

Article

# 10 Healthcare Essentials

Understanding what good care looks like can make a big difference to your emotional and physical wellbeing. NRAS have put together a list of 10 essential checks and services you should be entitled to and may benefit from knowing about.

#### **Print**



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. Being referred or self-referring to our New2RA Right Start is a good way to get the right information and support, at diagnosis when you are likely to be worried and

have a lot of questions going your head. Your Nurse Specialist can refer you or you can self-refer by filling in the online referral form on the above link. 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. Check your DAS (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. Read more about this and treat to target in our New2RA booklet.

## 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

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. Keep asking questions until you are satisfied, you understand.

#### 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 access 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, educational opportunities and resources to help you self-manage.

#### 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 and 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. You can ask for your blood pressure to be checked when you have your regular blood monitoring done.
- Have your eyes screened, particularly if you have gritty eyes which may be a sign of secondary Sjögren'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.

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