

Question Prompt List for Engaging with Your Health Care Professional



METHOD

Navigating an autoimmune diagnosis with your healthcare provider can be a daunting process. Time spent during the office visit is limited, and knowing what to ask can be challenging. Access to care is often difficult for women and men in lesser-served communities. It's essential to be prepared to ask the right questions and maximize your time when you go to your appointment.

SCOPE

The Autoimmune Association convened a series of round table sessions. During the discussion, we asked patients to share how they navigated their journey to diagnosis. We asked their recommendations for what they considered was most important to ask healthcare providers. We also asked healthcare providers to weigh in on what they recommended patients should focus on during their office visits.

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From our findings, we created the Question Prompt List (QPL) which is designed to be a starting point for planning your office visit. Each category of the QPL has a range of questions that you can select in advance and enter your responses digitally. There are also specific questions designed to help those in lesser-served communities.

SIDE EFFECTS

While the QPL is not comprehensive, it's a place to start the discussion. We encourage you to share your experiences with us so we can continue to add important questions that may benefit others who seek answers. From obtaining a proper diagnosis to identifying treatment options, accessing care, managing comorbidities, and improving quality of life, the Autoimmune Association is committed to empowering and educating patients to ensure they are supported throughout their journey.

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Can you provide more details about my specific autoimmune disease?

How does this condition affect women of color differently?

What exactly is my diagnosis? Is it common?

Can you explain in more detail what my diagnosis means for my overall health and well-being?

Should I be aware of different variations or subtypes of my autoimmune disease?

I've heard that some autoimmune diseases can be accompanied by other autoimmune conditions. Can you tell me if I am at risk of having another condition as well?

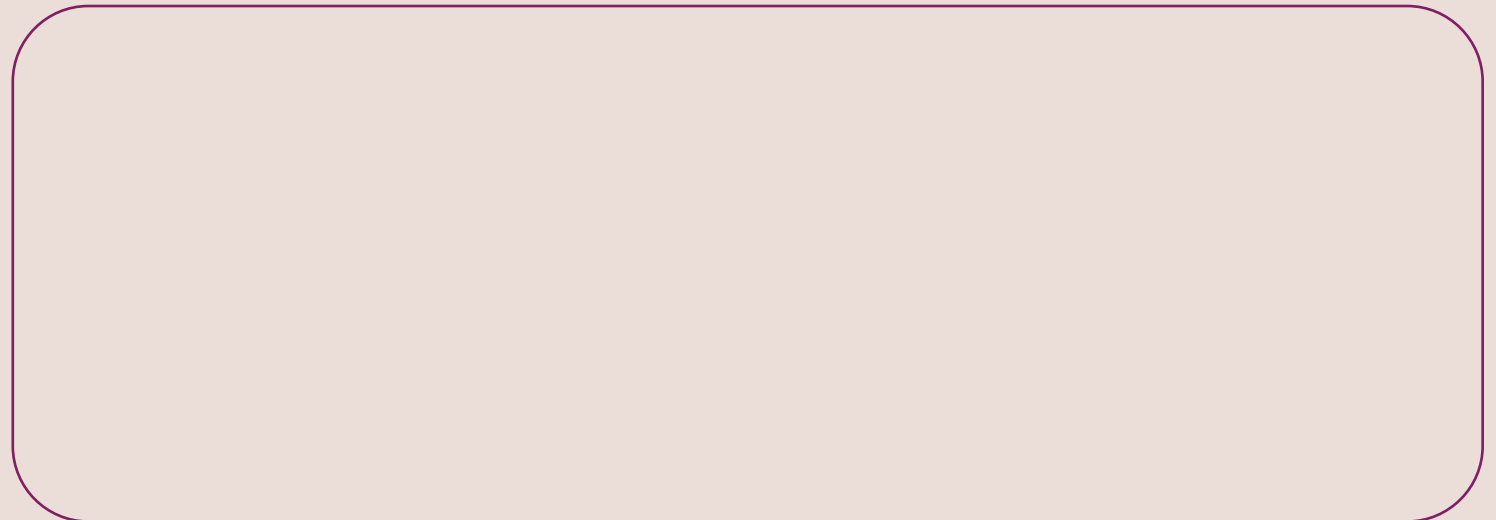
Are there any specific risk factors or patterns that are more prevalent in this demographic?

Besides the reported symptoms, has there been any evidence of damage to my body or organs and how will you monitor and assess potential damage over time?

Is it possible that my condition may cause further damage?

Is there a hereditary component to my autoimmune disease?

Should I encourage my siblings or children to undergo specific screenings or tests for early detection?



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Symptom Management:

What are the most common symptoms associated with my autoimmune disease?

Are there specific symptoms women of color might experience more frequently?

Should I document my symptoms and the frequency at which they occur?

How can I actively participate in controlling and managing flare-ups?

Are there specific triggers or lifestyle factors that may contribute to flare-ups that I should be aware of?

Are there tools or apps that you recommend for symptom monitoring?

Can you refer me to a nutritionist who has experience working with individuals with my autoimmune disease, particularly women of color?

Are there culturally relevant stress management approaches that may benefit me?



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Long-Term Outlook:

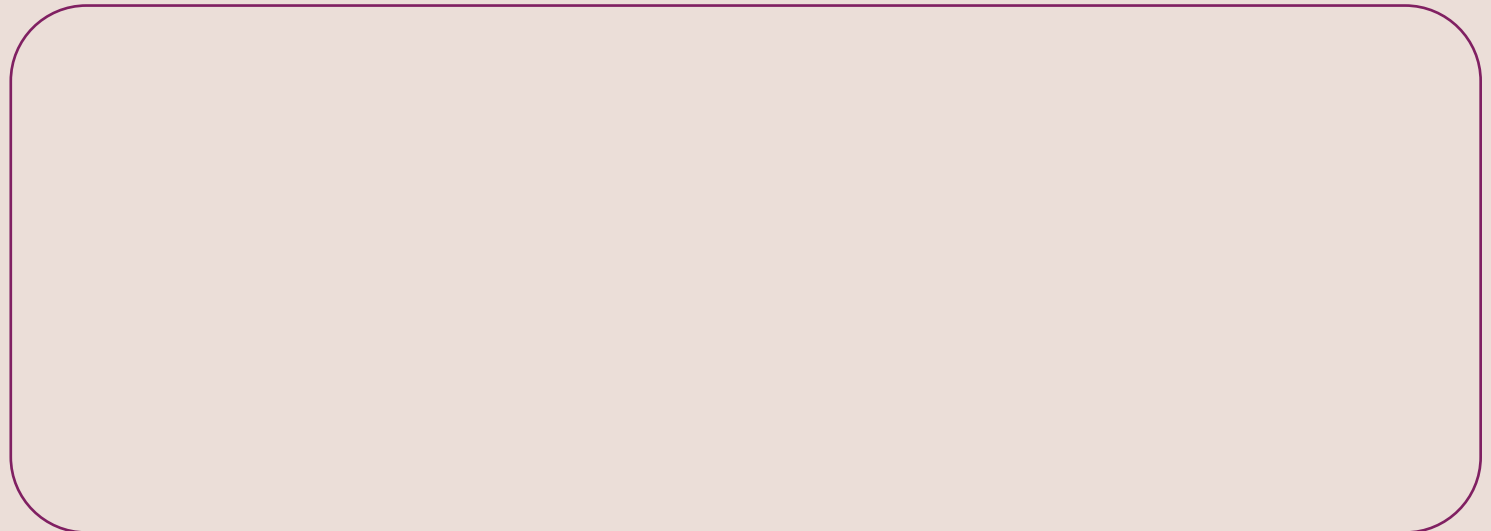
What is the expected course of this autoimmune disease in women of color?

Are there any known factors that might impact the progression of the disease in women of color?

Is it possible to achieve remission with this autoimmune disease, and if so, what does that process typically involve?

What factors contribute to maintaining a state of remission?

What types of testing would indicate that my autoimmune disease is in remission?



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What are the recommended treatment options for my autoimmune disease?

How personalized is my treatment plan, considering my unique background and experiences as a woman of color?

Should any cultural factors be considered in tailoring my treatment?

What traditional or culturally specific healing practices can be integrated into my treatment plan?

How open is the healthcare team to discussing complementary therapies that align with my cultural background?

How will adjustments be made to my treatment plan if needed, and what factors might prompt modifications?

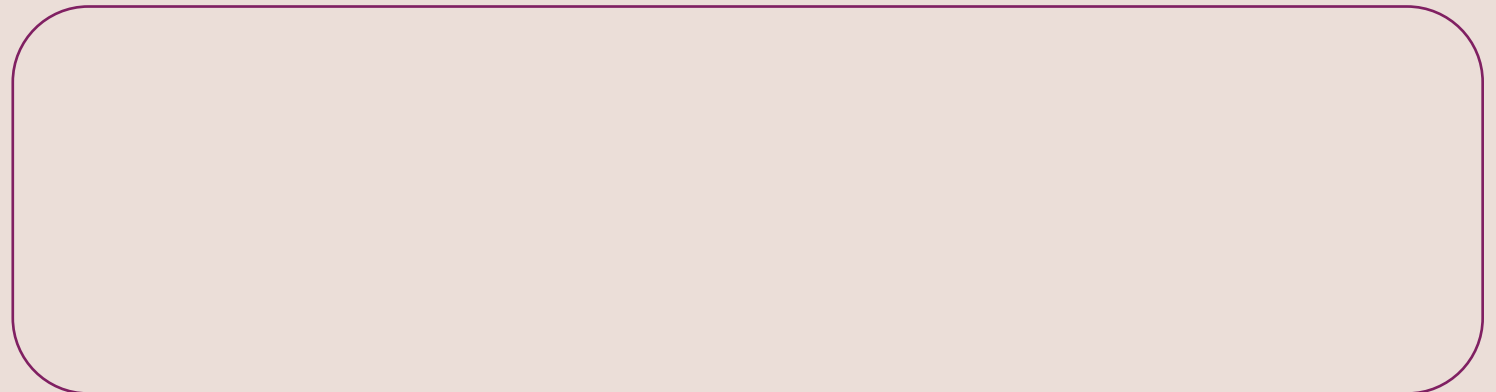
If my insurance does not cover the cost of my medication, are there other treatment options available to me?

What are the dietary or nutritional recommendations of my treatment plan if any?

Does my treatment plan take a holistic approach, considering the physical, emotional, and cultural aspects of my well-being?

How can I find clinical trials or research studies related to my autoimmune disease that I might be eligible to participate in?

Are there specialists or healthcare professionals from diverse backgrounds involved in my care?
How does that contribute to a comprehensive treatment approach?



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Are there any potential interactions between the prescribed medications and other supplements or over-the-counter medications I may be taking?

Can you describe exactly how this treatment works to combat the disease?

Can you tell me how I will feel when I start taking the medication?

How might my cultural background impact my response to certain medications?

Fertility and Pregnancy Concerns:

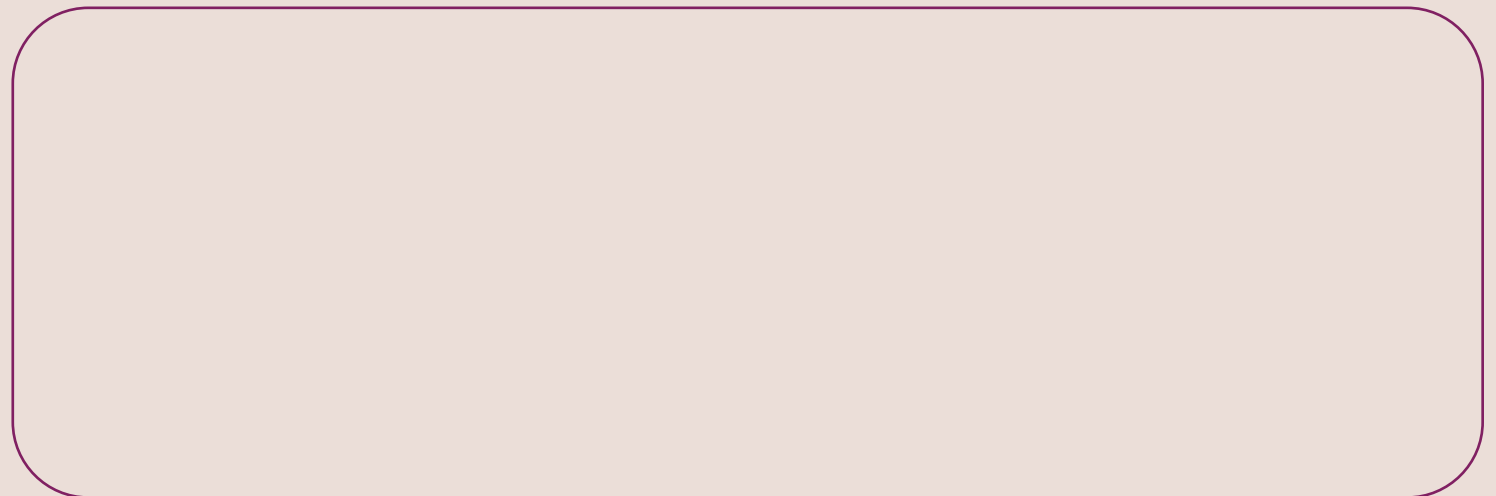
How might the prescribed medications impact my fertility or pregnancy, and what precautions should be taken?

Can alternative medications or adjustments be made if planning for pregnancy?

Transitioning Off Medications:

Under what circumstances might reducing or discontinuing certain medications be possible?

How will transitioning off medications be managed, and what should I expect?



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Complementary Therapies:

What complementary therapies could be beneficial, especially for women of color?

Where can I find a patient navigator to help me explore clinical trial opportunities as an complementary treatment option?

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Potential Side Effects:

What are the common side effects associated with the prescribed medications?
Are there any side effects that women of color should be particularly aware of?

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Managing Side Effects:

How can I proactively manage and cope with potential side effects?
Are there lifestyle changes or specific interventions that can help minimize side effects?
How should I communicate any concerns or unexpected side effects with you or the healthcare team?
Are there specific symptoms that should prompt immediate calls or visits?

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Communication Options and Preferences:

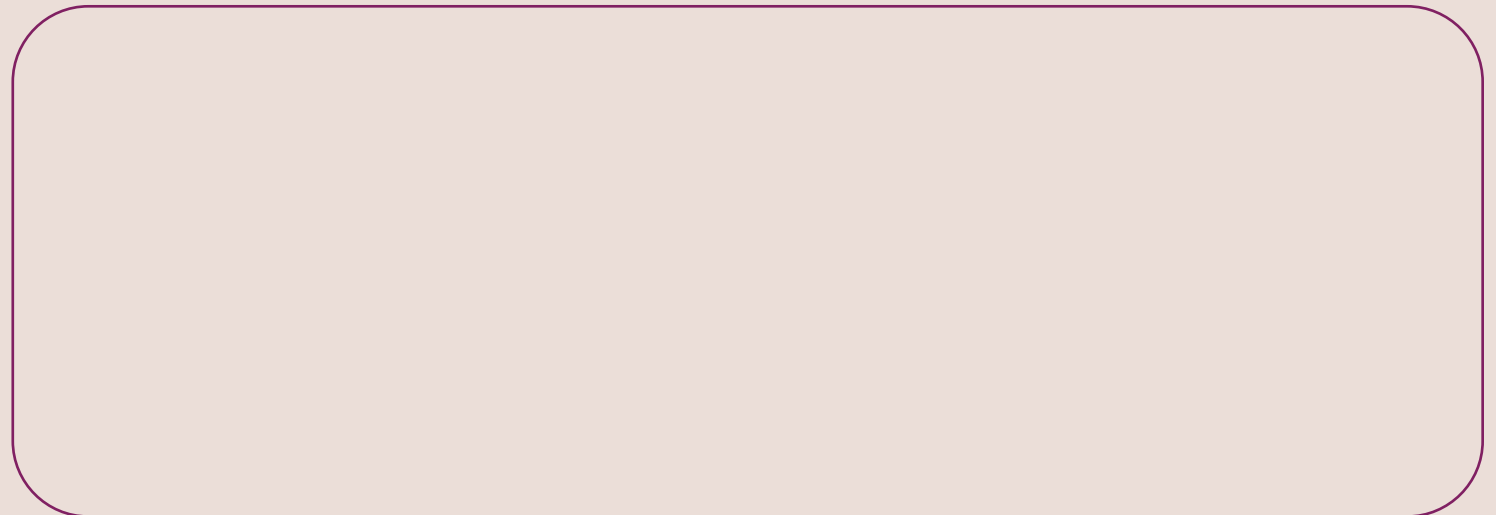
Are language interpretation services available, and how can I ensure effective communication if English is not my primary language?

How can I request information or clarification in a language that I'm more comfortable with?

How can I quickly and urgently reach a healthcare professional?

Are there specific hospitals you are affiliated with, particularly if I need to visit the emergency room?

Are there any secure digital platforms or apps facilitating communication with the healthcare team, especially for non-urgent questions or updates?



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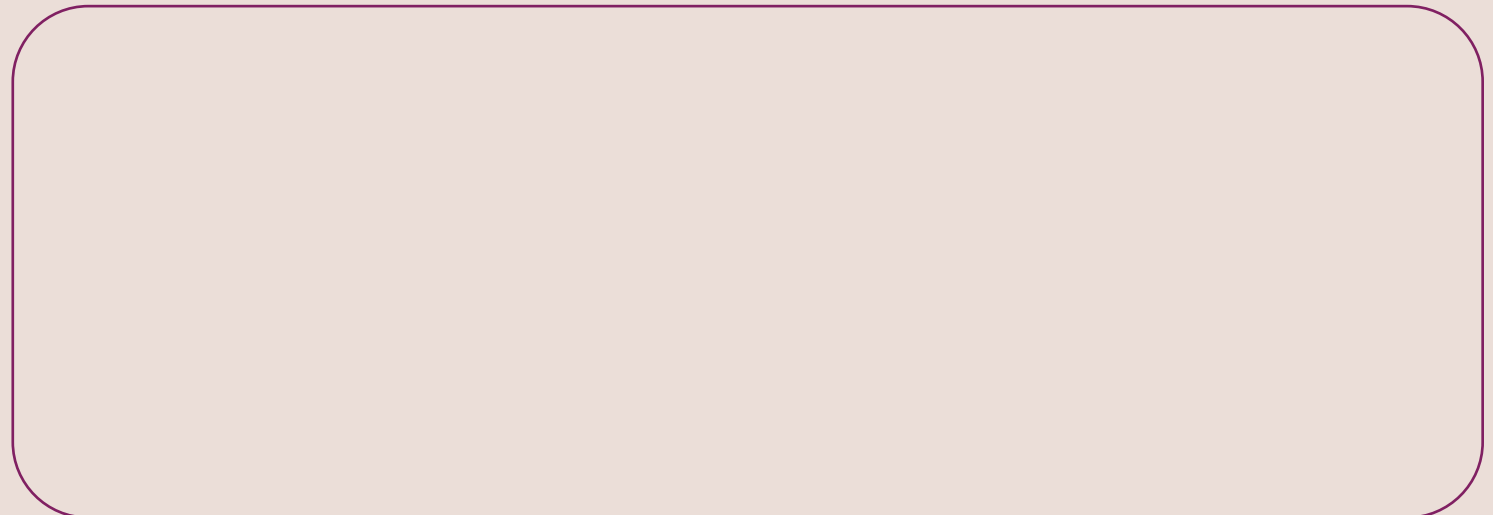
Shared Decision-Making and Family Involvement:

How can my family members be involved in the communication process, especially if they are an integral part of my support system?

Are there privacy considerations I should know regarding family involvement?

How is shared decision-making incorporated into my care plan, and what role do I play in the decision-making process?

Are there cultural nuances that should be considered in collaborative decision-making?



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Psychological Support:

Are there counseling sessions or support groups available for women and women of color with my autoimmune disease?

How does mental health play a role in managing this condition?

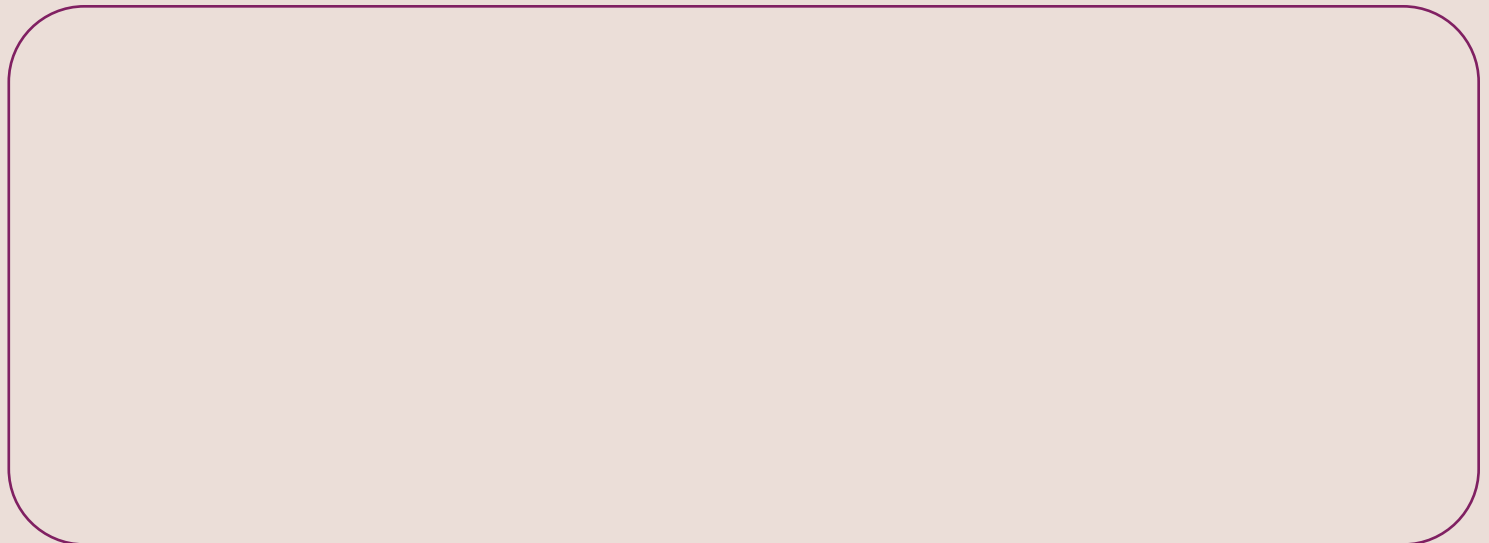
Community Resources:

Can you recommend local or online resources for women of color with autoimmune diseases?

Are there organizations or networks that provide additional support?

Where can I find patient advocacy, disability, or social service (in-home care) resources?

How can I find or request a medical case manager?



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Cultural Competence:

How is the healthcare team trained to be culturally sensitive and understand the unique experiences of women of color?

Are there initiatives to ensure an inclusive and supportive environment for patients from diverse backgrounds?

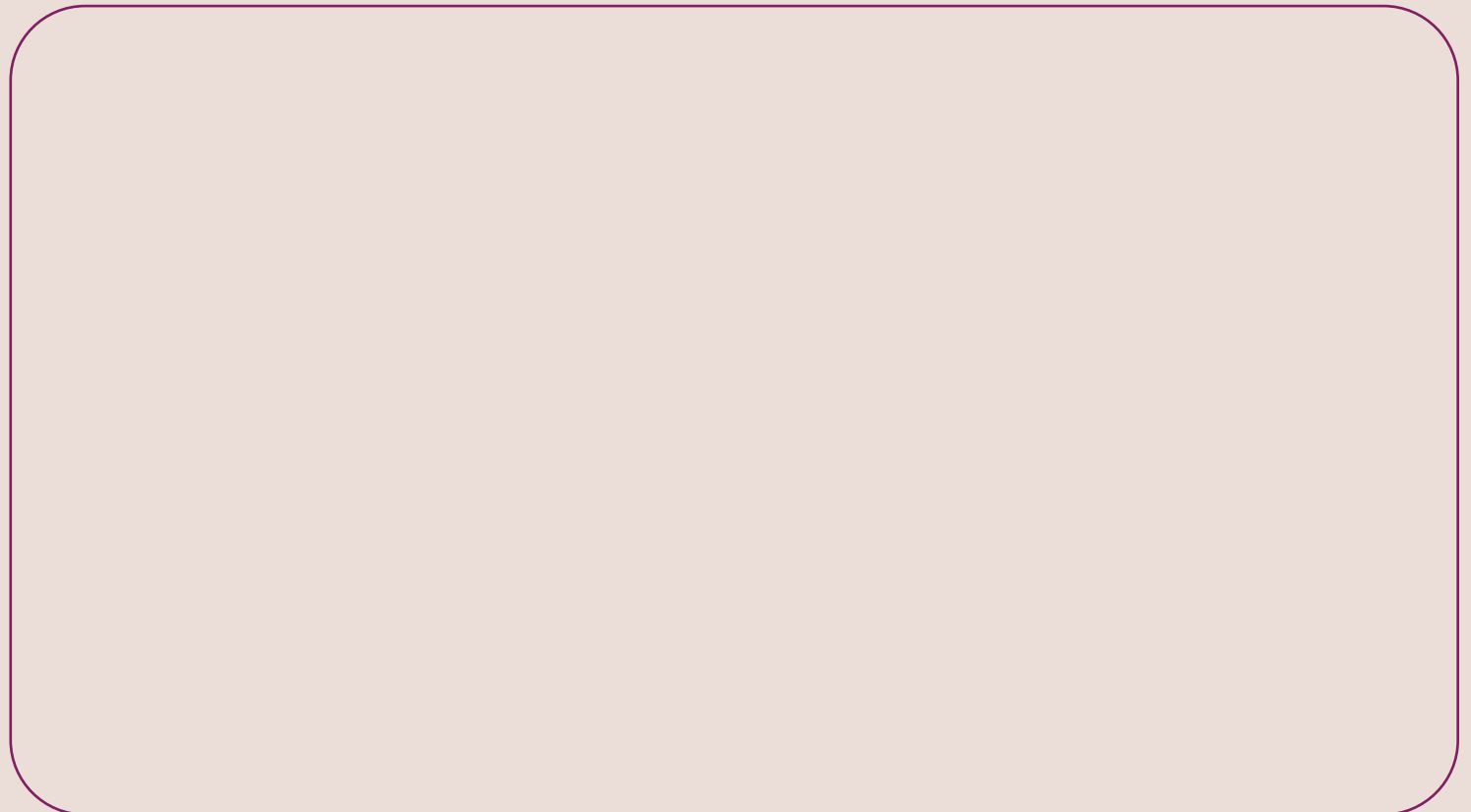
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How can I stay informed about the latest research and developments in a way that considers cultural perspectives?

Are there healthcare navigators or patient advocates who are culturally competent and can assist me in navigating the healthcare system?

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The Autoimmune Association is the world's leading nonprofit organization dedicated to autoimmune awareness, advocacy, education, and research. Our mission is to lead the fight against autoimmune disease by advocating and collaborating to improve healthcare, advance research, and empower the community through every step of the journey.

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