

Rheumatoid arthritis: the role of early intervention and self-management

Diane Home and Maggie Carr

Diane Home is a Rheumatology Nurse Consultant, West Middlesex University Hospital and Maggie Carr is a Rheumatology Consultant Nurse, Ashford and St Peter's Hospital

Email: diane.home@nhs.net
maggie.e.carr@gmail.com

Rheumatoid arthritis (RA) affects approximately 580 000 people in England and it is estimated that 26 000 new cases are diagnosed each year (National Audit Office (NAO), 2009). The peak age of onset is between 40 and 60 years of age, with women being three times more likely to develop the condition (King's Fund, 2009). RA is an inflammatory, auto-immune disease which typically affects the small joints in the hands and feet. It can also affect any synovial joint as well as having systemic manifestations, for example in the heart, lungs and skin. It is a chronic, progressive, potentially destructive disease which causes pain, stiffness and fatigue as well as limiting mobility and joint function. RA reduces life expectancy in severe cases by between 6–10 years (Pincus, 1993) either through co-morbidity such as cardiovascular disease or treatment-related adverse effects. It can affect all aspects of the person's life including their roles, relationships and independence (Young et al, 2000; Lempp et al, 2006).

A survey by the National Rheumatoid Arthritis Society (NRAS) found the RA significantly curtailed an individual's work life (NRAS, 2007). Studies show that after 5 years, 22% of those in employment at the time of their diagnosis were no longer working and this increased to 40% at 10 years (Barrett et al, 2000; Young et al, 2002). Therefore, RA is costly both to the individual and society; the National Institute for Health and Clinical Excellence (NICE) have estimated the total cost to the UK economy at between £3.8 and £4.75 billion per year (NICE, 2009). Health-care costs alone may reach £560 million per annum with the majority spent in the acute sector (NAO, 2009).

ABSTRACT

2009 has seen the publication of a number of key documents relating to the care of people with rheumatoid arthritis (RA). The National Institute of Health and Clinical Excellence issued guidance on the management of RA in adults while the King's Fund and National Audit Office have reported on the services that are available for people with RA. This paper will provide an overview of these reports and their implications for primary care. The role of early identification, referral and diagnosis will be explained as well as the treatment options available. The role of self-management and how community nurses can facilitate self-management will be discussed.

KEY WORDS

Rheumatoid arthritis • NICE • Self-management • Early intervention

Recent guidance

There have been three key publications in 2009 which have provided guidance and information related to the care of people with RA:

- ♦ January 2009: *Perceptions of patients and professionals on rheumatoid arthritis care. A Consultancy Report by the King's Fund for the Rheumatology Futures Group*
- ♦ February 2009: *Rheumatoid arthritis. The management of rheumatoid arthritis in adults.* (NICE, 2009)
- ♦ July 2009: *Services for people with rheumatoid arthritis.* National Audit Office (NAO, 2009).

Three messages emerged from the King's Fund report:

- ♦ Patients and professionals perceived* that there was an unacceptably wide variation in the level and quality of care available
- ♦ The role of primary care clinicians could be enhanced to ensure rapid referral for specialist assessment and support for ongoing management and treatment of people with RA
- ♦ Long-term specialist care to enable patients to self-manage was perceived to be lacking.

Recommendations for action were identified that would improve care in three areas: initial contact with the NHS, specialist intervention and ongoing care (Table 1). They also commented that more specialist and ongoing care should

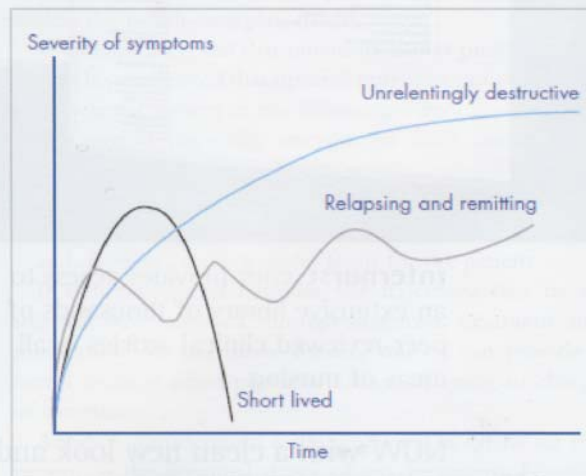


Figure 1. Possible trajectories for rheumatoid arthritis (NAO, 2009)

Table 1. King's Fund recommendations

Initial contact with NHS	Improvement in knowledge and competence of primary care teams in recognizing early signs and symptoms of rheumatoid arthritis Rapid referral to and availability of specialist care to support early diagnosis and initiation of treatment Increased information for the patient explaining the services available and treatment pathways to support self-management
Specialist intervention	Variations in the quality and accessibility of specialist care need to be addressed to avoid a postcode lottery Multidisciplinary input should be available Improved communication about the patients' treatment between primary and secondary care Integrating pathways and guidelines into development of future services
Ongoing care	Develop clear pathways for patients experiencing a flare-up of disease activity Improvement in quality of care and monitoring of co-morbidities

be available out of the hospital setting, which is in line with the current government agenda for care closer to home (Department of Health, 2006). However, while patients asserted that they wanted care more locally, they did not want to lose ongoing access to specialist clinical knowledge and skills during the transition of developing services away from the acute hospital setting.

In February 2009, NICE issued guidelines on the *Management of Rheumatoid Arthritis in Adults*. The key priorities for implementation by local commissioners and providers are detailed in *Table 2* (NICE, 2009).

The most recent guidance to be published was presented in the NAO report, *Services for People with Rheumatoid Arthritis* (NAO, 2009). It concluded that too few people were presenting or being diagnosed or treated quickly enough. The report identified that while initially more expensive, there could be long-term cost savings to the NHS and wider economy if patients had earlier access to specialist treatment and if services were better coordinated at a local level. For individuals there would be improvements in their quality of life and for those of working age they would have more chance of remaining in work.

Treatment for RA

Evidence suggests that adopting an aggressive approach to suppressing the disease process in RA is best practice in controlling the disease (Luqmani et al, 2006; NICE, 2009). This involves the use of disease-modifying anti-rheumatic drugs (DMARDs), corticosteroids, biologic drugs, non-steroidal anti-inflammatory drugs (NSAIDs) and analgesics.

DMARDs

It is recommended that treatment with DMARDs should be initiated as soon as possible, ideally within 3 months of the onset of persistent symptoms of RA in order to control the disease (NICE, 2009). Methotrexate taken once weekly (oral or subcutaneous) is now the most widely used DMARD in the UK, followed by sulfasalazine and leflunomide. Two or more of these drugs should be combined in order to bring about effective disease suppression if the

disease remains active with one DMARD (Luqmani et al, 2006; NICE, 2009). All of these treatments require regular monitoring of blood tests (and for some drugs, monitoring of blood pressure, urinalysis and weight) in order to identify and manage any adverse effects or toxicity at an early stage (Chakravarty et al, 2008).

Corticosteroids

Corticosteroids such as oral prednisolone and intramuscular (IM) depomedrone are used alongside DMARDs as they work quickly and can bridge the gap while waiting for DMARDs to take effect. IM depomedrone is a useful treatment for managing flares of disease activity and intra-articular injections of corticosteroids are effective at suppressing inflammation in individual joints (Luqmani et al, 2006). It is important that the risk:benefit ratio of using corticosteroids is considered and that they are used as a short-term treatment. Supplementation with calcium and vitamin D should be considered at an early stage to prevent the development of osteoporosis.

Biologic treatments

NICE have approved four biologic medications for the treatment of RA (NICE, 2007a; 2007b). Adalimumab, etanercept and infliximab block the action of tumour necrosis factor alpha (TNF α). TNF α is an important pro-inflammatory messenger or cytokine which, when blocked, can prevent messages passing along the inflammatory pathway. Adalimumab and etanercept are subcutaneous and can be self-administered while infliximab is given intravenously. Rituximab is also intravenous and works by depleting B cells. NICE have laid out eligibility criteria for these treatments which include the patient having active disease despite two conventional DMARDs at maximum tolerated doses.

NSAIDs and analgesics

These medications are used to provide control of pain and stiffness. Examples of NSAIDs include naproxen, diclofenac and ibuprofen. Commonly used analgesics include paracetamol, co-dydramol and tramadol.

Table 2. NICE Guidance on management of rheumatoid arthritis in adults (2009)**Referral for specialist treatment**

- ◆ Anyone with suspected persistent synovitis of undetermined cause
- ◆ Urgent referral if any of the following present:
 - ❖ The small joints of the hands and feet are affected
 - ❖ More than one joint is affected
 - ❖ There has been a delay of 3 months or longer between onset of symptoms and seeking medical advice

Disease-modifying and biological drugs (DMARDs)

- ◆ Offer combination DMARDs plus corticosteroids as first-line treatment in newly diagnosed rheumatoid arthritis (RA), ideally within 3 months of onset of persistent symptoms
- ◆ If combination is not appropriate rapid escalation of a single DMARD to a clinically effective dose
- ◆ Once satisfactory disease control has been achieved, cautiously reduce the drug dose to a level that maintains disease control

Monitoring disease

- ◆ Monthly monitoring of aspects of disease activity in people with recent-onset active RA, e.g. C-reactive protein (CRP) or a composite score of disease activity, e.g. DAS28

The multidisciplinary team (MDT)

- ◆ People with RA should have access to a named member of the MDT who is responsible for coordinating their care.

Implications for primary care

All of these publications identify the need for early referral and intervention; this approach is now the cornerstone of management of RA. Evidence shows that the earlier treatment is initiated the better. Conversely, patients who experience a delay in starting treatment have more irreversible joint damage (Finckh et al, 2006; Hyrich, 2008) which leads to poorer outcomes and increased disability. However, although early treatment is known to be the best approach, only 10% of people are treated within the first 3 months of symptom onset as recommended by NICE (NAO, 2009; NICE, 2009). Delays in starting treatment are two-fold: patients may not seek medical advice promptly on development of symptoms and delays in referral to specialist care have been identified, in some cases as long as 3 years (Kumar et al, 2007; King's Fund, 2009). Between 50–75% of people delay seeking medical help for over 3 months and 20% delay for a year or more (NAO, 2009). On average a person visits the GP four times prior to referral and 18% visit more than eight times (NAO, 2009). There are therefore issues relating to both general public and professional awareness about RA, its early manifestations and the need not to delay in seeking medical and specialist input. It is imperative that clinicians in the front line have the opportunity to update their knowledge and competences in relation to RA identification, diagnosis and management (King's Fund, 2009). The NAO report acknowledges that diagnosis can be difficult and most GPs will see a new presentation less than once per year (NAO, 2009). The NICE guideline defines those patients who should be referred for specialist opinion; these are outlined in Table 2 (NICE, 2009).

In addition to their role in the early identification of RA, primary care health professionals may become more involved in the ongoing care of people with RA as changes to the way services are commissioned and delivered are made (DH, 2006; 2009). However the NAO report identified that currently there is a lack of integration between primary and secondary care with little impetus to change

the way services are configured. They recommend that the number of people in a population with RA, current service provision and funding arrangements need to be identified in order to commission care to meet local need (NAO, 2009). The DH's 18 week commissioning pathway for RA (DH, 2009b) takes account of recent recommendations (King's Fund, 2009) and will provide a vital resource for commissioners of rheumatology services as well as clinicians undertaking service redesign.

The NICE guideline on RA suggests that review appointments should be at a frequency and location suitable to the individual's need (NICE, 2009). The guidelines also recommend the adoption of an annual review in RA, aspects of which may be undertaken in primary care, e.g. checking for co-morbidities such as depression, hypertension and ischaemic heart disease. This is particularly important as RA is an independent risk factor for developing cardiovascular disease (Goodson, et al, 2004; Luqmani et al, 2006). Health promotion such as advice on diet, weight reduction, exercise and stopping smoking is essential. Smoking is a risk factor for the development of RA (Symmons et al, 1997). There is also evidence to suggest that those patients who continue to smoke after diagnosis are more likely to develop severe joint disease and extra-articular manifestations such as vasculitis and nodules (Saag et al, 1997).

Self-management

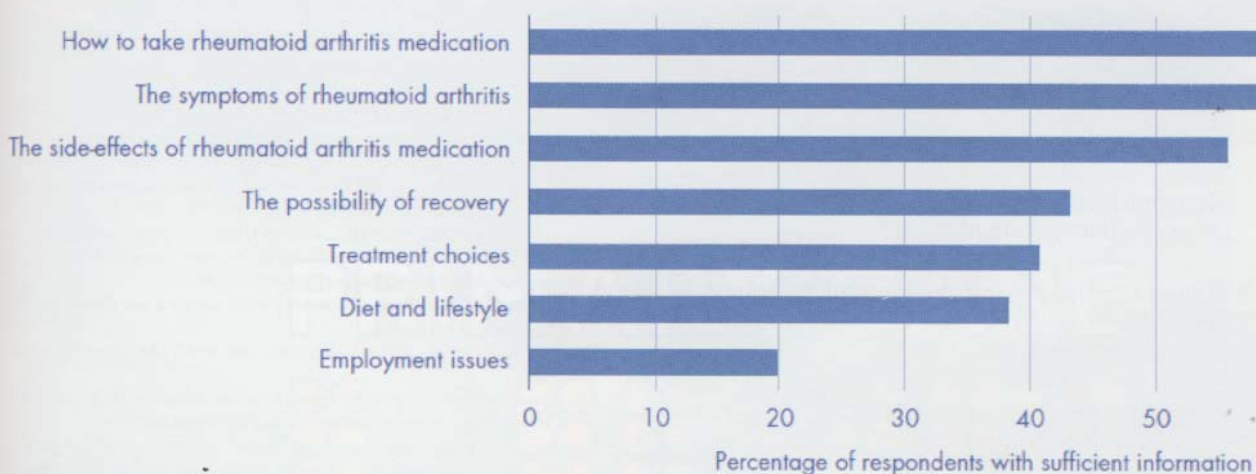
Self-management has been defined as:

'The individual's ability to manage the symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with a long term condition' (Barlow, 2002).

RA is unpredictable in its nature and course; self management skills are vital in helping people to cope with the impact of their condition and to be able to make informed choices about treatment options. The NAO audit explored

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Figure 2. Availability of information for people with arthritis



Source: National Audit Office survey of 1,400 people with rheumatoid arthritis

the extent to which people felt they had enough information to manage their RA. This is shown in Figure 2.

There are many sources of information available to the person with RA to aid self-management and the health-care professional should play a role in guiding people to the appropriate resource such as the National Rheumatoid Arthritis Society (NRAS) publication *Managing well: Living with Rheumatoid Arthritis* (NRAS, 2009). This booklet provides readers with a wealth of information and advice about living with established RA. 'Arthritis Care' and 'Arthritis Research Campaign' (**arc**) also produce numerous booklets covering all aspects of arthritis and these can be obtained and made available to patients in primary care and community settings. Information about RA can be found electronically on the NHS Choices website or via the NHS Information Prescription site. These sites, along with the NRAS, Arthritis Care and **arc** websites, are an invaluable resource for both patients and health-care professionals.

Flare-ups of RA are common during the course of the disease. The NAO audit found that individuals employ a number of different strategies to cope with flares, with 59% of those questioned agreeing that having a named person to contact when they flare would help them to manage their disease better (NAO, 2009). This person could be a rheumatology health-care professional in secondary or primary care and support and advice is often provided by means of a telephone advice line. NICE guidelines recommend that people with RA should know how and when to gain rapid access to specialist care (NICE, 2009). Telephone advice is also available from NRAS and Arthritis Care. NRAS have a number of local support groups for people with RA and also offer a 'buddy' system, whereby individuals can link up and support one another thus aiding self-management.

Recent guidelines and standards related to the care of people with RA have stressed the importance and desirability of access to self-management programmes (Arthritis and Musculoskeletal Alliance (ARMA), 2004; Luqmani et

al, 2006; DH, 2006; King's Fund, 2009; Luqmani et al, 2009; NICE, 2009). NRAS, in collaboration with the Expert Patient Programme Community Interest Company (EPP CIC), has recently developed an RA-specific self-management programme which continues to be piloted and developed in the UK. In addition, Arthritis Care runs the Challenging Arthritis course for people with all forms of arthritis and the EPP CIC runs generic self-management programmes. These are all held in community settings with a combination of expert and lay leaders who have been trained to deliver the courses.

EPP CIC has identified a number of skills that, once acquired, can help individuals have more understanding of and confidence to manage their condition on a daily basis.

These include:

- ◆ Setting goals and making action plans
 - ◆ Problem solving
 - ◆ Developing communication skills
 - ◆ Managing emotions
 - ◆ Pacing daily activities
 - ◆ Managing relationships with family, friends and work colleagues
 - ◆ Communicating with health and social care professionals
 - ◆ Finding other health-care resources in the community
 - ◆ Understanding the importance of exercise, keeping active and healthy eating
 - ◆ Managing fatigue, sleep, pain, anger and depression.
- (EPP CIC, 2007)

Community-based nurses can facilitate and support self-management in RA by identifying appropriate courses in their geographical area and encouraging people with RA to take part in these. Having knowledge of the content and aims of such courses, as shown above, will enable nurses to reinforce strategies and provide appropriate support and advice. The King's Fund (2009) identified this as one of the major roles for primary care teams. Community nurses are also well placed to support patients by identifying the

Useful websites

Arthritis Research Campaign
www.arc.org.uk

Arthritis Care
www.arthritiscare.org.uk

National Rheumatoid Arthritis Society
www.rheumatoid.org.uk

Expert Patients Programme Community Interest Company
www.expertpatients.co.uk

NHS Information Prescriptions
http://tinyurl.com/lbkcqt

NHS Choices
www.nhs.uk/Pages/HomePage.aspx

NHS 18 weeks
www.18weeks.nhs.uk

impact that RA may be having on their daily activities, work and family life. They can be helped to access available services and input from other allied health-care professionals if appropriate, such as physiotherapy, occupational therapy and/or podiatry. There also needs to be a recognition of the loneliness and fear that may accompany a diagnosis of RA and patients may need psychological support (King's Fund, 2009). Community nurses may be involved in some of the annual checks needed by people with RA in view of the known associated co-morbidities. This presents an ideal opportunity to give advice regarding a healthy lifestyle and other self-management issues.

Conclusion

In conclusion RA is a common disease that carries a high economic burden on the individual and society. Early diagnosis and intervention with aggressive combination therapy is recommended as the evidence-based approach to treat-

ment in order to bring about the best possible outcome for the patient. This requires collaborative working between primary and secondary care as well as patient involvement through self-management.

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KEY POINTS

- Rheumatoid arthritis (RA) is a common disease which is chronic, progressive and has the potential to damage joints, limit mobility and reduce life expectancy.
- Early specialist referral to enable diagnosis and effective intervention is vital to improve an individual's outcome.
- People with RA need support and education to develop effective self-management strategies.
- Effective working between primary and secondary care is needed to develop care pathways. These should incorporate recently published guidelines to improve the care and services available to people with RA.
- RA is costly to the individual and to society with a high economic burden caused by health costs and shortened work lives. Early intervention can prove to be cost effective in the long term.