

Talking to your doctor about vasculitis

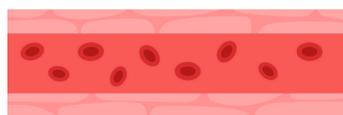


What is vasculitis?

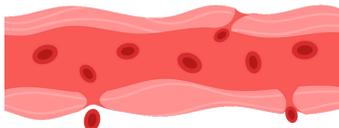
Vasculitis is a type of disease that causes blood vessels to become inflamed. When your blood vessels are inflamed, they become weak, narrowed or scarred. This makes it harder for blood to get through to important organs and tissues. Less blood flow can cause damage to those organs and tissues. There are over 20 different types of vasculitis.

What is renal (kidney) vasculitis?

In renal, or kidney, vasculitis, the damaged blood vessels are in the kidneys. An important part of the kidneys are the glomeruli, which are networks of tiny blood vessels called capillaries. Glomeruli filter waste out of your blood. When the capillaries in your glomeruli are damaged, your kidneys cannot filter blood as well as normal. Over time, this damage can lead to permanent kidney injury or kidney failure.



Healthy blood vessel



Inflamed blood vessel

There are two main types of renal vasculitis:

Microscopic Polyangiitis (MPA):

Affects small- to medium-sized blood vessels, often in your kidneys, lungs, nerves, skin and joints.

Granulomatosis with Polyangiitis (GPA):

Affects small- to medium-sized blood vessels in your kidneys, lungs and sinuses.

What are the symptoms of vasculitis?

Vasculitis can be hard to diagnose, and symptoms can vary depending on the type of vasculitis. You cannot tell what kind of vasculitis you have based on symptoms alone.

Vasculitis symptoms include:

- Feeling tired
- Fever
- Muscle and joint pain
- Feeling less hungry than normal
- Weight loss

Kidney-related symptoms include:

- Bloody urine
- Swelling in your legs and feet
- Itching
- A metallic taste in your mouth

Advocate for yourself and ask your doctor about the different types of testing for vasculitis that are available. This is especially important if you have kidney disease, but don't know the cause.

Vasculitis treatments

Doctors will usually treat vasculitis with medicines that lower the immune system, called **immunosuppressants**. There are several types of these medicines that treat vasculitis. Some are given through an IV (through a vein), and others are in pill form.

Your doctor will determine which medicine is best for you. The decision about which medicine to use will depend on your type of vasculitis and how severe your symptoms are.

One type of immunosuppressant is glucocorticoids, also known as steroids. Although steroids can help vasculitis symptoms, long-term effects may include:



Weight gain



Diabetes



Weakend
bones



High blood
pressure



Mood swings or other
psychological effects
like confusion



Talk to your doctor to learn more about which medicines are best for you.

As medicines are being developed, a goal is to reduce the use of steroids to avoid these side effects.

Preparing for your healthcare provider visit

Vasculitis can be hard to diagnose, and some people with vasculitis are misdiagnosed. It can take lots of tests and a long time to get the correct diagnosis. So here are tips to be prepared for your doctor visit:



Ask if you need to send any previous imaging, biopsy or test results before the visit.



Consider bringing a family member or friend to help remember what the doctor says.



Bring a list of:

- Your symptoms, even if they seem unrelated to the purpose of your visit
- Your medicines, vitamins, and supplements
- Other medical information, such as other health problems or stressors in your life
- Your questions

Questions to ask your healthcare team about vasculitis

Because it can be hard for many people to get the correct vasculitis diagnosis, it is very important to advocate for yourself, and ask all of your questions.



Questions about diagnosing vasculitis

- Could my symptoms be directly related to renal vasculitis?

- Is there any type of testing that I need to have?

- Which symptoms may be due to other conditions, and how can we rule those out?



Questions about a vasculitis diagnosis

- What type of vasculitis do I have?

- What could have caused my vasculitis?

- How serious is my vasculitis diagnosis?

- Has any part of my body been damaged by vasculitis?

Questions about vasculitis treatment



- Will my vasculitis go away on its own?

- Can my vasculitis be cured?

- What are my treatment options, and what are the benefits and risks of those treatments?



Questions about vasculitis treatment (continued)

- How long will treatment last?

- How can I manage treatment side effects?

- How can I best manage my other conditions along with managing vasculitis?



Questions about next steps

- Will I need more or ongoing tests?

- What type of specialist should I see? (example: **a rheumatologist**, a doctor who treats the immune system and diseases of the muscles and bones, or **a nephrologist**, a kidney doctor)

- Should I have a specialized care team and who will that consist of?

- How can I learn more about my diagnosis?

For more resources and to learn more visit:

KidneyFund.org/Vasculitis



Or scan this code with your mobile device