

Standards of care for people with rheumatoid arthritis

INTRODUCTION

Patients and experts have worked together to produce standards of care for people in Europe who have rheumatoid arthritis. They hope that this means everyone with rheumatoid arthritis will get the best possible treatment from their doctors, nurses, and healthcare services, no matter where they live.

WHAT DO WE KNOW ALREADY?

Most countries have their own guidelines or recommendations about how to treat various diseases and conditions. In England, Wales, and Northern Ireland, the National Institute for Health and Care Excellence (NICE) set guidelines for rheumatoid arthritis and other conditions. The Scottish Intercollegiate Guidelines Network (SIGN) set guidelines in Scotland, and there are also recommendations made by groups of specialist doctors, support groups, and charities.

Guidelines set out things such as the tests doctors should use to find out if a person has a particular condition, what treatments work best, and who should get which treatments. But spreading the recommendations in guidelines can take time. So people in different areas may still be treated differently. And, while guidelines are useful, they often don't say what kind of support people should get or what people with a particular condition should know about their care.

This report explains how rheumatology experts created a set of recommendations to support people with rheumatoid arthritis across Europe.

WHAT DOES THE NEW STUDY SAY?

An expert group of patients and doctors reviewed all the guidelines on rheumatoid arthritis from 44 European countries. They then agreed on 16 recommendations they considered most important for patients. These 'standards of care' set out exactly how people with rheumatoid arthritis can learn more about their condition, ways that they can care for themselves, and what to expect from healthcare services and healthcare professionals.

For example, everyone with rheumatoid arthritis should expect:

- ▶ Relevant information and education about living with their condition and taking care of themselves. People should ask for the information in whichever form is easiest for them – leaflets, recommended websites, or educational DVDs, for example.
- ▶ A treatment plan that explains what the goals of their treatment are, based on what they decided with their doctors.
- ▶ An explanation of the possible benefits and risks of the treatments that they are considering or that their doctors suggest.
- ▶ An assessment and a referral to a specialist if this is needed
- ▶ Information about whether complementary or alternative medicines work.

HOW RELIABLE ARE THE FINDINGS?

To create these standards of care, the expert group reviewed published guidelines on rheumatoid arthritis (although, for practical reasons, they could only review guidelines published in English or German) and examined the results of good-quality studies.

There were four patients included in the group that developed the standards of care, along with 17 specialist doctors and healthcare professionals. Other people with rheumatoid arthritis may find that different things are important to them or helpful for getting the most out of their care.

WHAT DOES THIS MEAN FOR ME?

If you have rheumatoid arthritis, these standards of care were created to help inform you about what good care looks like and what to expect from healthcare professionals. You may find the standards useful for starting a discussion about the best ways to manage your condition with your GP, specialist doctor, or nurse. The standards may also help you think about the kinds of questions you would like to ask. The full set of standards is available at www.eumusc.net.

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