

SENATE, No. 4541

STATE OF NEW JERSEY
222nd LEGISLATURE

INTRODUCED SEPTEMBER 28, 2026

Sponsored by:
Senator ANGELA V. MCKNIGHT
District 31 (Hudson)

SYNOPSIS
Establishes “Tom’s Friends with ALS Bill of Rights” Act.

CURRENT VERSION OF TEXT
As introduced.



1 AN ACT concerning amyotrophic lateral sclerosis and other motor
2 neuron diseases and supplementing Title 26 of the Revised
3 Statutes and chapter 9 of Title 45 of the Revised Statutes.

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5 **BE IT ENACTED** *by the Senate and General Assembly of the State*
6 *of New Jersey:*

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8 1. This act shall be known and may be cited as the “Tom’s
9 Friends with ALS Bill of Rights.”

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11 2. The Legislature finds and declares that patients with
12 amyotrophic lateral sclerosis (ALS) or other motor neuron diseases,
13 including, but not limited to, progressive bulbar palsy, primary
14 lateral sclerosis, and progressive muscular atrophy, receiving
15 palliative care, comfort care, or hospice care services have a
16 fundamental right to receive quality care and comfort and nothing
17 shall infringe upon that right.

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19 3. a. Every person with ALS or other motor neuron diseases in
20 this State shall have the right to receive equitable hygiene and
21 health care services in their home, including, but not limited to, a
22 podiatrist, manicurist, or pedicurist for personal nail care and
23 hygiene, and to a barber for personal hair care and hygiene.

24 b. Persons with ALS or other motor neuron diseases shall have
25 the right to receive therapy services in the home. Therapists
26 choosing to provide such in-home services shall not be required to
27 apply for any additional licensure to provide services the therapist
28 would otherwise provide in a non-home setting.

29 c. (1) Notwithstanding any law, rule, or regulation to the
30 contrary, prior authorization shall not be required for the provision
31 of durable medical equipment for patients with ALS or other motor
32 neuron diseases, including, but not limited to, non-invasive
33 ventilators, cough assist machines, and suction machines. A public
34 or private insurance carrier operating in this State shall be
35 prohibited from enforcing such prior authorization provisions
36 against such patients.

37 (2) Notwithstanding any law, rule, or regulation to the contrary,
38 prior authorization shall not be required for the provision of liquid
39 medications for patients with ALS or other motor neuron diseases,
40 and a public or private insurance carrier operating in this State shall
41 be prohibited from enforcing such provisions against such patients.

42 d. (1) A person with ALS or other motor neuron diseases
43 receiving palliative, comfort, or hospice care services shall be
44 allowed continued use of all durable medical equipment while in
45 such care. Such person shall not be denied access to durable
46 medical equipment that was previously provided prior to receiving
47 palliative, comfort, or hospice care.

1 (2) A person with ALS or other motor neuron diseases receiving
2 palliative, comfort, or hospice care services shall be allowed
3 continued use of speech therapy services. Such person shall not be
4 denied access to speech therapy services that were previously
5 provided prior to receiving palliative, comfort, or hospice care.

6 e. (1) The Department of Health shall provide free, yearly
7 training for nurses, physical therapists, doctors, occupational
8 therapists, and respiratory therapists on the changing needs of
9 patients with ALS or other motor neuron diseases. Such training
10 may be used to fulfill continuing medical education requirements, if
11 needed. This training shall be required for nurses, physical
12 therapists, doctors, occupational therapists, and respiratory
13 therapists who work with ALS patients or patients with other motor
14 neuron diseases.

15 (2) Within 120 days of the effective date of this act, the
16 Department of Health shall create a continuing medical education
17 compliant training for health care workers on the changing needs of
18 patients with ALS or other motor neuron diseases.

19 (3) Emergency room physicians shall be knowledgeable on best
20 practices as developed by the American Academy of Neurology for
21 patients with ALS or other motor neuron diseases to promote
22 comfort care during emergency visits.

23 f. A patient with ALS or other motor neuron diseases shall not
24 be denied a request for an inpatient bed. Such bed shall be made
25 available as soon as practicably possible or a transfer to facility
26 with an open inpatient bed shall be made.

27 g. As used in this section, “motor neuron diseases” means a
28 group of progressive neurological conditions that destroy motor
29 neurons, which are the cells that control skeletal muscle activity
30 such as walking, breathing, speaking, and swallowing; and include
31 amyotrophic lateral sclerosis, progressive bulbar palsy, primary
32 lateral sclerosis, progressive muscular atrophy, spinal muscular
33 atrophy, Kennedy’s disease, and post-polio syndrome.

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35 4. An emergency room physician shall be required to complete
36 the yearly training created pursuant to paragraph (2) of subsection
37 e. of section 1 of this act.

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39 5. a. The Commissioner of Human Services shall apply for
40 such State plan amendments or waivers as may be necessary to
41 implement the provisions of this act and to secure federal financial
42 participation for State Medicaid expenditures under the federal
43 Medicaid program.

44 b. If federal waivers are not received, the State shall not be
45 required to implement the provisions of section 3 of this act to the
46 State’s Medicaid programs.

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48 6. This act shall take effect immediately.

STATEMENT

This bill creates a bill of rights for those with ALS called “Tom’s Friends with ALS Bill of Rights.”

The bill provides that every person with ALS or other motor neuron diseases shall have the right to equitable health and hygiene care services in their home. This includes access to a podiatrist, manicurist, or pedicurist for personal nail care services and access to a barber for personal hair care services. The bill also provides for the patient to be able to access other health care services such as therapy, speech therapy while receiving palliative, hospice, or comfort care services. Additionally, a person with ALS or other motor neuron diseases would be allowed continued access to all durable medical equipment the patient was using prior to accessing palliative, comfort, or hospice care and eliminate the requirement for prior authorization for liquid medications and durable medical equipment for patients with ALS or other motor neuron diseases.

The bill also requires the Department of Health to develop a yearly training to be made available to health care providers working with patients with ALS or other motor neuron diseases on the changing needs of such patients. The training would be required to be compliant with continuing medical education requirements and emergency room doctors would be required to complete the training yearly. The training would also be required for other health care workers providing care to patients with ALS and other motor neuron diseases.

The bill defines “motor neuron diseases” to mean a group of progressive neurological conditions that destroy motor neurons, which are the cells that control skeletal muscle activity such as walking, breathing, speaking, and swallowing; and include amyotrophic lateral sclerosis, progressive bulbar palsy, primary lateral sclerosis, progressive muscular atrophy, spinal muscular atrophy, Kennedy’s disease, and post-polio syndrome.