

National Academies Committee on ALS Accelerating Treatments and Improving Quality of Life

Bruce Rosenblum -- ALS patient

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ALS care and private health insurance key challenges

- Challenges obtaining Prior Authorization for FDA approved medications
- Overly restrictive coverage for durable medical equipment
- Lack of financial support for caregivers

Prior Authorization for FDA approved medications

- Riluzole
- oral Radicava
- Relyvrio

Prior Authorization for FDA approved medications

- Riluzole (Rosenblum) ✓
- oral Radicava
- Relyvrio

Prior Authorization for FDA approved medications

- Riluzole (Rosenblum) ✓
- ~~oral Radicava (Rosenblum)~~ ✗
- Relyvrio

Prior Authorization for FDA approved medications

- Riluzole (Rosenblum) ✓
- ~~oral Radicava (Rosenblum)~~ ✗
- Relyvrio (Rosenblum) ✓

Killing us softly...

- To paraphrase singer Roberta Flack, best known for the song *Killing Me Softly*, and who was diagnosed with ALS last year:

It's as though the insurance companies are looking right through us as if we weren't there.

Overly restrictive durable medical equipment coverage



Covered... or not

- Covered, but not useful for me:
 - Semi-electric hospital bed
 - Manual Hoyer lift
- Not covered, and useful for me:
 - Fully electric hospital bed
 - Electric Hoyer lift

Not covered, and essential for me

- Bathroom equipment
- Electric sit-to-stand lift



Lack of financial support for caregivers

- Serving as the primary caregiver for a spouse who is progressing through ALS is a physically and emotionally draining job
- Additional support is necessary
- Thirty hours of weekly paid caregiving, which we have to pay for out-of-pocket, exceeded 50% of my take-home pay each of the last 3 years
- Additional uncovered costs of ALS have left us drawing on our retirement savings for most non-medical living expenses

Recommendation 1: Prior Authorization changes

- AMA letter to the Centers for Medicare & Medicaid Services in February 2023: urgently needed changes related to Prior Authorization in Medicare Advantage plans
- <https://searchf.ama-assn.org/letter/documentDownload?uri=%2Funstructured%2Fbinary%2Fletter%2FLETTERS%2FPA-sign-on-letter-Part-C-and-D-rule.zip%2FPA-sign-on-letter-Part-C-and-D-rule.pdf>
- Adopt AMA recommendations on Prior Authorization *immediately* for *all* insurance plans

Recommendation 2: durable medical equipment

- Acknowledge the heterogeneous presentation of ALS and rapid progression timeline
- Adopt faster and more flexible policies for Prior Authorization of durable medical equipment
- Account the needs of the individual patient *and that patient's caregiving situation*

Recommendation 3: caregiving financial support

- Shortages of qualified caregivers
- ALS patients need loving care at home
- Broader and consistent support is needed to provide financial remuneration to family members who serve as caregivers of ALS patients

ALS is not a hopeless disease!

- The policies and actions of insurance companies rob patients and families unnecessarily of time and hope that can allow us to focus on living.
- ALS can be made a more livable disease

Thank you for considering my recommendations!