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From Fear to Confidence

Managing Treatment Concerns in RMDs

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What does the patient hear when we name the disease?

“Will I become disabled?”

“Will I lose my independence?”

“Will I still be able to work?”

“How will this affect my family?”

“What will my life look like in five years?”

A diagnosis can bring relief.
It can also bring fear.

First, we need to understand what the diagnosis means to the person receiving it.

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What is the patient really afraid of?

Pain, disability or organ damage

Side effects and long-term risks

Depending on medication

Treatment failing to help

Losing independence or becoming a burden

“What worries you most about your diagnosis or treatment?”

Some patients speak openly. Others remain silent or postpone decisions.

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What does the rheumatologist say … when we name the disease?

Everything will be ok ☺

We will control the disease!

Regular check-ups are needed.

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Treatment has advanced. Trust takes time.

More treatment possibilities

Biologic and targeted therapies have expanded choices and improved outcomes for many patients.

Established medicines remain important.
Response and risks vary between patients.

Old fears may remain

Patients may still associate their diagnosis with disability or difficult treatment experiences.

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Treatment has advanced. Education and science bring new horizons.



Recommendation

EULAR recommendations for the management of systemic lupus erythematosus: 2023 update

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ABSTRACT

Objectives To update the EULAR recommendations for the management of systemic lupus erythematosus (SLE) based on emerging new evidence.

Methods An international Task Force formed the questions for the systematic literature reviews (January 2018–December 2022), followed by formulation and finalisation of the statements after a series of meetings. A predefined voting process was applied to each overarching principle and recommendation. Levels of evidence and strengths of recommendation were assigned, and participants finally provided their level of agreement with each item.

Results The Task Force agreed on 5 overarching principles and 13 recommendations, concerning the use of hydroxychloroquine (HCQ), glucocorticoids (GC), immunosuppressive drugs (ISDs) (including methotrexate, mycophenolate, azathioprine, cyclophosphamide (CYC)), calcineurin inhibitors (CNIs, cyclosporine, tacrolimus, voclosporin) and biologics (belimumab, anifrolumab, rituximab). Advice is also provided on treatment strategies and targets of therapy, assessment of response, combination and sequential therapies, and tapering of therapy. HCQ is recommended for all patients with lupus at a target dose 5 mg/kg real body weight/day, considering the individual's risk for flares and retinal toxicity. GC are used as 'bridging therapy' during periods of disease activity; for maintenance treatment, they should be minimised to equal or less than 5 mg/day (prednisone equivalent) and, when possible, withdrawn. Prompt initiation of ISDs (methotrexate, azathioprine, mycophenolate) and/or biological agents (anifrolumab, belimumab) should be considered to control the disease and facilitate GC tapering/discontinuation. CYC and rituximab should be considered in organ-threatening and refractory disease, respectively. For active lupus nephritis, GC, mycophenolate or low-dose intravenous CYC are recommended as anchor drugs, and add-on therapy with belimumab or CNIs (voclosporin or tacrolimus) should be considered. Updated specific recommendations are also provided for cutaneous, neuropsychiatric and haematological disease, SLE-associated antiphospholipid syndrome, kidney protection, as well as preventative measures for infections, osteoporosis, cardiovascular disease.

Conclusion The updated recommendations provide consensus guidance on the management of SLE, combining evidence and expert opinion.

INTRODUCTION

Since 2008, when the first EULAR recommendations for the management of systemic lupus erythematosus (SLE) were published and widely adopted,[1] a series of specific recommendations on disease monitoring, neuropsychiatric SLE and lupus nephritis (LN), pregnancy and women's health issues in SLE have been developed.[2–5] More recently, updated recommendations on the management of general SLE and LN were published in 2019 and 2020, respectively, the latter jointly with the European Renal Association/European Dialysis and Transplant Association (ERA/EDTA).

Since the 2019 update, the pace of new developments in SLE has accelerated. A second biological drug, anifrolumab, has been approved for the management of the disease, while the field of LN has also witnessed major breakthroughs; the approval of belimumab and voclosporin, a novel calcineurin inhibitor (CNI), for patients with active LN has inspired discussions on a 'paradigm shift' in the treatment of LN, moving from the traditional 'induction-maintenance' regimen to the early use of combination therapies.[6 7] These advances created the impetus for an update of the recommendations, to provide guidance on an evolving landscape and capitalise on the experience gained thus far. Given



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Recommendations

EULAR recommendations for the management of Behçet's syndrome: 2025 update

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Recommendations

EULAR recommendations for use of antirheumatic drugs in reproduction, pregnancy, and lactation: 2024 update

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Why treatment can still feel frightening

A previous adverse reaction

A relative with severe disability

A frightening medicine leaflet

Conflicting stories online

Feeling dismissed in a consultation

"What have you heard or experienced that makes this treatment difficult to trust?"

A recommendation meets a lifetime of experiences and beliefs.

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Quality of life gives treatment a personal meaning

“Can I sleep through the night?”

“Can I get through a working day?”

“Can I walk or climb stairs more easily?”

“Will I have energy for my family?”

“Can I make plans with confidence?”

“What would you most like treatment to help you do again?”

The answer should help shape our treatment goals.

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Listening is part of the treatment conversation

"You are worried that side effects could stop you caring for your family. Have I understood you correctly?"

Ask what remains unspoken

Patients need space to tell their story.

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Empathy in words and attitude

Acknowledging fear	“I can see why that possibility worries you.”
Recognising experience	“That experience matters when we plan your care.”
Respecting uncertainty	“Which questions do we still need to answer?”
Offering support	“Let us agree on what to do if a problem occurs.”

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Benefits, risks and realistic expectations

What the treatment aims to improve

How long improvement may take

Common and important serious risks

Risks of insufficient disease control

Alternatives and their trade-offs

“How do these options compare for someone with my condition and medical history?”

Explain risk using absolute numbers and a clear time period when reliable estimates exist.

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A clear safety plan supports confidence

Which symptoms should I report?

When should I seek urgent help?

Whom can I contact?

What should I do if I become unwell?

When are my tests and review?

Monitoring helps manage risk.
It cannot remove every risk.

Written instructions should be specific to the patient and the medicine.

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Shared decisions

Clinical expertise

Evidence and medical assessment
Options, benefits and risks
An explanation of uncertainty

The patient's expertise

Personal goals and priorities
Previous treatment experiences
Everyday challenges
Chat GPT

Together: a treatment goal, a plan, support and a review date.

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When treatment becomes difficult

"Many people find parts of treatment difficult.
What has it been like for you?"

Possible barriers

Side effects or persistent fear
Unclear instructions or treatment fatigue
Access and affordability

Practical support

Managing adverse effects
Training, reminders and clarification
Reviewing treatment together

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Progress includes the life the patient wants to live

“What has become easier?”

“What is still difficult?”

“How manageable is the treatment?”

“Have your priorities changed?”

Clinical assessment and lived experience

Persistent pain, fatigue or limitations deserve assessment, even when inflammation improves.

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A conversation that builds confidence

Illustrative scenario, not a real patient case

PATIENT “I am afraid to start methotrexate. Someone I know had a difficult experience.”

RHEUMATOLOGIST “What happened, and what worries you most about your own treatment?”

PATIENT “I am worried I will feel too unwell to care for my family.”

RHEUMATOLOGIST “Let us discuss the benefits, possible side effects and how we would respond if you felt unwell.”

Together: a plan, monitoring, contact instructions and a review date.

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From Fear to Confidence

“I had the chance to speak.”

“My concerns were taken seriously.”

“I understand my options.”

“I helped shape the decision.”

“I know where to find support.”

Care that helps
patients live better

With confidence in their care and an active voice in decisions.

Thank you. Questions and discussion.

Thank you for your attention

