Partnering for Better Care with your Healthcare Team

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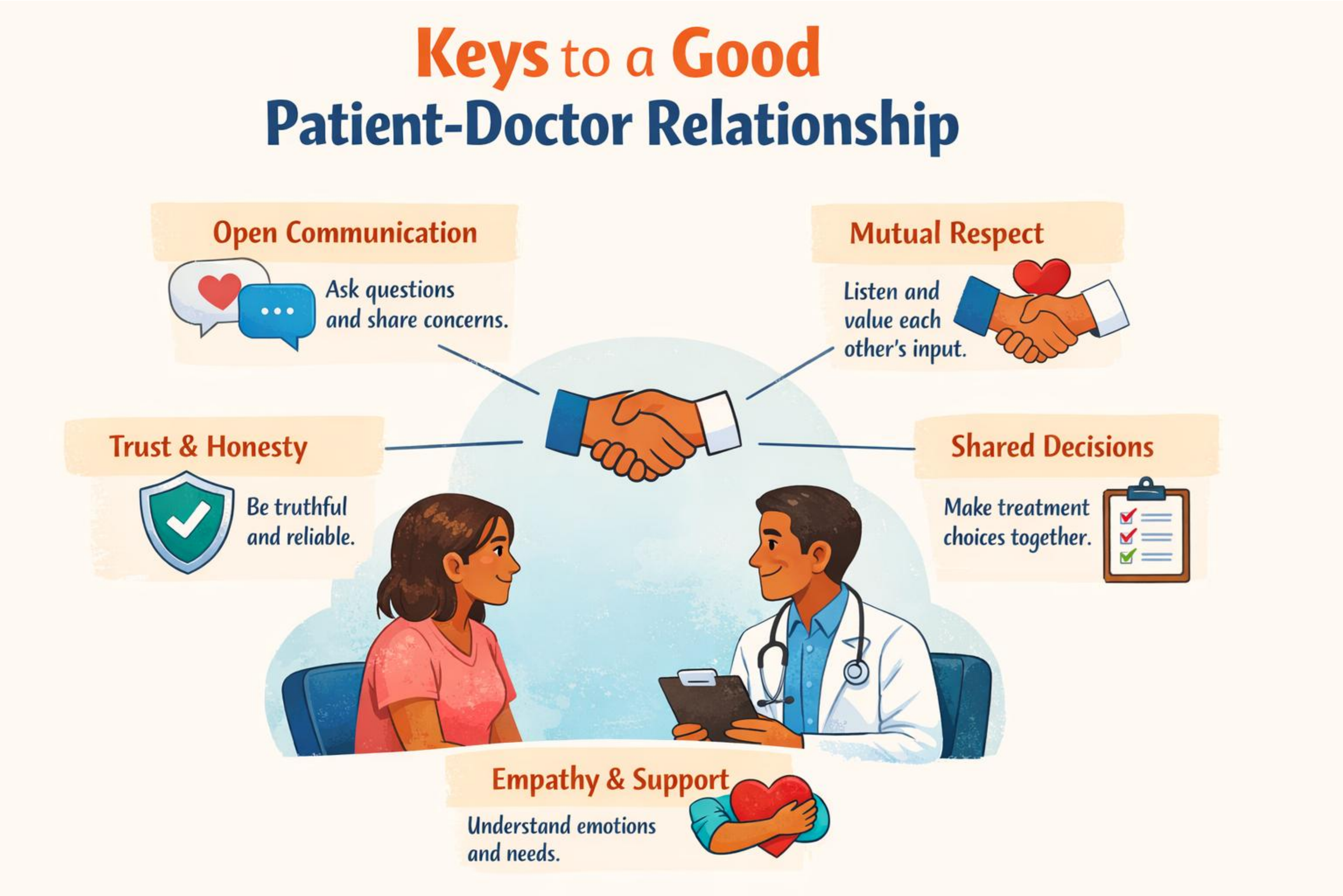
Building a Strong Patient–Doctor Partnership

- You are the expert on how lupus affects your daily life.
- Your doctor is the expert on diagnosis and treatment.
- Best care happens when both perspectives are valued.



Keys to a Good Patient-Doctor Relationship

Open Communication

Ask questions and share concerns.

Mutual Respect

Listen and value each other's input.

Trust & Honesty

Be truthful and reliable.

Shared Decisions

Make treatment choices together.

Empathy & Support

Understand emotions and needs.

Preparing for Your Appointment

- Write down symptoms, flares, and medication side effects.
- Bring medication lists and questions.
- Prioritize your top 2–3 concerns.

How to Prepare for Your Rheumatologist Appointment

Update Symptoms
Track your symptoms, flares, and triggers.

Make a List of Medications
Include dosages, and any allergies or side effects.

Prepare Questions
Jot down concerns and questions ahead of time.

Set Goals
Prioritize what you want to discuss.

Arrive on Time
Be punctual and prepared.

Bring Info
Insurance card, medications, notes.

Arrive on Time
Be punctual and prepared.

Systemic lupus erythematosus (SLE): Why guidelines matter

- Guidelines are expert recommendations based on research and patient outcomes.
- They help doctors choose safer and more effective treatments.
- They support shared decision-making between you and your rheumatologist.

What’s New in SLE Guidelines: 2025

- Goals of SLE management: achieve and maintain remission or a low level of disease activity, to reduce morbidity and mortality, and to minimize treatment-related toxicities for those living with SLE.
- Focus on controlling inflammation early to prevent organ damage
- Emphasis on steroid-sparing treatments when possible
- Greater attention to quality of life, fatigue, pain, and mental health

What’s New in SLE Guidelines

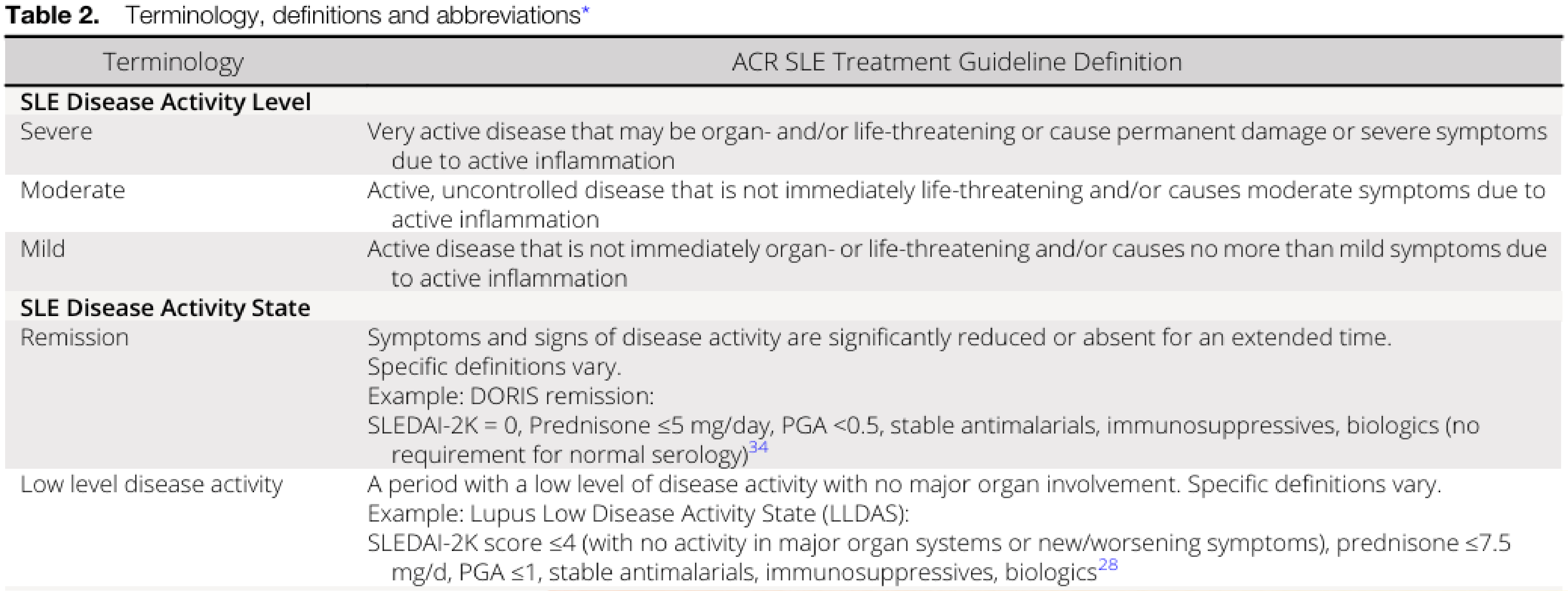
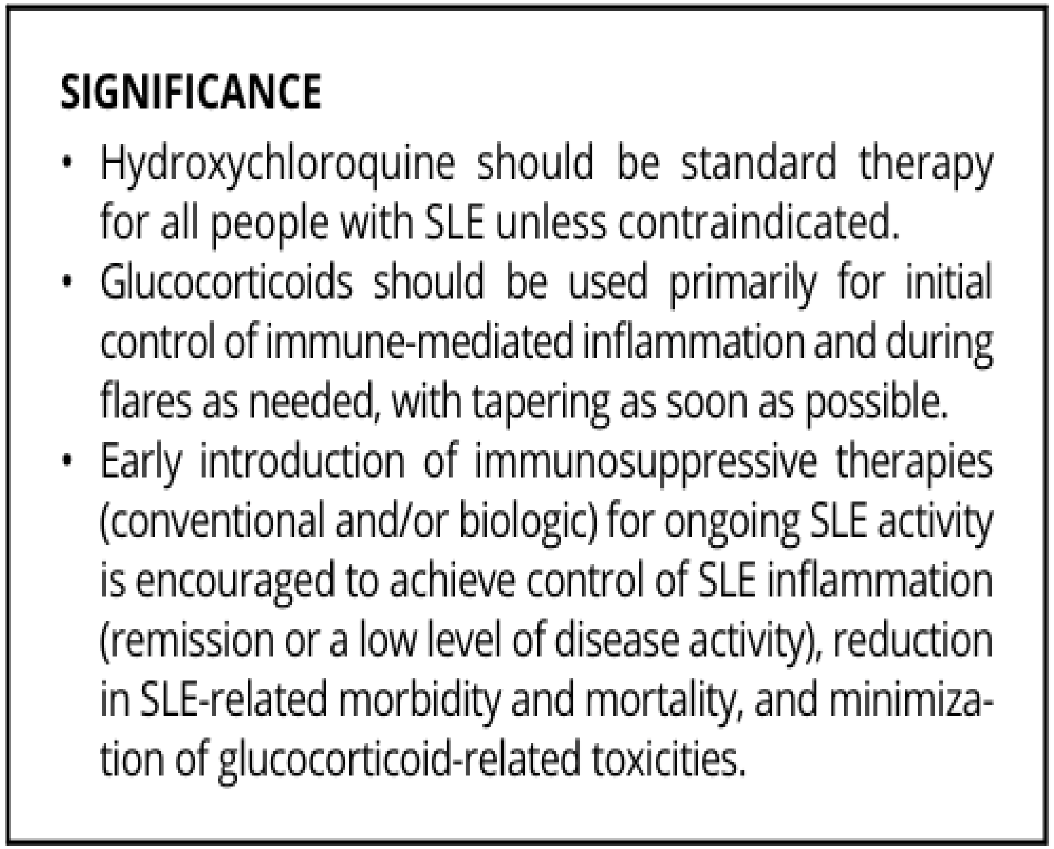


Table 2. Terminology, definitions and abbreviations*

Terminology	ACR SLE Treatment Guideline Definition
SLE Disease Activity Level	
Severe	Very active disease that may be organ- and/or life-threatening or cause permanent damage or severe symptoms due to active inflammation
Moderate	Active, uncontrolled disease that is not immediately life-threatening and/or causes moderate symptoms due to active inflammation
Mild	Active disease that is not immediately organ- or life-threatening and/or causes no more than mild symptoms due to active inflammation
SLE Disease Activity State	
Remission	Symptoms and signs of disease activity are significantly reduced or absent for an extended time. Specific definitions vary. Example: DORIS remission: SLEDAI-2K = 0, Prednisone ≤5 mg/day, PGA <0.5, stable antimalarials, immunosuppressives, biologics (no requirement for normal serology)[34]
Low level disease activity	A period with a low level of disease activity with no major organ involvement. Specific definitions vary. Example: Lupus Low Disease Activity State (LLDAS): SLEDAI-2K score ≤4 (with no activity in major organ systems or new/worsening symptoms), prednisone ≤7.5 mg/d, PGA ≤1, stable antimalarials, immunosuppressives, biologics[28]

ACR, 2025

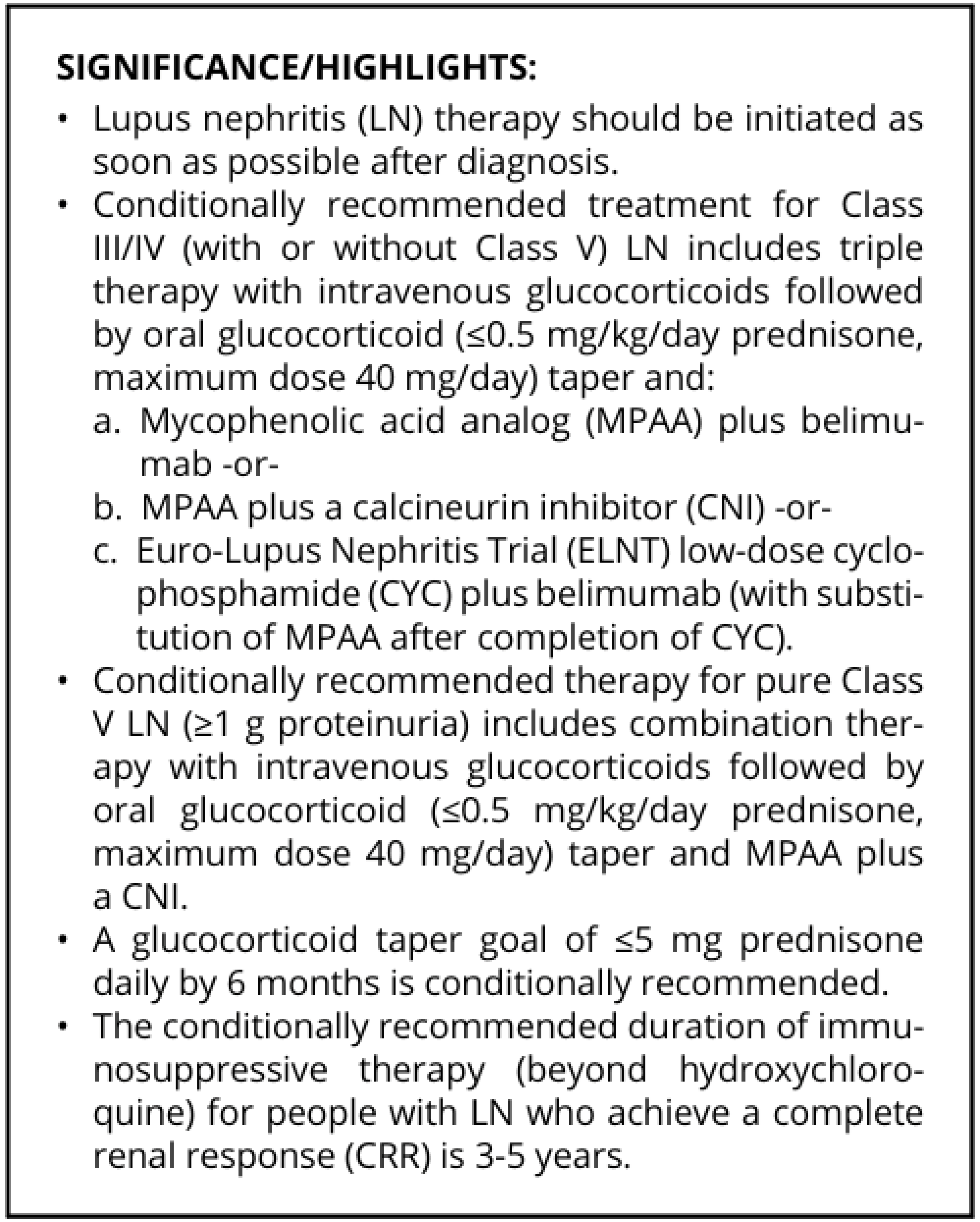
What’s New in SLE Guidelines



SIGNIFICANCE

- Hydroxychloroquine should be standard therapy for all people with SLE unless contraindicated.
- Glucocorticoids should be used primarily for initial control of immune-mediated inflammation and during flares as needed, with tapering as soon as possible.
- Early introduction of immunosuppressive therapies (conventional and/or biologic) for ongoing SLE activity is encouraged to achieve control of SLE inflammation (remission or a low level of disease activity), reduction in SLE-related morbidity and mortality, and minimization of glucocorticoid-related toxicities.

ACR, 2025



SIGNIFICANCE/HIGHLIGHTS:

- Lupus nephritis (LN) therapy should be initiated as soon as possible after diagnosis.
- Conditionally recommended treatment for Class III/IV (with or without Class V) LN includes triple therapy with intravenous glucocorticoids followed by oral glucocorticoid (≤0.5 mg/kg/day prednisone, maximum dose 40 mg/day) taper and:
  a. Mycophenolic acid analog (MPAA) plus belimumab -or-
  b. MPAA plus a calcineurin inhibitor (CNI) -or-
  c. Euro-Lupus Nephritis Trial (ELNT) low-dose cyclophosphamide (CYC) plus belimumab (with substitution of MPAA after completion of CYC).
- Conditionally recommended therapy for pure Class V LN (≥1 g proteinuria) includes combination therapy with intravenous glucocorticoids followed by oral glucocorticoid (≤0.5 mg/kg/day prednisone, maximum dose 40 mg/day) taper and MPAA plus a CNI.
- A glucocorticoid taper goal of ≤5 mg prednisone daily by 6 months is conditionally recommended.
- The conditionally recommended duration of immunosuppressive therapy (beyond hydroxychloroquine) for people with LN who achieve a complete renal response (CRR) is 3-5 years.

Talking With Your Rheumatologist About Treatment Options

- Ask how your treatment aligns with lupus guidelines.
- Discuss benefits, risks, and alternatives of each option.
- Share your personal goals (symptom relief, work, family, pregnancy plans)

Using Guidelines in Your Appointments

- Bring a list of current symptoms and concerns.
- Ask: “What do the guidelines suggest for someone like me?”.
- Review your labs and imaging together

How to Talk About Sensitive Topics

- Pain: describe how it affects sleep, work, and function
- Side effects: be honest—medication changes are possible
- Mental health: anxiety and depression are common in lupus

Common Communication Breakdowns

- Not mentioning symptoms because they seem minor
- Feeling rushed and not asking questions
- Assuming your doctor knows how you feel day-to-day

Asking Tough Questions Is OK

- It’s reasonable to ask about other treatment options.
- Second opinions are part of good medical care.
- Shared decisions lead to better outcomes.

When the Relationship Isn’t Working

- You feel unheard or dismissed.
- Your concerns are consistently not addressed.
- You don’t understand your treatment plan.

What You Can Do If Problems Arise

- Speak up and ask for clarification.
- Request longer visits or written plans.
- Seek a second opinion if needed.

Key Takeaways

- Guidelines support safer, more effective lupus care.
- Preparation and communication empower patients.
- You deserve to be an active partner in your care.

References

- https://rheumatology.org/lupus-guideline#2024-lupus-nephritis-guideline

Thank you.

When You’re Not Heard

The Emotional Cost & How to Reclaim Your Voice

A PRESENTATION CREATED AND STYLED BY **DR. JOY MCNEIL,** LICENSED CLINICAL MENTAL HEALTH COUNSELOR, COUNSELING PROFESSOR, AND LUPUS THRIVER

Hi, I'm Dr. Joy

I work hard so that my dog, Maggie May, can live in luxury.

I'm a recovering perfectionist.

I've worked in mental health since 2006, and I have a journalism and public relations background.

Diagnosed with lupus at age 24, the day before my birthday.

Completed my PhD in 2017. **"I noticed something wrong": Lived experiences of women of color who faced a protracted journey to diagnosis with lupus**

I love creative writing, creating music, binge watching Korean dramas, therapy/coaching/speaking, and spending time with family and friends.

When You're Not Heard
The Emotional Cost & How to Reclaim Your Voice

- The Impact of Not Being Heard
- Renew Your Thoughts
- Reclaim Your Voice
- Reward Your Progress
- Win with Resilience
- Resources

What are some ***stressors*** *we face?*

- Financials
- Relationships/Divorce/Marriage
- Childrearing
- Medication Management
- Doctors Appointments
- Obtaining Education
- The Stigma of Autoimmune Illness
- Absenteeism and the guilt of saying ***no***
- Aging
- Life Transitions
- The Death of a Loved One
- Caregiving Responsibilities
- Unrealistic Expectations
- Media
- Insurance coverage
- Change… period.

The Psychological Impact of Not Being Heard

Repeated dismissal in medical settings and beyond can lead to:

- Increased anxiety before appointments
- Self-doubt and internalized gaslighting
- Emotional shutdown or people-pleasing behaviors
- Avoidance of care

When Appointments Go Sideways

Lupus thrivers report challenging medical encounters, including:

- Feeling rushed or dismissed
- Symptoms being minimized or attributed to stress
- Being talked at rather than partnered with
- Leaving appointments feeling unseen or unheard

Imagine

Imagine walking into an appointment feeling grounded, prepared, and respected.

- Your provider listens without interrupting
- Your symptoms are taken seriously
- Questions are welcomed
- You leave with clarity, not confusion

This experience is reasonable and achievable.

The Way Forward

I. Renew Your Thoughts

a. Support System
b. Cognitive Reframe
c. Preparation

II. Reclaim Your Voice

a. Speak with Confidence and Clarity
b. Asking Questions with Precision
c. Caregiver Presence
d. Summarizing the Appointment

III. Reward Your Progress

a. Lists of ways to reward yourself

Renew Your Thoughts

Renewing your thoughts does not mean minimizing your pain. It means reminding yourself:

- ❖Your symptoms are real
- ❖Your experience matters
- ❖You deserve attentive and respectful care
- ❖Your voice is worth hearing

Renew Your Thoughts – Support System

Support improves both emotional resilience and medical outcomes.

- Trusted people before or after appointments
- Lupus-informed peer communities
- Education
- Mental health support

Support is not weakness—it is strategy.

Renew Your Thoughts – Cognitive Reframe

Shifting internal narratives can restore confidence.

- Old: “*I’m bad at explaining my symptoms.*”
- New: **“I deserve time and clarity.”**

- Old: “I don’t want to be difficult.”
- New: **“I want to be understood.”**

Renew Your Thoughts – Preparation

Confidence Is Established Prior to the Appointment

- ❖Document your symptoms, including their frequency, severity, and effects
- ❖Prioritize your top 2–3 concerns
- ❖Bring your notes—healthcare professionals do as well
- ❖Take a calming breath before you begin speaking

Reclaim Your Voice

You are the expert on your body and lived experience.

- Confidence is a skill, not a personality trait
- Clear communication improves collaboration
- Advocacy strengthens over time

Your voice deserves space.

Speaking with Confidence and Clarity

Clear, concise language helps providers understand urgency.

Examples:

- ❖ "The symptom affecting my daily life most is…"
- ❖ "What I need clarity on today is…"
- ❖ "I want to be sure I understand the plan."

Slow, steady speech communicates confidence.

Asking Questions with Precision

Strategic questions improve shared decision-making.

- “What are we ruling out?”
- “What are the risks and benefits of this option?”
- “What is the plan if this does not improve?”

Questions are collaboration, not confrontation.

Caregiver Presence

Caregivers play a vital support role during appointments.

- ❖Emotional grounding and reassurance
- ❖Note-taking and recall support
- ❖Clarifying questions when energy is limited
- ❖Advocating respectfully when needed

Summarizing the Appointment

End with a summary reinforces understanding.

Example:

- "Today we decided ___. The next step is ___. We will follow up in ___."

This reduces confusion and supports follow-through.

Reward Yourself!

Medical appointments require emotional labor.

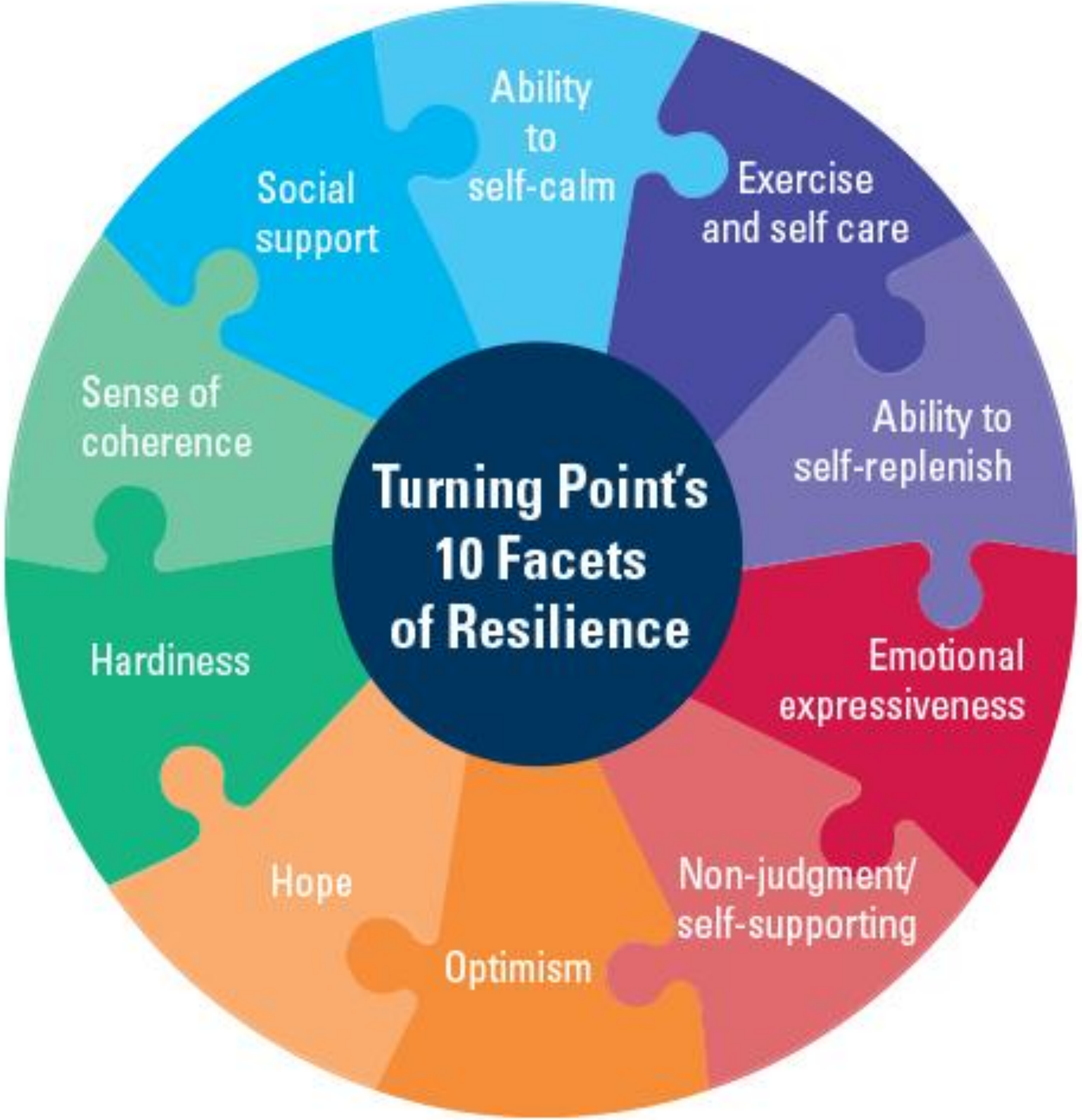
Rewarding yourself reinforces **resilience**.

Examples:
- ❖Rest without guilt
- ❖A favorite meal or drink
- ❖Gentle movement or quiet time
- ❖Journaling one personal win

Meet my long-time friend, Resilience

- ABILITY TO SELF-CALM
- SELF-CARE
- SELF-REPLENISHMENT
- EMOTIONAL EXPRESSIVENESS
- NON-JUDGMENTAL AND SELF-SUPPORTING
- OPTIMISM
- HOPE
- HARDINESS
- SENSE OF COHERENCE
- SOCIAL SUPPORT

University of Kansas Healthcare System
Turning Point Program



Journal on these…

- **Self Calm** – What calms you and makes you feel confident?
- **Self Care** - What are some ways you show your body you value it?
- **Self Replenishment** – How do you replenish your energy bucket?
- **Emotional Expressiveness** – Take time to notice where emotions show up in your body.
- **Nonjudgmental and Self Supporting** – What is one sentence you can say in support of yourself and your journey?

And these…

- **Optimism** – What strengths and resources do you hold to face the challenges in your life?
- **Hope** – Write a hopeful story about your future self.
- **Hardiness**– Focus on what you can control. Name some of those aspects of your life.
- **Sense of Coherence** – Learn to hold two truths at once…
  - **For example**:
  - *"I feel like I'm not doing enough with my life.*
    AND
    I'm doing what I can in this moment. I'm doing the things I can control and that's enough."
  - ***Write your own two truths.***

- **Social Support** – Do you find yourself dumping or discussing? What are your boundaries?

Reminders

- You are not too much.
- Your symptoms matter.
- Your questions matter.
- Your voice matters.
- You are worthy of care.

Let's Talk Resources

You do not have to navigate this alone.

Make room for mental wellness.

Questions? Comments? Let's chat.

CONTACT DR. JOY:

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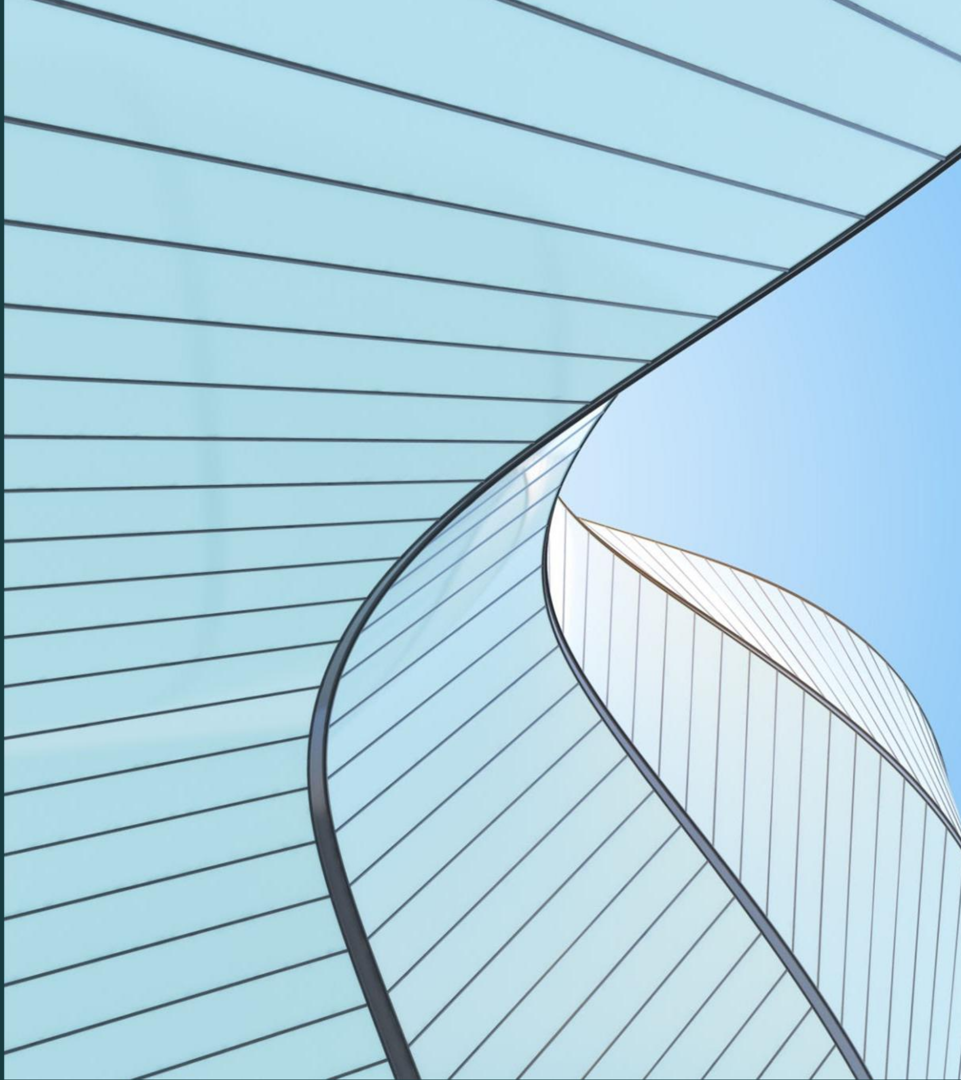
Confident Communication: Your Medications, Your Voice

Brian Ung, PharmD, MS, Pharmacist, Man Cave Support Group Facilitator, Lupus Warrior



Preparation is Power

Create a master medication/supplement list

Drug, Dose, Reason, Prescriber + Allergies!
OTC products too!

Brain Fog Security

Enlist help!
Share medication/supplements and medical history with caregivers/family/friends.

Develop a Routine

Utilize pill boxes, phone reminders, app,
Integrate medication tasks (i.e. refills, day/night) into your lifestyle

Write Down Questions

Prior to appointments and picking up medication, develop a list of questions for the pharmacist and doctors

Partnering With Your Pharmacist

Empower Them With Information

Share master medication/supplement list, symptoms, allergies (*pharmacists do not have your full records*)

Share with each pharmacy (i.e. retail, mail order, speciality)

Reserve Your Time

If rushed, say: 'I have a few safety questions. **Can we schedule 5 minutes or should I call back later?'**

Continue to check in over time and update as things

Set You Up For **Success**

Ask about food/alcohol interactions, drowsiness (safe to drive?), and what to do if you miss a dose

Ask about frequency of side effects, severity, what to do if you have side effects

Write questions ahead of time, share and brainstorm with caregivers

Partnering To Develop Medication Goals

Aligning On Goals

- What are our goals for this medication?
- How will we define success?
- What will we do next if this doesn't work?

Doctor Experience

- What is your experience prescribing this?
- What are common side effects reported?

Defining Timeline

- How long will I be on it?
- When will we know if it is working?
- When will side effects go away?

Connecting Multiple Doctors

- If in the same health system, ask them to message each other.
- If not in the same system, request they talk with each other
- You may need to send records

Special Safety Considerations

Illness

Which meds (immunosuppressants) MUST be held if I get sick? (Doctor/Pharmacist)
Which medications can I take?

Vaccines

Is there a special plan for vaccines?
(Pharmacists often administer them!)

Tapering

Ask the doctor for the full, written prednisone taper schedule.
Ask the pharmacist for withdrawal tips.

Controlling Costs & Insurance Coverage

Proactive Check

Ask your doctor/staff: 'Will this require a Prior Authorization (PA)?'

Don’t Accept Denial

Denial usually means the insurance needs a PA. Ask the office: 'Who is the specific staff member handling the PA?'
If the PA is denied, the doctor can still appeal. Persistence works.

Financial Assistance Options

Manufacturer co-pay/insurance programs
GoodRx, Mark Cuban Cost Plus Drugs
Patient advocacy organizations

How To Be Your Strongest Voice

Your Evidence is Power

Keep a log of symptoms and side effects (severity, timing, duration).

Bring an Advocate

Bring a caregiver to give their perspective and take notes.

Set Boundaries

If a provider is repeatedly rude or dismissive, it is okay to switch.

Communicate Concerns: The S.E.T. Framework

S – Symptom: What exactly are you feeling? Be specific!

E – Experience: Share your history. ("I've had trouble with this class of drug before.") Your experience matters!

T – Timing: When did it start? Does it coincide with the dose?

Your Toolkit for Confidence

1. Preparation is Power

Maintain and share your Master Meds List.

2. Partnering With Your Pharmacist & Medication Goals

Ask the "What If" (Illness/Vaccine) questions upfront.

Partner with Pharmacists and Physicians to identify goals and answer

3. Controlling Costs & Insurance Coverage

Track the PA process and appeal.

4. Boundaries & Communicate Concerns

You have the right to a respectful provider.

Thank You