

Resource

Rheumatology Specialist Nurse

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Hearing about your diagnosis

When you are first diagnosed with rheumatoid arthritis, this may come as a shock, but it may also come as a relief at finally knowing what has been causing your pain, joint swelling, stiffness and fatigue. However, you feel about your diagnosis; you are probably going to need a lot of support, and it is accepted that early support after diagnosis is beneficial to people with rheumatoid arthritis. You will undoubtedly receive support from your family members and friends, but the RCNS can also provide invaluable support at diagnosis, through the early stages and later on as required.

What is an RCNS?

The RCNS is a nurse who has chosen to specialise in caring for people with arthritis, and they will have received extensive training in rheumatology and musculoskeletal care.

How do I access my RCNS, and what services do they offer?

Most rheumatology departments have a team of RCNS's. The services offered may vary, but most patients can expect the following:

- A dedicated rheumatology helpline
- Nurse-led follow up clinics
- Opportunities for education and self-management

What is a dedicated rheumatology Helpline?

The helpline service provided by the RCNS may be an answerphone where you can leave a message, and the nurse will get back to you, usually within 24 hours or sooner. Sometimes rheumatology helplines are manned by the RCNS, and you will be advised to call at a specified time when a nurse will be available to speak to you directly and deal with your enquiry. The helpline takes calls from patients seen in the rheumatology clinics, carers, members of the public and other health

professionals working in the hospital or community. You can be reassured that confidentiality is always upheld.

Advice may be given for the following:

- Dealing with the symptoms of a flare-up of arthritis
- Managing side-effects from drug treatments
- Providing sooner appointments if required especially for flare-ups of arthritis
- Liaison with other members of the rheumatology team such as physiotherapist or occupational therapist etc.
- Other general advice and signposting to information about arthritis and treatment

What happens in nurse-led follow-up clinics?

At the time of your diagnosis, your rheumatologist may introduce you to the RCNS, and if this is not possible, they will usually provide you with the rheumatology helpline number. It is good practice for your care to be picked up by the RCNS within the first 1-2 weeks after diagnosis where you will be given an appointment in the nurse-led clinic. Increasingly patients will be starting drugs to control the arthritis at diagnosis or very soon after as early treatment will get you feeling better more quickly, allow you to continue working and will help to reduce the long-term damage that may be caused by arthritis.

The assessment in the clinic may involve:

- Blood pressure, weight, urine and blood test monitoring if required
- Asking you about your general well being
- Recording which joints are affected and what other symptoms you are experiencing
- Some clinics have nurses or sonographers who can ultrasound to assess joints
- Recording your current drug treatment
- Informing you about the results if you don't already know of blood tests and x-rays that were carried out when you saw the rheumatologist
- Finding out what you already know about arthritis and the treatments and offering you individualised education and written information
- Finding out how well you are managing and if you need advice on your daily activities such as work, caring for yourself and your family, and taking part in leisure and hobbies
- Referring you to another health professional who may help, e.g., physiotherapist, dietician, psychological support etc.
- The RCNS will provide you with education and written information on:
 - The process of inflammation in RA
 - Pain relief and disease-modifying treatments
 - There are a wide range of leaflets provided on a diet, footwear etc. so just ask if you want this information

Many RCNS services support the day to day management of patients with RA and other types of inflammatory arthritis, and they may be working with you to introduce a disease-modifying drug such as methotrexate. If so, they will be responsible for monitoring the safety and effectiveness of the

treatment. The RCNS may be responsible for altering the dose and changing some of your drug treatments via agreed guidelines, and some RCNS's will be able to prescribe your medication. Increasingly RCNS's are now using a tight control and goal setting approach to your care which involves partnership working to enable you to develop control over your RA and better-coping strategies. It is likely that the RCNS will examine your joints to establish more clearly how active your arthritis is. This is known as the DAS score and helps to decide whether the treatments you are having are working or whether you need a change in drug therapy. The RCNS may be able to offer you group education outside of the one to one education they can offer in their nurse-led clinics. Group education is an invitation to attend classes where you will meet other people with arthritis in a similar position to you.

How group education is provided varies around the UK, but they usually cover the following aspects:

- How to manage a flare
- How to manage your pain
- How the rheumatology department works and what services it can offer you
- The members of the multidisciplinary team and what services they offer
- The cause of arthritis and drug and non-drug treatments
- Information on support groups locally and nationally

Some group sessions include information on blood tests and x-rays, the patient held record card, relaxation, diet, physiotherapy, a question and answer session with a rheumatologist, access to benefits etc. Once you have come to terms with your diagnosis and you have been stabilised on an effective treatment for your arthritis you may like to consider going on a self-management programme known as "The expert patient". These are run over 6 x two-hour sessions in the community and are available through your local Primary Care Trust. NRAS are a source of information on this as they have extensively researched the best way to deliver self-management education and how best this is delivered.

What other activities might the RCNS be involved in?

- Educating and training other health professionals about rheumatology
- Research to help improve the care of the rheumatology patient
- Developing future rheumatology services
- Working on national groups
- Assessment of patients for biologic drugs such as infliximab, etanercept, adalimumab and rituximab. These RCNS's are often referred to as "Biologics Nurses."

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Diagnosis

RA can be very difficult to diagnose, as there is no single test to show whether or not you have the disease. Diagnosis is decided through a combination of blood tests, scans (such as X-ray or ultrasound) and an examination of your joints by a consultant rheumatologist.

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