

Vasculitis: A guide for caregivers

We've developed this guide to support you on your care journey and share practical ways you can live your life to the fullest while caring for a loved one with vasculitis.





Understanding vasculitis

Whether your loved one has been recently diagnosed with vasculitis or has been living with it for some time, this complex disease will impact not only their daily life and wellbeing, but also yours as their caregiver.

Vasculitis is an inflammation of the wall of blood vessels, arteries, veins, or capillaries. When inflammation occurs, it can cause weakening and narrowing of the blood vessels that can progress to the point of blockage or hemorrhage.

Your loved one may experience poor blood flow to tissues throughout the body, such as the lungs, nerves, and skin, potentially resulting in pain, tissue damage, and malfunction of certain affected organs.

There are many types of vasculitis, and symptoms may vary greatly in terms of severity and duration.

Depending on the type of vasculitis, the person's symptoms may include:

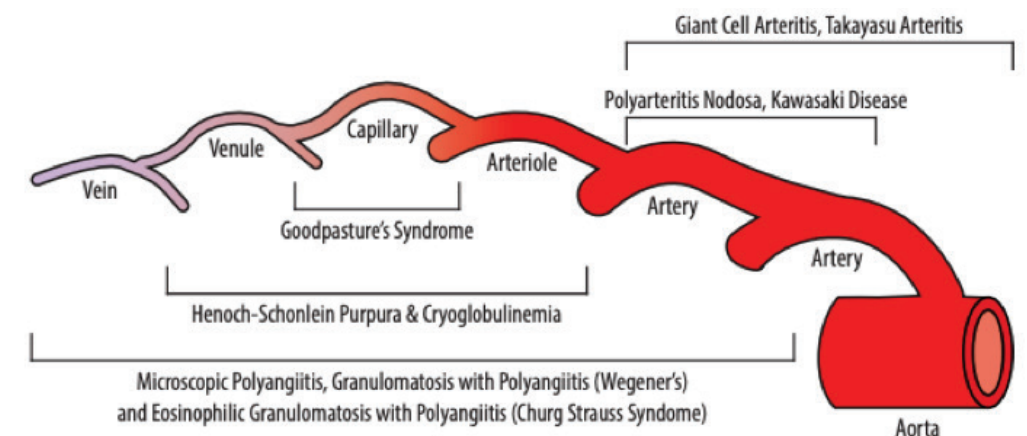
- General body changes such as fever, fatigue, weakness, or weight loss
- Joint pain and swelling or arthritis
- Sinus-related issues such as chronic sinusitis, nasal allergies, a runny nose that fails to respond to the usual therapeutic measures, facial soreness, or saddle nose deformity
- Respiratory symptoms such as cough (with or without blood), shortness of breath, lung inflammation, or asthma
- Abdominal pain and gastrointestinal bleeding
- Kidney problems such as trace blood in urine or dark urine
- Peripheral nerve problems such as numbness, weakness, or pain in limbs, hands, and feet
- Eye inflammation and vision problems or changes
- Ear inflammation and hearing problems or changes
- Headaches, strokes, or seizures
- Skin irritation such as lesions or rashes

Vasculitis is a family of about 26 separate but related arthritic diseases that affect people of all ages, genders, and ethnicities. Most types of vasculitis are rare, and the causes are generally not known.

A few forms of the disease affect people in certain age groups:

- Kawasaki disease occurs only in children.
- IgA Vasculitis (Henoch-Schönlein) is much more common in children than adults.
- Giant cell arteritis occurs only in adults over 50 years old.

The different types of vasculitis are classified according to the size and location of the blood vessels that are affected.



Adapted from Vasculitis Foundation Canada Living with Vasculitis patient brochure.

- Giant cell arteritis, Takayasu's arteritis, aortitis in Cogan's syndrome, aortitis in spondyloarthropathies, and isolated aortitis affect the aorta and its major branches
- Kawasaki disease and polyarteritis nodosa affect medium-sized arteries
- IgA (Henoch-Schönlein) vasculitis, cryoglobulinemic vasculitis and anti-GBM disease affect the body's smaller arteries. The small arteries can also be impacted by vasculitis related to rheumatoid arthritis, systemic lupus erythematosus, and Sjögren's syndrome, as well as drug-induced vasculitis
- Behçet's disease and relapsing polychondritis affect arteries and veins of various sizes

ANCA (antineutrophil cytoplasmic antibodies), GBM (glomerular basement membrane) This list is not complete. It does not include some forms of vasculitis related to infection or diseases such as cancer.



Living with vasculitis

Early diagnosis and proper treatment can bring vasculitis into remission. Many people lead full, productive lives with the right management of their chronic disease, others do not.

Most patients living with vasculitis can maintain long-term remissions with medications and close management. Regular laboratory tests will help your loved one's medical team to monitor the disease and detect a relapse at its earliest and most treatable stage

Whether the person's vasculitis is short-term or lifelong, their doctor will focus on preventing permanent damage to their vital organs (such as the lungs, kidneys, and brain) and the nerves. However, other issues may trouble your loved one.

As a result of their vasculitis, they may experience:

- Compromised quality of life
- Deterioration in physical functioning, including fatigue, pain, arthritis, and nose and sinus problems
- Side effects from medications, especially glucocorticoids
- Risk of infection from immunosuppressants
- Financial issues related to medical treatment and employment changes
- Psychological impacts such as increased risk of depression and anxiety



— Understand the symptoms of vasculitis to know what to expect



Working as a team

Fortunately, with current treatments, the outcome for patients with vasculitis is often good, but the impact of the diagnosis is significant.

Your loved one needs help and support to manage their disease. People with vasculitis often report extreme tiredness and weakness, to the point where they may be unable to walk and need help with dressing and bathing. Their treatment may require a team approach.

The health care team

In addition to consulting with their vasculitis specialist—usually a rheumatologist/immunologist—their medical team may include, among others:

- A nephrologist, to care for their kidneys
- An otolaryngologist, to care for their ear, nose, throat, and sinus issues
- An ophthalmologist, to care for their eyes
- A pulmonologist/respirologist, to ensure their lung health

As a caregiver, you are an important part of their health care team!

A key part of your role will focus on maintaining a good relationship with their doctors and working together to understand and follow their medical team's instructions carefully.

In addition, you can support your loved one as they navigate their complex medication regime by helping them understand when to take their medications and the need to report symptoms and side effects.

You may find it useful to maintain a diary to list medications, test results, and notes on any symptoms your loved one is experiencing. These notes can be reviewed during appointments.

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Talk to your
healthcare provider
about strategies to
help you manage



Strategies for caregivers

Vasculitis does not just affect the patient. It impacts the daily life of caregivers, families, and friends. Knowing what to expect will help you care for both your loved one and yourself.

Patients and caregivers managing a rare condition face several challenges. They often have little or no previous experience or knowledge to draw upon when dealing with an unpredictable disease, the risk of relapse, and the seriousness of treatment side effects.

People caring for someone with vasculitis often report common struggles, including:

- The **physical and psychological impact** of caring for someone with a serious rare illness, particularly during the acute phase
- The **need for constant vigilance** requiring regular and careful monitoring of disease symptoms
- A **fear of the future**, triggering emotional distress about what the future holds for your loved one and the inability to plan ahead

In addition, caregivers may develop feelings of inadequacy, guilt, and self-blame despite their commitment to their loved one. They might also struggle to stay organized and perform care tasks effectively.



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Take care of yourself is as important as look after your loved one



Recognizing caregiver burnout

Providing care is a demanding job and many caregivers place their loved one's needs before their own, but this can lead to self-neglect and high stress levels which endanger your own health and make it hard to provide quality care.

Be mindful of these signs of caregiver burnout:

- 1 Feeling **overwhelmed** or constantly worried
- 2 Feeling **tired** often
- 3 Getting too much **sleep** or not enough sleep
- 4 Gaining or **losing weight**
- 5 Becoming easily **irritated** or **angry**
- 6 **Losing interest** in activities you used to enjoy
- 7 Feeling **sad**
- 8 Having **frequent headaches**, bodily **pain**, or other **physical problems**
- 9 **Abusing alcohol or drugs**, including prescription medication



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Ask for support
before you feel
overwhelmed



Take care of yourself

As a caregiver, it is important to know that it is okay to take time for yourself to tend to your mind and body.

Walking, reading, knitting, journaling, and breathing exercises are great examples of relaxing self-care activities. Caregiving can be demanding, so it's important to take care of yourself.

The following tips may help you feel better able to cope with the emotional and practical demands of caring for someone with vasculitis:

- Know that you don't have to tackle everything alone; reach out for help when you need it and keep a list of specific tasks others can do when they offer
- Avoid bottling up your feelings. Seek out someone to talk to, such as a partner, friends, or an online support group
- Nurture your relationship with your loved one, focus on ways to stay connected, and talk to them openly about your emotions
- Take breaks when you can so that you're able to relax and do things you enjoy
- Stay active and try to get some fresh air each day
- Try using relaxation techniques and try to get enough sleep so you do not become overtired
- Find out whether you or your loved one are eligible for government support to assist with financial demands, or if there are any laws or policies in place to support you at work

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The best way to avoid burnout is to have the support of others



Ask for help

You may be a spouse, partner, child, family member or friend providing care on a regular basis to someone with vasculitis. Your role as a caregiver is an important one.

Accept that you may need help with everyday household and caregiving tasks. Family and friends can be vital members of your circle of care. Tell your friends and family that you need their help. Most people want to help, but they don't know what you need. Friends often worry that offering help might seem intrusive, so let them know their help is welcome. Don't hesitate to be specific with your support needs.

Keep a list of projects, errands and services that others can do. Then, the next time someone offers to help in some way, you can guide them on how to best support you.

People with vasculitis often need significant help with daily care. In many cases, family and friends may not be able to do it alone, and additional help may be needed. Talk with your medical team or Vasculitis Foundation Canada to determine what additional professional care is available. This additional help may be covered by the government or private insurance.



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Additional resources

Huddol

Visit the largest online caregiver support network in Canada, where you can learn, share and connect with experts and other caregivers.

huddol.com

Vasculitis Foundation Canada

With a mission to encourage and support research efforts for the cause and cure for all forms of vasculitis, Vasculitis Foundation Canada strives to assist vasculitis patients and their families with clinical information and coping strategies, to help them develop a strong and positive outlook.

Vasculitis.ca

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