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Opinion

For people like me, Medicaid is a lifeline | **READER COMMENTARY**

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It's safe to say that being diagnosed with the terminal neuromuscular disease amyotrophic lateral sclerosis or ALS three years ago changed my life. Aside from being given between two and five years to live, there are many challenges that I never would have expected from home care to doctor visits to hospital stays to affording medications and so much more.



U.S. Rep. Sara Jacobs holds a "Save Medicaid" protest sign as President Donald Trump addresses a joint session of Congress at the U.S. Capitol in Washington, D.C., on March 4, 2025.

I'm not alone. Roughly 30,000 Americans are living with ALS and 250,000 are living with neuromuscular diseases. Accessible, affordable and adequate health care is not a luxury for us, it is a lifeline. As Congress works to address the federal budget and agenda this year, I urge all legislators to stand firm in protecting Medicaid and ensure it remains fully funded. Lives depend on it (["Big Beautiful Tax Bill' faces a July 4 deadline amid spending cut debates,"](#) April 29).

ALS is progressive and requires increased care over time as it becomes exceptionally expensive to manage. Over the years, the average cost of an in-home caregiver is roughly \$660,000, the average cost of ventilation is \$212,000, and the average cost of hospital care is \$114,000 — tallying to nearly a million dollars on its own. We want to spend our remaining years living, laughing and making memories with loved ones and not racking up insurmountable medical debt.

Medicaid is not a low-hanging fruit for cutting costs. Medicaid is a lifeline for the 72 million Americans who depend on it to lead healthy and independent lives. Before deciding to revoke funding for this critical program, I encourage all members of Congress to consider individuals whose livelihoods are protected by the crucial program.

— Brooke Eby, Potomac