DOCTOR DISCUSSION GUIDE

Managing Complement 3 Glomerulopathy

Complement 3 glomerulopathy (C3G) is a complex genetic disorder that causes the kidneys to not work properly. It affects adults and children. Asking the right questions and understanding certain terms can help you know what to expect and empower you to make informed choices if diagnosed with this rare but manageable disease.

**Vocabulary to Know**

Your doctor might mention these common terms. Here’s what they mean.

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tr>
<td><strong>Chronic Kidney Disease (CKD)</strong></td>
<td>As your kidneys become less able to filter blood, remove excess water, and maintain the normal balance of chemicals in your body, they can start to fail, leading to kidney failure.</td>
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<td><strong>Complement Component 3 (C3)</strong></td>
<td>C3 is a protein in the blood that helps the immune system fight viruses and bacteria. A malfunction of the immune system causes C3 to break down. The breakdown products then become lodged in the kidneys, damaging the filtering units.</td>
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<td><strong>Glomeruli</strong></td>
<td>Glomeruli are the kidney's filtering units. This tiny network of blood vessels removes waste and excess fluids from your blood.</td>
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<td><strong>Creatinine Clearance (CrCl)</strong></td>
<td>This test measures how effectively your kidneys are removing waste products in your body. Your kidney function is determined by measuring the clearance of creatinine produced in the muscles and filtered by the kidneys. It's calculated on a 24-hour urine specimen.</td>
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<td><strong>C3 Glomerulonephritis (C3GN)</strong></td>
<td>This is one of two forms of C3G. It causes a diffuse accumulation of C3 in the glomeruli. It tends to develop later in life in older adults.</td>
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<td><strong>Edema</strong></td>
<td>C3G can cause fluid buildup in tissues, known as edema, as the kidneys become less able to remove water from the body.</td>
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<td><strong>Hematuria</strong></td>
<td>Hematuria occurs when glomeruli in the kidneys become damaged, causing red blood cells to leak into the urine.</td>
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<td><strong>Kidney Biopsy</strong></td>
<td>This procedure removes a tiny piece of your kidney with a needle for microscopic examination in a lab. With C3G, the biopsy will show your C3's breakdown products in the glomeruli.</td>
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<td><strong>Proteinuria</strong></td>
<td>A medical term for protein in urine. When glomeruli become damaged, they are less able to retain essential proteins in the blood, causing excess amounts to leak into the urine. It's a key sign of kidney disease.</td>
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Learn more at www.verywellhealth.com
Questions to Ask
These questions will help you start a conversation with your doctor about how to best manage your C3G.

About Symptoms
- How much urine should I be passing, and when should I be worried?
- What can I do about my swollen feet and ankles?
- Can the yellow dots in my eyes affect my vision?
- What are the signs my kidneys are starting to fail?
- What symptoms should I immediately call you about?

About Causes
- If C3G is genetic, can I pass it on to my kids?
- Are there things I’m doing that makes C3G worse?
- Am I at risk of infection because of my immune system?
- Does C3G put me at risk for other diseases?

About Diagnosis
- What does the kidney biopsy say about my disease?
- What routine tests do I need and how often?
- Do any tests require fasting?
- What does high or low creatinine clearance mean?
- What test results indicate that I’m in remission?

About Treatment
- Are there any proven treatments for C3G?
- Why are you recommending steroids or immunosuppressants?
- Are there reasons why I’m not on immunosuppressants?
- Why do I need to reduce salt or protein in my diet?
- I heard about exchanging plasma for C3G. Does that work?

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About Prognosis
- What type of C3G do I have and what does it mean?
- What is my prognosis based on my lab tests and exams?
- Is C3G going to affect my (or my child's) ability to function normally?
- What are the chances of kidney failure?

About Coping
- How can I tell if I’m depressed or having symptoms of C3G?
- Are there support groups for people with C3G?
- Is there a counselor I can speak to if I have trouble coping?
- Can you recommend a nutritionist who specializes in kidney disease?
- Are there payment assistance programs to reduce the cost of treatment?

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