

Self-managing your inflammatory arthritis

This is the lay version of the EULAR recommendations for self-management in people with types of inflammatory arthritis. The original publication can be downloaded from the EULAR website: www.eular.org.

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Introduction

EULAR recommendations give advice to doctors, nurses and patients about the best way to treat and manage diseases. In 2021, EULAR wrote new recommendations about self-management for people with inflammatory arthritis. These are designed to sit alongside other standard medical recommendations to help you achieve good self-care, and help get the best outcomes from treatment.

Doctors, nurses, physiotherapists, psychologists and other health professionals and patients worked together to develop this advice. The patients in the team ensured that the patient point of view was included. Nine patient organisations were also consulted, representing eight different countries. The authors looked at the evidence on effective interventions for inflammatory arthritis, and self-management resources available across Europe.

What do we already know?

Inflammatory arthritis is the name for a group of diseases that cause pain and swelling in your joints. This happens because the body's immune system attacks its own tissues and causes inflammation. Types of inflammatory arthritis include rheumatoid arthritis, psoriatic arthritis, and axial spondyloarthritis.

An important aspect of living with inflammatory arthritis is being able to manage the daily impact. This can be practical, physical, or emotional. This is called *self-management*, and it goes beyond the medicine you take for your disease. Self-management is defined as a person's ability to manage symptoms, treatment, lifestyle changes, and the emotional or cultural consequences of their health condition. Self-management aims to give you independence, but with the support you need to achieve it.

What do the recommendations say?

In total, there are three overarching principles and nine recommendations. The principles stress that self-management means taking an active role in learning about your condition, and taking part in a shared decision-making process with your doctor. They also say that having the personal confidence to carry out an activity with the aim of achieving the result that you are aiming for has a positive effect on various aspects of living with inflammatory arthritis. The third principle highlights that patient organisations can provide valuable resources to support patients and healthcare teams.

Each recommendation is based on the best current knowledge and studies of scientific evidence or expert opinion. The more stars a recommendation has the stronger the evidence is. However, recommendations with limited scientific evidence may also be important, because the experts can have a strong opinion about their usefulness and importance even when the published evidence may be lacking.

One star (*) means it is a recommendation with limited scientific evidence.

Two stars (**) means it is a recommendation with some scientific evidence.

Three stars (***) means it is a recommendation with quite a lot of scientific evidence.

Four stars (****) means it is a recommendation supported with a lot of scientific evidence.

- Healthcare providers should encourage people with inflammatory arthritis to be an active partner with their healthcare team.***

An important step in self-management is taking an active role. Your healthcare provider should make you aware of the people and patient organisations involved in all aspects of the care pathway. This might mean signposting you to specialist doctors or healthcare professionals who can help with specific aspects, such as occupational therapists or psychologists. You should be introduced to all the members of the healthcare team looking after you. You should also be put in touch with the relevant patient organisation which can help provide support.
- Education should be the starting point and underpin all self-management interventions.******

Self-management can be complicated, and involve lots of different aspects and ideas. Education around your condition – and how best to manage it – can set you up with the tools you need.
- Problem solving, goal setting and – where relevant and available – cognitive behavioural therapy should be part of routine practice to support people with inflammatory arthritis.******

Self-management interventions that include problem solving, goal setting and, cognitive behavioural therapy might be useful and appropriate for some people with inflammatory arthritis. Cognitive behavioural therapy (often shortened to CBT) is a talking therapy that can help you deal with the social and emotional aspects of your condition.
- Healthcare providers should actively promote physical activity at the point you are diagnosed with inflammatory arthritis, and regularly afterwards.******

Physical activity can be really important to help you keep well and retain movement in your joints. Some people might need to see a physiotherapist to help them with physical activity. Other people can join suitable exercise programmes. For example, aquarobics, swimming, dancing, yoga, or pilates. Your healthcare team should talk to you about staying active and may refer to you a specialist if you need it.
- You should get lifestyle advice to help manage common comorbidities and adopt healthy behaviours.***

There are some lifestyle behaviours that can affect your inflammatory arthritis. For example, smoking or being overweight can make inflammation worse. In addition, cardiovascular complications are common in people with inflammatory arthritis and can also be related to things that you can change, so you should have your lipid levels and blood pressure checked. Your healthcare team should give you advice on modifiable risks, including adopting healthy behaviours such as how to achieve a healthy, balanced diet, the benefits of exercise, and support to quit smoking.
- Your mental health needs to be assessed periodically, and appropriate intervention made if necessary.***

Better emotional well-being leads to better self-management. CBT or other forms of psychotherapy might be offered if you need it to help deal with mental health issues. If you need specialist advice and support, you may be referred to a psychologist or psychiatrist. Patient organisations often provide peer and other forms of emotional support which can be helpful.
- Healthcare providers should discuss your work with you, and direct you to sources of help where appropriate or where needed.***

Inflammatory arthritis affects people of working age. Being able to work is important for people's emotional and financial well-being, and can give you a sense of self-esteem and purpose. Your healthcare team should direct you to resources to help you stay in work and maintain your

independence. Sometimes it is possible to stay in work with small changes to your workplace or the tasks that you need to do.

- **Digital healthcare can help you self-manage, and should be considered as part of supported self-management where appropriate.****

Mobile health apps are becoming very common. Where appropriate and available, digital healthcare tools can support you in achieving self-management – perhaps by giving you reminders, or a place to record disease activity measurements. Talk to your healthcare team to see what is available where you live. Patient organisations can also provide healthcare apps which can be helpful.

- **Healthcare providers should be aware of available resources to help optimise and support people's self-management.***

Everyone in the healthcare team looking after people with inflammatory arthritis should be aware of the resources that are available to them. That might be locally within a healthcare system, or from a patient organisation. It is important that the healthcare team can direct people to the right resources for their specific needs.

Summary

Overall, the recommendations show that self-management does not mean you have to deal with your condition on your own. Your healthcare team should give you the information and resources you need to manage on a daily basis, but there are often extra tools and support available if you need them. What self-management looks like for you will depend on your own personal circumstances. Once you find the tools you need that work for you, self-management should help you retain your independence, and get the best outcomes from your treatment.

Recommendations with just one or two stars are based mainly on expert opinion and not backed up by studies, but these may be as important as those with three or four stars.

If you have any questions or concerns about your disease or your medication, you should speak to a health professional involved in your care.