, and this can make us feel guilty. One explanation for this is our need to be appreciated: we learn as children that we typically get praised for good behaviour and so we try to impress other people with our achievements – and we carry this with us into adult life. It’s often what motivates us most. So becoming ‘unable’, through illness, can upset this and make us doubt ourselves or fear ‘failure’.

By exploring our thoughts and feelings, we can enhance our ability to adapt positively to RA, regain a sense of confidence in our bodies and restore control over our lives.
HOW DO YOU FEEL ABOUT CHANGES IN YOUR LIFE BECAUSE OF RA?

When you or someone close to you has RA, you face a continuous process of making adjustments in order to have the best quality of life you can.
HOW DO YOU FEEL ABOUT CHANGES IN YOUR LIFE BECAUSE OF RA?

"Initially I was so sad that I had RA. Now I don’t let it worry me, I love life and make the very best of it I can. The pain on the whole is less intense and I have learned to get on with it."

When you or someone close to you has RA, you face a continuous process of making adjustments in order to have the best quality of life you can. It’s important to believe that you can make the psychological adjustments you need to, and it’s realistic to understand that things will change. You can’t organise every aspect of the future so it helps to be prepared to reassess your situation as you go along.

- 70% of people with RA said it has a negative emotional impact on them
- 7% said RA has a positive impact
- 23% said the impact is neither positive or negative
- 84% agreed that the emotional side of having RA is as significant as the physical side
- 8% disagreed
- 7% neither agreed nor disagreed
- 1% did not answer
A SENSE OF SECURITY

Feeling ‘safe’ is important when you’re coping with RA. Sarah Collins, counsellor, suggests ways to build your own sense of security.

We can learn to focus on the here and now, and try to put aside any frightening thoughts about what could happen.

We can arm ourselves with information, as ignorance can create fear. When it comes to choosing sources of information, listen to your own instincts and avoid other people’s tales of woe.

We can also work at developing relationships with the people we can trust. When we’re vulnerable and need help to feel secure, we rely on the instincts we formed when we were small children (what psychologists call our early experiences of ‘attachment’), when ideally we could trust that we would be cared for. Your medical team......people understand you, NRAS can help with this too.’

“I find it extremely difficult to mentally cope with RA as well as the physical issues. As a PE teacher in his 30s, three years ago I’m playing county standard cricket and rugby and sport is my life. Now I can’t play with my three year old daughter – I am too old to play ‘good’ sport again anyway, but to go from all sport to nothing in career and life is hard – I have put on over three stone and all I want now is to play with my three year old daughter and most days I can’t at all! I feel low and down and it’s just not me and how I’ve been all my life! I’m fighting and WILL get it under more control but for two years and no drugs working at all staying strong can be hard.”
BEING WELL AND BEING ‘ILL’

Human beings naturally value good health and often work hard for it. And nowadays we’re surrounded by a huge number of health products and fitness regimes. They all suggest that we can improve ourselves, if we have the determination and/or the money. But if being healthy and fit is so desirable and (says the advertising) possible, what might this mean for people who have RA?

Some people respond by being as fit as they possibly can, while others feel defeated, and there are many variations in between. It’s true that how people think and feel is influenced to some extent by what has come before in their lives, but it’s possible to change this, too. To be able to make changes, it helps to understand what it means to us personally to be ‘unwell’.

We might feel resentful and that life is ‘unfair’ or we may feel that RA isn’t as bad as other conditions, and we’re better off – is your cup half empty or half full? If people stay resentful they turn away from possibilities to improve things, and their negative frame of mind can put other people off seeing what lies behind it. On the other hand, if they face the problems of RA more optimistically they are more likely to manage better and attract people and opportunities. Research supports this thinking\(^2\) – but no one’s suggesting it’s easy.

“I feel angry that, having reached retirement age, we’re not able to do all the things we’d planned. I also feel guilty that this affects my (loving, supportive and understanding) husband.”

\(^2\) Vriezekolk, JE et al. (2011)
IT MAKES A DIFFERENCE WHEN YOU DEVELOP RA

One important factor in how RA affects us is the stage of life we’re in when we develop it. In different stages of life, it brings different disruptions and challenges.

Those who develop juvenile idiopathic arthritis (JIA) as children can now look forward to a much healthier future than was once the case. Still, some people don’t remember much of a life without their condition by the time they are adults. Ideally they’ll recall feeling cared for and encouraged by their family and friends, with their disease controlled so early that it barely featured. If this isn’t their experience, though, they may remember feeling left out or teased, and frightened of pain, hospital visits and attending school. As adolescents, they may have felt rejected by other people their age, and possibly they felt ‘smothered’ by well-meaning parents as they faced the challenge of separating from them and becoming independent.

If you develop RA as a young adult, there can be particular anxieties about your social life and relationships, for example about when to tell a new partner (there’s more about this on page 69). There are other concerns if you develop the condition when you’re in a relationship, if you have children or if you’re planning a pregnancy. RA affects people’s careers at all stages of life. And in later years, it affects people’s retirement plans and perhaps their role as grandparents.

RA is, unavoidably, something to think about in all these circumstances. But it is possible to lessen its impact by working to build positive experiences and relationships. How we think about the future can influence how we arrive there.

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3 Juvenile idiopathic arthritis (JIA) refers to a group of conditions involving joint inflammation (arthritis) that first appears before the age of 16. This condition is an autoimmune disorder, which means that the immune system malfunctions and attacks the body’s organs and tissues, in this case most commonly the joints. Researchers have described seven types of JIA. The types are distinguished by their signs and symptoms, the number of joints affected, other possible symptoms, the results of laboratory tests and the family history.
WHAT IS ADJUSTMENT, AND WHY DOES IT MATTER?

Adjustment means making changes to our attitudes and behaviours – and we can be aware or unaware (conscious or unconscious) that we’re doing it. An example of conscious adjustment is finding a solution to a problem, such as using a grip to open a jar. In the case of unconscious adjustments, we aren’t aware of what we’ve changed. For example, you can hold a pen differently for months before realising what you’re doing, or you might react calmly now to something that used to really wind you up.

Adapting like this helps people feel in control, as they find ways to reduce the impact of RA. If people don’t make adjustments, they are likely to find themselves feeling less able to cope, emotionally and practically.

We might feel resistant to changes, as they weren’t in our ‘plan’ for how life would be. We might be angry about having RA or someone close to us having it. We might believe that if we manage our condition better, we won’t get as much help. Some of us are ‘creatures of habit’, used to doing things the same way, and some of us are more open to creative problem solving. If we know that we do feel resistant to change, it can help to examine why. If we understand it, we can choose to change.

When we can think about how RA is affecting us, we have a chance to solve the problems. The solutions we come up with are our own, but we also learn from other people’s experiences, which is why information and support can be so helpful. And sometimes, we may just have to accept that there isn’t a solution and concentrate instead on something that we can do.
BEING ANGRY IS PART OF BEING HUMAN

Living with a chronic condition can involve constant effort, frustration and feeling helpless. It can tip us into rage and despair at times. Without an ‘enemy’ at which to direct our anger, it may show itself in ways that the people closest to us find hard to understand and tolerate.

We’re often taught that anger is somehow unacceptable, but it’s a natural expression of unhappiness or fear and it’s helpful if we can accept that. Who wouldn’t be angry when an illness intrudes on their life? It’s how we express anger that matters, and we can choose to do it constructively rather than destructively.

Expressing anger constructively involves acknowledging that you’re angry, considering the situation and what others might feel, and what you feel about it. Then you can explain what you need, or your views about what’s making you angry – this can achieve much more than verbally lashing out (the destructive version). That might feel satisfying at the time, but it rarely achieves much.

Anger does motivate some people, but fighting RA as an invisible ‘enemy within’ may end up being a waste of energy. It’s pointless to engage in an emotional fight with fate over our bodies – far better to use our precious energy for something satisfying.

Families, too, feel the strain and may be angry at times. They also have to make adjustments to their lives, because of the changes RA brings about. And they may feel guilty about feeling angry and where to direct those feelings. Even in the most supportive families, anger is bound to blow up unfairly. Being angry at times is an inevitable part of being human and occasionally we lose self-control and upset each other. (See page 75 for suggestions about handling conflict).

It can help to separate the person from their disease: that is, for family and friends to see that the person with RA is still the person they knew although they’re affected by illness. It can also help for the family to see ‘we’re all in this together’, determined to manage as best they can. This means – although they’re committed to their family member with RA – everyone has their own life, too. Otherwise all of family life can end up being shaped by the limitations of one person’s RA, which can lead to people feeling frustrated or resentful.
LOSS AND GRIEVING

“Being diagnosed with RA felt like a loss of my health with a major impact on my lifestyle, it was like a grieving process.”

Living with RA can mean facing a number of losses, whether you have RA or live with someone who does. In many ways it’s like bereavement, particularly if a significant relationship ends because someone you loved couldn’t come to terms with RA. To move towards a state of acceptance and adaptation, we first have to grieve for our losses, whatever they are. We have to acknowledge that some things we valued and others that we took for granted may no longer be possible.

You may have lost physical activities that you found exciting, a job you loved or part of your independence. You may miss the company of a partner who enjoyed certain pastimes with you.

“For someone who loved fashion, shoes, make up etc. this disease is a real kick in the teeth as one by one I have had to leave all this behind and each time lost a part of me.”
“My marriage ended because my husband couldn’t cope with “my disease” as he put it. Physically I had always been very fit and the decline in fitness and an inability to be the person I used to be caused him to have an affair. Our sex life had diminished and as this turned out to be of prime importance to him, the marriage ended.

You may be grieving for an aspect of a loved one’s personality, which has been overwhelmed by the demands of RA. Grief is personal and unique to you. Whatever you feel, allow the feelings.

However, there can be gains as well as losses. The changes illness brings can sometimes be made positive: a change of direction, achieving something we never thought possible, or meeting people we wouldn’t otherwise have met. Some people use their new knowledge and experience for the benefit of others. And some find that facing challenges helps them to think about life and understand things in ways they wouldn’t have done without RA.

“I have lost my job […] because of rheumatoid arthritis. However, I am making the most of the opportunity to have a career change, which many people of my age don’t get, and am thinking hard about what I can manage to do and what I would like to do. That said, it has been very stressful.”
WHAT DOES ‘ACCEPTING’ RA MEAN TO YOU?

If you know that other people accept you, irrespective of RA, is that enough to accept it yourself? Or does acceptance sound like defeat, being resigned to RA?
WHAT DOES ‘ACCEPTING’ RA MEAN TO YOU?

‘Accepting RA’ suggests different things to different people. If you know that other people accept you, irrespective of RA, is that enough to accept it yourself? Or does acceptance sound like defeat, being resigned to RA?

Acceptance doesn’t mean you’re happy about something; it means that you acknowledge what is happening. So why could it be helpful for someone with RA to be accepting of their situation? Possibly because if we don’t come to terms with something important in life, it can cause low mood and unhappiness. Acceptance, the opposite of rejection, means accurately acknowledging the reality of a situation—something that self-help ‘gurus’ often recommend when you can’t change it.

Some people are determined that they’re not going to ‘accept’ RA. This can be powerful as long as it doesn’t stop them looking after themselves, for example by pacing their activities, rest and exercise—as always, the right balance is important. Other people see acceptance as something positive, about achieving things in spite of RA and refusing to be defined by an illness. It can bring them a level of calm, or a sense of being at peace.

Whatever it means to you, it’s likely to be a state of mind you move in and out of, according to what’s happening in your life. It’s a personal choice.
IT IS POSSIBLE TO MAKE YOURSELF FEEL MORE ‘POSITIVE’?

People often talk about having a positive attitude, a ‘can do’ rather than ‘can’t do’ approach to RA. This can help, as being positive has been shown to produce better patient outcomes. Our attitude is influenced by our thoughts and beliefs, and by the behaviours we developed earlier in life (see page 13) and these may not always be positive. However, over time new experiences can change our beliefs and contribute to feeling positive: a new relationship, for example, or being in new places, or being proud of something we’ve achieved in spite of RA.

Success breeds success. The more victories you have, the more you believe in yourself and your ability to be positive. Be realistic and remember that change takes energy, time and determination. Whatever you want to do, you’re more likely to achieve it if you’re kind to yourself.

POSITIVE THINKING?

Some people have found that even if they don’t feel positive to begin with, they can work on having a positive attitude.

- It starts with a conscious choice to be happy despite RA.
- Make some decisions, such as: to believe in yourself; to think about problems with a ‘can do’ attitude; to imagine success rather than failure.
- It helps to meet others who approach life this way.
- Keep a journal. On one page, note how you’d previously have tackled a problem. On the opposite page, write down how you’d like to tackle it now, imagining you’re a happy and positive person.
- Think yourself into the mind of someone you admire, or pick a cheerful and positive character from a TV programme. What would they do?

Seligman, MEP and Csikszentmihalyi, M (2000)
“I am a private person and don’t like telling people about my health. It’s been a few years since I was diagnosed and most people now know what is wrong with me but I still hide my crutch behind me when having photos taken so I suppose it still affects me how others see me.”
IF YOU TELL PEOPLE ABOUT HAVING RA, WHAT DO YOU FEEL?

Many people with RA find there are times when they’re confused or hurt by other people’s responses or behaviour.
When you’re weighing up whether or not to tell people about your RA, it can help to think about why people may react in different ways.

TELLING FAMILY

You may be quite happy sharing the news of your RA early on, or you may need time to come to terms with it yourself first. Illness brings with it the fear of losing control of our lives. Our self-esteem may suffer. We may feel that telling others shows our vulnerable side, and we’re not ready for that – even if we don’t realise this at the time.

Some people prefer not to talk about RA, even to family, as they’re concerned about being treated differently or worried about people’s reactions. And it’s true that even the most devoted families may not react in the way you’d like or expect. They may also be feeling anxious, angry or upset.

Many people with RA find there are times when they’re confused or hurt by other people’s responses or behaviour. Reactions that seem unsympathetic can be hard to deal with, whether they’re from total strangers or close family. A curious glance at a fumbling hand, or an inconsiderate remark made in ignorance – these may seem minor but they can really upset and demoralise you if RA is giving you a bad day.
They may be worried about RA disrupting their lives and might think it’s not fair to discuss that with you. Family dynamics aren’t always straightforward, and if one thing changes (such as an illness) then other things won’t go on as before either; the whole system has to change. Few people like change when it’s forced on them, especially by illness.

And RA affects the whole family. Children may worry about developing RA; parents may feel ‘responsible’ for the genes they have passed on, if they’re aware that genes play a role in RA. They might not fully appreciate how it feels to have RA or they might want to believe ‘it can’t be that bad’, as a way of protecting themselves from difficult feelings. Parents have to readjust their thinking about their child’s life, too, now that RA is part of the picture.

If you have children, they may be upset and worry about how your illness will affect you and them. And at other times they may show no concern for you at all. This is natural, as children deal with difficult experiences a bit at a time. It may seem uncaring, but it’s ‘nature’s way’ of protecting them from coping with too much at once. Older children may seem more bothered about how your illness could affect your ability to look after them. This may seem selfish but in fact it’s healthy: young people are creating their own ‘plan’ of what their life will be and up to now, you’ve probably been central to it – you could even see this as a compliment to you! Young brains are very adaptable, and with time any changes will come to feel normal for them.

IF YOU DON’T HAVE FAMILY

Coping with RA without close family may leave you feeling isolated, and it can be more difficult to come to terms with anxieties about other people’s reactions to your RA and how they see you. However, many people say it’s easier to talk about their RA to someone who is not their close family.

A sympathetic GP or rheumatology nurse should listen to your concerns and may be able to suggest where to find more information and support. NRAS has a helpline you can call, and NRAS can also put you in touch with a volunteer ‘buddy’, someone else who has RA. Many people with RA find it reassuring and valuable to speak to and learn from others who have the condition.

RA is not directly inherited though there is a genetic element involved, whether or not someone in your family has RA. See Steer, S (2003). Environmental factors, such as infection, also contribute to someone developing RA. See Symmonds, D (2004).
OTHER PEOPLE’S REACTIONS

It’s reassuring when people understand us – when they respond in way that acknowledges our feelings and views. So it can be upsetting if we don’t get the response we wanted, especially when it’s about an experience as personal as RA. It can help to know that people’s reactions may not truly reflect what they’re thinking or feeling.

Loved ones and friends, when you tell them you’re ill, want to express their sympathy in the right way, or at the right level – and to do that they need to know what you are feeling. It helps if you can explain what RA means to you, even if that means explaining you have no idea what to expect. You don’t have to be brave if you don’t feel it: if people believe you’re coping, they may think you don’t need help or support.

If you’re uncertain about someone’s attitude to you and your RA, you can always ask. It doesn’t come naturally to everyone to talk about what’s on their mind, so how about writing them a note or an email? That way, you can think through what you want to say and the other person has time to think about what you’ve told them and how they feel.

It might help to know that some people express distress as anger while others withdraw and stay silent. This may seem uncaring but it can be far from the truth. What people say often suggests more about them and how they’re feeling. Being realistic, we may not always get the reactions we’d ideally like from people, and if we know that, it might stop us feeling upset and resentful.
TACKLING MISUNDERSTANDINGS

When people notice changes in how you are, physically or emotionally, they may treat you differently. And this works both ways: you might then behave differently towards them. Being aware of this can help in sorting out misunderstandings. If you do feel that someone’s treating you differently, you could try starting a conversation with them about what’s happening.

To give an example: you might feel that you’ve been left out of something that you used to do, though no-one’s given you a reason. It could be a role that’s always been yours at family events, or at the children’s school; something you did regularly. But this time, no one’s asked you. You believe it’s because they think you won’t be any use: they’ve seen you walking really slowly recently. But you believe you could do other things instead. So you tell whoever it is that you’re a bit slow but you’d still like to help, even if that’s in other ways.

And the other person tells you they’re really pleased to hear from you – they’d been anxious not to burden you in case it was too much and you felt you couldn’t say no. They’re sorry you feel you’ve been overlooked as nothing could be further from the truth...

If we start the conversation, we give the other person a chance to mention their concerns. If there is a misunderstanding, we’ve created an opportunity to do something about it. Or we may find out there’s another reason entirely!
TELLING PEOPLE AT WORK

If you’re working, raising the subject of RA presents its own challenges. You may fear a negative response, but you can’t always predict an employer or potential employer’s reaction and you may be surprised. (The box on page 38 has information that may be helpful.)

It’s easier to adapt some roles than others, and to some extent this will influence how you feel about your working life with RA. Another factor is the relationships you have with colleagues and managers, which influence how they see you once they know about your RA. If they’ve always thought of you as someone committed and hard working, you’re more likely to have their sympathy and respect if you struggle.
RA has affected my movement, and this means that I have invited sympathy at work. I hated this, but it didn’t affect my status or others’ respect for me. What it did affect, though, and badly, was my time-keeping. It took me longer to move from place to place, I couldn’t climb stairs, which was problematical if there was no lift or if it was somewhere else [ ].

Sometimes I had to sit, rather than stand, to train, which was awkward and drew attention to me not to the training. Oh, and I need to drink nearly all the time to keep my mouth moist, and that’s really difficult to arrange, means I have to pee more often than others, and, of course, it takes me ages to wake and rise in the morning. Travelling on public transport is also difficult – I can’t use the underground anywhere because of the stairs, so my employers or myself have to pay for taxis, which is hard for us all.
EMPLOYMENT AND RA: HELP AND SUPPORT

- Employers are required by law to make reasonable adjustments for people who need them because of a disability. This is set out in the Equality Act 2010, which replaced the Disability Discrimination Act.

- Many companies also have their own occupational health facilities that provide emotional as well as practical support around sickness and disability.

- The Government scheme Access to Work can pay for some kinds of support including equipment or fares to work if you can’t use public transport.

There’s up-to-date information about these issues and links to more help at www.nras.org.uk. NRAS booklets, including I want to work and When an employee has rheumatoid arthritis, are free to download.

If you have no visible signs of RA, some colleagues may find it harder to acknowledge the challenges you face. When it comes to fatigue, they may not understand that their experience of fatigue is nothing like the deadening fatigue of RA, which you can’t fight against however much you’d like to.

Some people may be jealous if you have shorter working hours, or any adjustment that appears to give you an ‘advantage’.

While most people can realise that RA isn’t good news and be sympathetic, colleagues may need your help to understand that RA is not at all the same as osteoarthritis and what it means. It’s up to us how we put that message across, and if we can do it with a positive attitude it’s more likely to encourage a positive response. People’s compassion can wear off if they find someone constantly miserable about life!
Colleagues may well not understand that RA can make you feel vulnerable. RA can dent your confidence, and it’s entirely natural if you don’t feel as strong (emotionally and physically) as you once did. Some people will understand this better than others if you need to explain, depending on their sensitivity.

**IF YOU DECIDE TO TELL PEOPLE AT WORK**

- Be clear about what it is you want colleagues to know, and ask them what they think or feel about what you tell them.
- Be mindful of and acknowledge any impact you feel your RA is having at work.
- Express regret about something if you choose to, but you don’t have to apologise – it may suggest shortcomings that aren’t there or that you don’t feel.
- Set aside time to talk, and to listen. If you’re not open to what someone is trying to tell you, they may not want to try telling you again.

Many people with RA find that in the end they just can’t manage to keep working, or they have to leave their employment before they choose to. This is a significant loss to have to face. It can feel like a rejection, and it’s understandable that people resent feeling ‘thrown away’ and prevented from leading a productive life. It can feel wholly unfair to have to deal with the financial implications as well as cope with illness. While no one says this is easy, with time some people manage to find new satisfactions in what they can do, and regain some level of contentment. (There’s more about facing loss on page 24.)
“I have learned to deal with any issues which may arise and do not let this disease define me or who I am. I had a very active life prior to RA and still remain as active as possible. I do not see this as a reason to stop living though it has affected others who have been a part of my life.”
HOW DO YOU FEEL ABOUT YOUR BODY?

Our bodies are our packaging, yet few people seem content with theirs: they mind how they look.
EMOTIONS, RELATIONSHIPS & SEXUALITY

HOW DO YOU FEEL ABOUT YOUR BODY?

“Because I can’t exercise as much as I would like, I end up gaining weight which I don’t feel good about.

We all have a relationship with our bodies. It may seem an odd concept as we don’t remember, but even as infants we began developing a sense of our own bodies, from our experiences of being handled and fed. As children, for example, we may have heard relatives comparing us with people we physically looked like in the family. You may remember your experience of changes that happened during puberty and feeling self-conscious about some of them, or you may remember remarks people made. This is how we develop a body image. Our bodies are our packaging, yet few people seem content with theirs: they mind how they look.

IT’S NOT ABOUT VANITY

People whose RA started years ago, before the more effective drug treatments available today, may have visible signs of bone damage.

79% of people with RA said that having RA has a negative effect on their confidence, some of the time or all of the time

72% of women with RA and 48% of men said that RA negatively affects how they feel about their appearance, some of the time or all of the time
Many people whose disease activity is noticeable say that they mind about people’s reactions to the differences in their bodies – they say the differences seem to change how people see them. They dislike seeing photos of themselves or their reflections, because the image they see doesn’t match the person they feel they are: their ‘psychological sense’ doesn’t match up with their ‘physical sense’. This may explain why people feel so self-conscious about the physical damage caused by RA. It’s not about vanity: it’s because the image they see no longer matches the image they have developed over a lifetime.

FEELING DESIRABLE

“My partner is kind and understanding but I don’t feel as sexy or desirable as I used to before being diagnosed with RA.”

It’s hard to feel attractive if you’re not happy with your body image. Many people with RA dislike what they see, and so they don’t expect others to like it either. It’s not only bone damage or shortening of ligaments that can cause these negative beliefs. Weight gain or weight loss, drug-induced acne, body odour, hair loss and loss of muscle mass – to name just a few side effects of RA drug treatments – can bring about similar feelings. Yet many partners of people with visible changes to their body have a very different reaction. They say their partners are still attractive and sexy, and it saddens them that their partners are not convinced.

You may have had to make compromises in how you look because of RA: perhaps you’ve changed your clothes or the kind of shoes you wear. Maybe you’ve had to ask for help getting dressed. And you may not have wanted to do any of these things. You’d rather persist with fiddly shoelaces than give in to sensible Velcro... and it could be because you resent having to change.

We don’t expect to have to make practical adaptations until much later in life. Under normal circumstances as we grow older we notice others, older than we are, adapting to the circumstances of old age. When we come to it ourselves, even if we don’t actually welcome it, we do have an awareness of it. But a body altered by RA is different from a body marked by age, and having to adapt doesn’t fit with what we expect in somebody younger. So as well as practical changes, there are ‘cognitive adjustments’ to make: changes in how we see ourselves.

BEGINNING TO SEE YOURSELF DIFFERENTLY

“My attitude has changed either over time or with age, possibly the latter. It affected my confidence in the early years, but as I’ve learned that it’s liveable with and as I’ve grown towards an age when people are more likely to wear flat shoes/ unfashionable shoes the impact is less felt.”

Some people experience a loss of identity: they feel they no longer know who they are, or they don’t feel comfortable with themselves. It varies, depending on when someone develops RA, but many people have this reaction. They’re struggling to accept changes to much of what has been familiar, especially if they’ve lost significant relationships or their employment.

So what might you do, if you’re feeling like this or feeling unattractive? And what can help if you didn’t have a positive body image before RA?

No one suggests solutions are easy, but people with RA say it has helped them to change how they see themselves. This means dismantling old beliefs about ‘who we are’ or ‘how we should look’ and replacing them with new ones. To overcome concerns about image and identity we have to like ourselves, and that means having a sense of worth, self-confidence and self-esteem (see box).

Having RA can damage our confidence and self-esteem, but we aren’t powerless and there are things we can do to build it. We can try to do things that remind us of the qualities and skills we have and give us a chance to use them in an activity we consider worthwhile. As we experience a sense of satisfaction from doing this, we reinforce our sense of our own value. We do this, too, when we can tell that other people value something about us or about a contribution we’ve made. And we can learn to re-interpret negative experiences: things are not always what they seem. To increase our self-esteem, we have to hold on to what we believe about ourselves, rather than believe negative things other people may think about us.
“I have learned to deal with any issues which may arise and do not let this disease define me or who I am. I had a very active life prior to RA and still remain as active as possible. I do not see this as a reason to stop living though it has affected others who have been a part of my life.”

SELF ESTEEM

Sarah Collins, counsellor, explains what it is and why we need it.

‘Self-esteem describes how we value ourselves: the opinion we each have of our own worth. We build on this throughout our lives and we need it to feel good about ourselves.

‘Research suggests that if we show ourselves compassion – if we’re not too hard on ourselves – we become less judgmental about our shortcomings and we can learn from our mistakes. If we don’t judge ourselves harshly, we won’t feel threatened and we avoid the need to be defensive. This allows us to learn from mistakes and have confidence in what we want to do.

‘Self-esteem allows us to believe that we can change ‘weakness’, and this makes us more motivated so we become more likely to achieve our goals. And if we can be more optimistic and kinder to ourselves, we’re less likely to experience anxiety and depression.’

“I just feel ugly all the time. My hands are twisted as are my toes, in fact I hate my body now. PS. My husband says he still fancies me but I can’t see how he can. In clothes in the day I can cover my body but in bed...”

“Talking about it can cause even more problems; the last thing I want is sympathy! Tears seldom appear from me these days, but sympathy can bring them (and I HATE to cry about my problems).”
DOES TALKING MAKE YOU FEEL BETTER OR WORSE?

Talking about how you feel with RA may help – or it may not.
YOU MIGHT DREAD BEING MISUNDERSTOOD, BEING PITIED, BEING DEFINED BY YOUR ILLNESS OR PEOPLE THINKING YOU’RE BEING NEGATIVE.

People who enjoy supportive relationships with families and friends, or who’ve had a positive experience of counselling, say they feel better when someone understands them and when they can let off steam. If you find the right person to talk to, it can defuse powerful feelings and help get your thoughts clear.

Some relationships are supportive in every way except when it comes to talking about emotions. But if a person won’t talk, it doesn’t follow that they don’t care.

Some people find it difficult or downright impossible to see or hear something that upsets someone they care about: their own feelings about another person’s distress may be too difficult to cope with. And some people dare not say much at all because they’re afraid of ‘getting it wrong’ or causing offence. If you’re the person with RA and you feel someone’s ignored you or brushed off what you’ve said, it might help to know this.

“I feel better talking about RA, it enables people to see that you are a person. I think it helps people understand how you may feel.”

33% said they rarely or never talk to those close to them about how they feel.
If you care about someone with RA but you don’t think you’re a good listener (perhaps you feel you’ve heard too much already), it might help you both if you can find the courage to say so. If someone knows why you don’t feel able to talk, it may help them understand where you’re coming from. It may even be the start of a different kind of conversation.

You may decide not to discuss your RA in order to protect people. It’s natural to want to protect children, for example, from feeling worried about your illness and in any case it’s not something that infants can understand. But once children can understand enough, it’s better for them to know that you’re feeling unwell: it’s important that what they see and hear matches what they’re told. You don’t have to go into detail, but if Dad is clearly limping or too tired to play, it’s confusing for a child to be told he’s ‘too busy’, or to be told that ‘nothing’s wrong’ when someone’s crying.

Ultimately, for each of us, what we decide to reveal and how are entirely personal decisions.

WHY SOME CONVERSATIONS TURN OUT BETTER THAN OTHERS

How a conversation turns out depends on so many factors: when you have it; how you feel about revealing yourself; how you describe your experiences; what you’re sharing and what kind of mood you project. It depends too on the other person:

how do they feel knowing this about you? are they a good listener? do they have the imagination to understand what you describe?

You might catch someone at an inconvenient time, for example, or you might think they’re more interested in your problems than they actually are. Perhaps they simply can’t relate to what you’re describing, or they respond in a way that seems judgmental or impatient. When this happens, you might feel very alone, or that talking is not worth the effort. It can feel just as bad, too, for someone who realises they’ve ‘got it wrong’.

We’re not likely to go through a checklist every time we want a conversation, but it can help to be aware of how misunderstandings can happen.

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8 There are publications to help explain rheumatoid arthritis to children: a comic book for children aged 8 to 15, What’s up with Eloise’s Mum? Medikidz Explain Rheumatoid Arthritis, is available from www.medikidz.com
When I experience a severe flare up of RA it prevents me from going to the gym and taking part in a yoga or pilates class, this makes me feel very down and depressed. I was a very fit and healthy person before I was diagnosed with RA in 2010. But once the flare up has passed either by steroid injections or by changing my medication and I am once again able to go to the gym – I feel on top of the world – the grey cloud has lifted – until the next time.
WHAT WORRIES YOU OR GETS YOU DOWN?

Coping with a condition like RA is stressful. It’s a perfectly normal reaction to feel sad and down from time to time.
WHAT WORRIES YOU OR GETS YOU DOWN?

"The emotional impact of RA is more difficult to deal with than the physical."

Even without RA, people face fears and uncertainties in life that can cause deep unhappiness. Knowing that the life you’d planned may have to change because of RA can be distressing. Enforced change is hard to think about, and likely to be very challenging. Different anxieties can surface, at the time you’re diagnosed and later when you know the difficulties you’re facing. We may dread drug treatments not working; worry about becoming a burden to our families, or believe that our jobs and livelihoods are at stake.

It’s not weakness to ask for help. Coping with a condition like RA is stressful and it’s never a failing to ask for support. Faced with an incurable long-term condition – yours or a loved one’s – it’s a perfectly normal reaction to feel sad and down from time to time. If it’s OK to get help when you have a physical pain, why hesitate over the emotional equivalent?

94% of people had felt frustrated because of their RA
82% worried their drug treatment may stop working
80% of people had felt anxious
61% were anxious about managing their finances

The emotional impact of RA is more difficult to deal with than the physical.
Some people hold back from seeing a doctor because they’re worried about being diagnosed with depression or about what their friends or family may say. If people do react negatively, however, it may well be because they just don’t understand – not because they mean to be unkind. Don’t hold back from asking for help because you’re worried it’ll look as if you’re not coping: if you carry on ‘being strong’, it may make a low mood or depression more severe.

**TOWARDS BETTER DAYS**

We can help ourselves through feeling low and some types of depression, with patience and effort. Understanding what led to us feeling that way is helpful, and can prevent further episodes. It helps to focus on what we can do, rather than dwell on all that we can’t. This can help you realise that you are still you: a valuable and worthwhile person.

Making sense of your experience and talking about it can be calming, whether that’s with a partner, a friend, a support group or a professional. Developing a positive attitude (see page 29) can also help to lift a low mood and help people to recover from the kind of depression that may occur in response to stress. There are some further suggestions and stress-busting techniques on page 55.

Exercise can help too. Most of us are aware of the physical benefits of exercise, when we’re feeling well enough, and research has also shown that it can improve mood. Physical activity stimulates the production of endorphins, the body’s natural opiates, which soothe body and mind.

Some people say that reviewing their diet has had a positive effect on their mood. Research is ongoing in this area and there are different opinions, but it may be something you choose to explore.  

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9 Callaghan, P (2004); Scully, S, Kremer, J, Meade MM et al. (1998)
10 The mental health charity Mind publishes *The Mind guide to food and mood*. Available from www.mind.org.uk
A ‘COULD TRY’ LIST FOR LIFTING YOUR MOOD

- Talk to someone who you can trust to be non-judgmental. Ask them to listen without offering solutions.
- Talk to others who face similar challenges.
- Set realistic goals for yourself (a little at a time) and celebrate any achievements.
- Keep a journal in which you examine your thoughts and feelings. No more than half an hour a day, though, or helpful self-reflection turns into unhelpful dwelling on problems.
- Find a self-help book to be a source of understanding and comfort.
- Approach life one day at a time.
- Listen to what your body needs and learn to pace yourself. Consider taking up MINDFULNESS.
- Try to become more accepting of yourself as you are.
- Add your own suggestions to this list.
STRESS-BUSTING TECHNIQUES

Make sure you get enough sleep

- Avoid caffeine, nicotine or too much alcohol in the late afternoon and evening.
- Allow at least three hours between vigorous exercise and going to bed at night. This doesn’t include sex, which is a good relaxant!
- Choose comedy TV rather than scary or exciting programmes. Laughter produces relaxing chemicals in the body called endorphins, but a horror film can get your adrenalin pumping.
- Establish a regular, relaxing bedtime routine. This encourages you to unwind and sends a signal to your brain that it’s time to sleep. A hot bath or massage may help.
- Keep your bed only for sleep and sex, so that it has no other associations.
- Make your bedroom as quiet, cool, dark and comfortable as possible.
- If you don’t fall asleep after 20 minutes, get up and do something relaxing. Listen to soothing music or read something light until you feel sleepy. Don’t use this time to think through problems.

Practise relaxation

- By breathing: Settle yourself into a comfortable position. Take a deep breath in through your nose feeling your lungs expanding for as long as you can, then breathe out through your nose for as long as you can comfortably exhale. Repeat this several times until you feel calm.
- By muscle relaxation: To create a pleasant state of relaxation, start by tensing and clenching every muscle that your RA will allow from your toes upwards: calf muscles, thighs, abdomen and shoulders (though not your jaw). Then release them, slowly.

(If you’re recovering from an operation or have other health conditions, check with your doctor before trying any exercises).
DEPRESSION

“I thought at first my life and capabilities would be nothing. I was very depressed. Now, particularly as a result of excellent counselling, I generally have a positive approach to life and my physical abilities, but am not the same as before being diagnosed.”

Clinical depression is something very different from periods of unhappiness or low mood, and fewer people experience it. The word ‘depression’ is often misused, or confused with feeling low and miserable (though this can be difficult enough).

There are different types of depression. It can be caused by a chemical imbalance in the brain and many psychologists believe it can be triggered by an emotional trauma. It can be a side effect of some drug treatments, though this is rare. There is also reactive depression – the type we’re more likely to encounter in RA – which can occur when we feel stuck and unable to resolve something that troubles us.

Any depression is hard to endure. It’s also difficult for people living alongside the sufferer. Their own discomfort can make them impatient, wanting the person to ‘snap out of it’. This reaction may be understandable, but it’s also extremely discouraging for someone suffering from depression. Recovery from depressive illness can be a long and difficult process, and no one should expect a quick fix.

Remember that depression is an illness, not a failing. It’s time to see your GP if, for example: you feel unhappy, or numb (unable to feel emotion); you’re waking up early or unable to sleep; you notice changes in your eating habits; you cry easily or want to cry and can’t; you feel hopeless; you feel that life is too much effort; or you just want to withdraw from normal activities.

Try not to fear the worst. While it’s true that people with RA are more likely than the general population to experience depression, it’s also true that the majority of people with RA won’t suffer from it. And if you do, there are things that can help, such as a talking therapy and antidepressants. Seeing a counsellor or a psychotherapist can help, by providing insights and a safe place to understand what you’re thinking and feeling. Your GP may be able to refer you, or you can find a qualified practitioner from a professional register.

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11 Dickens, C and Creed, F (2001)
12 UK Association for Humanistic Psychology Practitioners (UKAHPP) www.ahpp.org; United Kingdom Council for Psychotherapy (UKCP) www.psychotherapy.org.uk; British Association for Counselling and Psychotherapy (BACP) www.bACP.co.uk
WHAT DOES IT FEEL LIKE WHEN YOU ASK FOR HELP?

For many people with RA, this is a hugely difficult area.
When we can’t manage alone, we need help to do something – but we might not want to ask. For many people with RA, this is a hugely difficult area.

If you’ve always been proudly independent it might feel uncomfortable to ask, or you might be unsure how people will take your request. But then again, if you don’t ask, you may not get the help you need.

Why can it be so difficult to ask? It’s partly about having that ‘stiff upper lip’, and it’s also about independence.

We need help as children, so not needing help represents reaching maturity and becoming able to cope on our own. If we need help as an adult, it can feel like a backward step to being childlike again, which few people welcome: we feel less self-sufficient, and it damages our pride and self-esteem. But it is possible to see it differently. We could acknowledge that to ask for help is actually a mature way to strengthen our independence and take control of the limitations created by illness, rather than seeing it as about our own weakness.

There are a couple of practical tasks which I cannot do safely at work due to RA. This does frustrate me as I am used to getting on with my job and find it difficult to ask for help.

When we can’t manage alone, we need help to do something – but we might not want to ask. For many people with RA, this is a hugely difficult area.

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HELP CAN BE A TRICKY ISSUE

What can make asking for help – and accepting it – easier? An important factor is the strength of the relationship between the person with RA and the person helping. Another is their attitude: what they each think about giving and receiving help.

Sometimes people don’t ask for help because they don’t want to see whatever it is done ‘badly’ (that is, not the way they would do it!) and get frustrated. Perhaps they don’t trust themselves not to be critical. And if you’re angry with someone you depend on to help you – emotionally if not physically – that can be an uncomfortable feeling.

But if you don’t like asking, you risk offending people who would like to help. They might believe you don’t think they’re capable. They might think you’re making things harder for yourself, or they might feel frustrated because they care for you, as a friend, a partner or a colleague. Often family and friends feel powerless because they can’t change the fact that you have RA, and having something to do makes them feel useful and less helpless.

It’s also tricky for the people who are giving help. They didn’t necessarily ‘sign up’ for the role, and they could of course refuse it. To take it on is a choice, ideally one they make because they care about someone so it comes naturally. It may not be hard work at all: they may just need to offer a sympathetic ear and sensitivity. But a helping role can also be challenging – when the drugs haven’t kicked in, for example, or when you’ve both been living with RA for some years.

People who help in the longer term also go through their own stages of adapting to the changes RA brings, and accepting their limitations. You can’t make RA disappear but you can help the person who has RA to feel better, about themselves and about the impact their RA is having on you. To be able to do this, you need to look after yourself: eat well, get enough sleep, go out and have some fun to relieve stress. It’s not being selfish to do this. The person you care for may be glad you have a social life, even if they’re sad they can’t share it all. They might even be relieved; otherwise they might feel guilty because you’re missing out. If you’re helping someone in the longer term, it’s emotionally healthy for you both to maintain some independence and have time away from each other as well.
ASKING FOR HELP AT WORK

This can be particularly difficult: having to ask for help at work can affect your confidence, professional pride and relationships with colleagues. So much of our confidence and self-esteem depends on us believing that we are competent and effective. If accepting help is unavoidable (for example because of a change in your role) and you feel uncomfortable about it, perhaps some of the following thoughts may help.

- Would it ‘even things out’ if you could find ways to offer help in turn?

- People respond better when they understand why you’re asking them to help and exactly what you’d like them to do. You may have an understanding manager who prepares the ground for you but if not then it’s up to you. Too much detail about your joints probably isn’t appropriate, but it helps if others know you have a genuine health condition, especially if your RA isn’t obvious.

- A sense of humour can help things along, such as the odd self-deprecatory remark – if that feels comfortable. But if colleagues join in and don’t know where to draw the line, are you strong enough to tolerate others poking fun at you when you do it yourself? Perhaps you’d prefer to make a genuine comment about your frustration at having to ask for help.

- Have your own ‘survival technique’ for emergencies. An SOS text to someone who does understand can preserve your self-esteem, for example, if you’re feeling patronised by help or advice you didn’t ask for. While this may show that people are sympathetic, it’s annoying to be treated as if you’re suddenly incompetent. Colleagues probably don’t intend this; they just don’t know what having RA feels like.

- Some people find it’s useful to think about help in terms of ‘delegation’. They think of themselves as the ‘manager’ of their life (this could be at home as well as in the workplace) who is ‘delegating’ opportunities for others to help them.

- Remind yourself that you’re still the person you were before RA. Be proud of what you do achieve and believe that you’re worthy of any help or changes you need to ask for.
HOW DO YOU FEEL WHEN YOU TALK TO THE HEALTHCARE TEAM?

It can be hard to raise personal issues with someone you don’t know well, but that can also be an advantage.
Your relationship with your rheumatology team may come to matter to you a great deal, so it’s worth examining what you expect from them, and what they might need from you. People with RA speak of the need to have a supportive rheumatologist, someone who is ‘on their side’. Ideally, you have a partnership with the rheumatology team: together you decide what is right and they welcome you being actively involved. But we know that for many people, it just doesn’t feel that way and there isn’t the continuity or quality of care they need. Your rheumatology team may be aware of shortfalls themselves, and be working under financial and time constraints. While this isn’t ‘our problem’, how we feel about it can make it harder to achieve a partnership.

If you’re unwell and feeling vulnerable, you can feel far from your usual, coping self. And any relationship in which we express vulnerability can also make us feel exposed. We need to know we’ll be treated respectfully and that our concerns will be taken seriously. When we have confidence in our rheumatology team, it can help lessen our feelings of isolation if we’re anxious – this is so important because anxiety can increase inflammation and tension can increase pain. There are things we can do to help build the relationship and guide the team about what we need, including starting conversations about issues that are troubling us.
DOCTORS AND NURSES ARE HUMAN TOO!

It can be hard to raise personal issues with someone you don’t know well but that can also be an advantage: you meet clinicians in a professional setting where you expect confidentiality and to be treated with respect.

Clinicians are human beings, with their own personalities and personal backgrounds. Some doctors and healthcare professionals keep a professional distance, either through choice or personality. Some show more empathy than others. They might feel the pressure of our expectations, possibly being seen as all-knowing one moment and caring and understanding the next.

We’re in touch with our experiences of RA constantly but the consultant sees us a few times a year (at best) to assess our needs. We may feel under pressure to ‘fit it all in’ and so might they. Your consultant may not believe that their role involves being aware of your emotional needs, but this needn’t stop you raising them.

If you don’t ask, they can’t answer – and you’re not responsible for their reactions to whatever you wish to discuss! Other professionals (specialist nurses, physiotherapists or occupational therapists) can be very insightful too, and may have more time available to spend with you.

13 For more information, see NRAS’ publications Managing Well, Newly Diagnosed and Raise it with your doctor. Available from www.nras.org.uk
14 Walker, JG et al. (1999)
It’s not always easy to talk about your personal life, especially about sex. Vicky Chamberlain, Rheumatology Nurse Specialist and Chair of the Royal College of Nursing Rheumatology Forum, shares a professional’s point of view.

‘We know this is a really important issue for people with RA, but we also know we’re not always giving people the support they need. There can be a number of reasons for this. Some patients find it difficult to raise an issue but equally so do some nurses. Also, nurses receive no formal training in how to broach sensitive and intimate issues with patients.

‘It’s a legacy from Victorian times that we don’t talk about sex. Many people – professionals included – still aren’t comfortable talking about sexuality, either their own or other people’s. That’s the biggest barrier to having the conversations we need to have.

‘Our cultural attitudes can make even professionals reluctant to initiate a conversation about sex. Some nurses may worry about embarrassing you, or they may worry that they won’t know the best advice to give, for example about erectile dysfunction or about a side effect of a drug that they haven’t encountered before. However they will try and find out so that they can best advise you.

‘Annual review appointments may be an ideal opportunity to raise a number of different issues including an opportunity to talk about any concerns about intimate issues. I often ask patients if there’s anything in particular they’d like to discuss about how their RA is affecting their life. This often provides a general opening for a number of different topics, including sex. If the nurse doesn’t mention it or give an opening for discussion then we’d encourage patients to feel comfortable raising the issue themselves.
'How comfortable you feel about doing this depends on how close the relationship is between you and your nurse specialist. You may feel that you have a closer relationship with a particular nurse (if there’s more than one specialist nurse in your unit) and if that isn’t the nurse you are seeing, then ask for a phone conversation or arrange to see them.’

‘Privacy is important, and you should be able to insist on that. If you’re interrupted – for example by another professional coming into the room – and that makes you uncomfortable, it’s fine to say so. You should be able to expect that people will knock and wait, rather than just come on in.’

‘Our sex lives are a vital part of our lives and who we are. Given that the aim of treating RA is to help people live a full and active life, addressing intimate and sexual issues has to be part of this.’

IF AN APPOINTMENT DOESN’T GO WELL

It can be frustrating and demoralising to leave an appointment believing that your concerns haven’t been answered. You may recognise the feeling of being cross with the rheumatologist, or with someone else on the team. Perhaps you’ve felt cross with yourself, for not saying what you wanted, or because there wasn’t enough time.

What could you do about feeling dissatisfied? You could ask for another appointment rather than wait for the next review, or write or email to express your concerns. You could decide to ask for an appointment with the specialist nurse. It helps to avoid making judgements, as people are more likely to listen to requests than accusations. But be active. If members of the team don’t know you have concerns, they could assume all is well. If you can highlight what you need, people may take your concerns more seriously the next time.
I don’t want someone to have to look after me when I am ill so I don’t encourage relationships even though I have had people interested in me.
HOW DOES RA AFFECT YOU AS A SINGLE PERSON?

For some people, being single is a choice; others have it imposed on them.
For some people, being single is a choice; others have it imposed on them, for example by bereavement. Being single may be a state that you confidently expect to change, or you may have decided that you cannot face a romantic or sexual relationship because of RA. Why we are single matters, when we examine our feelings and think about the future.

It matters, too, what stage of life people are at when they’re diagnosed. Developing RA in adolescence, when dating is likely to become important for the first time, brings particular uncertainties about what the future may look like. If you’re diagnosed after you’ve begun your independent life, the stresses of studying or earning a living may add to those of being single with RA. Keeping up with friends and activities as you used to can be impossible when RA isn’t yet effectively controlled with drugs, and people can get left out. Coping with RA alone can feel isolating and frustrating at any time, and particularly if you haven’t chosen to be single.

Even the most sociable and self-reliant person finds that RA brings uncertainty and anxiety, and being single can add
another dimension to coping with illness. How you react depends on your own personality and many other factors. Do you have a support network, for example, either socially or at work? Are you generally confident and assertive? Does it come naturally to you to reflect on your own feelings and needs?

LOOKING FOR A RELATIONSHIP

“It was one of the first things I told him on the very first date, so he knew exactly what he was getting into!”

Some people might decide that looking for a partner is too fraught with difficulty or that there are advantages to being single: they won’t worry about being a burden, there’s no one to upset and no one to have to look after when all they want to do is rest. On the other hand, it could mean there’s no one to share the anxiety or share decisions about treatment, no one to take care of them when they need it.

It takes confidence to believe you can attract someone when you already have RA. You could understandably be fearful about falling for someone who later decides that the reality of RA is not for them, or you may have been through that already. You may be concerned about being rejected or found lacking. If you do have visible signs of disease or scars, you may feel daunted by the idea of sexual intimacy. It can be hard, too, to deal with feelings of embarrassment that may arise when you’ve been brave enough to reveal your body to someone new.

And when should you raise the subject of RA? Will it jeopardise a new relationship? Doubts in the early stages of a relationship are natural, but they can be much more intense for people if their self-image has been dented by RA. But it’s likely that what we think about ourselves and how we put that across are going to matter more to a partner than the fact of having RA. And if that isn’t true, perhaps it’s better to find out sooner rather than later. Many people have taken the plunge and discovered that they didn’t need to be afraid after all: personalities matter far more than any physical imperfections.

“Being single is an advantage when I am unwell, at least it does not affect anyone else.”
THINKING ABOUT RELATIONSHIPS

- There are different ways to have a relationship. It doesn’t have to mean settling down together. It may suit you both to be close but remain independent. Some people are used to living alone and prefer to keep their own space.

- People like happy people. Happy people come in all kinds of shapes and sizes. People are drawn to people who like themselves – people with self-esteem. There’s more about this on page 45.

- Did your relationship end because of RA? Think back to how it was, and how you were. Is there anything you might want to do differently or avoid doing next time? Are there attitudes or behaviours you’d want to avoid in a new partner?

“Nobody knows what kind of pain you feel or where it hurts. It can come on within [...] half an hour and subside in the same time frame. Explaining this to someone I think I might have sex with is out of the question. I don't think I have ever spoken to a boyfriend about it before we had sex. I think I just hoped all my limbs would work.”
DO YOU FEEL RA HAS AFFECTED YOUR RELATIONSHIP?

“I feel that when you have had RA for many years it becomes a burden on your partner to keep talking about it especially when they have had a hard day at work.”
Our most important relationship in life is the one we have with ourselves. That may sound odd, but understanding ourselves matters, especially when we set out to find a partner. It involves all our experiences of forming attachments in infancy, the behaviours we’ve learned and the expectations we’ve developed. And we may not appreciate just how much effort relationships entail.

"Due to RA and disturbed sleep we now have separate rooms which has affected our physical relationship. Sex cannot be spontaneous as I never know how I am going to feel. This has put a strain on our relationship."

LETTING A PARTNER IN

Loving relationships are created by two people, who in the early days see all sorts of qualities in each other that they may not actually have. As time goes by (and perhaps the rose-tinted glasses come off) we can feel a little less enchanted. This is when it’s even more important to maintain

41% of people in a relationship agreed that RA has negative effects on their relationship; 34% disagreed
an interest in a partner’s thoughts and feelings. However well we do this, we’re still likely to be confused by their behaviour at times and possibly our own when we interact with them. Add RA to the mix and it’s even more complex: illness inevitably has some effect on a relationship.

When our self-esteem is affected, as it can be by RA (see page 45), unfortunately we’re more likely to misinterpret what happens around us.

We may make negative assumptions or believe the worst. This can further damage our self-esteem, and it can quickly create disharmony in a couple.

A successful relationship involves letting the other person ‘in’ and allowing them to understand you, so that they don’t need to make assumptions. This doesn’t mean that you insist on knowing everything about each other; it means sensing when something is wrong and trying to put misunderstandings right.

It’s important for you to confront together what you believe is happening and how it’s affecting your relationship. Partners’ attitudes really do matter. Researchers investigating this have found evidence that partners’ beliefs about RA can affect both their own wellbeing and that of their partner with RA.15

It can be hard to acknowledge that anything’s changed in your relationship, but deep down you probably both know it has, or worry that it might. If you can say what worries you, it may make it possible for your partner to talk about what troubles them, too.

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15 There is more information about this research, carried out by Carr, M, Hughes R, et al., at www.nras.org.uk/relationships
PROTECTING EACH OTHER

“Discussing it with my wife is difficult because she has already had to shoulder so much more than I would have liked, so I don’t want to add to her burden.”

We might think we’re protecting our partners by keeping quiet, but the opposite is more likely to be true. And if we feel angry or disconnected, then something is wrong and ideally we should try and do something about it.

There can be so much you don’t say when you have RA: that seeing others leading normal lives makes you sad; that having a rest doesn’t remove your fatigue; that it irritates you to see your usual tasks being done by others or not done at all; that you miss just doing all that you did together with ease; how you hate cancelling commitments because you’re not feeling up to it on the day… The list goes on, and your partner probably knows some of this already.

Partners of people with RA hold back too. Perhaps as a partner, you don’t say when you aren’t feeling well yourself, because your loved one’s RA is ‘so much worse’ than what you’re putting up with. You don’t admit that you’d like support and help too; or how hard it is to be optimistic on behalf of you both. You don’t say what you miss, or that you rarely initiate sex because the time never seems right… and your partner also probably knows some of what you’re thinking.

We might duck the issues because we dread conflict, but the ability to handle conflict in a safe and productive way is an essential part of a healthy relationship. People who are nervous of conflict tend to stay quiet but their angry feelings don’t always die down. Instead they can fester, and be even stronger when they do emerge later on.

It’s possible to avoid tension mounting if we can have conversations sooner rather than later and give them our full attention – not snatching a few minutes while we’re cooking a meal or checking emails. And if raising an issue does result in a row, perhaps a reasonable conversation will feel more possible after you’ve vented the angry
feelings. Eventually, the two of you may not argue because you’ve learnt to spot the mounting dissatisfaction and defuse it.

Tackling uncomfortable truths together can bring you closer, but you both have to acknowledge the need to do it. If your partner doesn’t appear receptive at first, it’s worth persevering. Change doesn’t happen overnight and people can feel threatened if their partner introduces something new that alters the dynamics of the relationship. Respect that your partner may not want to talk when you do, and just make it clear that you’d like to, soon. You could try sharing this booklet with them, too. And even if nothing changes, it can be a relief in itself to make your views known, and to believe that you’re worthy of attention.

RESOLVING CONFLICTS: SOME SUGGESTIONS
1. Recognise that someone is doing something that causes you to feel angry.
2. Calm yourself so that you can think.
3. In your mind, try to put what you are feeling into words, as clearly as possible.
4. Tell the other person what you are thinking or feeling – in a non-aggressive way, without shouting.
5. Really listen to what the other person has to say, even if you think they’re wrong. Don’t dismiss what they’re saying. Don’t argue. Just listen.
6. When the other person has totally finished, ask if there is anything you can both do to compromise, so that each person gets some of what they want, but not all. There aren’t winners and losers in this kind of conflict resolution.
7. Find a solution. This may not be what either of you had in mind at the beginning, but something new and different. Be creative. Think outside the box...
“My partner is very understanding but I find as time goes on I am finding it more difficult to enjoy the physical side of things. It doesn’t take long for my joints to start aching during sex and this interferes with me enjoying myself at times.”
HOW WOULD YOU DESCRIBE THE IMPACT RA HAS HAD ON YOUR SEX LIFE?

“It is probably the thing that causes most problems between us.”
We have a strong loving relationship but unfortunately, the sexual side is difficult due to pain and fatigue. We don’t talk about our lack of sex life we just don’t have one. Neither of us has ever broached the subject unfortunately.

Expressing ourselves sexually is one of life’s pleasures but RA can make it even more complicated than it already is. RA may never affect your sexuality but it might: pain, fatigue and a lack of mobility in your joints can cause difficulties, as can the side effects of some drug therapies. If your roles in the relationship change – with one of you taking on more caring responsibilities – this too can affect whether you feel sexy or aroused. For some people, it’s a mild disappointment to find that they can no longer enjoy their body in the way they’d like to; for others it’s a major cause of frustration and distress.

Sometimes sex feels important and at other times we close ourselves off from thoughts that we might enjoy it. If we’re worn down by pain and the effort of daily life we can forget the pleasure.

63% agreed that with RA, they have been less able physically to have sex in the way they would like to, while only 10% disagreed.
of sexual contact, especially if it’s been disappointing in the past. We all have varying levels of desire, perhaps more so as we grow older. Unfortunately, for many of us, our desire shuts down as we think of all the reasons why we ‘shouldn’t’ or ‘can’t’ have sex. There can be genuine physical reasons to be concerned, but if we can get past thinking ‘can’t’ to thinking ‘maybe’, we can explore new ways to find pleasure from our own bodies.

This section is for people who would like to enhance or restore the pleasure of sex in their lives, so please be aware that it has sexually explicit information.

MYTHS AND FALSE MESSAGES

Glance at any book on sexuality and you’ll probably spot the word ‘myth’. The subject thrives on them! While sex is discussed freely and can seem to be everywhere in the media, much of what people claim to be doing (including how often, how long and with whom!) is exaggerated. This can be discouraging as we measure ourselves, consciously or unconsciously, against what others say. We pick up so many false messages about sex that it can become difficult to separate them from our own feelings and needs.

Many myths might affect us, whatever our sexual orientation and whether or not we have RA. Here are just some of them and why they’re not helpful.

‘Sex should happen naturally’ – but having sex spontaneously, only when you’re in the mood, isn’t the only way to enjoy satisfying sex. If you hold on to that belief when one of you has RA, it could mean that sex never happens. It’s fine to ask or plan ahead. It can build excitement to agree to try later. If you and your partner have been together for a long time, ‘date nights’ might help you recapture the feeling of how things were, for example before mortgages, children and RA.
‘My partner should know what I want in bed’ – but you can only know what your partner enjoys if they tell you, or show you, and with experience. If either of you has physical constraints caused by RA, you’ll need to understand exactly what is possible and what isn’t.

‘Sex is for the young’ – but sexual activity can continue well into old age if you want it to. Men continue producing semen for the rest of their lives, and many women enjoy sex more after the menopause, relieved of the bother of menstruation and contraception. Retirement might mean more opportunities for lovemaking and more time for rest to overcome fatigue.

‘Good sex always ends in an orgasm’ – but an orgasm isn’t essential, even if it’s enjoyable. It can be satisfying to enjoy each other’s bodies in other ways. We might feel too tired or sore to achieve an orgasm but still enjoy lovemaking.

‘There’s no point if we can’t have intercourse’ – but there are many ways to enjoy lovemaking and intercourse is only one of them. You can discover new ways to give each other pleasure. It can be dull to do the same thing all the time. Conveying love and affection via touch is an essential prelude to any kind of lovemaking. Penetration and/or orgasm don’t have to be the goal every time. Kissing and caressing can build sexual tension and there are other ways to achieve orgasm if that’s what you want.
A man doesn’t need a full erection to enjoy sex. Most women need steady clitoral stimulation to achieve orgasm and what seems to matter most to women is having a considerate lover.

‘Proper sex is in the missionary position’ – but it may become essential to experiment with other positions or other ways to enjoy sex. It’s natural to explore each other’s bodies with mouths and hands and whatever makes it possible to continue having sex is normal, provided you both agree.

YOUR BIGGEST SEX ORGAN IS YOUR BRAIN

Chronic illness can make us feel we’ve been ‘let down’ by our bodies, but if we can be open to exploration and fantasy, we may find new ways to enjoy them. This is healthy for us emotionally and also for our partners.

Your biggest sex organ is your brain. You don’t need a partner to enjoy sex; you can use your imagination to create a state of arousal. Masturbation helps you to know your body and what your own sexual response is. It helps to be aware of what excites you and how you feel when you are aroused. Some people can lose this awareness if RA or drug treatments affect their sex life or their desire.

Many things go on in the body when we feel excited in response to desire. Our heart rate and blood pressure increase as more blood is pumped to our sexual organs, and to extremities like earlobes and lips. For both women and men, nipples harden and become more sensitive. We breathe faster and feel warmer. In men, erectile tissue swells as blood fills the penis as does the erectile tissue of a woman’s clitoris and vaginal lips. And women produce greater vaginal lubrication. All this can happen before we’ve even been touched.

And when you let yourself anticipate sexual activity, you set this chain reaction in motion. We escape physical disabilities and enhance our ability to enjoy sex through fantasy. Fantasy, intercourse and sex play all increase the production of chemicals in the body called endorphins, which are a natural form of pain relief and can also help us sleep.
TALKING TO PARTNERS

Good sex means giving each other information. We don’t always need to find words; we can convey intentions and loving thoughts by touch and facial expressions. But if we can find a way to talk to our partners, it will help them understand us better sexually.

Many people do feel anxious about their sexual performance and body image, and worry that they or their bodies are ‘not good enough’. Anxiety can cause tension, and neither of these is helpful in bed. How we think about something affects our behaviour, so if we believe in myths about sex and how it ‘should be’, it will discourage us. But our partners may not know this, and may think that if we’re anxious or reluctant, it’s because of them. Other aspects of living with RA can affect how you feel too, such as needing help for example (see page 34). You may not always feel attractive or sexually responsive with a partner whom you rely on for help. But your partner may not know any of what you feel, if you haven’t spoken about it. When they do know, they may be able to reassure you that you are still as sexy as you ever were (see page 43).

Shyness may cause you to feel inhibited – unable to do what you’d like to in bed. If you can have a conversation about this, it could help you trust each other more. It might be helpful, too, to ask yourself what it is that makes you feel embarrassed or self-conscious? Do you actually know what your partner thinks about your body or are you making assumptions based on what you think?

It might help if you can avoid thinking about what you look like or how your partner is seeing you; try instead to concentrate on the physical sensations. When we do think (or worry) about ourselves being sexually active, we usually do so at another time, when we’re not aroused. When we’re actually in the throes of passion, we’re unlikely to be so concerned about how either of us looks. Setting the scene can make you feel more confident. As might dimming the lights.
**SAY HOW IT MAKES YOU FEEL**

With a subject as sensitive as sex, it’s important that our partner doesn’t hear anything we say as blaming them.

- ‘Own’ what you say. Make it about your experience rather than about what they do. For example, you could say, “when you do x, I feel y…” rather than “you never…”, or “you always…”

- Ask for what you’d like to happen, rather than complain about what doesn’t. If you’re unhappy about something your partner does or doesn’t do in bed, they’ll hear you more readily if you tell them how it affects you, rather than put it as a criticism.

Try not to let problems remain unresolved, as they can cause resentment and get in the way of enjoyable sex. Talking doesn’t come naturally to everyone, but if you avoid the bigger issues it may result in a rift that grows over time.
GETTING AROUND THE OBSTACLES

We may have physical constraints to overcome as well as shyness, and these can take time and experimentation to negotiate.

Some people are afraid that they’ll feel pain or that they’ll cause their partner pain, and this puts them off initiating sex. Sore hips, knees, wrists and toes can all get in the way. If you have a stiff jaw then oral sex can be uncomfortable. Sore hands, wrists, elbows and shoulders may tire easily during masturbation, whether that’s alone or together.

- It could be enjoyable to try finding new things that work for both of you – as long as you can give up the idea that it’s a ‘failure’ if something doesn’t work out. If you do discover a new position, for example, that’s comfortable and keeps pain to a minimum, it can be a relief and a boost for your sexual confidence.

- It may help to avoid taking yourself too seriously. Some people find it helps them and their partner to be at ease if they can joke about it all. But in a sexual situation people can feel quite exposed, so do be sensitive.

- Try varying the time of day to make the best use of your energy. Perhaps take painkillers beforehand or loosen up tense muscles with a warm bath or shower as a prelude to sex.

- You could try using vibrators, stimulators or sex toys too. There’s a wide variety on the market, many of which can help you enhance arousal or simply enjoy the pleasure of being massaged anywhere on the body. There are many sellers online but if you visit a shop and handle items you can be certain of operating the controls comfortably. There are outlets in many high streets now. Sexually suggestive novels, films and lingerie are all options too – it’s literally a case of seeing what ‘turns you on’.
FINDING NEW POSITIONS

Painful, immobile joints and weakened muscles make certain sexual positions uncomfortable or impossible for people with RA.

The positions described below are some suggestions, for heterosexual intercourse, and these can be adapted. Whatever your sexuality, if you and your partner can experiment according to which joints can be weight-bearing, it could help you find new ways to excite each other. All you need is imagination, some lubricant and plenty of time. You might find pillows, cushions and rolled-up towels useful for support and comfort.

In any position, you may find that less movement means more sensation, and it might heighten the excitement to start with gentle rocking. Particularly if you have joint problems, it’s worth taking things slowly, saving yourself for faster action as you feel a climax building. If a position proves too difficult, try kissing, stroking or sucking again instead. Try not to be discouraged. If your body has become tense because of pain, it will take time to be able to relax and rediscover pleasurable sensations.

MISSIONARY

This position is more suitable for women with RA. For deeper penetration, place cushions under the small of the woman’s back so that her pelvis is tilted towards the man. However if her hips are sore, the man should take care to thrust gently and let her tell him what weight and pressure are comfortable. The missionary position isn’t so good for men with RA because it means putting weight on sore knees, hips and toes and arms and wrists.

Fig 1.
SCISSORS

This position can work well whichever person has RA. The man lies on his side and his partner lies on her back next to him at 45 degrees, with her knees up and her calves over his hips, resting on his bottom, or on a cushion to keep them level if her knees are sore. His pelvis should be nestled against hers so that he can gently insert his penis into her vagina. She may need to bend her legs up a little to help. Rock gently together. (You could also try one of her legs between his – see figure 2a). In this position, he can reach her clitoris and breasts. And if either partner feels too tired for intercourse, he can stimulate her clitoris externally and internally at the same time, with his thumb and forefinger.

SPOONS

This position is suitable for most joint problems. Both partners lie on their sides and the man enters the woman’s vagina from behind. If the woman can draw up her knees a little, penetration is deeper. Either partner may use their hand to guide the penis into position. In this position, the man can also stimulate his partner’s clitoris during intercourse.
WOMAN ON TOP

Fig 4.

This can be comfortable if the man has RA and the woman has no problems with hips and toes or wrists. She sits astride him and faces him while he lies flat. Penetration is deeper while she sits upright, less as she leans forward. He can be passive while she is responsible for thrusting. Both partners can kiss and the woman can reach behind to stroke the man’s testicles. He has both hands free to caress her breasts and clitoris.

You can adapt this position using an upright chair that has no arms – the woman needs to be able to spread her legs wide apart and have strong thigh muscles for this. He sits normally while the woman sits astride him as he guides his penis into her vagina, or she can face away from him. Sitting in whichever direction, she moves her pelvis up and down, and he helps with his hands on her hips.

MAN ON TOP

Fig 5.

In this position, a woman can lie comfortably on her front with a pillow under her pelvis and her arms in whatever position she chooses, provided she can turn her head comfortably. The man takes his own weight on his knees, elbows and forearms while entering her vagina from behind. If she has sore toes, a pillow under her ankles may prevent pressure on them. You can also adapt this position if she bends over the back of an armchair or a table, using cushions for support.
MORE ADVICE

With or without RA, the need to practise safe sex is the same for everyone. It’s up to each of us to understand and think about risks and to take appropriate precautions to keep ourselves safe. For more information on this and all the issues discussed here, visit the ‘Sex and intimacy resources’ section at www.nras.org.uk. You’ll find advice, suggestions for further reading and links to suppliers.

THERE ARE WAYS AROUND MANY PROBLEMS

Some women with RA experience vaginal dryness, which can make intercourse uncomfortable. This could be caused by: fatigue, anxiety, some drug treatments, Sjögren’s Syndrome, Systemic Lupus Erythematosus (SLE) or menopause. Water-based lubricants (‘lube’) can help and any couple might like to try them as they make you more sensitive to being touched. Oil-based lubricants last much longer but can damage condoms. There are newer silicone lubricants available (which are waterproof) but you can’t use these with silicone sex toys.

Some women worry about leaking urine during sex because of lax pelvic floor muscles, which is understandably off-putting for them. There are exercises you can do (called Kegel exercises) to help regain control of your pubococcygeal muscle, which have other benefits too – they can improve the quality of orgasms for example.

Over time, large doses of steroids can make your vaginal wall thinner and subject to tearing (fissures). This distressing fragility is irreversible. However, with enough lubrication you may still be able to enjoy the intimacy and sensation of feeling your partner inside you, as long as your partner understands and has the self-control not to thrust. There are other ways to have an orgasm without penetration, and you may find it possible, too, for your partner to simulate the sensation of ‘coming’ inside you. With some oil-based lubricant on his penis you both
lie in the spoons position (figure 3). Instead of entering the vagina from behind, your partner places his erect penis between your thighs while you simulate the entrance to your vagina with your fingers or by cupping both hands. Or he could use his own hand. This position may allow you to feel that you’ve helped him have an orgasm and for him it may allow ejaculation while being close to your body.

When you’re considering contraception, some types may not be suitable for women with RA: a diaphragm, for example, can be awkward if your fingers are weak or it’s difficult to bend your hips and back. Condoms can be fiddly, though putting them on your partner can be an erotic part of foreplay. Ask a health professional for individual advice about contraception, as there may also be interactions with your medications to consider.

If you have a dry mouth, for example because of Sjögren’s Syndrome, waking up in the morning with bad breath can be unpleasant and may get in the way of spontaneous lovemaking. Keeping peppermints by the bed can help if brushing your teeth is inconvenient.

**Erectile dysfunction** (ED) is an upsetting problem for many men, more so because very few speak about it. ED can occur in any man and it’s not uncommon if you’re under physical or emotional stress. Some drug treatments, recreational drugs, alcohol and smoking can all be factors too. Generally speaking, if night-time and morning erections decline over time or are less likely than ‘normal’ during masturbation, the root of the problem may be a physical reason, and if you have full erections on your own, the problem may be psychological. Anxieties about RA and/or your relationship may be relevant in this situation. Fortunately, whatever the cause of ED, there are many treatments so you don’t have to suffer in silence.

An occasional disappointment doesn’t mean you have ED but it may put you off trying again. Just as a woman may not have an orgasm every time, it’s not helpful either to think that a ‘rock-hard erection’ is necessary for all sexual contact. ED is not a sign of male weakness. A really potent lover can satisfy a partner with or without his penis.
If you avoid sex (for example, by staying up late and going to bed after your partner) this will only perpetuate the problem – and your partner may start to believe you don’t desire them. It may help you both to enjoy each other’s bodies with no expectation of penetrative sex: stroking, kissing, and avoiding genitals altogether until you feel more aroused. And if an erection still doesn’t happen, try not to feel you’ve ‘failed’; your partner is just as likely to think they’ve ‘failed’ you. GPs may not be experienced in this area so you may want to research the condition before you see your doctor. Ask them whether Viagra (sildenafil citrate) or a similar drug may be suitable for you. It may be possible for your doctor to refer you to a specialist NHS clinic.

FOR MORE INFORMATION AND LINKS TO FURTHER ADVICE VISIT WWW.NRAS.ORG.UK/RELATIONSHIPS
The full results of the survey, which was completed by 1,343 people with RA, are available from www.nras.org.uk or you can phone 0845 458 3969 to ask for a copy.
NRAS SURVEY 2013

All the statistics in this booklet are from the NRAS Survey 2013: Relationships, emotions, sexuality.

This booklet is based on the experiences of hundreds of people with RA, and their partners, who participated in new research we carried out to develop it. It covers the issues that people with RA have told us are important, and the contents and quotations reflect the diversity of the experiences they shared.

THE NEXT STEPS

The survey has shown just how important these sensitive issues are for people with RA, and it has highlighted the need for health professionals to have better training on how to support people with RA with these concerns.

FOR PEOPLE WITH RA

We hope that this booklet is helpful for anyone facing the challenge of living with RA, and that it has shared the very wide range of emotions that people experience. Whatever you may be feeling, others feel it too. We hope that this booklet helps you to feel that you can discuss personal and emotional issues with your rheumatology team, as these issues are part of living with RA. We’d encourage you to take a first step, and raise any issue you’d like to discuss with the health professional in your rheumatology team you feel most comfortable with.

Perhaps it may help to share this booklet with others, as a way to begin a conversation about something that can be difficult to talk about. We hope, too, that you’ll feel able to pick up the phone to the NRAS helpline team, who are here to listen and to talk in confidence when you need to.

FOR NRAS

Nurse specialists are often the health professionals whom people tend to approach about sensitive subjects. We know that they don’t usually have any training in how to deal with the kind of issues raised in this booklet, and we know they’d welcome it. 

We’d like to do something about this.
NRAS has agreed with the Royal College of Nursing to collaborate on a project in 2014. Together we will apply for funding in order to provide professional regional training workshops for Nurses and Allied Health Professionals. The training will cover how to communicate with patients about emotions, relationships and sexuality, and will be accredited with Continuing Professional Development points. We would like the project to continue and reach as many health professionals as possible, so we are also considering how to develop on-line resources, which could include film of the training workshops.

We will also continue to develop the resources on our website about emotions, relationships and sexuality.

THE RESEARCH METHODOLOGY

This is a summary of our methodology. Full details are in the report NRAS survey 2013: Emotions, relationships, sexuality, available at www.nras.org

We carried out the research between November 2012 and February 2013, using focus group and teleconference discussions, and individual self-completed on-line questionnaires.

FOCUS GROUP AND TELECONFERENCE DISCUSSIONS

We set out to gather information that would inform the contents of the questionnaire and the booklet. In particular we wanted to:

- encourage people to talk about the emotional impact of RA, including the impact on their intimate relationships and sex life
- understand the concerns about which people with RA and their partners would welcome more information or support
- get a better understanding of the priorities and issues to cover in the booklet
- hear about support and strategies that people have found helpful.

18 Ryan, S and Wylie E (2005)
We held three discussions, one as a focus group and two as teleconferences. The teleconference format was designed to enable people to discuss more intimate issues than they may have felt able to do in person. We recruited participants to include: a range of ages; people in relationships and not in relationships; men and women; people with RA and their partners. A total of 25 people participated, 16 women and nine men, including four couples. Their ages ranged between 33 and 75. Of the 25, 19 had RA and six were partners of someone with RA. Duration of RA ranged from between one and 5 years to over 21 years.

We analysed written notes from the discussions and categorised them into themes, to identify issues to be included in this booklet and questions for the questionnaire.

THE QUESTIONNAIRE

We set out to gather quantitative and qualitative data from people with RA about its emotional impact on their lives and intimate relationships. Our areas of research covered different aspects of: feelings about living with RA; talking about RA with people close to them; relationships; being single; and getting support.

We designed and distributed a questionnaire. We used:

- multiple choice questions to collect data about respondents’ lives and circumstances
- scaled questions to measure respondents’ subjective views and assessments
- free text responses, to give respondents opportunities to explain their answers and express their views.

We developed the questionnaire in online format, tested it with a pilot group of 10 people with RA, and then revised and finalised it. We made the survey available on the NRAS website and publicised it online via NRAS Enews, the NRAS Members’ Forum, Facebook, Twitter and Health Unlocked NRAS blogging site. It was live from 11 December 2012 to 18 January 2013 inclusive.

WE CARRIED OUT:

- numerical analysis of the responses to multiple choice and scaled questions, to calculate the proportions of respondents answering
qualitative analysis of respondents’ free text responses, categorising these into themes and subthemes, depending on the weight given to these by respondents.

We received 1,343 valid responses, 85% from women and 15% from men. Eight questions gave the opportunity for free text responses. Between 8% and 18% of respondents answered each of these, often in considerable detail, providing a wealth of data.

DRAFTING AND REVIEWING THE BOOKLET

We developed the booklet structure and contents, drawing on the results of the focus group and teleconference discussions, and the results of our analysis of the completed questionnaires.

The booklet narrative draws on a combination of psychotherapeutic approaches, research evidence about the emotional impact of chronic illness, and the author’s experience in clinical practice as a psychotherapeutic counsellor. A draft was peer reviewed by two psychotherapists and one psychosexual psychotherapist. Drafts have also been reviewed by nine people who have RA or whose partner has RA, and by NRAS’ medical advisers, including two consultant rheumatologists and two rheumatology nurse specialists. Their feedback contributed to the booklet’s development.

ETHICAL CONSIDERATIONS

We took steps at all stages to protect participants’ anonymity, privacy and confidentiality. Project team members who were not NRAS staff members undertook the recruitment for the discussion groups, facilitated the discussions and analysed the results, erasing all personal information from the notes. We facilitated discussions with care for participants’ wellbeing, offering opportunities to contribute rather than asking direct questions and following up afterwards when required. We gave participants information about how the research would be used and to what purpose. We gave participants the opportunity to receive a copy of the notes. We asked questionnaire respondents for their permission to use their responses anonymously in this booklet and for their consent to contact them further.
With thanks to all the people with RA who have contributed to this research. All the quotations in this booklet are from NRAS survey responses – the full report is NRAS survey 2013: Emotions, relationships, sexuality, available from www.nras.org.uk

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Sarah Collins, psychotherapeutic counsellor, who has lived with RA for 33 years, and researched and wrote the booklet

Kate Wilkinson, researcher and editor

Clare Jacklin, NRAS Director of External Affairs for project managing the production of this book
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