EOSINOPHILIC GRANULOMATOSIS WITH POLYANGIITIS

A PATIENT'S GUIDE TO RESOURCES AND HOPE

THIS RESOURCE WAS DEVELOPED COLLABORATIVELY BY:

Apfed
American Partnership for Eosinophilic Disorders

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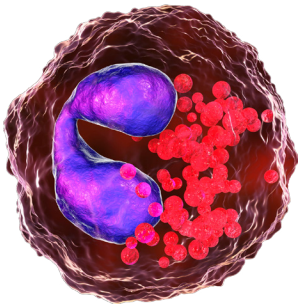
Welcome



An eosinophil

Eosinophilic granulomatosis with polyangiitis (EGPA), formerly known as Churg-Strauss Syndrome, is a rare form of vasculitis. Vasculitis is inflammation of blood vessels.

EGPA is an autoimmune disorder characterized by inflammation of small blood vessels and having a high number of a type of white blood cell, known as an eosinophil. The inflammation caused by EGPA can restrict blood flow to organs and tissues, causing damage.

EGPA often involves the respiratory tract, and people who have EGPA frequently also have allergies and/or asthma, sinusitis, and pulmonary infiltrates. While the lungs and sinuses are commonly affected, it can also affect other organs, including the skin, heart, kidneys, nerves, and bowels.

This toolkit was developed in collaboration between the American Partnership for Eosinophilic Disorders (APFED) and the Vasculitis Foundation (VF). APFED is a nonprofit organization that assists and supports patients and families affected by eosinophil-associated disorders, such as EGPA, by providing education, creating awareness, supporting research, and promoting advocacy. The VF is the world's leading advocacy organization dedicated to diagnosing, treating, and curing all forms of vasculitis.

This kit includes:

- **Getting started checklist.** Navigate a new diagnosis with this checklist to guide you as you learn.
- **FAQs.** Read answers to questions that are commonly asked by patients and caregivers.
- **Glossary.** Learn terms commonly used when discussing EGPA.
- **Types of specialists.** Learn about the team of doctors or specialists that you may need to manage EGPA.
- **Research progress.** Discover how EGPA research is progressing and learn about recent discoveries.
- **Tips and strategies for successful management.** Explore practical strategies for symptom management.
- **Tips for living well.** Access tried and true tips to help improve your quality of life with EGPA.
- **Helpful resources.** Connect with others and tap into a supportive community.

We hope these resources will help you be better prepared to manage your EGPA diagnosis. For more information or questions or support, please reach out to APFED or the VF. You may connect with them via their websites, listed below, or on social media.

EGPA: Getting Started Checklist

A diagnosis of eosinophilic granulomatosis with polyangiitis (EGPA) is life-changing and can feel overwhelming. You are not alone. Here are some tips to get you started on your journey.

Educate yourself

- **Read this toolkit.** The material inside is designed to help patients, families, and others understand EGPA and how to manage it.
- **Ask your doctor for resources.** Some large hospitals and health systems also have information about EGPA available on their websites.
- **Browse resources from patient advocacy groups.** Both APFED and the VF have expansive e-libraries that offer expert-led presentations, webinars, and podcasts that people with EGPA will find helpful. The material can help you explore treatment options, work in partnership with your doctors, and manage the challenges of living with EGPA.

Find a doctor

- **Build your care team.** EGPA requires ongoing care and monitoring by a healthcare provider. Many people living with EGPA receive their medical care through large institutional settings where there are multiple specialists in one place. However, a general practitioner, a pediatrician, or a specialist in private practice can oversee your EGPA care and can help you determine which, if any, additional specialists you may need. See the **Types of Specialists** section in this toolkit for more information.
- **Find the right doctor.** Managing a chronic illness requires a good doctor-patient relationship, and you should feel comfortable with doctors and specialists you work with. If you are seeking care, both APFED and VF have tools to help you find a doctor.
- **Ask your doctor(s) questions.** Before your next doctor's appointment, write down your questions. We've included a template in this guide. Some questions to consider are included on the next page.

Questions to ask your doctor

- What types of tests or procedures will be performed? How often will they need to be repeated?
- What treatments do you recommend, and why?
- How will it be determined if treatment is effective?
- Will I need to take (or continue to take) any medicine? Are there any special instructions (e.g., dose, frequency, storage, how to administer)?
- Could my EGPA relapse? Can I prevent a relapse?
- What other specialists might I need?
- How will my medical information be shared with other specialists involved in my care? How will appointments with other specialists be coordinated? Is a care coordinator available to help facilitate this?
- Will I need special accommodations at work or school?
- Are there clinical trials for EGPA for which I might be eligible to enroll?

Have a treatment plan

Develop a written plan to follow for symptom and medication management. For medication management, include the dose, frequency, and any special instructions for administering and storing medication(s). Speak to your doctor about which symptoms may require urgent medical attention.

Keep a daily journal to track how you feel, any symptoms you might have, and what you eat. This information could help you and your doctor identify any patterns, or foods that could be contributing to your symptoms. Bring your journal to each doctor's appointment.

Schedule follow-up visits with your doctor and be sure to keep the appointments. EGPA is a chronic condition that requires ongoing care. Symptoms of EGPA can change over time. Your doctor may recommend regular blood tests so that they can see any changes in your eosinophil levels or other markers of inflammation. The results of these tests can help your doctor to determine if any changes are needed to your treatment plan.

Build a support system

- **Teach your friends and family about EGPA** and how symptoms impact your daily activities or your mood. Let them know how they can help you.

- **Join an online support group.** APFED's "Eos Connections" online community on the Inspire Network is at **apfed.inspire.com**. Join the EGPA board to connect with other patients and caregivers for peer support. The VF offers weekly and monthly virtual community support groups that are designed for peer support, including a support group for teens. Join the group that works best with your schedule to connect with other patients and caregivers of EGPA.

- **Attend an event to meet other people living with EGPA.** Both APFED and the VF host local events around the country and offer networking opportunities. Visit their websites to learn more about events.

EGPA: Frequently Asked Questions

Patients and caregivers frequently ask the following questions about eosinophilic granulomatosis with polyangiitis (EGPA):

What is EGPA?

EGPA is an autoimmune disorder characterized by inflammation of small blood vessels and having a high number of a certain type of white blood cell, known as eosinophils. The inflammation caused by EGPA can restrict blood flow to organs and tissues, causing damage. EGPA is a chronic, but manageable condition.

What causes EGPA?

While the exact cause of EGPA is not yet known, it is believed to result from an interaction of genetics and the environment, complicated by an overactive immune system. Because all patients with EGPA have high levels of eosinophils at some point during their disease, it is thought that there may be some dysregulation of eosinophil production, maturation, or development.

Who has EGPA?

EGPA is often diagnosed in adults 35-50 years old. Children can also have EGPA, although it is not seen very often in children. The disease affects males and females equally.

It is believed that there are roughly 14-15 cases per million people worldwide who have EGPA. This equates to roughly 5,000 people in the U.S. The number of people living with EGPA may be higher as it could be underreported due to the underdiagnosis or due to the masking of findings by treatment with corticosteroids for what is perceived to be just severe asthma.

What are the symptoms of EGPA?

People with EGPA can experience a variety of symptoms, which may change over time. For some, EGPA may affect different organ systems such as the lungs, nerves, heart, gastrointestinal tract, skin, and other organs. Some may have mild symptoms, while others have more severe symptoms.

Frequently reported symptoms include shortness of breath, chest pain, stomach pain, feeling of numbness, rashes, eye problems, runny nose, and fatigue. Almost all patients with EGPA have asthma.

Some of these symptoms can be debilitating and interfere with daily activities and hobbies, impacting quality of life and emotional well-being.

What are the three stages of EGPA?

EGPA typically manifests in three stages, but not all patients experience all phases. Different symptoms may be experienced at each stage.

1. **Allergic Phase** – In this stage, a person develops allergies, or their existing allergies worsen. Sinusitis and nasal polyps are also common.
2. **Eosinophilic Phase** – People may develop increased numbers of eosinophils. The eosinophils can cause inflammation and tissue damage, typically to the lungs and digestive tract. This phase is often accompanied by symptoms of asthma with coughing, wheezing and gastrointestinal issues.
3. **Vasculitic Phase** – In this stage, the blood vessels become inflamed, in turn restricting blood flow to various organs and tissues, such as nerves and skin. This phase often includes symptoms such as fever, fatigue, and weight loss.

How is EGPA diagnosed?

EGPA can be difficult to diagnose because its symptoms are similar to other diseases. Further, there is no single test to diagnose EGPA. Your doctor will consider a number of factors, including your medical history, especially if you have asthma and/or allergies. A physical examination can help your doctor identify which organs may be impacted and to rule out other potential causes for your symptoms.

Your doctor may also order several tests, including a blood test to check your eosinophil levels and other inflammatory markers. They may also order a urinalysis, tissue biopsy, imaging studies (X-rays or CT scans), and a heart echocardiogram.

Having a high level of blood eosinophils along with asthma and pneumonia are often the first clues that lead to diagnosis. EGPA is considered present when a person has a least four of the following six features:

Asthma

Elevated number of eosinophils in the blood

Nerve damage (numbness & pain in hands/feet)

Pulmonary infiltrates

Sinus problems

Presence of eosinophilic vasculitis

What are treatment options for EGPA?

The overall goal of treating EGPA is to reduce inflammation and the number of eosinophils in the blood. Many patients who have EGPA respond well to systemic corticosteroids. Some may also need immunosuppressant drugs, while others have symptoms that are resistant to these therapies.

Currently, therapies that are prescribed for EGPA include:

Systemic corticosteroids (e.g., prednisone) are often prescribed to treat EGPA. Corticosteroids change the way the immune system functions and reduce inflammation. A higher dose may be prescribed initially to get symptoms under control quickly, and then gradually decreased to the lowest effective dose.

Benralizumab (Fasenra®) is approved by the U.S. Food & Drug Administration to treat EGPA in adults. It is a biologic medicine (targeting interleukin-5α receptor, or IL-5αR, on eosinophils). It removes eosinophils from the blood and tissues. It is an injectable medicine and is available in auto-injectors in pre-filled syringes for self administration. It can reduce the usage of corticosteroids.

Mepolizumab (Nucala®) is approved by the U.S. Food & Drug Administration to treat EGPA in adults. It is a biologic medicine that works to recognize and block IL-5 and helps to reduce eosinophils. Mepolizumab is given as an injectable medication and is available in auto-injectors in pre-filled syringes for self-administration. It can reduce the usage of corticosteroids.

Immunosuppressant drugs (e.g., azathioprine, cyclophosphamide, methotrexate, mycophenolate mofetil, rituximab) can be used in conjunction with systemic corticosteroids to get the disease under control. These drugs are often well tolerated and commonly used for vasculitis. These medications are FDA-approved to treat certain diseases, but not EGPA; however, some doctors use immunosuppressant drugs to treat EGPA symptoms.

Omalizumab (Xolair®) is a targeted therapy that blocks the allergy antibody known as IgE, lessening allergic reactivity. This therapy may be considered for some patients with EGPA to help control their asthma when they have not responded to other therapies. This medication is FDA-approved to treat certain allergic and inflammatory conditions, but not EGPA; however, some doctors use it to treat EGPA symptoms.

What will happen if EGPA is left untreated?

EGPA is a chronic condition. Left untreated, EGPA could be fatal; therefore it is important to receive ongoing medical care to manage your condition.

References

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EGPA: Glossary of Terms

Allergen: A normally harmless substance, such as pollen or foods, which triggers the immune system to overreact in response. In some types of reactions, the body responds immediately and releases a chemical called Immunoglobulin E (IgE). In other reactions, called "cell-mediated," the reaction can be delayed as immune cells in the body errantly attack the substance.

Allergy: An abnormal immune system response to any stimulus, including food, pollen, or insect stings.

Antibody: A protein produced by the immune system that fights against foreign substances or toxins, called antigens.

Anti-neutrophil cytoplasmic antibodies (ANCA): A blood protein that mistakenly targets a type of white blood cell called neutrophils, which are important in fighting infection. ANCA tests can help diagnose certain types of vasculitis, including EGPA.

Asthma: Chronic inflammatory disorder that affects the airways in the lungs and causes breathing problems throughout a person's life.

Atopy: The genetic predisposition to develop allergic diseases including IgE-mediated food allergy, eczema, rhinitis, asthma, and conjunctivitis. This inherited tendency, which runs in families, is associated with hypersensitivity to certain foods, pollen, and other common allergens.

Autoimmune disorder: A condition where the immune system mistakenly attacks its own tissues, damaging healthy cells, tissues, and organs in the body.

Biologic medicine: Medications that specifically target cells, proteins, and pathways responsible for causing inflammation in your body. They are derived from the cells of living organisms, including humans, animals, or microorganisms. Biologic medicine is sometimes referred to as "targeted therapy."

Biopsy: A medical procedure that involves the removal of a sample of tissue or cells from an affected blood vessel or organ, which is examined under a microscope for signs of inflammation or tissue damage.

Cardiomyopathy: Disease of the heart muscle that affects its size, shape, or thickness. A condition in which the heart muscle becomes weakened, leading to a decrease in its ability to pump blood effectively.

Chronic: Referring to a disease or condition that persists for a long time or is constantly recurring.

Clinical trial: Research studies performed in people to evaluate effectiveness and safety of medical, surgical, or behavioral interventions. Clinical trials may involve evaluating new medications in people before the Food and Drug Administration has approved the drug. The trials may involve a placebo group (inactive "medicine") to see if the new medication offers an advantage over current treatments. Some trials are "open label," in which all participants know if they are receiving the experimental medication.

Corticosteroid (aka "steroid"): A type of medication that is a synthetic version of cortisol or other hormones. This type of medication is a potent anti-inflammatory and suppresses the immune system. It may be used to treat allergies, asthma, eosinophil-associated diseases, autoimmune disease, some forms of cancer, organ transplant rejections, and other diseases. It also may be prescribed to provide adrenal gland support in cases of adrenal insufficiency.

Echocardiogram: An ultrasound of the heart.

Eczema: An inflammatory skin condition that causes redness, scaling, and often itching. May be related to allergies, infection, diabetes, or environmental changes.

Eosinophil: A type of white blood cell that is part of our immune system. Eosinophils help us fight off certain types of infections and are involved in a number of medical conditions, such as parasitic infections and allergies. They are produced in the bone marrow and migrate throughout the body.

Eosinophil-associated disease: When a person has elevated numbers of eosinophils in their tissues, organs, and/or bloodstream, without a known cause, it may be because of an eosinophil-associated disease. These conditions are further characterized depending on where in the body the eosinophils are found. These diseases are usually chronic and require long-term management.

Eosinophilia: High numbers of eosinophils in the blood.

Eosinophilic granulomatosis with polyangiitis (EGPA): A rare form of vasculitis characterized by the inflammation of small to medium size blood vessels, which can restrict blood flow and damage vital organs and tissues.

Fibrosis: The formation of excessive fibrous tissue, usually in response to damage or injury.

Flare-up: A sudden worsening or return of disease symptoms.

Glucocorticoids (steroids): A class of corticosteroids often used to reduce inflammation in conditions like EGPA. Prednisone is a common example.

Granulomas: A collection of immune cells and a type of inflammation.

Immunosuppressants: Medications that suppress or reduce the strength of the body's immune system. These are often used in EGPA to control the immune system's overactivity.

Histamine: A chemical the body produces in response to an allergic reaction. It also mediates several other biological activities in the body. There are four histamine receptors (H1-4) that are found in cells. Antihistamines, like Benadryl®, block some of the histamine receptors, and may relieve symptoms of the allergic reaction.

Inflammation: Swelling of a tissue. It is part of the body's response to tissue injury, irritation, or damage. Inflammation can occur anywhere in the body and from many different causes.

Myocarditis: Inflammation of the heart muscle, occurring due to viral infections, bacterial infections, or autoimmune disorders.

Narrowing: Narrowing of a tubular or hollow structure in the body, such as the blood vessels.

Neuropathy: Damage to the nerves, which can cause weakness, numbness, and pain, often in the hands and feet.

Nodules: Raised bumps that can be caused by inflammation.

Parathesia: Sensation of pricking, tingling, or creeping on the skin, with no obvious cause.

Pneumonia: An infection that affects one or both lungs, causing the air sacs, or alveoli, to fill up with fluid or pus.

Pulmonary infiltrates: A substance denser than air, such as pus, blood, or protein, within the lung tissues, that are typically seen in chest x-ray or chest computed tomography (CT) as white spots.

Relapse: The return of disease symptoms after a period of improvement or remission.

Remission: A period during which the symptoms of a disease are reduced or disappear entirely, and the disease is considered inactive.

Urinalysis: An examination of a patient's urine, to assess for excessive protein or the presence of red blood cells which may indicate inflammation of the kidneys.

Vasculitis: A group of rare diseases characterized by inflammation, swelling, and narrowing of blood vessels, which can make it harder for blood to flow to organs and tissues. Vasculitis is classified as an autoimmune disorder.

EGPA: Types of Specialists

People with eosinophilic granulomatosis with polyangiitis (EGPA) may have more than one doctor or specialist involved with their care. Depending on the symptoms you have, you may be referred to one or more of the specialists below. Usually, one specialist will serve as the doctor who manages your EGPA care based on which part of the body is most affected. General practitioners or pediatricians can also head up care and refer to specialists as needed.

Allergist/Immunologist

Diagnoses and treats allergies, asthma, and immunologic conditions. If you experience cough and wheezing, you might be referred to an allergist/immunologist.

Cardiologist

Specializes in the care of the heart and blood vessels. They are experts in the diagnosis, treatment, and prevention of cardiovascular diseases, which include conditions such as heart attacks, irregular heart rhythms, and heart failure. You may be referred to a cardiologist if you have symptoms of chest pain or discomfort, or for tests and imaging to determine if EGPA is impacting your heart.

Dermatologist

Specializes in conditions that affect the skin, hair, and nails. You may be referred to a dermatologist for skin symptoms, such as itching or rashes.

Otolaryngologist/ENT (Ear Nose Throat Specialist)

Diagnoses and manages a wide range of conditions, from common ear infections, nasal polyps, and sinusitis to complex disorders. You may be referred to an otolaryngologist or an ENT specialist if you have symptoms impacting your nose or sinuses. Nasal polyps are common in EGPA.

Nephrologist

Specializes in diagnosis and treatment of kidney conditions, such as chronic kidney disease, kidney infections, and kidney failure, as well as related issues like high blood pressure, fluid retention, and electrolyte and mineral imbalances. Because EGPA and some of its treatments may cause kidney problems, you may be referred to a nephrologist who can analyze your urine.

Neurologist

Specializes in assessment, diagnosis, treatment, and management of disorders of the brain and nervous (brain, spinal cord, and nerves) function. Neurologists are experts in understanding the anatomy, function, and conditions that affect the nerves and nervous system, which is the body's command center. If your EGPA causes symptoms such as numbness or if your limbs feel weak, you may be referred to a neurologist.

Occupational Therapist

Focused on promoting health and well-being by enabling people to participate in everyday tasks, such as self-care activities, preparing food, working, and caring for others. Occupational therapists assess abilities and limitations of an individual and design individualized care plans to help patients attain the best outcome.

Physical Therapist

Licensed health professional who specializes in pain reduction, improvements and restorations of mobility, and ensuring the overall well-being of the patients. Physical therapists help in diagnosing and treating individuals with health conditions that result in limitations of movement or their ability to perform everyday tasks.

Pulmonologist

Specializes in diagnosis, treatment, and management of diseases and disorders of the respiratory system, which include the lungs, airways, and other organs that help you breathe. You may be referred to a pulmonologist if you experience symptoms of shortness of breath, cough, and wheezing.

Respiratory Therapist

Specializes in providing healthcare for patients with respiratory diseases or disorders. They collaborate closely with doctors to diagnose and treat patients with conditions such as asthma, bronchitis, COPD, pneumonia, and other respiratory issues.

Rheumatologist

Specializes in the diagnosis and treatment of conditions that affect the musculoskeletal system, including joints, muscles, and bones. They are also experts in treating autoimmune and inflammatory diseases that affect multiple organs, such as EGPA.

Vascular Specialist

Specializes in the vascular system. They manage diseases of the veins and arteries. You may be referred to a vascular specialist for problems like blood clots.

EGPA: Research Progress

Eosinophilic granulomatosis with polyangiitis (EGPA), previously known as Churg-Strauss Syndrome, was first identified in 1951, and was known as a syndrome consisting of asthma, eosinophilia, fever, and accompanying vasculitis of various organ systems. EGPA usually affects smaller- to medium-sized blood vessels and commonly causes inflammation and damage to the lungs, sinuses, skin, heart, intestinal tract, kidneys, and nerves.

The rarity and unique features of EGPA, such as eosinophilic inflammation, have had limited research progress over the years compared to other forms of antineutrophil cytoplasmic antibody (ANCA)-associated vasculitis (AAV).

Recent guidelines for the diagnosis and treatment of EGPA are now available; however, more research is needed to better support and strengthen these recommendations.[1] Attention to EGPA as a research subject has been recently increasing, and a better understanding of how the disease starts, develops, and affects the body is leading to a modest, but important growth in the investigation of new treatments.

Ongoing areas of research

The most important areas of investigation that will likely result in better drug trials include:

- the improvement of diagnostic criteria for EGPA;
- a better understanding of EGPA pathophysiology and different disease subtypes;
- larger and better powered genetic studies;
- the identification of diagnostic and disease activity biomarkers; and
- the optimal use of corticosteroids during both the remission induction and maintenance phases of treatment.

Studies of biologic therapies have primarily focused on their use in patients with refractory or relapsing disease; however, the potential benefit of early treatment with biologic agents needs to be investigated.

Future or ongoing investigational therapies

- Role of anti-IL-5 agents in severe organ manifestations
- Other IL-5 targeting antibody therapies
- Role of long-acting anti-IL-5 agents
- Efficacy of biologic therapies in different EGPA subsets
- New biologic therapies

Clinical trials

Clinical trials are research studies conducted with human participants to evaluate the safety, efficacy, and side effects of new medications, devices, or treatment protocols. Results from clinical trials provide critical information that helps regulatory authorities decide whether a new intervention should be approved for widespread use.

To learn about clinical trials that may be enrolling people with EGPA, visit **clinicaltrials.gov**, **apfed.org**, or **vasculitisfoundation.org**.

Citations

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EGPA: Tips & Strategies for Successful Management

Physical wellness and movement

Exercise is beneficial both physically and mentally. It is important to recognize that you have a new normal as someone living with EGPA. Disease symptoms and medications can take a toll on your body. Physical activity can help you regain a sense of control and improve your quality of life. Other benefits of physical activity include:

- **Reduce inflammation.** As little as a single bout of 20 minutes of light physical activity can reduce inflammation markers by 5%.[1]
- **Manage stress.** Living with a rare disease can increase feelings of anxiety and depression. While medication may be needed, multiple studies have shown physical activity to be equally as effective at reducing markers of anxiety, stress, and panic disorders.[2,3]
- **Maintain strength and bone density.** Sedentary lifestyles and glucocorticoids such as prednisone reduce bone density, decrease strength, and reduce muscle mass. Physical activity, particularly weight bearing, increases muscle mass and bone density. The greater the load, the higher the benefit.[4,5]
- **Improve sleep quality.** When you exercise you stimulate your body's recuperative process during sleep. This helps your body get into the deeper, more restful, and regenerative stages of sleep.[6]

Explore a wide variety of guided videos on stretching, flexibility, and strength training designed for people at all fitness levels. Many of these videos are led by experts in their field who also live with vasculitis.

https://www.vasculitisfoundation.org/living-well/wellness-movement/

Incorporate mindfulness into your day

The journey with EGPA can have an impact on emotional and mental health, and diagnosis can be life-changing. You may feel emotions such as grief and anger. Learning skills that can boost your resilience can help improve your mental health.

Studies have shown many benefits of mindfulness for both mind and body.[7,8] Mindful awareness is an anchor that can be especially helpful whenever you are feeling overwhelmed. It can help you to better recognize your physical, emotional, relational, or spiritual needs.

The “Pause and Scan” technique is a simple activity that invites you to briefly reflect on a single moment with mindful awareness.

Pause and name these three aspects of awareness using short, descriptive statements.

- **Thoughts:** Start at the top with your head and consider your current thoughts.
- **Emotions:** Next, shift down to your heart and the feelings you are experiencing.
- **Behavior:** Finally, shift your awareness to your hands and feet and describe your actions.

Example: Pause and Scan when walking the dog: “At this moment, I am thinking about everything I must do today. I feel anxious because there is a lot to do. I am walking quickly.”

When beginning a mindfulness practice, consider 5-10 minutes of guided meditation or an active practice like yoga every day. Build this activity into your daily routine where it fits best in your schedule. When the activity becomes a regular part of your day, consider increasing the time you spend on it. Learn more about how to incorporate mindful self-compassion into your life by exploring mental health and mindfulness resources including the VF’s Navigating Your Vasculitis Journey guidebook.

https://www.vasculitisfoundation.org/living-well/mental-wellness/

Advocate for yourself

School and Workplace Rights in the U.S.

Section 504 of the Rehabilitation Act of 1973 prohibits discrimination against people with disabilities in programs that receive federal funding. It creates the framework to ensure children receive reasonable accommodations at school, such as time to make up missed work and absences without penalty when related to their disorder. Every school-age child, whether meeting the definition of disabled or not, is legally entitled to a free, appropriate, and meaningful education. For more information, visit the website for the Office for Civil Rights at **https://www2.ed.gov/about/offices/list/ocr/504faq.html**.

APFED offers a school advocacy toolkit that includes information and templates for 504 planning at **apfed.org/advocacy/school-advocacy**.

The Family and Medical Leave Act allows employees to take up to 12 weeks of unpaid leave each year for medical or family emergencies. This applies to employers that have 50 or more employees. Learn more at **dol.gov/whd/fmla/**.

The Americans With Disabilities Act of 1990 (ADA) was amended in 2008 to expand the rights of disabled individuals. ADA requires employers to make reasonable accommodations for disabled workers who meet their definition of "disabled." This may include additional time off or modified work schedules. As amended, ADA applies to employers that have 15 or more employees. Learn more at **ada.gov/ada_intro.htm**.

Do your research and go to medical appointments with questions in hand. Educate yourself about the latest research, advances in treatments, and clinical studies. Typically, you only have about 10 minutes with your doctor. Make those 10 minutes count.

1. **Keep a journal of your EGPA symptoms**, including treatments and how you feel in general, and what you eat. Be specific; include details and the date. Take this journal to each doctor's appointment.
2. **Make a list of questions to take to your next doctor's appointment.** Put these in order of priority so you can ask the most important questions first. Make sure it is a brief list, ideally no more than three items, so you will have enough time to discuss them. Record responses to your questions and date the entry.
3. **Bring another person to take notes during your appointment, if possible.** Some topics can be difficult to understand, and the doctor may have limited time to explain them to you.
4. **Check in on the treatment plan**. How have you responded to treatments thus far? Any changes or adjustments to the treatment plan needed?

Learn more about how to be a successful self-advocate at

https://www.vasculitisfoundation.org/living-well/self-advocacy/

Prioritize rest

It is normal to feel fatigued when living with EGPA. Fatigue often begins before diagnosis and may persist even during or after treatment. There are many reasons for this.

- Fatigue can be related to anemia and other laboratory changes seen in EGPA. Specific organ involvement such as heart, kidney, or lung disease can also cause fatigue.
- Medications may contribute to a feeling of fatigue. For example, prednisone may cause insomnia and make it difficult to fall, or stay, asleep.
- Keeping up with multiple doctors' appointments or other medical-related visits and taking medications at separate times of the day can interrupt your daily schedule and not allow you the time you need to rest and sleep.

Prioritize rest without feeling guilty for needing a break. Take a nap during the day if you feel you need it.

What else can you do?

- **Maintain a regular daily schedule**, even for simple tasks, such as self-care and daily exercise.
- **Create good sleeping habits**, such as avoiding consumption of caffeine in the later part of the day, or using your computer/tablet/phone late into the evening.
- **Make a regular bedtime routine** such as taking a relaxing bath, reading a book, or listening to music.
- **Renew your mental energy** with activities such as meditation, spending time with friends or family, watching a favorite movie or television program, or reading a book. This quiet or downtime is necessary to help you cope with the fatigue and stressors of EGPA.

Citations

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EGPA: Tips for Living Well

If you or someone you love is diagnosed with eosinophilic granulomatosis with polyangiitis, it is important to:

Stay informed. Both APFED and the VF offer free e-newsletters that provide updates, resources, and events of interest. Visit their websites to subscribe.

Connect with others. Connecting with other people living with EGPA for emotional support and guidance is invaluable. For a calendar of local and national events, visit **apfed.org**. Stay connected 24/7 with other EGPA patients on APFED's online community "Eos Connections" on the Inspire Network at **apfed.inspire.com**, and follow APFED on social media. The VF offers online support group meetings for people with EGPA and their families. To find out more, visit **vasculitisfoundation.org/living-well/find-support/**.

Prioritize your health. Follow your treatment plan and your doctor's recommendations. Keep your prescriptions filled and schedule (and stick with!) your follow-up appointments.

Take care of yourself. Self-care can help you to reduce stress and will help you to nurture your mental and physical well-being. Use the ideas below to help you develop self-care habits and routines that work for you.

- **Set limits.** Recognize your strengths and weaknesses. Know what you can manage on your own and when it is time to ask for help. There is no shame in acknowledging your limits. It is better to ask for help instead of getting burned out. It is also a good idea to practice the art of saying "No." Do not agree to everything to please your friends or family members.
- **Learn calming breathing techniques.** The stress from having a chronic illness can be overwhelming at times. It is vital to slow down. Practice calming your nervous system with just a few deep breaths. Breathing affects the whole body; it increases feelings of calm and relaxation and can lead to a decrease in the feelings of pain. Close your eyes and breathe deeply – your abdomen should rise, but your shoulders should not. Count to four, then slowly release your breath. Repeat for one to two minutes. Do this whenever you need to feel more relaxed or focused.
- **Focus on what you can control.** Feeling sad, anxious, or even angry about EGPA is normal. Rather than letting these feelings overwhelm you, acknowledging and expressing them can help give you a sense of control. Seek professional counseling if you need help coping with a chronic illness.

  It is helpful to focus on the aspects of your life over which you do have control. One way you can take control is to set small, attainable goals and reward yourself for reaching them. Some examples include tracking your mindfulness activities, getting adequate restorative sleep, and making time for fun.
- **Share your story.** Everyone whose life has been touched by an eosinophil-associated disease has a story to share, and we can all learn from one another! Consider sharing your experiences with EGPA on social media, at a conference, or in an online support community (see page 22).

EGPA: Helpful Resources

Check out these resources for those affected by eosinophilic granulomatosis with polyangiitis (EPGA).

Websites

The following non-profit patient advocacy organizations have information on their websites about EGPA:

- **American Partnership for Eosinophilic Disorders**
  apfed.org
- **Vasculitis Foundation**
  vasculitisfoundation.org
- **American Lung Association**
  lung.org

The following website has information about biologic medicines, how they work, and who might be candidates for therapy:

- **Biologic Meds**
  biologicmeds.org

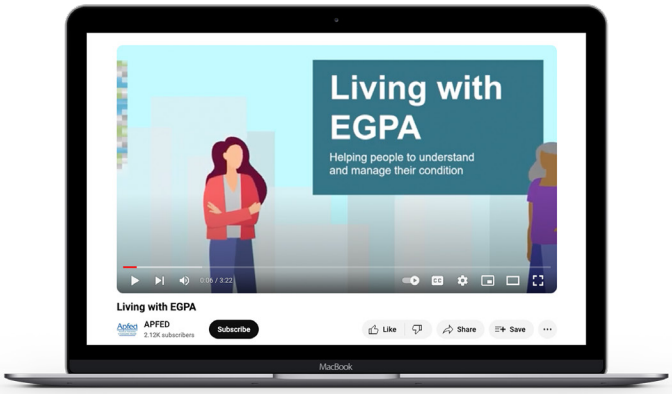
Online support communities

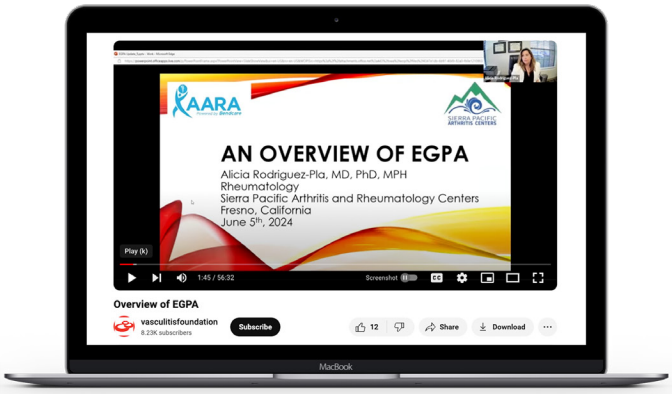
Eos Connections: APFED's online support community on the Inspire Network provides a forum for patients, caregivers, and family members to connect with others for support and to share information. Join the conversation today at **apfed.inspire.com**.

VF Virtual Support Groups: The VF provides both weekly and monthly virtual community support groups, including one specifically for teens. Join a group that fits your schedule to connect with other EGPA patients and caregivers. Learn more at **vasculitisfoundation.org/living-well/find-support/**.

Videos and webinars

APFED and the VF have YouTube channels that feature videos and recorded webinars for those with EGPA. See below how to find these channels on YouTube. Their websites list upcoming webinars of interest.





Podcast

The Real Talk: Eosinophilic Diseases podcast features conversations with researchers, clinicians, and people with lived experience. Discussions include disease management and treatments, research, and other topics of interest. You may find this podcast through Amazon Music, Apple, Audible, Spotify, and on **apfed.org**.

Social media

Facebook

- **facebook.com/APFED**
- **facebook.com/VasculitisFoundation**

Instagram

- **instagram.com/APFEDorg**
- **instagram.com/vasculitisfoundation**

X (Twitter)

- **x.com/APFEDorg**
- **x.com/VasculitisFound**

YouTube

- **youtube.com/APFED**
- **youtube.com/vasculitisfoundation**

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