

Clinical review

The patient's journey: rheumatoid arthritis

Carol Simpson, Chloe Franks, Catherine Morrison, Heidi Lempp

The map

Rheumatoid arthritis (RA) is a common chronic disorder of disturbed immunity that affects about 1% of adults in the United Kingdom. It typically develops in middle or late life and is three times more common in women than it is in men. It is characterised by joint pain, swelling, and stiffness, particularly of the small joints of the hands and feet. Its onset varies between gradual and acute. The classic pathological features include inflammation in the synovial lining joints and tendon sheaths. Patients feel sore, especially in the morning. Its natural course is variable, with disease severity changing over time, although in many patients there is increasing joint damage and functional disability. From the perspective of patients, pain, reduced mobility, fatigue, and psychological effects, such as depression, are the dominant concerns. In contrast, clinicians generally focus on measurable disease activity, along with radiographically identifiable progressive joint damage. They aim to achieve remission of the synovitis and to delay or limit functional disability, to minimise the effect on work participation and dependency on family, carers, and the health service.

Optimal treatment is now seen to be care provided by a multidisciplinary team and includes education, advice, exercise, drug treatment, and joint surgery in late disease. Treatment options comprise analgesics, non-steroidal inflammatory drugs, disease modifying drugs such as methotrexate, steroids, and the new biologicals (for example, anti-tumour necrosis factor agents). Despite these various treatments, the key features of rheumatoid arthritis are the unpredictability of both the acute flare-ups and of how patients respond to the drugs. This means that control over the illness is often difficult and requires patients and professionals to continuously adapt to the disease state.

The good news

Over recent years the emergence of the new biological drugs, with their palliative effect on patients' symptoms of pain, limited mobility, and fatigue, has given new hope to people living with rheumatoid arthritis and delayed to some degree the damaging physical consequences of the disease and their effect on work and functional ability.¹ For some patients the treatment can be effective and they can now continue full time or part time work, which in turn raises self confidence and a sense of achievement against the odds:

Carol's story

My journey with RA has been long. I was diagnosed 25 years ago and the disease was controlled with aspirin and intermittent rest until recently. Suddenly in my early 50s the RA advanced rapidly. I have always enjoyed travelling, starting when I was 10 years old in West Africa and subsequently living and working in Germany, Bahrain, India, South Africa, Zimbabwe, and the US. I used my vacation time to travel to different countries and to find out whether they were places I'd like to live and work. While I was in the US the RA caused my life to change. My health was too erratic to continue with work. I was granted long term disability and returned to the UK. Initially, back in the UK, my main concerns were receiving effective treatment, sympathy, and helpful support that I luckily found. Gradually I did learn how to adapt my lifestyle to my physical abilities. One of the biggest changes RA has had on my life is the limited travelling. I can only fly five hours maximum in aircraft with a decent seat pitch and only in an aisle seat, so I can move about. I cannot tolerate high heat or humidity and have to think about location (steps, steep hills, stony beaches are all unhelpful!). History and cities have always been a big pull for me, but they now have to be absorbed in minibreaks, because I can't walk too far any more. I still travel and intend to do so until I cannot move at all. This requires a lot of forward planning, not least: do I have enough pills to get me through the two weeks?

Chloe: I am 41 years old. I have chosen to continue to work, not just for fundamental financial reasons, but because I want to continue to make a difference to society. This decision has cost me dearly, as there is no such thing as work/life balance. When I am not working I have to rest

Carol: The biggest impact RA has had is around working. The delay in my illness progression has enabled me to work full time almost all my working life at a high administrative level. Interesting employment gives one a sense of identity and purpose, losing the ability to work can be isolating. The major danger of not working is that if you are not careful, you don't have much to talk about except the state of your health. Not a good idea and it bores everyone into a coma!

The bad news

Unsuccessful drug treatments are a major concern and reality for many patients, and there is anxiety and a high level of uncertainty for each new drug used:

Department of Rheumatology, King's College Hospital NHS Trust, London SE5 9RS

Carol Simpson
patient

Chloe Franks
patient

Catherine Morrison
clinical nurse specialist in rheumatology

Academic Department of Rheumatology, King's College London School of Medicine at Guy's, King's College, and St Thomas Hospitals, London SE5 9RJ

Heidi Lempp
senior qualitative researcher

Correspondence to: H Lempp
heidi.klempp@kcl.ac.uk

BMJ 2005;331:887-9



Contact details for organisations are on bmj.com

Chloe's story

I believe that my RA first showed itself back in 1994. I was under an orthopaedic surgeon with what was later diagnosed as a brachial plexus injury. My ESR was very elevated, but the information was dismissed as irrelevant. During 2001 I had a variety of symptoms, which constantly changed and moved around my body. These included aches and pains in the muscles and joints of both my arms and legs and constant tiredness. In October I attended a week long outward bound leadership course, and by the end the pain and stiffness was so acute I could not even dress myself or lift my hands to my head. On my return to London my husband took me straight to hospital. There an assessment nurse diagnosed an acute attack of rheumatoid arthritis and confirmed the diagnoses with blood tests for rheumatoid factor and ESR levels.

I made an appointment with my (now ex) GP, who when I informed her that I had been diagnosed as having RA said "Nonsense you probably just have flu." I finally persuaded her to order blood tests, which reconfirmed the diagnosis. However she flatly refused to allow me to keep the rheumatology appointment and insisted that I attend a hospital with a over one year waiting list, even for "urgent" first appointments. I was forced to see their rheumatologist privately. My initial reaction to my diagnosis had been relief as I had privately felt that I had been going mad. I felt that at least I finally had a name and an explanation. However as time progressed and my disease was still not under control I began to feel extremely depressed and desperate to talk to someone.

Carol: My drug treatment for RA has not been at all successful . . . frequently the effect of the medication was worn off after 2-3 weeks. My anger has not been towards the doctors but with myself. In my opinion the reactions to the medication are much worse than the disease itself. For example, the hair loss due to sulphur based drugs affected me badly because I had no control over it. The return to "normal" took well over a year, much longer than the usual recovery from an adverse reaction to a drug

Chloe: I have tried a variety of treatments, including all the anti-TNF medications. Unfortunately I have been extremely unlucky because they have not been effective or I have had an allergic reaction to them . . . I am now trying unlicensed treatment and we shall see if this gives me any kind of remittance . . . I have had very little or no remittance, which is very wearing both physically and emotionally

Commonly therefore patients say that they need an individual approach, as each person reacts differently to treatment. As so many of the treatments may fail, patients set great stock on having a sequence of new options to try in future, including complementary and alternative therapies, to sustain their hope.

Travelling alone

There are times when the journey with rheumatoid arthritis seems to be intolerable, in particular when the illness feels out of control and continues to progress despite self management by patient and the combined efforts of the multidisciplinary team. Such setbacks result in greater dependence and severe limitations to social and personal life. Inevitably such "bad patches" will also affect relationships with family, colleagues, and friends, who run out of knowing what to do for the best:

Carol: I do have off days, but so do people who are perfectly fit. If I have really "bad days" I tell myself that it will be probably better tomorrow. I have a low tolerance for anyone who feels sorry for me

Chloe: This disease can be very isolating . . . although I have accepted my disease, there is also a sense of continual loss. One day I can dress myself, the next day

I can't. I can no longer be independent, even with adjustments to my home and work. I have to rely on good deeds from others. That subtly changes the balance of power in a work situation; it also impacts on other people's perception of status

Companions on the journey

Living with a chronic and unpredictable illness, especially at times of crisis, is only manageable with the support of family, friends, and professionals. Patients invariably stress that from all these sources they most rely on are others who know them well and who take time to show a genuine interest in their wellbeing:

Carol: I have a wonderful group of friends and family, all with a great sense of humour . . . The rheumatology department has excellent support systems, whose members are always available to discuss any problems and will fit you in

Carol's sister:

I have to consider carefully what activities we do together when we visit as a family and Carol joins us. A day's shopping is definitely out of the question now which is a shame

I worry about Carol much more than before. I don't believe she is able to defend herself physically in the same way any more and can't move quickly enough from any disaster

I watch what I say slightly more than before. Carol has a lot less patience than previously and that's not saying a lot. She can be quite sharp

Chloe: My husband is wonderful and supportive, but he always wants to "fix" my disease, and his frustration at not being able to is heart rending . . . Ongoing contact with the rheumatology department is extremely important to me. No matter how busy they are they always make me welcome

Ways of coping

Living with rheumatoid arthritis means no longer taking for granted many activities that were—and are for most of the population—previously routine. Daily practicalities need to be tackled in new and sometimes creative ways, which might need to be changed or adapted day by day:

Carol: I have to break down my homework into manageable units—at my own pace. When washing my clothes I only fill the washing machine half full. When the clothes are wet they are heavy, and then I cannot shake the garments and hang them up. I can shop for three days at a time. I can only carry four plastic bags, two on each forearm, and climbing up three flights of stairs to my flat. In contrast, driving is relaxing and an escape from what I call "log cabinitis." Without my car I would feel very constrained

Chloe: Living on a daily basis with active RA is very tiring. The condition and treatment cause fatigue, but there are also emotional and practical issues to deal with. Every trip or commitment has to be carefully planned. Every action causes a subsequent reaction

What helps along the way?

How does rheumatoid arthritis look from the perspective of a nurse specialist? From this viewpoint chronic diseases, such as rheumatoid arthritis, can usually be managed well by patients at home when the disease is relatively stable. The success of this approach depends

on having enough up to date advice and education; a nurturing relationship with patients, offering empathy, encouragement, emotional support, and hope; listening and observing how the patient feels and taking their concerns seriously:

Carol: I have never found consultants particularly empathetic. I get the impression that they are trying so hard to find a solution, they forget to listen to the patient

Nursing staff deliver care by slowly building rapport and justifying trust by considering patients' worries. In practice, patients prioritise their own needs, to which nurses help with facilitating solutions, including following up appropriate requests within the healthcare system—for example, explaining the hospital infrastructure, referrals to other therapists, and finding answers to their questions. In secondary care, when a patient's condition destabilises, specialist staff are ready through rapid access to provide intermittent fast or even urgent medical and nursing expertise, as flare-ups can be excruciatingly painful:

Carol: When I am not well I want to have the opportunity to express my concerns. One important aspect for me therefore is that I want the relationship with staff members in the department to be a good one, so I can bounce things off them, such as am I over-reacting about something or questions around certain drugs and treatments

Chloe: My consultant has always included me in every clinical decision and has never belittled my concerns or fears . . . I know when life has just become too much I can drop in and see a friendly face. If I have a particularly bad flare-up the nurses will get me to see a doctor at the unit promptly and without fuss

Often the issue of respect is raised in patients' accounts. For example, Carol agrees to be seen by doctors who are teaching medical students, but she does not accept the way she is treated at times as if she was deaf:

I think they should be reminded that discussing patients (who are sitting in front of them) as if they are not there can be counterproductive. I have had: "she's obviously on steroids, she's got a steroidal face"

Journey's end

What improvements in services are needed most? Chloe is in not doubt about this

If funds were available here is my wish list of other ways in which the NHS could help patients of my age with rheumatoid arthritis: (i) A counsellor who is knowledgeable about long term pain issues who patients can see to discuss coping strategies. This needs to be without the risk of stigma or stereotyping which can arise from a patient having on their records that they are seeing someone with a psychology or psychiatry background. (ii) Access to other patients so that a users group could be set up of working age patients who could, in conjunction with knowledgeable staff, write a best practice guide for employers. (iii) There needs to be more information on RA available for employers. As it is generally associated with old age, employers are often perplexed when a younger member of staff comes to them with the diagnosis. The relapsing, remitting nature of the disease is difficult for them to understand. Physical "reasonable adjustments" (in line with the Disability Discrimination Act) alone are not enough, and the progressive nature of the disease needs to be understood

Additional educational resources for patients

Arthritis Research Campaign (ARC) (www.arc.org.uk)—this UK charity is funding research in universities, hospitals, and medical schools to investigate the cause and cure of a range of rheumatic diseases and health service research. In addition it provides over 60 free clear and well written information booklets for patients and carers, developed by experts and patients on a wide range of topics—for example, different rheumatic diseases, juvenile arthritis, treatment, lifestyle, drug information, and specific leaflets about body parts affected by arthritis, including the quarterly magazine *Arthritis Today*

Arthritis Care (www.arthritiscare.org.uk)—this UK voluntary organisation offers a helpline team for practical and confidential support; has a range of useful publications about drugs, treatment, and services, including a bimonthly magazine *Arthritis News*; runs several self management courses—for example, expert patient programmes and personal development courses; arranges over 500 local support groups; and campaigns for greater awareness about the needs of people who have arthritis

National Rheumatoid Arthritis Society (NRAS) (www.rheumatoid.org.uk)—this more recent established organisation (October 2001) describes itself as a "campaigning voice in the UK for people with rheumatoid arthritis." The website contains useful and clear summaries and detailed information about medical issues—for example, drugs, treatment, and non-medical topics such as emotional, social, and economic difficulties encountered with this long term chronic disease

Arthritis and Muscular-Skeletal Alliance (www.ama.uk.net)—a UK umbrella association that brings together support groups, professional bodies, and research organisations in the specialty of arthritis and other musculoskeletal conditions. The aims are to provide recommendations for high quality musculoskeletal services throughout the United Kingdom at all stages of patients' pathways through the health service, including developing and publishing standards of care for six main groups of musculoskeletal conditions—for example, inflammatory arthritis, osteoarthritis, back pain and others

Employers' Forum on Disability (www.employers-forum.co.uk)—This apolitical and non-profit organisation focuses on the issue of disability in the workplace for employers. Its aim is to provide information about best practice to make it easier to employ disabled people and to serve disabled customers

Disability Rights Commission (DRC) (www.drc-gb.org)—the commission acts as an independent organisation to stop discrimination and to promote equality of opportunity for disabled people generally and around employment specifically. It provides a helpline, casework, and a legal service

While living with rheumatoid arthritis, patients hardly ever feel completely free of the disease. Many patients usually wish to conceal their condition as far as possible, to avoid embarrassment and being stigmatised by visible physical deformity. Despite the emergence of new therapies, it remains difficult or impossible to make short term or long term plans for the future because of the unpredictability of the disease and patients' fluctuating reactions to treatment. What this means in practice is that patients have to plan and live one day at a time. An important implication of this is that everyone else involved with the patient also has to keep making changes according to the effects of the disease on any particular day. What patients can be sure of is that things will not go according to plan.

We thank the Arthritis Research Campaign for their support of our work.

Competing interests: None declared.

1 Scott DL, Smith C, Kingsley G. What are the consequences of early rheumatoid arthritis for the individual? *Best Pract Res Clin Rheumatol* 2005;19:117-36.

(Accepted 26 August 2005)