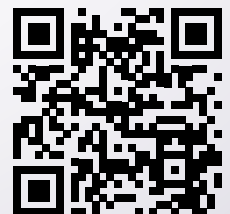


SEE ME HEAR ME

Carers and additional support

A booklet for people living with
ANCA-associated vasculitis (AAV),
and their families and friends



myANCAvasculitis.com/uk

See Me Hear Me is a disease awareness campaign
that has been created and funded by CSL Vifor.

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CARERS AND PATIENT ASSOCIATIONS



WII, GPA patient

Disclaimer: Although every effort has been taken to ensure the accuracy of information in this booklet, it is not intended to be a substitute for professional medical advice, diagnosis, or treatment. If you have any unanswered questions about AAV or your treatment, please speak to your specialist medical team.

How can I care for a relative or friend with AAV?

Caring for a friend or family member with AAV isn't always easy and you may face a number of challenges. Some of the more challenging times may be triggered by specific events (such as the initial stages of treatment, or during any disease flares) so it may help to know that these phases will usually only be temporary.

What challenges are common before diagnosis and during early treatment?

It can be difficult to take care of someone with AAV when you are both unaware of what is causing their symptoms.

During appointments with their doctors, there may be a lot of information to take in, and you may both find the emotional impact of finding out about the disease a struggle to cope with. Looking after someone who is unwell whilst also taking care of other responsibilities, such as work, family commitments and relationships, may be hard and some periods may be trickier than others.

Some of the more challenging times may be triggered by specific events (such as your friend or relative's reaction to the initial stages of treatment, or during any disease flares). It may help to know that these phases will usually only be temporary and that things may become easier to cope with when these events are over, or as the person you care for gets more used to them.

What challenges are common after initial diagnosis and treatment?

Over time, some of the initial challenges carry on, but others will usually resolve themselves or become easier to deal with. Other issues associated with caring for people with AAV after the early treatment stages include trying to find support for yourself, helping them cope with the ups and downs such as relapses, trying to manage the expectations of other family members and friends.

What support is available for me?

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

- Try to talk about your feelings and avoid bottling things up
- Take regular breaks to help you relax and do things you enjoy
- Stay active and try to get some fresh air each day
- Consider using relaxation techniques and try to get enough sleep

“As carers for GPA sufferers, it's not as easy as it may look. We have to endure the changing moods of our partners. There are phases when they're in pain and they'll blame other people.”

Heike (carer), Germany



Klaus, GPA patient and Heike, carer, Germany

For more advice and tips on caring for someone with AAV, visit myANCAvasculitis.com/uk/im-a-carer

PATIENT ADVOCACY GROUPS



Elisabeth, GPA patient
and Peter, husband, Netherlands

Role of PAGs

Patient advocacy groups, or PAGs, are supportive bodies set up to raise awareness and represent the needs of those living with or affected by a specific condition.¹

PAGs commonly seek to create positive conversations in their space with a view to generating improvements. They do this by:^{1,2}



Raising awareness
through social initiatives



Disease education
through helpful materials and
resources



Raising funding
through specific events



Creating a community
for those affected through social
media or in person meetings

Patient advocacy groups can act as the driving force behind disease education and public awareness.³ Through education, those affected can further understand their condition and better advocate for themselves and others.³ Education to wider audiences is also critical for rare diseases such as AAV, allowing for a better understanding of the patient experience.³ Through these methods, PAGs encourage more thoughtful conversations that recognise the lived experience of the condition and increase awareness.

With the help of digital technology, specifically social media and online forums, the number of patient advocacy groups are growing in number and accessibility.¹ Social media has created many communities for patients to access advice and connect with others through shared experiences nationally and internationally.¹ Social media sites provide the wider medical community with an unprecedented opportunity to hear patient voices, as well as dedicated online forums facilitated by PAGs.¹

Glossary

AAV ANCA-associated vasculitis

ANCA Anti-neutrophil cytoplasmic antibody

EGPA Eosinophilic granulomatosis with polyangiitis, previously called Churg-Strauss syndrome, is a type of AAV that often affects the lungs and/or sinuses

GPA Granulomatosis with polyangiitis, previously called Wegener's, is a type of AAV that usually begins in the nose, ears, eyes or mouth

MPA Microscopic polyangiitis, a type of AAV that typically affects the kidneys

PAG Patient association groups are groups aimed at creating positive conversations within their space with the view of improving education, awareness and community around the specific disease

VPAG Vasculitis patient advocacy groups, PAGs centred around vasculitis diseases

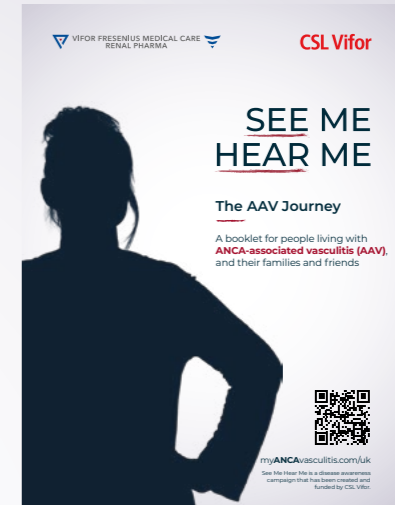
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1. How Pharma Can Build Better Relationships With Patient Advocacy Groups. Available from: <https://mdgroup.com/blog/how-pharma-can-build-better-relationships-with-patient-advocacy-groups/>. Date accessed: May 2025.
2. Fabbri A, et al. *BMJ* 2020;368:16925.
3. Rose S, et al. *J Law Med Ethics* 2013;41(3):680-7.

Other brochures in this series



To find out more about AAV and its signs and symptoms, read our 'What is AAV?' brochure



To learn about the AAV journey, from diagnosis and clinical management to treatment and self-management options, read our 'The AAV Journey' brochure

For more information on AAV, visit myANCAvasculitis.com/uk



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