

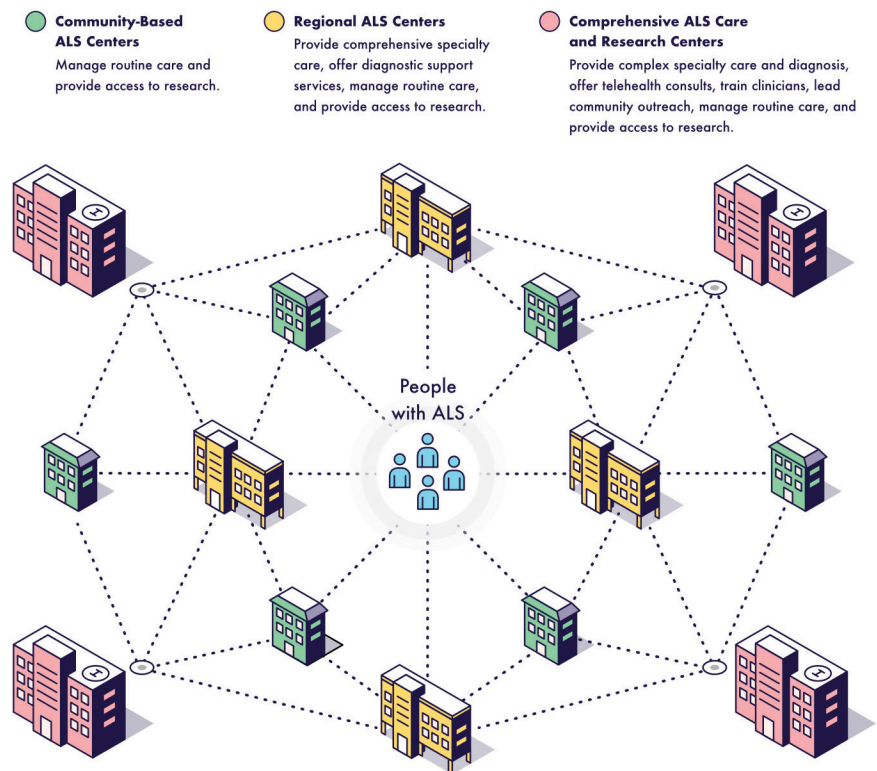
A Reimagined ALS Care System

Amyotrophic lateral sclerosis (ALS) is a rapidly progressive, fatal neurological disease affecting individuals, caregivers, at-risk genetic carriers, and others. A 2024 National Academies report, *Living with ALS*, recommends key actions public, private, and nonprofit sectors can take to make ALS a livable disease within a decade—actions that focus on earlier diagnosis and getting people connected to specialty care. Building on current clinics and programs, an ALS multidisciplinary care and research system would create newly integrated resources to identify and serve more people. The hub-and-spoke model would bring in community neurologists, private and group practices, and clinics that provide multidisciplinary care for neurological diseases other than ALS.

Each care setting would provide defined clinical care services, enrollment in the National ALS Registry, access to clinical research, and reports of quality metrics.

BUILDING THE IDEAL ALS CARE AND RESEARCH SYSTEM

An integrated and coordinated system of care and research that reaches all people with ALS



Community-Based ALS Centers
Manage routine care and provide access to research.

Regional ALS Centers
Provide comprehensive specialty care, offer diagnostic support services, manage routine care, and provide access to research.

Comprehensive ALS Care and Research Centers
Provide complex specialty care and diagnosis, offer telehealth consults, train clinicians, lead community outreach, manage routine care, and provide access to research.

Community-Based ALS Care Centers

These centers may be independent ALS clinics, multidisciplinary neurological clinics, integrated care networks of various specialists, solo or group neurology practices, or even certain VA clinics. They will still be accountable for providing care adhering to practice standards. People with ALS who live farther from a Comprehensive or Regional ALS Center would have access to:

- Initial diagnosis, with referral or consultation to other ALS centers available
- Day-to-day, routine follow-up care post-diagnosis, adhering to American Academy of Neurologists quality metrics and practice standards
- Participation in research, as a result of integration with regional and comprehensive centers
- Referral to other local specialists or community-based organizations

Regional ALS Centers

These centers would provide more complex, surgical, or specialized care needs. Regional ALS Centers can consult with Comprehensive ALS Care and Research Centers as needed. Services at Regional ALS Centers may include:

- Diagnostic assessment and confirmation
- Support for insurance approval of standard-of-care therapies
- Specialized follow-up needs in pulmonary care, eye-tracking communication devices, and medically complex cases surgical procedures or postprocedural intensive care.

Comprehensive ALS Care and Research Centers

These robust care hubs would actively conduct clinical trials and clinical research projects in addition to:

- Providing the research community with centralized imaging, biofluid and tissue biorepositories, and registry services
- Engaging genetic carriers in research
- Training and developing the workforce
- Enabling access to cutting-edge services for every ALS patient, including consultations, second opinions, and more via telehealth without state line restrictions
- Measuring and addressing racial equity in ALS diagnosis and care in the geographic area
- Piloting or expanding creative care delivery programs such as ALS house call nursing programs, mobile clinics, and travel satellite clinics