

LEGISLATURE OF NEBRASKA
ONE HUNDRED SIXTH LEGISLATURE
SECOND SESSION

LEGISLATIVE BILL 1138

Introduced by Wishart, 27.

Read first time January 22, 2020

Committee: Health and Human Services

- 1 A BILL FOR AN ACT relating to disease; to establish a dementia registry;
- 2 and to provide powers and duties for the Department of Health and
- 3 Human Services.
- 4 Be it enacted by the people of the State of Nebraska,

1 Section 1. It is the intent of the Legislature to require the
2 establishment and maintenance of a dementia registry for the State of
3 Nebraska. The department shall exercise the necessary powers to implement
4 sections 1 to 9 of this act.

5 Sec. 2. For purposes of sections 1 to 9 of this act:

6 (1) Dementia means diseases and conditions characterized by a
7 decline in memory, language, problem solving, and other cognitive skills
8 that affect a person's ability to perform everyday activities. Dementia
9 includes, but is not limited to, disorders grouped under the general term
10 dementia, Alzheimer's disease, Creutzfeldt-Jakob disease, Down-syndrome-
11 related dementia and Alzheimer's disease, Lewy body dementia,
12 frontotemporal dementia, Huntington's disease, mixed dementia, normal-
13 pressure hydrocephalus, posterior cortical atrophy, Parkinson's-disease-
14 related dementia, vascular dementia, or Korsakoff syndrome;

15 (2) Dementia registry means the system of reporting established
16 under section 3 of this act in which the cases of dementia in this state
17 are reported and recorded in order to achieve the goals of prevention,
18 cure, and control of dementia through research and education; and

19 (3) Department means the Department of Health and Human Services.

20 Sec. 3. The department shall establish and maintain a dementia
21 registry that includes a record of the cases of dementia that occur
22 within the state and such information concerning these cases that the
23 department determines necessary and appropriate to provide a basic source
24 of information for further scientific and medical research for the
25 prevention, cure, and control of dementia. Any information released from
26 the registry shall be disclosed as Class I, Class II, Class III, or Class
27 IV data as provided in sections 81-663 to 81-675.

28 Sec. 4. In order to implement the intent and purposes of sections 1
29 to 9 of this act, the department shall:

30 (1) Compile and publish a statistical report annually containing
31 information obtained from the dementia registry in order to provide

1 accessible information useful to physicians, medical personnel, state
2 agencies, and the public. Such report shall comply with sections 81-663
3 to 81-675;

4 (2) Comply with all necessary requirements to obtain funds or
5 grants;

6 (3) Coordinate with existing statewide dementia registry programs to
7 the extent feasible;

8 (4) Execute any contracts the department deems necessary to carry
9 out the purposes of the dementia registry program;

10 (5) Receive and record data obtained from reports made available
11 under section 5 of this act;

12 (6) Conduct education and outreach efforts to increase awareness of
13 and participation in the dementia registry program; and

14 (7) Consult with medical professionals, hospital registries, and
15 medical records representatives in formulating the plans and policies of
16 the dementia registry program.

17 Sec. 5. (1) On the request of the department or its authorized
18 representative, each physician or osteopathic physician within the state
19 may produce and make available to the department or its authorized
20 representative, in a manner prescribed by the department, data that the
21 department determines is necessary and appropriate from each medical
22 record of dementia under the physician's custody or control.

23 (2) Each hospital within the state may make available to the
24 department or its authorized representative on presentation of proper
25 identification of the department's representative, a list of names of
26 dementia patients, corresponding medical records numbers, and medical
27 records which document the diagnosis and treatment of dementia on the
28 premises of the hospital, office, or clinic during normal working hours,
29 for the purpose of recording specific data about a patient's dementia.

30 (3) The data produced pursuant to subsection (1) of this section may
31 include, but not be limited to, the:

- 1 (a) Patient's name and contact information;
- 2 (b) Patient's date of birth, race, and sex;
- 3 (c) Date of diagnosis of dementia;
- 4 (d) Primary type of dementia;
- 5 (e) Stage of the dementia;
- 6 (f) Diagnostic confirmation; and
- 7 (g) Any additional information the department deems necessary and
- 8 appropriate to carry out the purposes of the dementia registry program.

9 Sec. 6. (1) All data obtained from medical records of individual
10 patients is for the confidential use of the department and the private or
11 public persons or entities that the department determines may view such
12 records as provided in sections 81-663 to 81-675.

13 (2) No patient-identifying data, as defined in section 81-664, may
14 be disclosed, made public, or released by the department.

15 (3) For purposes of protecting the public health, local public
16 health departments in Nebraska, health departments or dementia registries
17 located outside Nebraska, and the United States Department of Health and
18 Human Services may have access to the data contained in the dementia
19 registry upon the department's approval based on the entity's written
20 application.

21 Sec. 7. No hospital, physician, or osteopathic physician nor any
22 administrator, officer, or employee of such hospital or office of such
23 physician in which any such professional practices take place who is in
24 compliance with sections 1 to 9 of this act and sections 81-663 to 81-675
25 shall be civilly or criminally liable for divulging the information
26 pursuant to sections 1 to 9 of this act. The department or any of its
27 officials or employees shall not be liable civilly or criminally for the
28 release of information contained in the dementia registry or for the
29 conduct or activities of any individual or entity permitted access to the
30 dementia registry if access is permitted pursuant to sections 81-663 to
31 81-675.

1 Sec. 8. Sections 1 to 9 of this act shall not be deemed to compel
2 any individual to submit to any medical examination or supervision by the
3 department, any of its authorized representatives, or an approved
4 researcher. No person who seeks information or obtains registry data
5 pursuant to sections 1 to 9 of this act or sections 81-663 to 81-675
6 shall contact a patient on the dementia registry or such patient's family
7 unless the registry has first obtained the permission of such patient or
8 patient's family. The department shall coordinate the activities with the
9 person desiring such contact and may authorize the person desiring such
10 contact to make contact under the direction of the department.

11 Sec. 9. The department shall submit electronically an annual report
12 to the Health and Human Services Committee of the Legislature with
13 documentation on the operation and performance of the dementia registry
14 program established pursuant to sections 1 to 9 of this act.