



Standards of Care for People with Rheumatoid Arthritis

eumusc.net standards of care aim to ensure that health care professionals know what should be done for people with rheumatoid arthritis, and so that people with the condition know what standards of care they should receive. There are also checklists for people with rheumatoid arthritis to use to ensure they are receiving the most appropriate care.

These recommendations are based on existing Clinical Practice Guidelines and expert consensus. The standards focus on prevention, access to care, early treatment and management of established disease.

Standards of Care for people with Rheumatoid Arthritis

- 1. People with symptoms of RA should have timely access to a clinician/ health professional competent in making a (differential) diagnosis (6 weeks according to EULAR recommendations).**
- 2. People with RA should be given relevant information and education about**
 - **their disease,**
 - **its management**
 - **and all aspects of living with and managing their RA, in written form and in a format suited and tailored to the individual, in a timely fashion appropriate to their needs.**

For people with RA there should be the opportunity (if required) to:

- have time to talk to someone face to face about their concerns at the clinic visit
- gain information and education at all stages of the patient journey
- discuss the care package and to know what to expect from it and when
- get self-management support at the right time
- discuss the emotional and psychological impact of the disease on life, for example as part of the annual review
- discuss work issues, and be provided with appropriate support to enable them to remain at work or get back to work when this is desired

3. People with RA should receive a treatment plan developed individually between them and their clinician at each visit.

The treatment plan should at least include:

- Diagnosis, physical examination and follow-up evaluations
- Assessment of signs and symptoms of the disease and its sequels: general health, functioning, psychosocial aspects, pain management needs, vocational issues, relationships, family, work issues, sleep disturbance, managing anxiety and depression including referral to occupational therapy or social services if appropriate. Family and carers should be involved where appropriate
- Goals: defined by person with RA and health professionals together
- Communication plan: e.g. contact detail of expert care in case of worsening of the disease
- Monitoring plan: at least one annual review should be done
- Education plan: access to personalized education programmes developed by health professionals, means to increase self-management and information (e.g. patient organizations, trusted sources of evidence based information)

4. At the start of any disease specific treatment, people with RA should be fully educated about the expected benefits and any potential risks, and fully evaluated to assess both clinical status and safety aspects.

The assessment for clinical status and safety aspects should at least include:

- Clinical status appraisal should include at least:
 - A measure of disease activity such as composite scores like DAS or any of its variants, CDAI or SDAI; individual components like joint counts, global assessment of disease activity by the person with RA and the clinician or health professional
 - A measure of functioning (such as HAQ, participation, work status, or an ICF- based instrument)
 - A baseline evaluation of the structural damage by X-rays (may be scored globally by any available system or just checked for structural joint damage); MRI or ultrasonography may provide additional insights (but should not replace x-ray).
- Based on clinical status, person with RA and clinician/health professional should state an individual shared target that should be realistic and relevant; such treatment target should be expressed in terms of status to be achieved and time to reach it.
- Assessment for comorbidities may lead to deviations from conventional or alterations of agreed treatment plans for RA, since some comorbidities constitute risk factors for developing specific adverse events, like COPD for infections; others may limit the dose, like renal function impairment; others may contraindicate some treatments, like active infections. Given the immunosuppressive nature of most therapies in RA and the high rate of infections in this population, it is very important that the vaccination status is reviewed and that the person is protected against avoidable infectious diseases in accordance with national vaccination plans.

5. People with RA should be fully assessed for symptoms, disease activity, damage, comorbidity and function at diagnosis; these assessments should also be done annually; if disease is not within target, clinical assessment should be done at least 3 monthly (all clinical variables) and possibly more frequently upon significant worsening.

Depending on the disease activity and status of the therapy and/ or person with RA, these intervals may range from few days or weeks to several months.

- People with RA in remission should be re-appraised at least once a year; People with RA not in remission should be scheduled at a rheumatologist within 3 months
- Clinical target should be reviewed by evaluating the change in disease activity measures.
- Safety should be evaluated by a complete work-up with laboratory examinations, review of possible adverse events, new comorbidities, complications of RA, and re-evaluation of protection against infections

Additionally the annual review/ assessment should also include:

- Persons participation in activities that are important to him or her, work capacity, functional status, CV risk and special needs.
- Progression of structural joint changes; since progression is usually faster in the first two years, the clinician/health professional may decide for less frequent intervals of x-ray assessment in situations of stable low disease activity or remission. When joint surgery is planned, imaging is mandatory.
- Non- pharmacological treatments require periodic reviews.

6. People with RA should have rapid access to care when they experience significant worsening of the disease.

Notwithstanding regular monitoring schemes, people with RA may need acute care at unpredictable time points; this should be warranted irrespective of other planned visits and the time-points for regular follow-up should generally not be affected by such emergency access to the team:

- Adverse event reporting should not be postponed until the next scheduled visit: therefore, a fast-track system should exist (i.e. telephone, rapid access slots or protocols developed in collaboration with the rheumatology team)
- Access in case of flares.
- It is advised to maintain regular check-ups despite in between visits, otherwise target may be lost, and some important safety aspects may be under-evaluated.

7. People with RA should be treated with a disease modifying anti-rheumatic drug as soon as the diagnosis is made.

Glucocorticoid may be needed in addition to DMARD treatment (lowest dose for the shortest period of time).

8. If the target of low disease activity or remission is not achieved using a synthetic DMARD (usually being methotrexate), treatment should be reevaluated at least every 3 months.

- If treatment target is not achieved with the first or combination DMARD strategy, addition of biological DMARD should be considered especially when poor prognostic markers are present (i.e. for bad outcome of physical disability or structural damage); when poor prognostic predictors are absent, switching to or adding another synthetic DMARD should be considered (as defined by appropriate guidelines).
- In people with RA lacking predictors for severe disease another synthetic DMARD monotherapy (or in combination with methotrexate) may be employed.
- If a biological agent has failed, another TNF inhibitor, abatacept, rituximab or tocilizumab is indicated, sequencing according to local protocols.
- In people with RA in persistent remission, tapering of biological agent should be considered and in long-term remission a careful titration of synthetic DMARD dose

9. People with RA should be evaluated for pain, and relief of pain associated with RA should be considered.

- Nonsteroidal anti-inflammatory drugs (NSAIDs) should be considered in symptomatic people with established RA and early arthritis after evaluation for gastrointestinal, renal, and cardiovascular risk.
- Replacement of conventional NSAIDs by COX-2 selective drugs, or the addition of gastroprotective agents to classical NSAIDs should be prescribed in persons at increased risk for NSAID GI toxicity (as defined by appropriate guidelines).
- Analgesics should be prescribed if NSAIDs are contraindicated or if NSAIDs convey inadequate pain relief.

10. People with RA who have residual joint problems despite state-of-art pharmacological (including intraarticular) and non-pharmacological therapy should be assessed by an orthopaedic surgeon within 3 months if there is joint damage/ soft tissue problems that can probably be solved by surgery.

People with RA should be offered a presurgical assessment along with information on the procedure, the risk and benefits, post-operative care and an individualised discharge plan.

11. People with RA should have access to evidence based pharmacological and non-pharmacological treatment.

People with RA should receive information about expected effects, benefits and possible risks of any pharmacological or non-pharmacological treatment that may be instituted or started by the person.

12. People with RA should have access to a specialised health professional to receive assessment, advice and training in all matters related to their disease.

- People with RA should be encouraged to carry out regular physical activities.
- People with RA should receive professional advice on exercises (aerobic and strengthening) specific to their joint involvement and adapted to the person's general health.
- Information should be given on the positive effect of exercises on general and cardiovascular health, as well as maintenance of mobility and prevention of muscle wasting.
- Information and education on joint protection should be given, tailored to the person's needs.
- People with RA should be assessed for the need (and the acceptance) of splints and should have access to a health professional providing them.
- The need for adapting the environment at home/ at work should be assessed and an experienced health professional advice should be available.
- People with RA should receive expert advice on assistive devices to improve/ maintain the ability to carry out activities of daily living.
- The psychological and social impact of the disease should be taken into account and appropriate interventions should be offered.
- In the treatment of people with RA attention should be given to foot problems and information provided on foot care, foot wear and orthoses / insoles.

13. People with RA should understand the benefit of exercises and physical activity and should be advised to exercise appropriately.

14. People with RA should receive information, advice and training on joint protection and ergonomic principles as well as activity-based methods to enhance functioning in daily life and participation in social roles. They should receive information, advice and training on splints, aids, devices and other products for environmental adaptations.

15. People with RA should receive information and advice about

- **a healthy lifestyle (such as discontinuation of all types of tobacco use, balanced use of alcohol, physical activity, healthy diet, management of sleep disturbance if necessary)**
- **prevention of accidents and injuries,**
- **support groups and patient organisations,**
- **when to think about surgery and**
- **additional treatment options provided some people might find useful.**

Reliable information based on a person's status assessment and best available knowledge should include material on:

- Discontinuation of all types of tobacco use
- Balanced use of alcohol
- Physical activity
- Diet: Advice regarding a balanced diet in order to control weight and on the need to supplement vitamins and minerals, even if there is current lack of scientific evidence on the impact of such measures on disease activity and course
 - avoidance of diets deficient in dairy products (contain calcium),
 - following a Mediterranean diet could be encouraged (fish)
 - minerals, vitamin C and D, calcium, fish oil and folic acid can be supplemented (and folic acid must be supplemented with use of MTX)
- Sleep: early management of sleep disturbances as a factor improving quality of life.

16. People with RA who wish to try alternative therapies that some people found symptomatically beneficial, should be informed about the limited evidence.

What this means for you and your rheumatoid arthritis...

1. Was my RA diagnosed by a specialised health professional within 6 weeks of onset of symptoms?
2. Do I understand my disease, my role in its management and the role of health professionals?
Have I been given information in different formats and/ or education about my disease?
Have I been given information and / or education about treatments, their benefits and risks?
Have I been given information and education relevant to my needs i.e. pain/flare management, drug reactions?
Have I been given information about, and given contact details of, relevant patient charities and organisations which are considered to be trusted sources of evidence based information?
3. Have I received a treatment plan which includes explanation of my management, expected goals and outcomes and important contact details?
4. Was I informed about expected benefits and potential risks of treatment?
Was I assessed for clinical status and safety before the treatment was started?
Was I informed about vaccination?
5. Have I received a schedule of regular assessments of my disease – The symptoms, disease activity and of what I can do?
6. Have I been informed when, how, and who I can contact in case my disease is worsening?
7. Am I receiving a disease modifying anti-rheumatic drug, and if not, do I understand why not?
8. If my target of low disease activity or remission is not achieved, is my treatment reappraised at least every 3 months?
9. Do I know how to control pain associated with my RA?
10. Have I been informed about the options of surgery and have the benefits and risks been explained?
11. Do I have access to pharmacological and non-pharmacological treatments according to my clinical need?

12. Do I have the opportunity to receive support if needed from health professionals such as rheumatologist, dietician, general practitioner, nurse, occupational therapist, physiotherapist, psychologist and social worker?

Have I been offered information about how, why and when to contact different members of the multi-disciplinary team as soon as possible after my diagnosis was made?

13. Have I been informed about physical activity and exercises specific for me?

14. Have I received information and if necessary advice and training on aids, devices and ergonomic principles to enhance function in daily life and participation in social roles?

15. Have I been informed about a healthy lifestyle?

Have I been informed about alternative therapies and the limited evidence available?

eumusc.net is an information and surveillance network promoting a comprehensive European strategy to optimise musculoskeletal health. It addresses the prevention and management of MSC's which is neither equitable nor a priority within most EU member states. It is focused on raising the awareness of musculoskeletal health and harmonising the care of rheumatic and musculoskeletal conditions.

It is a 3 year project that began in February 2010. It is supported by the European Community (EC Community Action in the Field of Health 2008-2013), the project is a network of institutions, researchers and individuals in 22 organisations across 17 countries, working with and through EULAR.

eumusc.net: creating a web-based information resource to drive musculoskeletal health in Europe
www.eumusc.net

Disclaimer

The Executive Agency for Health and Consumers is not responsible for any use that is made of the information contained within this publication