

Living Well with Vasculitis: Essential Topics to Discuss with Your Provider

Living with vasculitis requires a proactive approach to managing your health. Building a strong relationship with your healthcare team is essential to ensuring that you receive the best possible care. This fact sheet, a collaborative effort of the Rare Disease Diversity Coalition (RDDC) and the Vasculitis Foundation, is designed to help you navigate important conversations with your provider, empowering you to take an active role in your treatment. It explores key topics to help you, and your healthcare team create a personalized plan that addresses your unique needs and improves your quality of life.



Building Your Treatment Team

When managing vasculitis, it's important to have a team of specialists who can address the different areas of the body that may be affected by the disease. An ENT specialist treats inflammation in the sinuses, nose, and throat. A nephrologist monitors kidney health to detect early signs of damage, while a pulmonologist assesses lung function and manages respiratory issues. A dermatologist addresses skin symptoms and monitors for treatment-related side effects, such as skin thinning. Having a treatment team is crucial for effective treatment and preventing complications.

Kidney Monitoring

Regular kidney function monitoring is essential for vasculitis patients, particularly those diagnosed with microscopic polyangiitis (MPA) or granulomatosis with polyangiitis (GPA). It's important to discuss various tests, including urine tests, blood tests (such as serum creatinine), and other monitoring tools. Early detection of kidney involvement is crucial, as it can prevent serious complications from arising.



Long-Term Medication Side Effects

Long-term treatment with glucocorticoids and other immunosuppressants can lead to several side effects. These include osteoporosis, which weakens bones from prolonged steroid use; increased risk of infections due to immunosuppression; and elevated cardiovascular risks associated with some medications. Understanding the long-term side effects of vasculitis medications is crucial for patients to manage their health proactively and minimize potential complications. To learn more about long-term side effects of medications and find information on the risks associated with steroids and other treatments, please visit the [Immunity & Infection](#) and [Prednisone](#) pages on the VF website.

Relapse Risk and Monitoring

Even during remission, the risk of relapse persists, making regular monitoring essential for early detection and treatment adjustments. Recognizing symptoms promptly can prevent complications and improve long-term outcomes.



Mental Health and Emotional Support

Living with a chronic illness like vasculitis can greatly impact mental well-being. Signs that support may be needed include feeling overwhelmed, isolated, or depressed. Seeking mental health resources, such as support groups or counselors, is crucial for managing these challenges and enhancing quality of life. For further insights into the challenges faced by patients and caregivers, consider visiting the RDDC website to read the latest report on inequities in the rare disease community: [2024 Report: The Voices of Diverse Patients and Caregivers](#). For additional support, connect with others living with vasculitis by joining the VF's [virtual support groups](#) and explore resources on the VF [Mental Wellness page](#).

Lifestyle Adjustments and Infection Prevention

To lower infection risk and enhance overall health, discuss lifestyle changes with your provider, including vaccinations and a balanced diet. Gentle exercise can boost energy levels, while effective fatigue management strategies are vital for improving quality of life. For more resources and to get started, visit the VF [Living Well page](#) to learn more about the [Victory Over Vasculitis Physical Wellness Program](#).

Clinical Trials Participation

Participating in clinical trials is a valuable way to contribute to vasculitis research. Understanding your rights and the trial process is crucial for informed decision-making. Resources like the [Vasculitis Patient-Powered Research Network](#) and [RDDC YouTube channel](#) provide important information on clinical trials and related topics.

Key Questions to Ask Your Provider:

By discussing these points with your healthcare team, you can take an active role in managing your vasculitis and improving your quality of life. Here are some key questions to start the conversation:



- Does my care team include all the specialists needed to manage my vasculitis?
 - How will my long-term treatment plan incorporate regular kidney function tests, such as urine and blood tests?
 - How often should we review my medication plan to ensure we're effectively balancing disease control with minimizing side effects?
 - Could we develop a relapse monitoring plan, and what specific symptoms should I watch for that would indicate a need for treatment adjustments?
 - Can we discuss my emotional health, and could you provide referrals to mental health professionals if necessary?
 - What steps can we take to monitor my condition effectively and develop a plan for early detection of potential relapses?
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- How can we address my emotional health and explore mental health support options together?
 - Can we create a personalized plan to help me stay active, eat well, and reduce my infection risk?
 - Do you know of any ongoing clinical trials I might qualify for that could benefit my condition?

Key Questions for Caregivers to Ask Providers

- What signs or symptoms should I monitor closely to help detect potential relapses or complications early?
- How can I support the patient's treatment plan, especially with managing medications, appointments, and lifestyle changes?
- What resources are available for me as a caregiver to manage stress and prevent burnout while providing care?
- Are there specific ways I can help the patient manage their emotional well-being or access mental health support?

By having these conversations with your healthcare team, you take an active role in managing your vasculitis, ensuring that you receive personalized, equitable care that supports your long-term health and well-being.



The Black Women's Health Imperative (BWHI)

is a national non-profit organization dedicated to advancing health equity and social justice for Black women across the lifespan through policy,

advocacy, education, research, and leadership development. The organization identifies the most pressing health issues that affect the nation's 22 million Black women and girls and invests in the best strategies and organizations to accomplish its goals. You can find more information about BWHI at bwhi.org.



The Rare Disease Diversity Coalition™ (RDDC)

is an initiative launched by BWHI to address the extraordinary challenges faced by historically underrepresented populations with

rare diseases. RDDC brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to reduce racial disparities in the rare disease community. You can find more information about RDDC at rarediseasediversity.org.

Contact Information

For more information, visit our website or contact us:

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The Vasculitis Foundation (VF)

is the leading organization in the world dedicated to diagnosing, treating, and curing all forms of vasculitis. We work to inspire and empower those affected by vasculitis through education, research, clinical initiatives, and advocacy.

Contact Information

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