

Timely Access to Amyloidosis Treatment

Q&A WITH MORIE A. GERTZ, MD



Q. Why is timely access to amyloidosis treatment important?

Amyloidosis is a progressive, rare disease. Without treatment, amyloid proteins continue to build up in organs such as the heart and nerves, causing permanent damage. Research shows that treatment delays can lead to heart damage and irreversible loss of nerve function. In my experience, once that function is lost, patients do not fully recover it, even after treatment begins. That is why starting the right treatment as soon as possible is critical.

Q. What treatment options are available for amyloidosis?

Treatment depends on the type of amyloidosis. For AL amyloidosis, treatment focuses on stopping the abnormal plasma cells that produce amyloid proteins. Most patients receive chemotherapy. Some may also receive immunotherapies that help the immune system target and destroy the cells producing amyloid. For ATTR amyloidosis, treatments generally fall into two categories:

- **Stabilizers**, which help prevent proteins from breaking apart and forming amyloid deposits.
- **Gene silencers**, which reduce production of protein in the liver.

Q. What barriers do patients face when accessing treatment?

Insurance-related barriers are among the most common challenges I see. Some health plans require extensive prior authorization before approving treatment. Patients may be asked to undergo additional testing, even when the diagnosis is already confirmed through symptom tracking, genetic testing and family history. In some cases, insurance coverage policies may limit which treatments are available, regardless of the clinician's recommendation.

Q. What challenges do clinicians face when prescribing amyloidosis treatments?

Many amyloidosis treatments are highly specialized and are often prescribed through specialty pharmacies rather than local pharmacies. Clinicians who do not regularly treat amyloidosis may be unfamiliar with prescribing requirements, enrollment processes or medication delivery systems. Some therapies also require additional provider registration before they can be prescribed. Navigating these requirements can be challenging and may delay treatment.

Q. How do insurance requirements contribute to treatment delays?

Clinicians often spend significant time completing prior authorization requests, submitting documentation and responding to additional insurer questions. Some health plans request information that is not routinely collected in clinical practice, requiring additional appointments, testing, or specialist evaluations. In my experience, appeals and peer-to-peer reviews can further extend the approval process. These delays may last weeks or even months while the disease continues to progress.

Q. What policy changes could improve access to care?

I would like to see policies that reduce unnecessary delays and help keep treatment decisions centered on the clinician-patient relationship. Patients and clinicians need faster prior authorization decisions, standardized documentation requirements and policies that allow patients to begin treatment while coverage reviews are underway. There should also be greater use of electronic review systems instead of time-consuming peer-to-peer calls. Reducing administrative barriers can help ensure patients receive timely access to medically necessary care.



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ABOUT THE AUTHOR

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The Alliance for Patient Access is a national network of policy-minded health care providers advocating for patient-centered care.

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