



nras
National Rheumatoid
Arthritis Society

10 Healthcare Essentials for People with Rheumatoid Arthritis

When you are diagnosed with rheumatoid arthritis, understandably, you don't know what you don't know. It makes a huge difference if your initial experience of care is positive. Understanding what good care looks like from the word go and what to expect and ask for can make a big difference to your emotional and physical wellbeing.

Based on NICE (National Institute for Health and Care Excellence), SMC (Scottish Medicines Consortium), Sign Guidelines, the NHS and British Society for Rheumatology guidance, there is a minimum level of healthcare that every person with RA deserves and should expect. Here are 10 essential checks and services you should be entitled to and may benefit from knowing about. If you don't think you are getting all the care you need, take this checklist to your rheumatology healthcare team and discuss it with them.

- 1 Know your DAS** – DAS 28 (Disease Activity Score) NICE guidelines recommend that a DAS assessment should be carried out at least twice a year, but you should expect to have your DAS measured at every consultation, especially when newly diagnosed.
- 2 Regular Blood Monitoring** – Depending on the drug treatment prescribed, frequency of blood tests required may vary, but will commonly include ESR, CRP (inflammatory markers), liver function tests, FBC (Full Blood Count) and blood chemistry (monitoring effects on the kidney and liver). Ask your consultant or specialist if you are unsure about the frequency or relevance of blood monitoring. (Refer to the NRAS website for more information). It's also helpful to know whether you are Rheumatoid Factor positive or negative and Anti-CCP positive or negative as this may influence drug choices at some point in your treatment pathway.
- 3 Get support to quit smoking if you are a smoker** – Including advice and support on how to quit. Having RA puts people at increased risk of heart disease and smoking further increases this risk. Evidence shows that RA treatment and therapy is less effective in people who continue to smoke.
- 4 Annual Holistic Review** – People living with RA should be offered an annual holistic review which not only assesses disease progression but also gives you the opportunity to talk about your individual needs, any risk of conditions over and above your RA, and discuss the impact RA is having on your family and working life as well as your own emotional and mental health.
- 5 Access to the multidisciplinary team** – To help manage your RA you should have the opportunity to see specialist professionals including a rheumatologist, specialist nurse, physiotherapist, occupational therapist, podiatrist, dietician and psychologist if required. Use every meeting with a member of the team as an educational opportunity and don't be afraid to ask any questions you may have.
- 6 Learn how to self-manage** – To help you understand and manage your RA, its treatment, drugs and symptoms, you should be offered, and have the opportunity to attend, self management education, be given good quality approved information and have an individual care plan.
- 7 Access to a specialist nurse led helpline** – You should have access to a nurse led helpline when you need it, for instance when experiencing side effects to medications or for help if you flare.
- 8 Clear signposting to patient organisations** – Ask your rheumatology healthcare professionals about patient organisations that can offer comprehensive services including a helpline, peer to peer support, information booklets, online forums and educational opportunities.
- 9 Exercise** – Ask your physiotherapist about an individual exercise programme designed for you. Exercise is essential and plays a key role in controlling the symptoms of RA including fatigue, pain, and referred pain. It's also important to maintain a generally healthy lifestyle including healthy diet and appropriate weight.
- 10 Pregnancy** – Get information and specialist care if you are planning to have a baby. Your RA will need to be more tightly controlled and monitored during family planning for both prospective mothers and fathers. You should expect care and support from specialist healthcare professionals at every stage from preconception to postnatal care.

In addition, the following are highly recommended for people living with RA

- Have your blood fats (cholesterol) measured annually
- Have your blood pressure measured and recorded at least once a year and set a personal target that is right for you
- Have your eyes screened, particularly if you have gritty eyes which may be a sign of secondary Sjogren's syndrome. This can be a common side effect of RA and some medications
- Ask your rheumatology team about any opportunities to participate in research. Ideally, all patients should have opportunities to take part in research, whether it be related to drugs or observational studies on subjects such as fatigue or exercise.

For support, information, education and peer to peer contact become a member of the National Rheumatoid Arthritis Society (NRAS). Visit www.nras.org.uk or call 0845 458 3969 to join.

Call the NRAS freephone helpline on 0800 298 7650 if you need information, have a query on any aspect of your disease or need a listening ear.

Join an NRAS group near you. Meet others who have the disease and learn about how to better self manage your disease. Visit www.nras.org.uk/groups for a list of groups across the UK.

Contact us...

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References available on request from NRAS