

Rush University Medical Center

# Self Advocacy and Self Care with Lupus

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**LaShon Gurrola**  
MSN, APRN, FNP-BC

# Self Advocacy

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## Self Advocacy:

Advocacy is based on the foundation that everyone has the right to be heard, to have their concerns addressed and to be treated with respect and consideration.

# Self Advocacy

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## Health Literacy:

The degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.

# Self Advocacy

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The combination of self advocacy and understanding your health issues- having health literacy – gives you power!



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# Self Advocacy

## What Information should you know or have?

- Health history- medical conditions, surgeries, medications (why/dosages/freq), allergies
- Hospitalizations (where)/reasons
- List of your providers or specialist- names, phone numbers
- Last known visits with providers- eye doctor, dentist included
- Insurance- Plan Type HMO, PPO, EPO, Medicare, MC replacement plan, managed care Medicaid?

# Self Advocacy

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- Don't give up when faced with challenges
- Understand your own health
- Prepare to see the doctor

Write down questions or concerns before appt

- Educate yourself-
- Learn about the disease process, treatment, and medications you may be on.



# Self Advocacy

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- At your appointment, ask of questions. Limit new concerns to 1-2 issues to be addressed
- Build a relationship and rapport with your provider
- Ask for explanation in plain language.
- Keep records of your healthcare experience
- Communicate your concerns and understand the treatment plan and follow up plan.

# Self Advocacy

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- Be engaged in your care- show up and be present- be able to relay what has been going on since your last visit.
- Have a care partner with you if you need help writing things down or remembering.
- Have required labs/follow up diagnostics done before your visit.



# Self Advocacy

Your ability to advocate will be stronger if you partner with your providers.



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# Self Advocacy: Partnering with Your Provider

## • Your Expectations

- Listen to your concern
- Shows concern and interest in your problems
- Communicates timely with you about labs/test
- Include you in the treatment/care plan
- Shows respect
- Collaborates and coordinates care with other members of your healthcare team

## • Provider Expectations

- Keep Appointments
- Follow up on getting labs and test that were ordered/f/u on referrals
- Take medications/follow Tx plan
- Inform of changes in condition/symptoms/treatments
- Honesty/gives feedback
- Compliance/adherence

# Self Advocacy

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Unfortunately, despite best efforts provider/patient partnerships dissolve. Without blaming one side or the other- your right for a 2<sup>nd</sup> opinion is respected.

- Sometimes a patient is not a good fit for a provider and vice versa the provider may not be a good fit for the patient
- In this case- the provider may refer you elsewhere
- You may get referrals from family or friends

# Self Advocacy

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- Do your homework
- Lupus is complicated, you can't do it alone
- The main thing is to get follow up care somewhere



# Self Care

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WHAT IS  
SELF CARE?

*Self*  
CARE

IS NOT SELFISH

# Self Care

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**WHO defines self-care as “the ability of individuals, families and communities to promote health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a healthcare provider”.**

# Self Care

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Self care for the Lupus Patient- how you take ownership and participate in your care to reduce frequency and severity of flares. This encompasses all things listed on self advocacy plus these additional bullet points

- Getting proper rest
- Eating balanced healthy meals
- Incorporating physical activity

# Self Care

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- Drink water
- Take medications
- Keep medical appointment
- Reduce stress/manage stress
- Rally & Identify your support system
- Learn triggers and avoid them
- Set reasonable limits for yourself
- Remember its okay to say “NO”
- Smoking cessation
- “No I can't, No I am not able too, No Thanks”



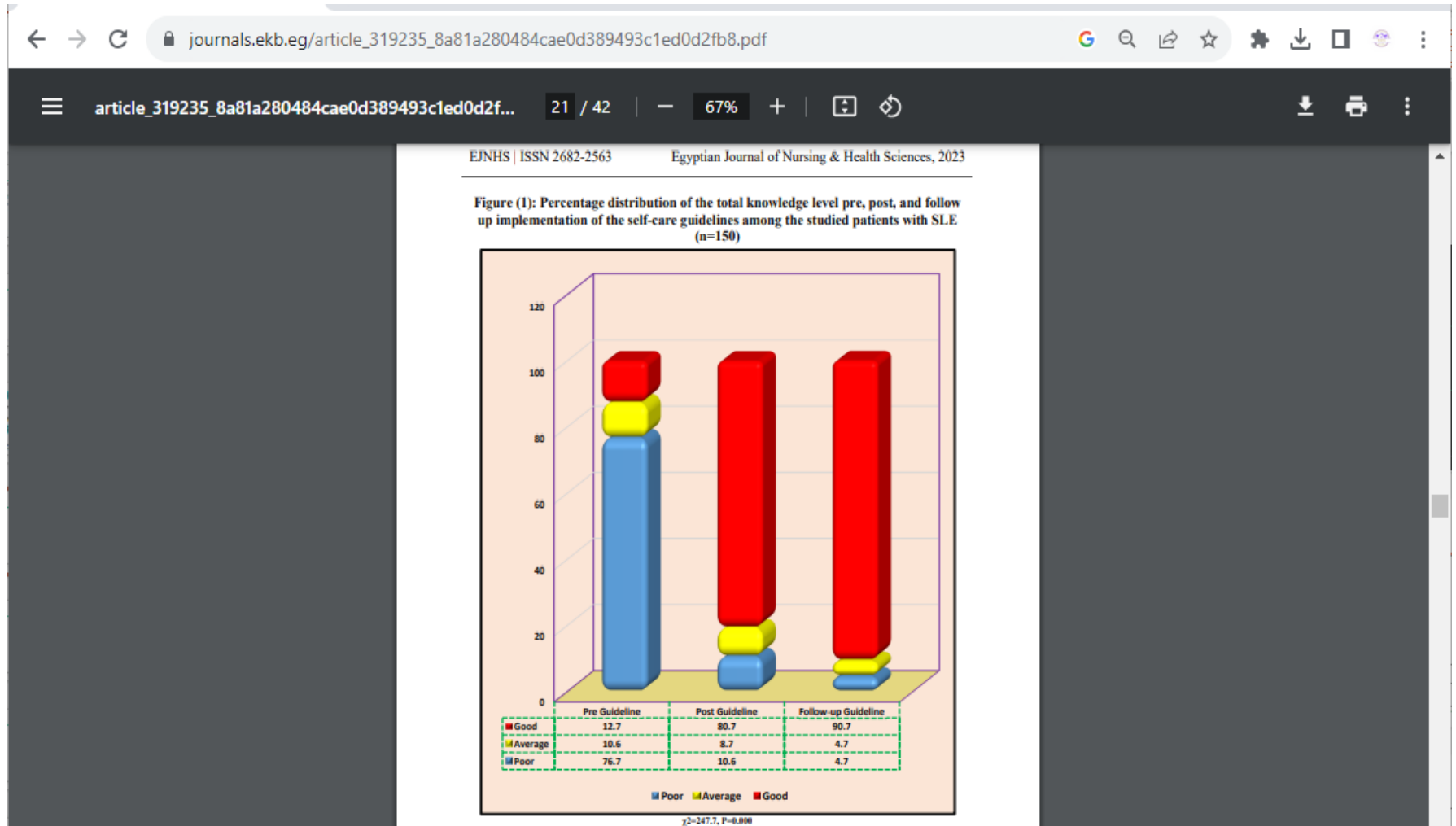
# Self Care



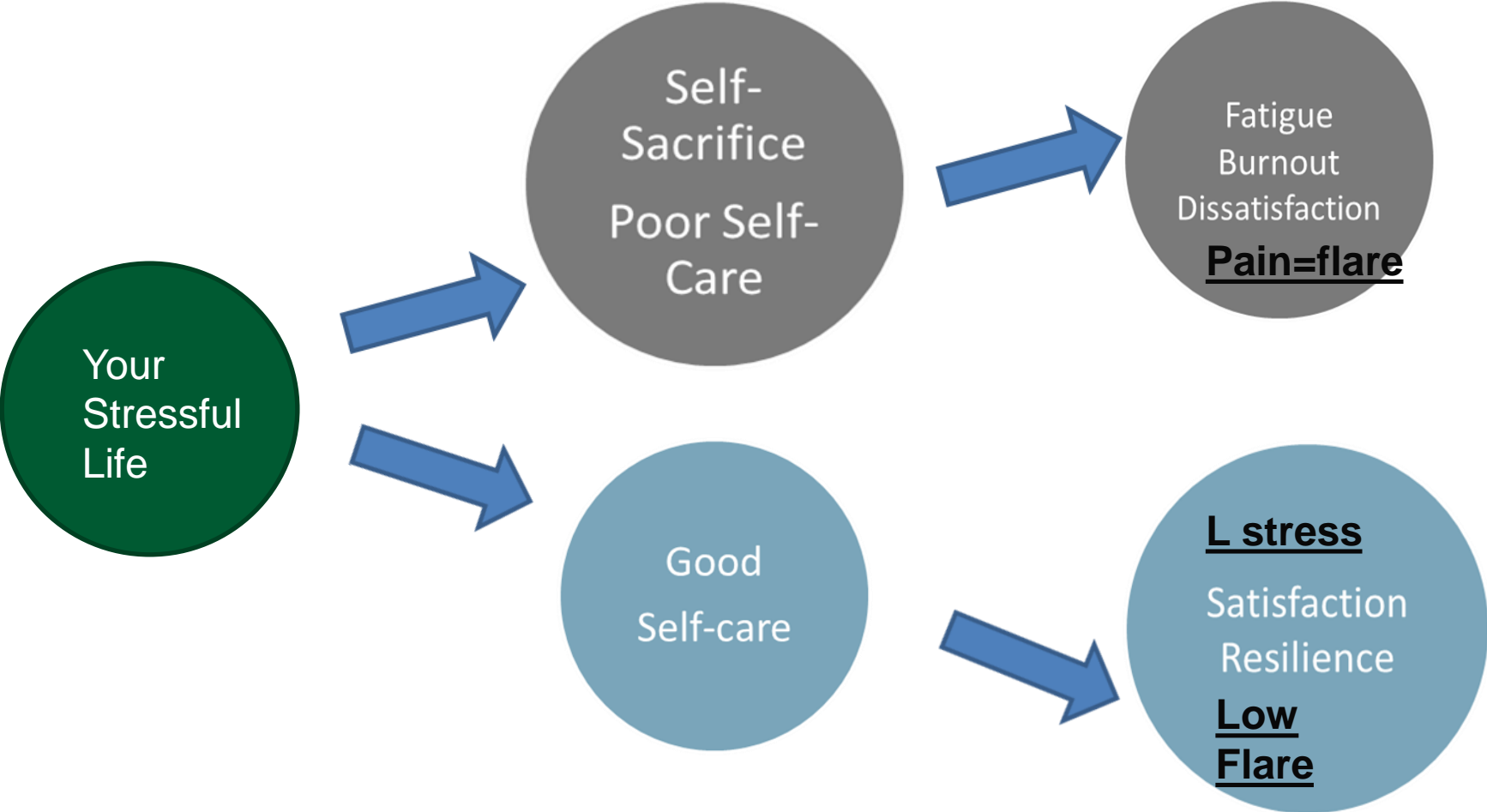
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## Why Is Self Care so Important ??

# Self Care



# Self Care- Why Is it so important?



# Self Care- Putting it all together

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Evidenced Based Research shows a correlation to self care and health outcomes in lupus management. Self care is related to your health literacy in that your education about lupus and ability to be engaged in your care gives you the power to self advocate.

# References

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Ahmed,R., Salehi,W., Mohamed-Elderiny,S.( 2023). Effects of self –care guidelines on health outcomes and self- efficacy among patients with systemic lupus erythematosus. *Egyptian Journal of Nursing & Health Science*. Vol. 4, No.2, pp 286-327

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<https://www.who.int/news-room/fact-sheets/detail/self-care-health-interventions#>

# The End

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