SB

72

<TARGET><BILL>SB 72</BILL><SUBJECT>SB
72</SUBJECT><COMM>SHSS29</COMM></TARGET>

SENATE COMMITTEE REPORT
First Committee of Referral

DATE: 3/11/15

FURTHER: Labor and Commerce

Date of 5-Day Notice: _____
(in accordance with Uniform Rule 23)

DATE TURNED IN TO OFFICE: 2/3/16

Health and Social Services Committee considered SENATE BILL NO. 72

SB 72-DESIGNATED CAREGIVERS FOR PATIENTS

"An Act relating to caregivers of patients after release or departure from a hospital; and providing for an effective date."

and recommends:

[✓] be **replaced** with **CS** SB 72 (HSS) *[ ] Same Title [✓] New Title*

[ ] adopt **previous CS** _____ (_____) *[ ] Same Title [ ] New Title*

[ ] attached amendment(s)

[ ] adopt _____ Letter of Intent

[ ] further referral to _____ Committee

Dept Abbr.	
ADM	LWF
CED	LAW
COR	LEG
EED	MVA
DEC	DNR
DFG	DPS
GOV	REV
DHS	DOT
AJS	UA

NEW FISCAL NOTE(S)				
Dept.	Fiscal	Indet.	Zero	FN #
DHS			✓	1

PREVIOUS FISCAL NOTE(S)				
Dept.	Fiscal	Indet.	Zero	FN #

[ ] **APPROPRIATION - no fiscal note**

SIGNATURES AND RECOMMENDATIONS:	PRINTED LAST NAME	DO PASS	DO NOT PASS	NO REC	AMEND
	Giessel	✓			
	STOLTZE	✓			
	ELLIS			✓	
CHAIR:	STEDMAN			✓	

ALASKA STATE LEGISLATURE

716 W 4th Avenue
Anchorage AK 99501-2133
907-269-0181
Fax: 907-269-0184

State Capitol
Juneau AK 99801-1182
907-465-4843
Fax: 907-465-3871
800-892-4843

North to the Future

Senator Cathy Giessel

Senate District N

CS for Senate Bill 72(HSS) - CARE Act - Sponsor Statement

SB 72 seeks to improve post-discharge health outcomes by improving coordination with designated caregivers, providing training in aftercare, reducing preventable and costly hospital readmissions and enabling older Alaskans to stay in their own homes longer.

At any given time, around 88,000 Alaskans are providing some type of caregiving services and supports to a loved one, friend or neighbor. Lay caregivers are increasingly being asked to perform complex nursing and medical tasks - such as dispensing numerous medications, administering injections and providing wound care - often with inadequate skill training.

Caregivers are a critical link in the transitional care for frail adults and those with disabilities; with few exceptions, caregivers are responsible for providing and coordinating much of the care received at home following discharge.

Untrained and unsupported caregiving jeopardizes the patient's recovery, as well as often puts the caregiver at risk for their own injury and burnout, frequent symptoms of those caring for others.

SB 72 contains these important provisions:

- The patient is given the opportunity to name a lay caregiver, with his or her consent, to provide aftercare to them following discharge from a hospital
- The designated caregiver is notified of the patient's discharge or transfer to another facility as soon as practicable
- The hospital shall consult with the designated lay caregiver and offer training to the caregiver for aftercare medical and nursing tasks
- The hospital will adopt and maintain written discharge policies

The value of family caregiving in Alaska is valued at over a billion dollars a year....money that would otherwise likely have to come from the state coffers for paid caregiving in the home or in a facility.

SB 72 will help people continue to live independently at home and support the family caregivers who make this possible.

Senator_Cathy_Giessel@akleg.gov

ALASKA STATE LEGISLATURE

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Anchorage AK 99501-2133
907-269-0181

State Capitol
Juneau AK 99801-1182
907-465-4843
800-892-4843

North to the Future

Senator Cathy Giessel

Senate District N

CS for Senate Bill 72(HSS)
Draft vsn F
Sectional Overview

Section 1. AS 18.20 adds new sections:

Sec. 18.20.500: Requires hospital, before discharge, assess the patient, provide patient opportunity to designate a lay caregiver, and that the lay caregiver consents/agrees to provide patient with aftercare in the patient's home

Sec. 18.20.510: Requires a hospital to provide opportunity for lay caregiver to participate in the discharge planning of the patient; and that the hospital provide training and/or instruction on how to perform medical and nursing aftercare to the lay caregiver prior to patient's discharge

Sec. 18.20.520: Requires a hospital to notify the lay caregiver of the patient's discharge or transfer

Sec. 18.20.530: Directs the hospital to adopt and maintain written discharge policies. The policies must comply with this chapter. The written policy must specify requirements for naming of the designated lay caregiver and those policies may incorporate best practices for hospital discharge planning, such as those outlined in Center for Medicaid and Medicare Services (CMS) ….and that the discharge plan is appropriate for the patient's condition. The discharge plan may not delay a discharge or transfer of a patient or oblige hospital to divulge patient's health information to lay caregiver without patient's consent

Sec. 18.20.540: The hospital and its contractors are protected from lawsuit in regard to the discharge planning of a patient

Sec. 18.20.550: This chapter many not interfere with or supersede the powers/duties of an agent or legal guardian acting upon a health care directive

Sec. 18.20.590: Provides definitions

Section 2: effective date of January1, 2017.

29-LS0047\F
Bannister
1/26/16

CS FOR SENATE BILL NO. 72(HSS)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-NINTH LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH AND SOCIAL SERVICES COMMITTEE

Offered:
Referred:

Sponsor(s): SENATOR GIESSEL

A BILL

FOR AN ACT ENTITLED

"An Act relating to the discharge of patients from hospitals and to caregivers of patients after discharge from a hospital; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 18.20 is amended by adding new sections to read:

Article 5. Discharge of Hospital Patients.

Sec. 18.20.500. Aftercare assessment and designation of caregiver. Before discharging a patient, a hospital shall assess the patient's ability for self-care after discharge and provide the patient with the opportunity to designate a lay caregiver who agrees to provide aftercare for the patient in the patient's home after discharge.

Sec. 18.20.510. Planning, instruction, and training. (a) A hospital shall give the patient and the patient's designated lay caregiver the opportunity to participate in planning for the patient's discharge from the hospital.

(b) Before discharge, a hospital shall provide a patient and the patient's designated lay caregiver with instruction and training as necessary for the designated

lay caregiver to perform medical and nursing aftercare following discharge.

Sec. 18.20.520. Notification of discharge. A hospital shall notify a patient's designated lay caregiver of the patient's discharge or transfer.

Sec. 18.20.530. Discharge policies. (a) A hospital shall adopt and maintain written discharge policies. The policies must comply with AS 18.20.500 - 18.20.590.

(b) The discharge policies of a hospital must specify the requirements for documenting the identity of a patient's designated lay caregiver and the details of the discharge plan for the patient.

(c) The discharge policies of a hospital may incorporate established evidence-based practices that include

(1) standards for accreditation adopted by a nationally recognized hospital accreditation organization; or

(2) the conditions of participation for hospitals adopted by the Centers for Medicare and Medicaid Services.

(d) The discharge policies of a hospital must ensure that the discharge planning is appropriate to the condition of the patient, and the hospital shall interpret the discharge policies in a manner and as necessary to meet the needs and condition of the patient and the abilities of the patient's designated lay caregiver.

(e) AS 18.20.500 - 18.20.590 do not require that a hospital adopt discharge policies that would

(1) delay a patient's discharge or transfer to another facility; or

(2) require the disclosure of protected health information without obtaining a patient's consent as required by state and federal laws governing health information privacy and security.

Sec. 18.20.540. Construction of provisions. The provisions of AS 18.20.500 - 18.20.590 may not be construed to

(1) create a right of action against a hospital, a hospital employee, or a contractor of the hospital, including an instruction contractor, based on an action performed or not performed under AS 18.20.500 - 18.20.590; or

(2) replace, change, or otherwise affect rights or remedies that are provided under another provision of law, including common law.

Sec. 18.20.550. Coordination with other authority. AS 18.20.500 - 18.20.590 may not be interpreted to interfere with the powers or duties of

(1) an agent operating under a valid advance health care directive under AS 13.52; or

(2) a legal guardian of the individual.

Sec. 18.20.590. Definitions. In AS 18.20.500 - 18.20.590,

(1) "aftercare" includes

(A) assistance with the activities of daily living or activities that are instrumental to the activities of daily living;

(B) wound care, medication administration, medical equipment operation, mobility assistance, and other medical or nursing tasks; and

(C) other assistance related to the patient's condition at the time of discharge;

(2) "designated lay caregiver" means a lay caregiver designated by the patient who agrees to provide aftercare to the patient;

(3) "discharge" means a patient's release from a hospital following the patient's admission to the hospital;

(4) "hospital" has the meaning given in AS 18.20.130, but does not include a hospital that is limited to the treatment of mental disorders;

(5) "lay caregiver" means an individual who provides aftercare to a patient in the patient's home after the patient's discharge.

* **Sec. 2.** This Act takes effect January 1, 2017.

29-LS0047\P
Bannister
2/24/15

SENATE BILL NO. 72

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-NINTH LEGISLATURE - FIRST SESSION

BY SENATOR GIESSEL

Introduced:
Referred:

A BILL

FOR AN ACT ENTITLED

"An Act relating to caregivers of patients after release or departure from a hospital; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

* **Section 1.** AS 18.20 is amended by adding new sections to read:

Article 5. Caregivers of Hospital Patients after Discharge.

Sec. 18.20.500. Naming a caregiver. (a) Except as otherwise provided in this section, a hospital shall provide a patient or the patient's legal guardian with the opportunity to name a caregiver to provide aftercare to the patient in the patient's home after discharge from the hospital. The hospital shall provide the opportunity as soon as possible after the patient's admission to the hospital or after the patient recovers consciousness or capacity if the patient is unconscious or otherwise incapacitated at the time of the patient's admission to the hospital.

(b) If a hospital discharges a patient before 24 hours have elapsed under (a) of this section, the hospital shall provide the opportunity before discharge to name a

caregiver.

(c) To name an individual to be a caregiver under (a) or (b) of this section, a patient or the patient's legal guardian shall provide the hospital with the name, telephone number, and address of the individual.

(d) A patient or the patient's legal guardian may change the patient's named caregiver at any time before discharge.

(e) A patient or the patient's legal guardian is not required to name a caregiver.

(f) A named caregiver may be a relative, partner, friend, neighbor, or another individual who has a significant relationship with the patient.

(g) If a patient or the patient's legal guardian declines to name a caregiver under this section, the hospital does not have any further obligations under AS 18.20.500 - 18.20.590, except to perform the documentation required by AS 18.20.560(b).

(h) The hospital shall make a good faith effort to contact and confirm the name, telephone number, and address of the named caregiver within a reasonable time after the patient or the patient's legal guardian names the caregiver under this section.

new - added to this draft.

Sec. 18.20.510. Release of medical information. (a) If a patient names a caregiver under AS 18.20.500(c), the hospital shall promptly ask the patient or the patient's legal guardian to consent to the release of the patient's medical information by the hospital to the named caregiver. If the patient or the patient's legal guardian consents to the release, the hospital shall release the information to the named caregiver. The hospital shall comply with federal and state law on the release of medical information and follow the hospital's established procedures for releasing medical information.

(b) If a patient or the patient's legal guardian does not consent to the release of the patient's medical information under (a) of this section, the hospital is not required to contact the named caregiver under AS 18.20.500(h), to provide notice to the named caregiver under AS 18.20.520, or to provide information in the patient's discharge plan to the named caregiver under AS 18.20.540 or 18.20.550.

reworded from version N.

Sec. 18.20.520. Notice to named caregiver. A hospital shall notify a patient's named caregiver of the date and time when the hospital will discharge the patient or

transfer the patient to another hospital or facility as soon as possible after the hospital determines the anticipated date and time of the discharge or transfer.

Sec. 18.20.530. Caregiver not obligated. Even if a patient or the patient's legal guardian names an individual to be the patient's caregiver under AS 18.20.500(c), the named individual is not required to provide aftercare to the patient after the hospital discharges the patient.

Sec. 18.20.540. Discharge plan. (a) As soon as possible after the hospital determines the anticipated date and time of a patient's discharge, the hospital shall meet with the patient's named caregiver and the patient or the patient's legal guardian to prepare a discharge plan and to assess the named caregiver's ability to provide aftercare for the patient.

(b) A discharge plan must include, at a minimum,

(1) the name and contact information of the named caregiver;

(2) a description of the aftercare needed to maintain the patient's ability to live at home; the description must consider the capabilities and limitations of the named caregiver;

(3) contact information for health care, medical resources, community resources, long-term services, and support services that are available and necessary to carry out the discharge plan successfully; and

(4) contact information for a hospital or the instruction contractor representative who is able to respond to questions from the named caregiver about the discharge plan and the instruction provided under AS 18.20.550.

new to this version

Sec. 18.20.550. Caregiver instruction. (a) A hospital shall instruct a named caregiver on how to perform each of the tasks to be performed by the named caregiver under the discharge plan.

(b) The hospital may provide the instruction required by this section by using a person with whom the hospital has contracted to provide the instruction, if the instruction contractor or the instruction contractor's employees have the necessary education, competence, and licensing to provide the instruction. If the hospital provides the instruction through an instruction contractor, the hospital shall provide the named caregiver with the instruction contractor's name and contact information.

new to this version

(c) At a minimum, the instruction provided under (a) of this section must

(1) include a live or prerecorded visual demonstration of each task by an individual who is licensed or otherwise authorized to perform the task; if the hospital or the instruction contractor is not able to provide a live or prerecorded visual demonstration under this paragraph because of the situation of the patient or the named caregiver, the hospital or the instruction contractor may provide the information contained in the demonstration by electronic means or by telephone; and

(2) allow the named caregiver and the patient or the patient's legal guardian to ask questions about each task and the discharge plan.

(d) A hospital or the instruction contractor shall, as necessary,

(1) provide the instruction under (a) of this section in a manner that demonstrates an understanding of, communication with, and effective interaction with individuals of different cultures, including, notwithstanding a provision of AS 44.12.300 - 44.12.390 to the contrary, translation or other language access services; and

(2) comply with applicable federal law, including 25 U.S.C. 2901 - 2906 (Native American Languages Act).

(e) A hospital or the instruction contractor shall provide the instruction required by this section before the patient is discharged from the hospital unless the instruction would delay the discharge. If the instruction would delay the discharge, the hospital or the instruction contractor shall provide the instruction as soon as possible after the discharge.

Sec. 18.20.560. Recording obligations. (a) A hospital shall promptly record in a patient's medical record

(1) the naming of a caregiver, the relationship of the named caregiver to the patient, and the name, telephone number, and address of the named caregiver;

(2) a summary of the instruction given under AS 18.20.550, including, at a minimum, the date, time, and contents of the instruction;

(3) a change of the named caregiver to another individual, the relationship of the new named caregiver to the patient, and the name, telephone number, and address of the new named caregiver; and

(4) the hospital's efforts to contact the patient's named caregiver under AS 18.20.500(h). new

(b) If a patient or the patient's legal guardian declines to name a caregiver under this section, the hospital shall promptly document that fact in the patient's medical record.

Sec. 18.20.565. No delay of discharge or transfer. Compliance with the provisions in AS 18.20.500 - 18.20.590 is not required if compliance would delay the discharge of a patient or the transfer of a patient from a hospital to another hospital or facility.

Sec. 18.20.570. Construction of provisions. The provisions of AS 18.20.500 - 18.20.590 may not be construed to

(1) create a right of action against a hospital, a hospital employee, or a contractor of the hospital, including an instruction contractor, based on an action performed or not performed under AS 18.20.500 - 18.20.590; or

(2) replace, change, or otherwise to affect rights or remedies that are provided under another provision of law, including common law.

Sec. 18.20.580. Coordination with other authority. AS 18.20.500 - 18.20.590 may not be interpreted to interfere with the powers or duties of

(1) an agent operating under a valid advance health care directive under AS 13.52; or

(2) a legal guardian of the individual.

Sec. 18.20.585. Regulations. The Department of Health and Social Services may adopt regulations under AS 44.62 (Administrative Procedure Act) to implement AS 18.20.500 - 18.20.590.

Sec. 18.20.590. Definitions. In AS 18.20.500 - 18.20.590,

(1) "admission" means accepted by a hospital for medical care on an inpatient basis;

(2) "aftercare" means the assistance provided by a named caregiver to an individual under a discharge plan;

(3) "caregiver" means an individual who provides, without pay, aftercare to an individual;

(4) "discharge" means, after a patient's admission to a hospital, the patient's departure or release from the hospital to the patient's home;

(5) "discharge plan" means the discharge plan a hospital issues under AS 18.20.540;

(6) "home" means a dwelling that the patient considers to be the patient's home; in this paragraph, "dwelling" does not mean a rehabilitation facility, hospital, nursing home, assisted living facility, or group home;

(7) "hospital" has the meaning given in AS 18.20.130, but does not include a hospital that is limited to the treatment of mental disorders;

(8) "instruction contractor" means the person with whom the hospital has contracted under AS 18.20.550(b);

new to this version

(9) "legal guardian" means

(A) if the patient is under 18 years of age,

(i) a parent of the patient;

(ii) an individual who acts as a guardian of the patient by testamentary or court appointment under AS 13.26.030 - 13.26.085; or

(iii) if the patient is committed to the custody of the Department of Health and Social Services under AS 47.10 or AS 47.12, a person who is under a duty to exercise general supervision over the patient;

(B) an individual who acts as a guardian of the patient by testamentary or court appointment under AS 13.26.090 - 13.26.150;

(10) "named caregiver" means an individual named as a caregiver under AS 18.20.500(c).

* **Sec. 2.** The uncodified law of the State of Alaska is amended by adding a new section to read:

TRANSITION: REGULATIONS. The Department of Health and Social Services may adopt regulations necessary to implement AS 18.20.500 - 18.20.590, enacted by sec. 1 of this Act. The regulations take effect under AS 44.62 (Administrative Procedure Act), but not before January 1, 2016.

* **Sec. 3.** Section 2 of this Act takes effect immediately under AS 01.10.070(c).

* **Sec. 4.** Except as provided in sec. 3 of this Act, this Act takes effect January 1, 2016.

Fiscal Note

State of Alaska
2016 Legislative Session

Bill Version: SB 72
Fiscal Note Number:
() Publish Date:

Identifier: SB072-DHSS-SDSA-1-28-16
Title: DESIGNATED CAREGIVERS FOR PATIENTS
Sponsor: GIESSEL
Requester: Senate HSS

Department: Department of Health and Social Services
Appropriation: Senior and Disabilities Services
Allocation: Senior and Disabilities Services Administration
OMB Component Number: 2663

Expenditures/Revenues

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

	FY2017 Appropriation Requested	Included in Governor's FY2017 Request	Out-Year Cost Estimates				
OPERATING EXPENDITURES	**FY 2017**	**FY 2017**	**FY 2018**	**FY 2019**	**FY 2020**	**FY 2021**	**FY 2022**
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants & Benefits							
Miscellaneous							
Total Operating	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Fund Source (Operating Only)

None							
Total	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**

Positions

Full-time							
Part-time							
Temporary							

Change in Revenues							

Estimated SUPPLEMENTAL (FY2016) cost: 0.0 *(separate supplemental appropriation required)*
(discuss reasons and fund source(s) in analysis section)

Estimated CAPITAL (FY2017) cost: 0.0 *(separate capital appropriation required)*
(discuss reasons and fund source(s) in analysis section)

ASSOCIATED REGULATIONS

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? no
If yes, by what date are the regulations to be adopted, amended or repealed?

Why this fiscal note differs from previous version:

Updated for new fiscal year; no other changes.

Prepared By: Duane Mayes, Director — Phone: (907)296-2083
Division: Senior and Disabilities Servcies — Date: 01/04/2016 12:00 AM
Approved By: Sana Efird, Asst. Commissioner, Finance and Management Services — Date: 01/14/16
Agency: Health and Social Services

FISCAL NOTE ANALYSIS

STATE OF ALASKA
2016 LEGISLATIVE SESSION

BILL NO. SB072

Analysis

This bill requires a hospital to give a discharging patient the opportunity to name a caregiver to provide aftercare; a patient is not required to choose or name a caregiver, and the named caregiver is not obligated to provide aftercare. It requires a hospital to attempt to contact the named caregiver, notify the named caregiver of when the patient will be discharged, meet and instruct the named caregiver in aftercare tasks, and record this information in the patient's medical record. The hospital may contract out the duty to instruct the caregiver. The bill allows non-compliance with the provisions of the statute if compliance would delay discharge, and specifies that the provisions of the statute do not constitute a "right of action" against a hospital, its employees or contractors.

These provisions do not represent an additional cost to the Department.

Fiscal Note

State of Alaska
2015 Legislative Session

Bill Version: SB 72
Fiscal Note Number:
() Publish Date:

Identifier: SB072-DHSS-SDSA-04-05-15
Title: DESIGNATED CAREGIVERS FOR PATIENTS
Sponsor: GIESSEL
Requester: Senate Health & Social Services Committee

Department: Department of Health and Social Services
Appropriation: Senior and Disabilities Services
Allocation: Senior and Disabilities Services Administration
OMB Component Number: 2663

Expenditures/Revenues

Note: Amounts do not include inflation unless otherwise noted below. (Thousands of Dollars)

	FY2016 Appropriation Requested	Included in Governor's FY2016 Request	Out-Year Cost Estimates				
OPERATING EXPENDITURES	**FY 2016**	**FY 2016**	**FY 2017**	**FY 2018**	**FY 2019**	**FY 2020**	**FY 2021**
Personal Services							
Travel							
Services							
Commodities							
Capital Outlay							
Grants & Benefits							
Miscellaneous							
Total Operating	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**
Fund Source (Operating Only)							
None							
Total	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**	**0.0**
Positions							
Full-time							
Part-time							
Temporary							
Change in Revenues							

Estimated SUPPLEMENTAL (FY2015) cost: 0.0 *(separate supplemental appropriation required)*
(discuss reasons and fund source(s) in analysis section)

Estimated CAPITAL (FY2016) cost: 0.0 *(separate capital appropriation required)*
(discuss reasons and fund source(s) in analysis section)

ASSOCIATED REGULATIONS

Does the bill direct, or will the bill result in, regulation changes adopted by your agency? no
If yes, by what date are the regulations to be adopted, amended or repealed?

Why this fiscal note differs from previous version:

Not applicable, initial version

Prepared By: Duane Mayes, Director Phone: (907)269-2083
Division: Senior and Disabilities Services Date: 03/18/2015 12:00 AM
Approved By: Sarah Woods, Deputy Director Finance & Management Services Date: 04/05/15
Agency: Health & Social Services

FISCAL NOTE ANALYSIS

STATE OF ALASKA
2015 LEGISLATIVE SESSION

BILL NO. SB072

Analysis

This bill requires a hospital to give a discharging patient the opportunity to name a caregiver to provide aftercare; a patient is not required to choose or name a caregiver, and the named caregiver is not obligated to provide aftercare. It requires a hospital to attempt to contact the named caregiver, notify the named caregiver of when the patient will be discharged, meet and instruct the named caregiver in aftercare tasks, and record this information in the patient's medical record. The hospital may contract out the duty to instruct the caregiver. The bill allows non-compliance with the provisions of the statute if compliance would delay discharge, and specifies that the provisions of the statute do not constitute a "right of action" against a hospital, its employees or contractors.

These provisions do not represent an additional cost to the Department.

Good Afternoon.

My name is Terry Snyder. I am a resident of Palmer and serve as state president of AARP.

Thank you in advance for allowing me to testify today in support of SB72. First I would like to thank Senator Giessel for her leadership in bringing this important bill forward for all Alaskans and especially seniors.

There are over 88,000 non-paid or lay caregivers in Alaska. All of us either are, have been or will be a caregiver at some time in our lives. It may come as a surprise to many of us that family caregiving is more than just household chores and rides to the doctor. Family caregivers are often asked to perform medical/nursing tasks such as medication changes, wound care, operating medical equipment, nebulizers and **more** that can quickly become part of a daily routine.

Most older persons with long-term care needs–65%–rely exclusively on family and friends to provide assistance. Within our complex system of long-term care, especially women's caregiving is essential in providing a backbone of that support. The percentage of women 55 and older continue to increase in our Alaskan workforce. These are women that are very often taken out of that workforce to provide care for spouses, parents, parents-in-law, friends and neighbors, and they play many roles **while caregiving**–hands-on health provider, care manager, friend, companion, surrogate decision-maker and advocate.

The nearly inevitable disruption in employment is costly to business and often time can result in the caregivers own poverty. It is essential the patient and caregiver are provided with information that fosters confidence, skill and successful outcomes that in fact will save health care dollars in care delivery and those caregivers that **can** are able to return to the workforce.

As the baby boomers age, they will move from providing care to needing it. And because the next generation is smaller, the demand for and on family caregivers is sure to increase.

In order to successfully address the challenges of a surging population of seniors and others who have significant needs for long-term services and supports, the state must develop methods to enable caregivers to continue to support their loved ones at home and in the community, and avoid costly hospital readmissions.

- This bill will benefit Alaskans of all ages and will support the patient and caregiver with information that fosters confidence, skill and successful outcomes.
- It will continue to save health care dollars in care delivery and potentially fewer hospital readmissions
- It will not cost the state additional dollars

Again thank you for listening to my testimony today. I urge you **to as I do** lend your full support to SB 72 the designated caregivers act.

TABLE B1

Number of Family Caregivers and the Economic Value of Caregiving, by State, 2013

State	State Population	Number of Caregivers	Number of Care Hours (millions)	Economic Value per Hour	Total Economic Value (millions)
Alabama	4,830,000	761,000	708	$10.89	$7,720
Alaska	735,000	84,900	79	$15.05	$1,190
Arizona	6,630,000	804,000	749	$12.60	$9,430
Arkansas	2,960,000	452,000	421	$11.20	$4,710
California	38,300,000	4,450,000	4,140	$13.94	$57,700
Colorado	5,270,000	584,000	543	$13.68	$7,430
Connecticut	3,600,000	459,000	427	$13.87	$5,930
Delaware	926,000	123,000	114	$13.86	$1,580
District of Columbia	646,000	75,200	70	$12.44	$870
Florida	19,600,000	2,670,000	2,490	$11.93	$29,700
Georgia	9,990,000	1,330,000	1,240	$11.29	$14,000
Hawaii	1,400,000	154,000	144	$14.59	$2,100
Idaho	1,610,000	196,000	183	$12.06	$2,210
Illinois	12,900,000	1,560,000	1,450	$12.77	$18,500
Indiana	6,570,000	837,000	779	$12.17	$9,480
Iowa	3,090,000	317,000	295	$13.08	$3,860
Kansas	2,890,000	345,000	321	$12.01	$3,850
Kentucky	4,400,000	648,000	603	$11.57	$6,980
Louisiana	4,630,000	660,000	615	$10.53	$6,470
Maine	1,330,000	178,000	165	$13.41	$2,220
Maryland	5,930,000	771,000	717	$13.09	$9,390
Massachusetts	6,690,000	844,000	786	$14.75	$11,600
Michigan	9,900,000	1,280,000	1,190	$12.21	$14,500
Minnesota	5,420,000	585,000	544	$14.45	$7,860
Mississippi	2,990,000	501,000	467	$11.53	$5,380
Missouri	6,040,000	792,000	737	$11.52	$8,490
Montana	1,020,000	118,000	110	$12.97	$1,430
Nebraska	1,870,000	195,000	182	$13.81	$2,510
Nevada	2,790,000	348,000	324	$13.19	$4,270
New Hampshire	1,320,000	173,000	161	$14.42	$2,330
New Jersey	8,900,000	1,120,000	1,040	$13.07	$13,600
New Mexico	2,090,000	277,000	257	$12.19	$3,140
New York	19,700,000	2,580,000	2,400	$13.02	$31,300
North Carolina	9,850,000	1,280,000	1,190	$11.27	$13,400
North Dakota	723,000	62,100	58	$14.88	$860
Ohio	11,600,000	1,480,000	1,380	$11.95	$16,500
Oklahoma	3,850,000	524,000	488	$12.45	$6,070
Oregon	3,930,000	469,000	437	$13.06	$5,700
Pennsylvania	12,800,000	1,650,000	1,540	$12.47	$19,200
Rhode Island	1,050,000	134,000	124	$14.26	$1,780
South Carolina	4,770,000	706,000	657	$11.49	$7,550
South Dakota	845,000	84,600	79	$13.12	$1,030
Tennessee	6,500,000	981,000	913	$11.24	$10,300
Texas	26,400,000	3,350,000	3,120	$11.39	$35,500
Utah	2,900,000	336,000	313	$13.26	$4,150
Vermont	627,000	74,900	70	$14.55	$1,010
Virginia	8,260,000	1,030,000	956	$12.36	$11,800
Washington	6,970,000	828,000	771	$13.83	$10,700
West Virginia	1,850,000	282,000	263	$10.62	$2,790
Wisconsin	5,740,000	578,000	538	$13.15	$7,070
Wyoming	583,000	66,200	62	$13.27	$817
United States	**316,000,000**	**40,000,000**	**37,000**	**$12.51**	**$470,000**

Note: State numbers may not add up exactly to the U.S. totals because of rounding.

AARP Public Policy Institute
"Valuing the Invaluable: 2015 Update
- Senator Giessel

Elder care costs keep climbing; Alaska's highest in nation
Posted: Thursday, April 9, 2015 12:37 pm
Associated Press via Fairbanks Daily News-Miner

NEW YORK - The steep cost of caring for the elderly continues to climb.
The median bill for a private room in a nursing home is now $91,250 a year, according to an industry survey out Thursday.

The annual "**Cost of Care" report from Genworth Financial** tracks the staggering rise in expenses for long-term care, a growing financial burden for families, governments and insurers like Genworth. The cost of staying in a nursing home has increased 4 percent every year over the last five years, the report says. Last year, the median bill was $87,600.

"Most people don't realize how expensive this care can be until a parent or family member needs it," said Joe Caldwell, director of long-term services at the National Council on Aging. "And then it's a real shock."

The annual report from Genworth, which sells policies to cover long-term care, looks at costs for a variety of services, including adult daycare, and home health aides.
And it's nursing home bills that are rising at the fastest pace, double the rate of U.S. inflation over the last five years.
One year in a nursing home now costs nearly as much as three years of tuition at a private college.

For its report, Genworth **surveyed 15,000 nursing homes, assisted living facilities** and other providers across the country in January and February.
It found wide differences from state to state. In Oklahoma, for instance, the median cost for a year in a nursing home came out to $60,225. In Connecticut, it was $158,775.
Alaska had the highest costs by far, with one year at $281,415.

So, who pays the nursing-home bill? "A lot of people believe Medicare will step in and cover them, but that's just not true," said Bruce Chernoff, president and CEO of The Scan Foundation, a charitable organization. Medicare will cover some short visits for recovery after a surgery, for instance, not long-term stays.
Often enough, people wind up spending their savings until the last $2,000, and at that point Medicaid, the government's health insurance for the poor, starts covering the bill.

Less-intensive care remains much cheaper than staying at a nursing home, according to Genworth's survey. One year in in an assisted-living facility runs $43,200.
A year of visits from an agency's home health aides runs $45,760.

David Scott

From: Jane Conway
Sent: Thursday, January 28, 2016 11:34 AM
To: David Scott
Subject: explanation of changes SB 72 CARE Act
Attachments: changes - SB 72 -marked up P.pdf

Importance: High

Dave:
I have marked up the previous SB 72 from last session. See pdf.

Over the interim, we came up with a couple other versions, each time running them by ASHNHA and AARP, the two most pertinent stakeholders on the topic.

We finally ended up with this new version that ASHNHA feels comfortable with and now supports. It closely models the Oregon CARE Act .

The bill went from 7 pages to 3, which seems like a lot of change but **fundamentally the changes are more simple.**

The original bill put in statute the mandates and guidelines for the discharge plan – which took up a large portion of the bill – and now the language simply charges the hospitals to do these things:

- Assess patient's ability to take care of themselves, give them the opportunity to name a lay caregiver (who must consent)
- Gives the patient and caregiver opportunity to provide input to hospital on the plan for discharge
- Provide training and instruction necessary to the caregiver on how to perform tasks for aftercare of the patient following discharge
- Notify the caregiver about the upcoming discharge of the patient
- Mandates that the hospital adopt and maintain written discharge policies, but gives the hospital authority to develop its own policies for discharge, rather than all details to be mandated by statute.

The new bill still provides that the discharge policies cannot delay a patient's discharge, protects the hospital from liability relating to the discharge plan, cannot supersede the authority of a health care directive or a legal guardian. It also defines "aftercare" in more detail.

The effective date was requested by ASHNHA to give them ample time to organize their discharge planning policies and procedures.

Should also be noted that hospitals are expecting new CMS regulations on this topic to be hitting them soon, so SB 72 just gets this done even before and will put them already in compliance with that upcoming directive.

The new bill is broader and allows the hospitals greater berth in developing their own patient discharge policies, **keeping the main objective of the bill, which is to TRAIN THE CAREGIVER in techniques to help them care for the patient following discharge to the best of their abilities.**

This will, hopefully, reduce the number of readmissions to the hospital and keep patients at home under the loving care of their families.

Does this cover it for you and your boss Dave??
jmc

Jane Conway
Chief of Staff to Senator Cathy Giessel
Senate District N
Alaska State Capitol, Rm 427
Juneau, Alaska 99801
907-465-4843

SENATE BILL NO. 72

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-NINTH LEGISLATURE - FIRST SESSION

BY SENATOR GIESSEL

Introduced: 3/11/15
Referred: Health and Social Services, Labor and Commerce

A BILL

FOR AN ACT ENTITLED

"An Act relating to caregivers of patients after release or departure from a hospital; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 18.20 is amended by adding new sections to read:

Article 5. Caregivers of Hospital Patients after Discharge.

Sec. 18.20.500. Naming a caregiver. (a) Except as otherwise provided in this section, a hospital shall provide a patient or the patient's legal guardian with the opportunity to name a caregiver to provide aftercare to the patient in the patient's home after discharge from the hospital. The hospital shall provide the opportunity as soon as possible after the patient's admission to the hospital or after the patient recovers consciousness or capacity if the patient is unconscious or otherwise incapacitated at the time of the patient's admission to the hospital.

(b) If a hospital discharges a patient before 24 hours have elapsed under (a) of this section, the hospital shall provide the opportunity before discharge to name a

caregiver.

(c) To name an individual to be a caregiver under (a) or (b) of this section, a patient or the patient's legal guardian shall provide the hospital with the name, telephone number, and address of the individual.

(d) A patient or the patient's legal guardian may change the patient's named caregiver at any time before discharge.

(e) A patient or the patient's legal guardian is not required to name a caregiver.

(f) A named caregiver may be a relative, partner, friend, neighbor, or another individual who has a significant relationship with the patient.

(g) If a patient or the patient's legal guardian declines to name a caregiver under this section, the hospital does not have any further obligations under AS 18.20.500 - 18.20.590, except to perform the documentation required by AS 18.20.560(b).

(h) The hospital shall make a good faith effort to contact and confirm the name, telephone number, and address of the named caregiver within a reasonable time after the patient or the patient's legal guardian names the caregiver under this section.

Sec. 18.20.510. Release of medical information. (a) If a patient names a caregiver under AS 18.20.500(c), the hospital shall promptly ask the patient or the patient's legal guardian to consent to the release of the patient's medical information by the hospital to the named caregiver. If the patient or the patient's legal guardian consents to the release, the hospital shall release the information to the named caregiver. The hospital shall comply with federal and state law on the release of medical information and follow the hospital's established procedures for releasing medical information.

(b) If a patient or the patient's legal guardian does not consent to the release of the patient's medical information under (a) of this section, the hospital is not required to contact the named caregiver under AS 18.20.500(h), to provide notice to the named caregiver under AS 18.20.520, or to provide information in the patient's discharge plan to the named caregiver under AS 18.20.540 or 18.20.550.

Sec. 18.20.520. Notice to named caregiver. A hospital shall notify a patient's named caregiver of the date and time when the hospital will discharge the patient or

Now
Notification of Discharge

transfer the patient to another hospital or facility as soon as possible after the hospital determines the anticipated date and time of the discharge or transfer.

Sec. 18.20.530. Caregiver not obligated. Even if a patient or the patient's legal guardian names an individual to be the patient's caregiver under AS 18.20.500(c), the named individual is not required to provide aftercare to the patient after the hospital discharges the patient.

Sec. 18.20.540. Discharge plan. (a) As soon as possible after the hospital determines the anticipated date and time of a patient's discharge, the hospital shall meet with the patient's named caregiver and the patient or the patient's legal guardian to prepare a discharge plan and to assess the named caregiver's ability to provide aftercare for the patient.

Now "Discharge Policies"

(b) A discharge plan must include, at a minimum,

(1) the name and contact information of the named caregiver;

(2) a description of the aftercare needed to maintain the patient's ability to live at home; the description must consider the capabilities and limitations of the named caregiver;

(3) contact information for health care, medical resources, community resources, long-term services, and support services that are available and necessary to carry out the discharge plan successfully; and

(4) contact information for a hospital or the instruction contractor representative who is able to respond to questions from the named caregiver about the discharge plan and the instruction provided under AS 18.20.550.

Sec. 18.20.550. Caregiver instruction. (a) A hospital shall instruct a named caregiver on how to perform each of the tasks to be performed by the named caregiver under the discharge plan.

(b) The hospital may provide the instruction required by this section by using a person with whom the hospital has contracted to provide the instruction, if the instruction contractor or the instruction contractor's employees have the necessary education, competence, and licensing to provide the instruction. If the hospital provides the instruction through an instruction contractor, the hospital shall provide the named caregiver with the instruction contractor's name and contact information.

(c) At a minimum, the instruction provided under (a) of this section must

(1) include a live or prerecorded visual demonstration of each task by an individual who is licensed or otherwise authorized to perform the task; if the hospital or the instruction contractor is not able to provide a live or prerecorded visual demonstration under this paragraph because of the situation of the patient or the named caregiver, the hospital or the instruction contractor may provide the information contained in the demonstration by electronic means or by telephone; and

(2) allow the named caregiver and the patient or the patient's legal guardian to ask questions about each task and the discharge plan.

(d) A hospital or the instruction contractor shall, as necessary,

(1) provide the instruction under (a) of this section in a manner that demonstrates an understanding of, communication with, and effective interaction with individuals of different cultures, including, notwithstanding a provision of AS 44.12.300 - 44.12.390 to the contrary, translation or other language access services; and

(2) comply with applicable federal law, including 25 U.S.C. 2901 - 2906 (Native American Languages Act).

(e) A hospital or the instruction contractor shall provide the instruction required by this section before the patient is discharged from the hospital unless the instruction would delay the discharge. If the instruction would delay the discharge, the hospital or the instruction contractor shall provide the instruction as soon as possible after the discharge.

Sec. 18.20.560. Recording obligations. (a) A hospital shall promptly record in a patient's medical record

(1) the naming of a caregiver, the relationship of the named caregiver to the patient, and the name, telephone number, and address of the named caregiver;

(2) a summary of the instruction given under AS 18.20.550, including, at a minimum, the date, time, and contents of the instruction;

(3) a change of the named caregiver to another individual, the relationship of the new named caregiver to the patient, and the name, telephone number, and address of the new named caregiver; and

(4) the hospital's efforts to contact the patient's named caregiver under AS 18.20.500(h).

(b) If a patient or the patient's legal guardian declines to name a caregiver under this section, the hospital shall promptly document that fact in the patient's medical record.

Sec. 18.20.565. No delay of discharge or transfer. Compliance with the provisions in AS 18.20.500 - 18.20.590 is not required if compliance would delay the discharge of a patient or the transfer of a patient from a hospital to another hospital or facility.

SAME

Sec. 18.20.570. Construction of provisions. The provisions of AS 18.20.500 - 18.20.590 may not be construed to

(1) create a right of action against a hospital, a hospital employee, or a contractor of the hospital, including an instruction contractor, based on an action performed or not performed under AS 18.20.500 - 18.20.590; or

SAME

(2) replace, change, or otherwise to affect rights or remedies that are provided under another provision of law, including common law.

SAME

Sec. 18.20.580. Coordination with other authority. AS 18.20.500 - 18.20.590 may not be interpreted to interfere with the powers or duties of

(1) an agent operating under a valid advance health care directive under AS 13.52; or

SAME

(2) a legal guardian of the individual.

Sec. 18.20.585. Regulations. The Department of Health and Social Services may adopt regulations under AS 44.62 (Administrative Procedure Act) to implement AS 18.20.500 - 18.20.590.

NOT NEEDED

Sec. 18.20.590. Definitions. In AS 18.20.500 - 18.20.590,

(1) "admission" means accepted by a hospital for medical care on an inpatient basis;

(2) "aftercare" means the assistance provided by a named caregiver to an individual under a discharge plan;

(3) "caregiver" means an individual who provides, without pay, aftercare to an individual;

(4) "discharge" means, after a patient's admission to a hospital, the patient's departure or release from the hospital to the patient's home;

(5) "discharge plan" means the discharge plan a hospital issues under AS 18.20.540;

(6) "home" means a dwelling that the patient considers to be the patient's home; in this paragraph, "dwelling" does not mean a rehabilitation facility, hospital, nursing home, assisted living facility, or group home;

(7) "hospital" has the meaning given in AS 18.20.130, but does not include a hospital that is limited to the treatment of mental disorders;

(8) "instruction contractor" means the person with whom the hospital has contracted under AS 18.20.550(b);

(9) "legal guardian" means

(A) if the patient is under 18 years of age,

(i) a parent of the patient;

(ii) an individual who acts as a guardian of the patient by testamentary or court appointment under AS 13.26.030 - 13.26.085; or

(iii) if the patient is committed to the custody of the Department of Health and Social Services under AS 47.10 or AS 47.12, a person who is under a duty to exercise general supervision over the patient;

(B) an individual who acts as a guardian of the patient by testamentary or court appointment under AS 13.26.090 - 13.26.150;

(10) "named caregiver" means an individual named as a caregiver under AS 18.20.500(c).

*** Sec. 2.** The uncodified law of the State of Alaska is amended by adding a new section to read:

TRANSITION: REGULATIONS. The Department of Health and Social Services may adopt regulations necessary to implement AS 18.20.500 - 18.20.590, enacted by sec. 1 of this Act. The regulations take effect under AS 44.62 (Administrative Procedure Act), but not before January 1, 2016.

NOT NEEDED

* **Sec. 3.** Section 2 of this Act takes effect immediately under AS 01.10.070(c). NOT NEEDED

* **Sec. 4.** Except as provided in sec. 3 of this Act, this Act takes effect January 1, ~~2016~~ 2017 ASHNHA'S REQUEST

29-LS0047\F
Bannister
1/26/16

CS FOR SENATE BILL NO. 72(HSS)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-NINTH LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH AND SOCIAL SERVICES COMMITTEE

Offered:
Referred:

Sponsor(s): SENATOR GIESSEL

18.20 → HOSPITALS ! NURSING FACILITIES

A BILL

FOR AN ACT ENTITLED

"An Act relating to the discharge of patients from hospitals and to caregivers of patients after discharge from a hospital; and providing for an effective date."

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

*** Section 1.** AS 18.20 is amended by adding new sections to read:

Article 5. Discharge of Hospital Patients.

Sec. 18.20.500. Aftercare assessment and designation of caregiver. Before discharging a patient, a hospital shall assess the patient's ability for self-care after discharge and provide the patient with the opportunity to designate a lay caregiver who agrees to provide aftercare for the patient in the patient's home after discharge.

Sec. 18.20.510. Planning, instruction, and training. (a) A hospital shall give the patient and the patient's designated lay caregiver the opportunity to participate in planning for the patient's discharge from the hospital.

(b) Before discharge, a hospital shall provide a patient and the patient's designated lay caregiver with instruction and training as necessary for the designated

lay caregiver to perform medical and nursing aftercare following discharge.

Sec. 18.20.520. Notification of discharge. A hospital shall notify a patient's designated lay caregiver of the patient's discharge or transfer.

Sec. 18.20.530. Discharge policies. (a) A hospital shall adopt and maintain written discharge policies. The policies must comply with AS 18.20.500 - 18.20.590.

(b) The discharge policies of a hospital must specify the requirements for documenting the identity of a patient's designated lay caregiver and the details of the discharge plan for the patient.

(c) The discharge policies of a hospital may incorporate established evidence-based practices that include

(1) standards for accreditation adopted by a nationally recognized hospital accreditation organization; or

(2) the conditions of participation for hospitals adopted by the Centers for Medicare and Medicaid Services.

(d) The discharge policies of a hospital must ensure that the discharge planning is appropriate to the condition of the patient, and the hospital shall interpret the discharge policies in a manner and as necessary to meet the needs and condition of the patient and the abilities of the patient's designated lay caregiver.

(e) AS 18.20.500 - 18.20.590 do not require that a hospital adopt discharge policies that would

(1) delay a patient's discharge or transfer to another facility; or

(2) require the disclosure of protected health information without obtaining a patient's consent as required by state and federal laws governing health information privacy and security.

Sec. 18.20.540. Construction of provisions. The provisions of AS 18.20.500 - 18.20.590 may not be construed to

(1) create a right of action against a hospital, a hospital employee, or a contractor of the hospital, including an instruction contractor, based on an action performed or not performed under AS 18.20.500 - 18.20.590; or

(2) replace, change, or otherwise affect rights or remedies that are provided under another provision of law, including common law.

Sec. 18.20.550. Coordination with other authority. AS 18.20.500 - 18.20.590 may not be interpreted to interfere with the powers or duties of

(1) an agent operating under a valid advance health care directive under AS 13.52; or

(2) a legal guardian of the individual.

Sec. 18.20.590. Definitions. In AS 18.20.500 - 18.20.590,

(1) "aftercare" includes

(A) assistance with the activities of daily living or activities that are instrumental to the activities of daily living;

(B) wound care, medication administration, medical equipment operation, mobility assistance, and other medical or nursing tasks; and

(C) other assistance related to the patient's condition at the time of discharge;

(2) "designated lay caregiver" means a lay caregiver designated by the patient who agrees to provide aftercare to the patient;

(3) "discharge" means a patient's release from a hospital following the patient's admission to the hospital;

(4) "hospital" has the meaning given in AS 18.20.130, but does not include a hospital that is limited to the treatment of mental disorders;

(5) "lay caregiver" means an individual who provides aftercare to a patient in the patient's home after the patient's discharge.

* **Sec. 2.** This Act takes effect January 1, 2017.

ALASKA STATE LEGISLATURE

716 W 4th Avenue
Anchorage AK 99501-2133
907-269-0181
Fax: 907-269-0184

State Capitol
Juneau AK 99801-1182
907-465-4843
Fax: 907-465-3871
800-892-4843

North to the Future

Senator Cathy Giessel

Senate District N

Senate Bill 72 - CARE Act - Sponsor Statement

SB 72 seeks to improve post-discharge health outcomes by improving coordination with designated caregivers, providing training to them on discharge tasks, reducing preventable and costly hospital readmissions and enabling older Alaskans to stay in their own homes longer.

At any given time, around 88,000 Alaskans are providing some type of caregiving services and supports to a loved one, friend or neighbor. Caregivers are increasingly being asked to perform complex nursing and medical tasks - such as dispensing numerous medications, administering injections and providing wound care - often with inadequate skill training.

Caregivers are a critical link in the transitional care for frail adults and those with disabilities; with few exceptions, caregivers are responsible for providing and coordinating much of the care received at home following discharge.

Untrained and unsupported caregiving jeopardizes the patient's recovery, as well as often puts the caregiver at risk for their own injury and burnout, frequent symptoms of those caring for others.

SB 72 contains three important provisions:

- The name of a caregiver is recorded when a loved one is admitted into a hospital facility, if the patient so desires to name a caregiver.
- The designated caregiver is notified of the patient's discharge home or transfer to another facility as soon as practicable
- The hospital must attempt to consult with the designated caregiver about the discharge plan describing the patient's aftercare needs and offer training to the caregiver for aftercare tasks.

The value of family caregiving in Alaska is valued at over a billion dollars a year....money that would otherwise likely have to come from the state coffers for paid caregiving in the home or in a facility.

Unsupported caregivers are more likely to experience burnout, develop their own health problems, or see their loved one moved into a facility for more expensive care. Most of all, SB 72 will help people continue to live independently at home, and will support the family caregivers who make this possible.

Senator_Cathy_Giessel@akleg.gov

ALASKA STATE LEGISLATURE

716 W 4th Avenue
Anchorage AK 99501-2133
907-269-0181
Fax: 907-269-0184

State Capitol
Juneau AK 99801-1182
907-465-4843

Fax: 907-465-3871

North to the Future

Senator Cathy Giessel

Senate District N

Sectional Analysis

Senate Bill 72 Designated Caregivers for Patients

Sec. 1: Amends 18.20 by adding a new section:

Article 5: Caregivers of Hospital Patients after Discharge

Sec. 18.20.500 Naming a caregiver. Gives a patient the opportunity to name a caregiver to provide aftercare following discharge and outlines the details of that process.

Section 18.20.510 Release of medical information. This section provides hospital to ask for patient consent to release the patient's medical info to the caregiver. (b) allows for the patient to prohibit the release of the medical records, thereby releasing the hospital from its obligation to notify or inform a caregiver.

Section 18.20.520 Notice to named caregiver. Requires the hospital to notify the named caregiver of the planned discharge date and time or of a transfer to another facility as soon as it can.

Section 18.20.530 Caregiver not obligated. This section says that if a person is named by the patient as the caregiver, that person has the right to refuse the designation.

Section 18.20.540 Discharge plan. Requires the hospital to prepare a discharge plan for the patieint and assesses the named caregiver's skills to provide the prescribed aftercare to the patient. It outlines what needs to be included in the discharge plan and provides a hospital contact or hospital contractor contact who can answer questions the caregiver might have.

Section 18.20.550 Caregiver instruction. Requires a hospital or hospital contractor to instruct a named caregiver on the tasks outlined in discharge plan for aftercare.

The section outlines the various means by which this can be done and that the instruction must be culturally sensitive and comply with federal law. It requires that the training be done before the discharge if possible, unless that would delay the discharge; in that event the training can take place as soon as possible after the patient's discharge.

Section 18.20.560 Recording obligations. This section outlines what must be recorded in the patient's medical record.

Section 18.20.565 No delay of discharge or transfer. This section states that the required caregiver instruction cannot delay a patient's discharge or transfer to another facility.

Section 18.20.570 Construction of provisions. States that the provisions of this bill do not create a liability for the hospital, a hospital contractor or employee for their performance or non performance of tasks.

Section 18.20.580 Coordination with other authority. The provisions in this bill do not override the duties of an agent under an advance health care directive or the powers or duties of a legal guardian.

Section 18.20.585 Regulations. Gives the Department of Health and Social Services the authority to write regulations to carry out the provisions of this bill.

Section 18.20.590 Definitions. Provides 10 definitions of terms used in the bill.

Sec. 2 Adds a new section that gives the Department of Health and Social Services the authority to adopt regulations necessary to implement the provisions of the bill and that the regulations will take effect on January 1, 2016.

Sec. 3 Allows the Department to begin the regulation process immediately

Sec. 4 Provisions of the bill are effective on January 1, 2016.

AARP Real Possibilities in Alaska

3601 C Street, #1420 | Anchorage, AK 99503
1-866-227-7447 | Fax: 907-341-2270 | TTY: 1-877-434-7598
aarp.org/ak | ak@aarp.org | twitter: @aarpalaska
facebook.com/AARPAK

March 19, 2015

Sen. Cathy Giessel
Alaska State Capitol, Room 427
Juneau, AK 99801

Re: SB 72 – Designated Caregivers for Patients – SUPPORT

Dear Sen. Giessel,

On behalf of AARP Alaska's 86,000 members, many of whom are caregivers, we are pleased to support SB 72, Designated Caregivers for Patients. This bill addresses a specific problem many unpaid caregivers face with providing complex care to a loved one discharged back home from a hospital, and ensures that three critical things happen to make a hospital discharge to home more successful and less stressful, for both the patient and the caregiver: (1) designation, (2) notification and (3) education.

First, designation: the hospital inquires of the patient (or their representative) if there is someone who will be providing post-discharge aftercare at home. It could be a family member, friend, or even a neighbor. The hospital is not obligated to find a caregiver where there is none, and a named person is not obligated to accept the role of caregiver. Certainly not all patients will require assistance of a family member. If the patient identifies such a person, the hospital records the name and contact information in the patient's record and the patient is asked for permission to share medical information with the named caregiver.

Second, notification: as soon as practicable, the named caregiver is notified of the patient's planned discharge. This gives the caregiver the time needed to stock supplies, make necessary home modifications, and otherwise attend to the myriad tasks necessary to assume responsibility for their charge.

Third, education: upon notification the caregiver is offered live or recorded visual instruction on how to perform the tasks identified in the discharge plan and answer any questions the caregiver might have pertaining to performance of the care tasks. If the named caregiver declines instruction, the hospital has no further obligation.

By ensuring these three critical things happen, SB 72 will benefit not just caregivers and the care recipients, but also hospitals (through lower readmission rates) and the state (through family caregivers providing a service that would otherwise fall in the public realm).

Caregiving for a family member, friend or neighbor is a daunting and sacrificial undertaking, filled with uncertainties and anxiety. In Alaska, at any given time there are about 88,000 unpaid or "lay" caregivers providing some level of support to another person. A 2011 report by the AARP Public Policy Institute valued the unpaid care provided by Alaskan caregivers at 1.1 billion dollars annually, a figure certain to be larger today as Alaska's older population continues to grow at a rate that leads the nation. Without this army of family/friend

caregivers, the responsibility for care and for paying for it would shift increasingly to the state. We believe it is not only right, but fiscally prudent to support and strengthen family caregivers.

Families remain the most important source of support to older individuals, even though many family members wouldn't even identify themselves as a "caregiver," but rather just see themselves doing what any other family member would do. Nevertheless, people who take on this task for a loved one experience stress, financial hardship, physical strain, competing demands, and consequently are themselves highly vulnerable to physical and emotional problems.

A recent study by AARP Public Policy Institute, the Hartford Foundation, and United Hospital Fund (*Home Alone: Family Caregivers Providing Complex Chronic Care*, 2012), found that increasingly family caregivers report performing medical/nursing tasks for care recipients with complex physical and/or cognitive conditions. These tasks can include managing multiple medications, providing wound care, giving injections, providing mobility and transfer assistance, and operating specialized medical equipment...in addition to more customary tasks of assisting with activities of daily living and personal care. And most caregivers reported they received little or no training to perform these tasks.

More than half (57%) of family caregivers who reported that they felt pressured to take on medical/nursing tasks said they did not feel they had a choice. Of these, 43% felt they had a personal responsibility (there was no one else to do it, or insurance would not cover it). Family caregivers who performed medical/nursing tasks were most likely to believe they were making an important contribution, primarily preventing nursing home placement (51%).

Most care recipients (69%) did not have a have a home visit by a health care professional. Even when professional home care is part of the discharge plan there is a window of 24-48 hours before the home care agency is to make their initial visit. A lot can go wrong for a patient and their caregiver in that period of time.

Family caregivers who performed medical/nursing tasks were most likely to report feeling stressed and worried about making a mistake. More than half reported feeling down, depressed, or hopeless in the last two weeks, and more than a third reported fair or poor health. These negative impacts increased with the number of the care recipients' chronic conditions.

SB72 sets out relatively simple steps in hospital procedure that can make a very significant difference for a family caregiver. Although some hospitals are actively developing just such procedures (and they should be commended for doing so), others are not. For any caregiver to be expected to assume responsibility for complex care of a loved one without proper preparation or demonstration of the tasks is unreasonable. In this time of severely diminished state resources, we firmly believe strengthening families for self-sufficiency is prudent public policy and good health practice.

Thank you, Sen. Giessel, for your leadership with SB 72. We encourage passage and enactment.

Sincerely,

Ken Helander
Advocacy Director

Terry Snyder
AARP Alaska State President

AMERICAN LUNG ASSOCIATION®
IN ALASKA

500 W Int'l Airport Road
Suite A
Anchorage AK 95518
Phone: (907) 276-5864
Fax: (907) 565-5587

www.aklung.org

March 23, 2015

To Whom it May Concern:

I am writing in support of Senate Bill 72 (SB72) Designated Caregivers for Patients, as introduced by Senator Cathy Giessel.

The mission of the American Lung Association is to save lives by improving lung health and preventing lung disease through education, advocacy and research.

This bill aligns with one of our mission goals, to reduce the burden of lung disease on patients and their families.

Chronic Obstructive Pulmonary Disease (COPD) is just one lung disease that afflicts senior Alaskans. COPD is the fourth leading cause of death in Alaska, and it's a leading cause of disability across the country.

800-LUNG-USA
(800-586-4872)

Managing a chronic lung disease takes a team, including doctors, respiratory therapists, pharmacists, patients, and patient caregivers. This bill would ease the burden of lung disease on patients and their families by facilitating communication between caregivers, patients, and physicians.

Sincerely,

Marge Stoneking
Executive Director

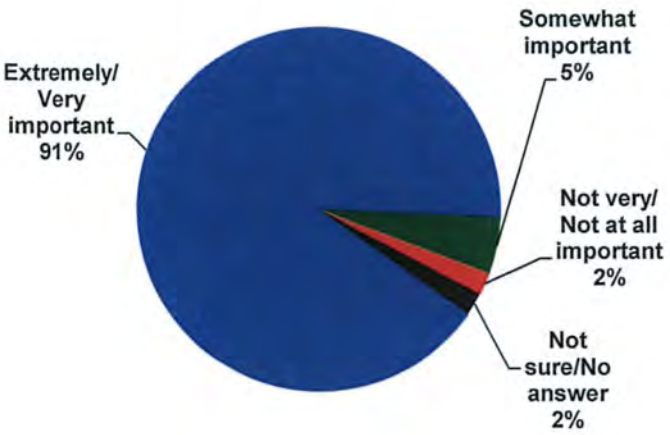
2015 AARP Caregiving Survey: Opinions of Alaska Registered Voters Age 45 and Older Who Are Family Caregivers

Most Alaska registered voters age 45 and older have experiences as family caregivers, or believe they are likely to be caregivers in the future. Alaska registered voters age 45 and older say they have provided care—either currently (18%) or in the past (38%)—on an unpaid basis for an adult loved one who is ill, frail, elderly or who has a disability. Of those who have never provided care, one half say they are at least somewhat likely they will do so. **Typical current family caregivers in Alaska are women (57%) and over 55 years old (72%). They are likely to be married (78%), have some college education (58%), and are employed (50%). The average age of the person they care for is 73 years old.**

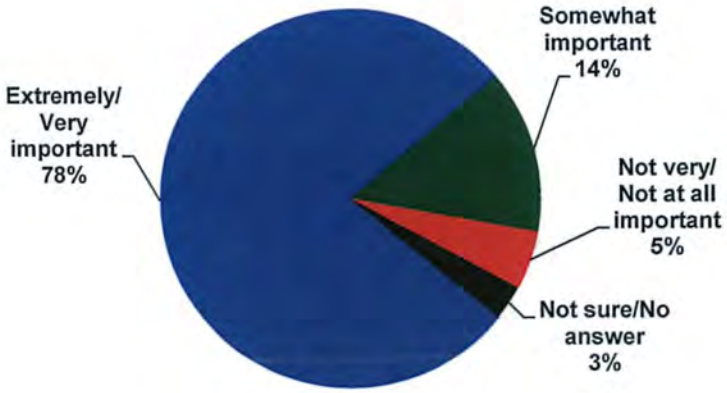
Both current and former caregivers have provided care in a myriad of ways, with more than two-thirds assisting with complex care like medication management (69%) and other medical tasks (67%). More than eight in ten have helped loved ones in their care with household management activities like shopping (87%), preparing meals (86%), chores (84%) and transportation (82%). Two-thirds are also helping to manage finances for their loved ones (66%).

Many (57%) current and past caregivers say it is likely that they will need to provide care again in the future. As such, nearly all of these caregivers believe it is important to be able to provide care so that their loved ones can keep living independently in their own home. Many also say having more caregiver resources and training that allows family caregivers to continue to provide in-home care is important.

**Importance of Being Able to Care So Loved Ones Can Live Independently*
(n=397, Respondents Who Are Current or Past Caregivers)**



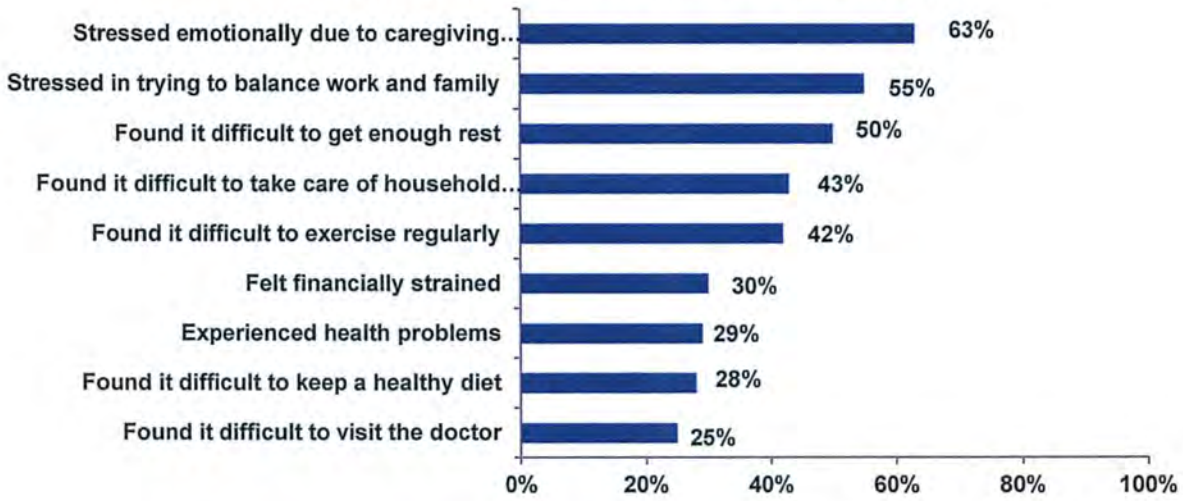
**Importance of Having More Resources and Training for Caregivers*
(n=397, Respondents Who Are Current or Past Caregivers)**



*Due to rounding the chart may not total 100%

Alaska respondents who are current or past caregivers report feeling emotionally (63%) and financially stressed (30%). They are also stressed about not being able to take care of their needs and the needs of their other family members. Caregivers report they are finding it difficult to get rest (50%), exercise regularly (42%), keep a healthy diet (28%), or visit their own doctor (25%). They also express feeling stressed about trying to balance their work and family (55%) and take care of their household (43%).

Experiences of Alaska Caregivers Age 45-Plus*
(n=397, Respondents Who Are Current or Past Caregivers)



*Graph shows respondents who responded "yes" to each type of stressor.

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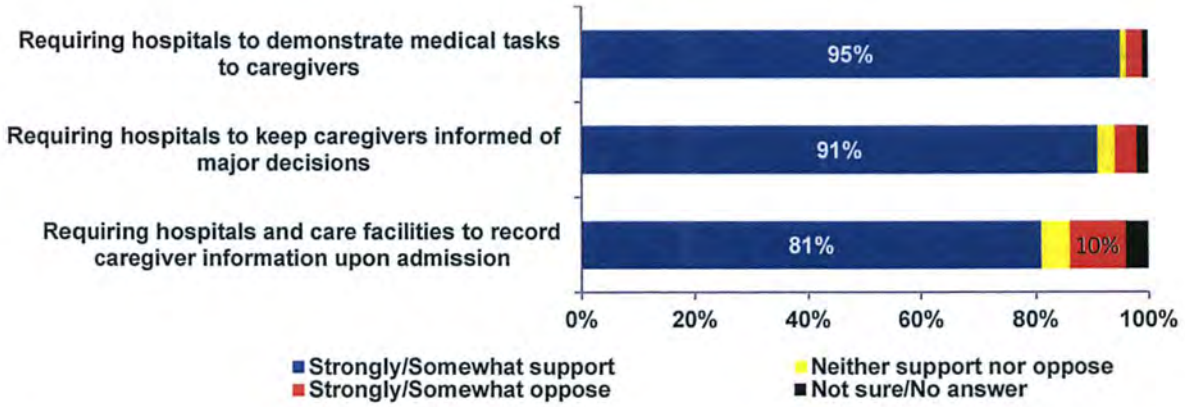
2015 AARP Caregiving Survey: Opinions of Alaska Registered Voters Age 45 and Older on Support for The Caregiver Advise, Record, Enable (CARE) Act

More than 80 percent of Alaska registered voters age 45 and older supports measures in The Caregiver Advise, Record and Enable (CARE) Act, which will help unpaid family caregivers when their loved ones go into the hospital and as they transition home. The bill features three important provisions that require hospitals to provide instructions on the medical tasks the family caregiver may need to perform at home, keep a family caregiver informed of major decisions, like transferring or discharging the patient, and to engage with caregivers by recording the name of the family caregiver when a loved one is admitted into a hospital.

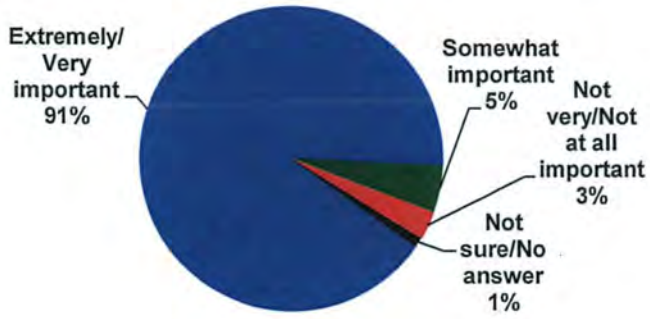
Support for Proposals to Help Family Caregivers When Loved Ones Go into Hospitals Among Alaska Registered Voters Age 45+* (N=800)



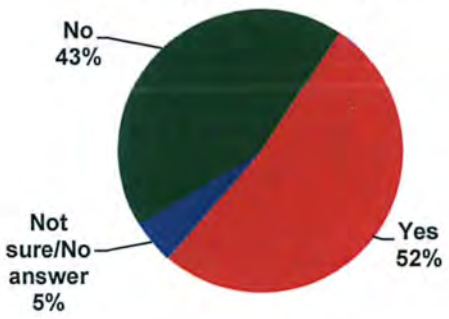
*Percentages less than 10 percent are not shown.

More 90 percent of Alaska registered voters age 45 and older who are current or past caregivers say it is important for them to receive training or instruction on medical tasks they may need to perform upon hospital discharge of a loved one. Seven in ten of these caregivers indicated that a loved one or family member was hospitalized during a period of time while they were providing care. Of those caregivers, four in ten say they did not receive a live demonstration of any medical tasks that they would need to perform.

Importance of Receiving Training or Instruction on Medical Tasks To Be Performed After Hospitalization of Loved Ones (n=397 Respondents Who Are Current or Past Caregivers)

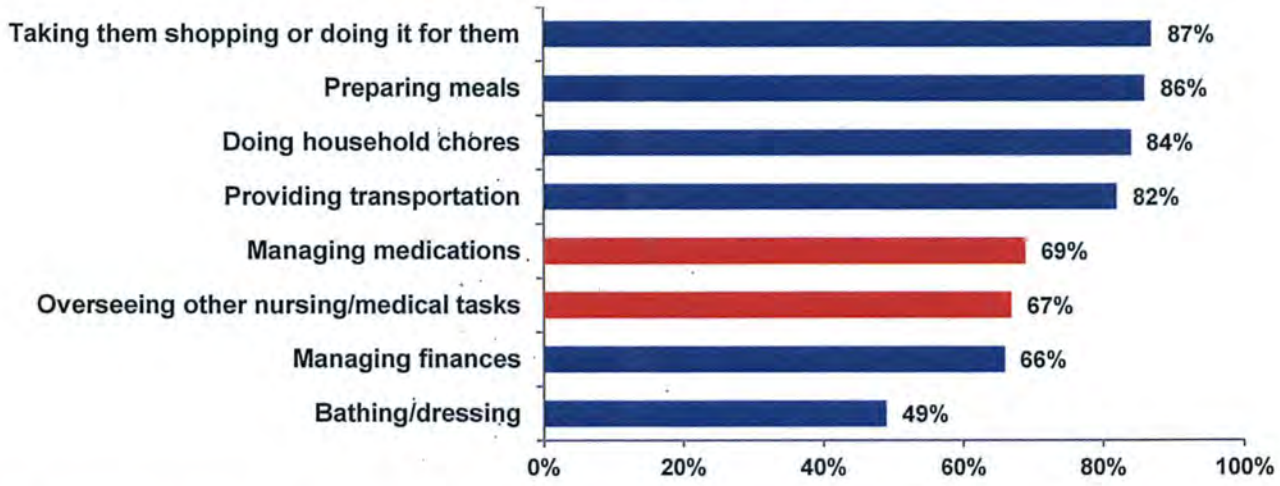


Was Live Demonstration of Medical Tasks Given Prior to Discharge of Loved Ones? (n=279 Current or Past Caregivers Who Had A Loved One That Was Hospitalized)



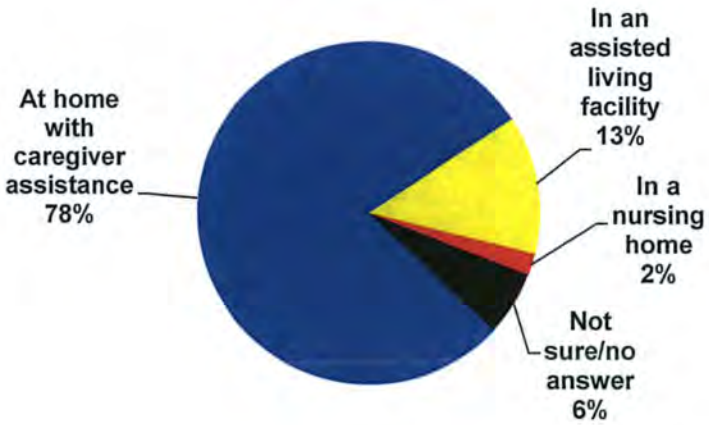
Both current and former caregivers have provided care in a myriad of ways, with more than two-thirds assisting with complex care like medication management (69%) and other medical tasks (67%). More than eight in ten have helped loved ones in their care with household management activities like shopping (87%), preparing meals (86%), chores (84%) and transportation (82%). Two-thirds are also helping to manage finances for their loved ones (66%).

Daily Activities that Alaska Caregivers Age 45+ Are Providing or Have Provided (n=397 Respondents Who Are Current or Past Caregivers)

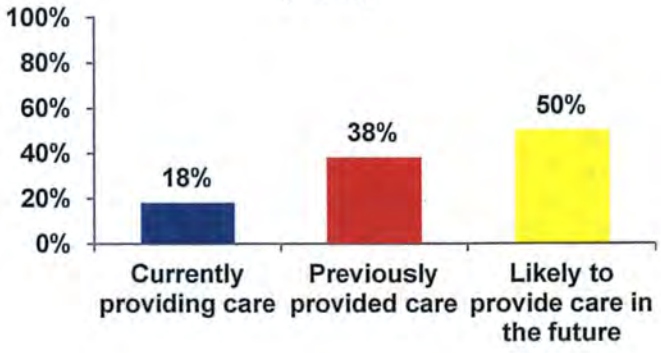


Most Alaska registered voters age 45 and older have experiences as family caregivers, or believe they are likely to be caregivers in the future. Alaska registered voters age 45 and older say they have provided care—either currently (18%) or in the past (38%)—on an unpaid basis for an adult loved one who is ill, frail, elderly or who has a disability. Of those who have never provided care, one half say they are at least somewhat likely they will do so. **Typical current family caregivers in Alaska are women (57%) over 55 (72%). They are likely to be married (78%), have some college (58%), and be employed (50%). The average age of the person they care for is 73 years old.**

Where Do Alaska Registered Voters Age 45+ Want to Live When Basic Life Tasks Become More Difficult? (n=800)

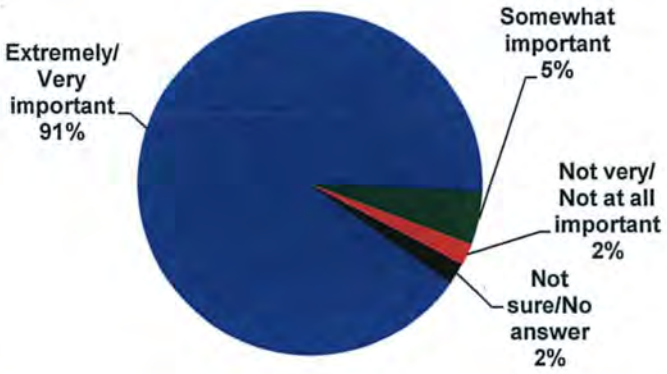


Are Alaska Registered Voters Age 45+ Currently Providing or Have They Provided Unpaid Care to an Adult Loved One? (n=800)

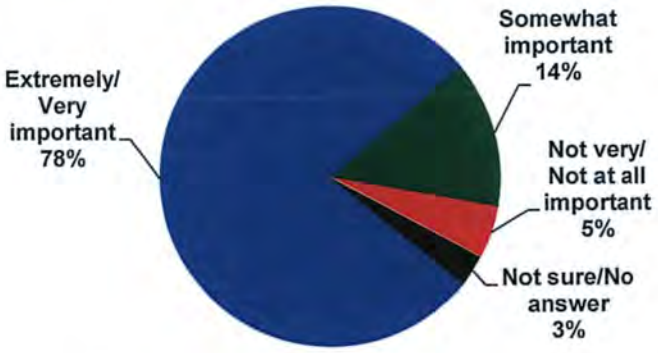


Many (57%) current and past caregivers say it is likely that they will need to provide care again in the future. As such, nearly all of these caregivers believe it is important to be able to provide care so that their loved ones can keep living independently in their own home. Many also say having more caregiver resources and training that allows family caregivers to continue to provide in-home care is important.

Importance of Having Services that Allow People to Stay in Their Own Homes as They Age (n=397, Respondents Who Are Current or Past Caregivers)

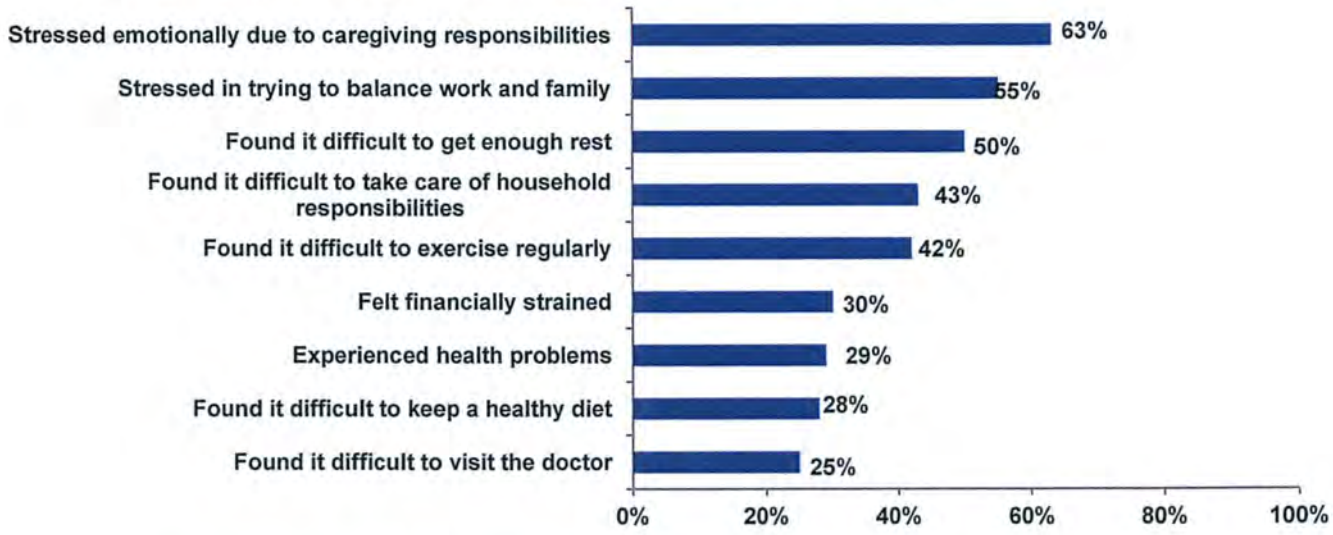


Importance of Having More Resources and Training for Caregivers (n=397, Respondents Who Are Current or Past Caregivers)



Many Alaska caregivers age 45+ are still working either full or part-time. Alaska respondents who are current or past caregivers report feeling emotionally (63%) and financially stressed (30%). They are also stressed about not being able to take care of their needs and the needs of their other family members. Caregivers report they are finding it difficult to get rest (50%), exercise regularly (42%), keep a healthy diet (28%), or visit their own doctor (25%). They also express feeling stressed about trying to balance their work and family (55%) and take care of their household (43%).

Experiences of Alaska Caregivers Age 45+* (n=397, Respondents Who Are Current or Past Caregivers)



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AARP Alaska commissioned a telephone survey of 800 registered voters age 45 and older to learn about their experiences with family caregiving. This report highlights results from registered voters interviewed between February 24th and March 6th, 2014. The data has been not weighted. The survey has a margin of error of ±3.5 percent. The survey annotation will be made available at www.aarp.org

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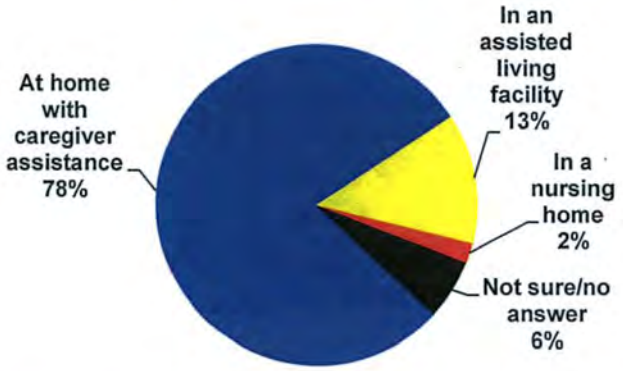
2015 AARP Caregiving Survey of Alaska Registered Voters Age 45 and Older: Living Independently

Most Alaska registered voters age 45 and older have experiences as family caregivers, or believe they are likely to be caregivers in the future. Alaska registered voters age 45 and older say they have provided care—either currently (18%) or in the past (38%)—on an unpaid basis for an adult loved one who is ill, frail, elderly or who has a disability. Of those who have never provided care, one half say they are at least somewhat likely they will do so. **Typical current family caregivers in Alaska are women (57%) and over 55 years old (72%). They are likely to be married (78%), have some college education (58%), and are employed (50%). The average age of the person they care for is 73 years old.**

Where Do Alaska Registered Voters Age 45+ Want to Live When Basic Life Tasks Become More Difficult? (n=800)



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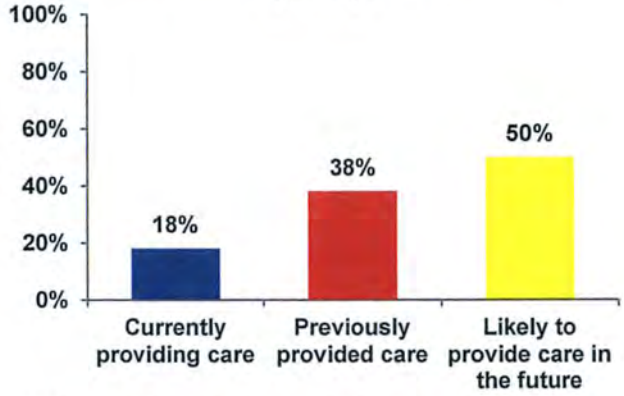
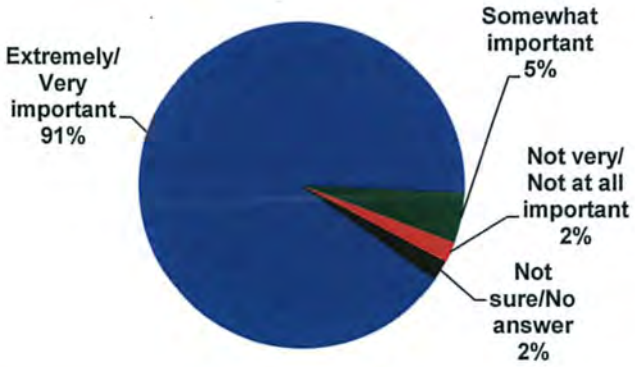


Many (57%) current and past caregivers say it is likely that they will need to provide care again in the future. As such, nearly all of these caregivers believe it is important to be able to provide care so that their loved ones can keep living independently in their own home. Many also say having more caregiver resources and training that allows family caregivers to continue to provide in-home care is important.

Importance of Having Services that Allow People to Stay in Their Own Homes as They Age* (n=397, Respondents Who Are Current or Past Caregivers)



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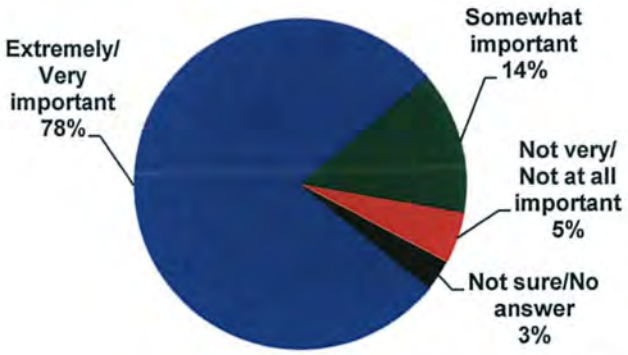
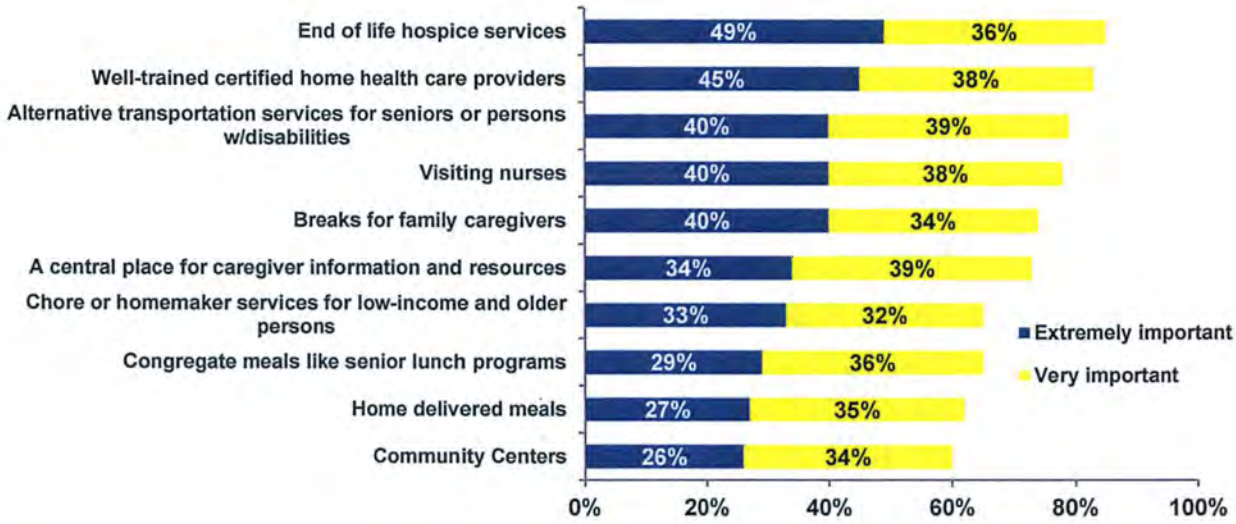


Among the top community services that Alaska registered voters age 45 and older believe are extremely or very important to help people remain in their own homes as they age are hospice (85%), well-trained certified home health care providers (83%), special transportation services (79%), visiting nurses (78%), breaks for family caregivers (74%), a central place for caregiving information (73%), congregate meals (65%), chore or homemaker services (65%).

Top Community Services of Importance to Alaska Registered Voters Age 45-Plus (N=800)



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AARP Research

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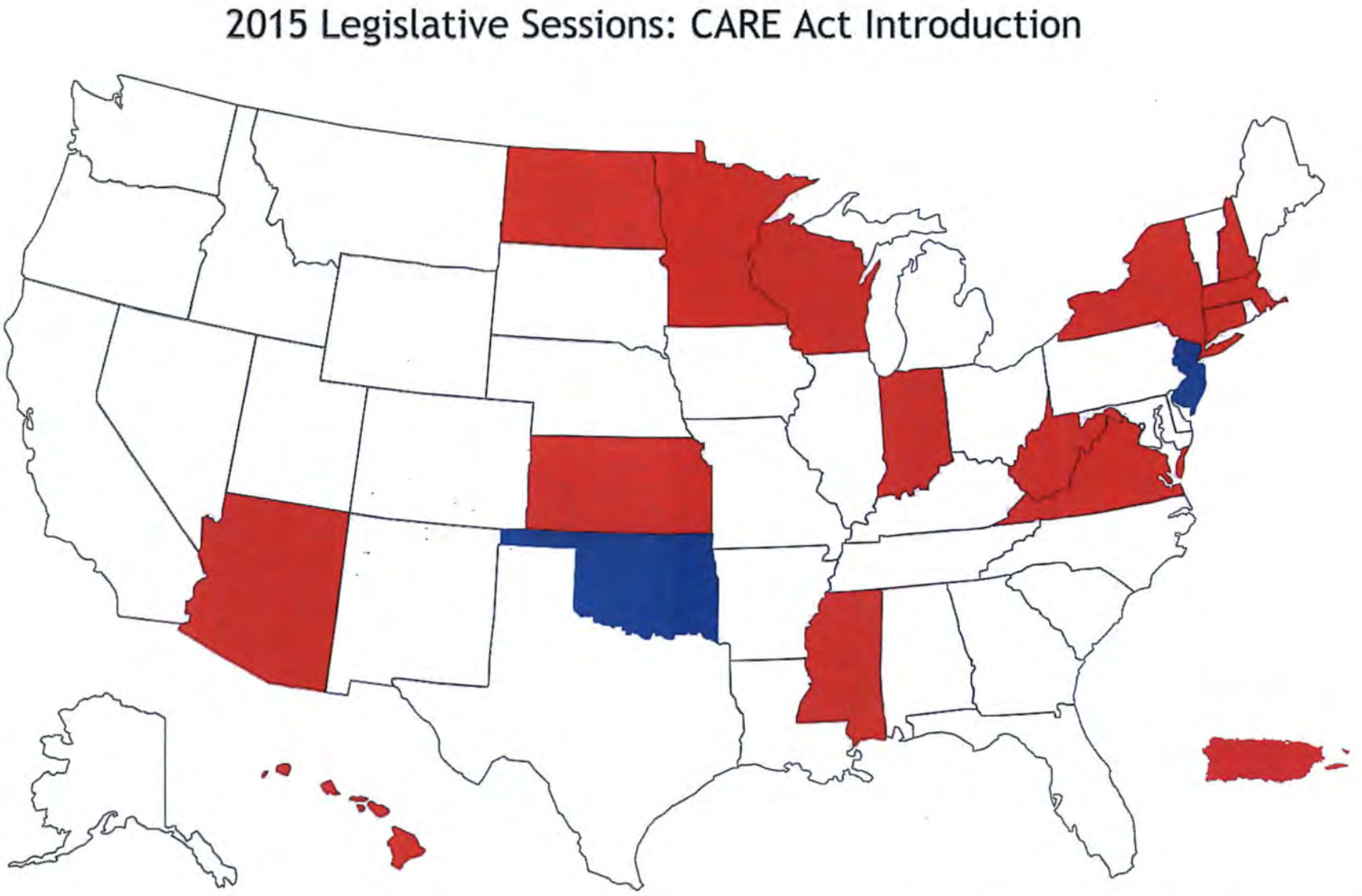
States where CARE Act legislation has been introduced in red. States that have passed the CARE Act are in blue. Map provided by AARP national office.



*New Jersey and Oklahoma passed the CARE Act in 2014.

Helping the Helpers

New state laws support the millions of Americans who minister to aging relatives and form the backbone of the nation's long-term care system.

BY JULIA C. MARTINEZ

When Kristen Mitchem's father was diagnosed with a malignant brain tumor in 2013, the North Carolina pastry chef quit her dream job at a five-star restaurant to help care for him in Oklahoma.

After several surgeries, Alphus Mitchem needed round-the-clock attention to recuperate at home, where patients report a higher quality of life.

Overnight, Kristen, her mother and sister joined the ranks of the 42.1 million family caregivers who form the backbone of the nation's long-term care system. Their work entails much more than cooking, cleaning and doctors' trips.

Today, nearly half of them also manage medication, monitor feeding tubes, dress wounds and perform other tasks normally done by health care professionals. Valued at $450 billion a year, family caregiving is a critical component of the U.S. economy, outstripping public spending for Medicaid in 2012.

"I didn't consider it a sacrifice to leave my job," Kristen Mitchem says. "When you spend your whole life with your parents taking care of you, it's something I didn't think twice about."

Still, because she's not trained as a caregiver, Kristen says the job has been frustrating at times and has caused setbacks for her father.

With the nationwide shift to home-based care from institutional care, family caregivers like the Mitchems lack supports, including flexibility, training and respite care, which could lead to caregiver burnout.

Numerous studies show demand for long-term services and supports will soon outpace the availability of potential family caregivers, according to data from AARP's Public Policy Institute, the National Alliance for Caregiving and other organizations.

The looming shortage of caregivers reflects a rapidly aging population, longer lifespans, a preference for home-based care, the need for more chronic disease care and changes in family demographics. Adding to this are the leading edge of baby boomers, who will turn 69 this year. Many never married or have fewer children to care for them than did their parents.

"If you look at the ratio of people who need care and people available to care for them, we're looking at a sleigh ride going downhill," says Susan Reinhard, director of AARP's Public Policy Institute. "It's a steep decline over the next 20 to 30 years. We have fewer people available to care for people who need it."

Without unpaid family caregivers, the economic cost of long-term care to state and federal governments would be a larger burden on Medicaid budgets.

To head off a potential crisis—and in the absence of a substantial federal long-term care strategy—state legislatures are finding ways to help fill the gap.

Julia C. Martinez is a freelance writer and former Denver Post reporter.

Representative Brian Crain Oklahoma

"I have a lot of sympathy for the plight of caregivers who care for loved ones being released from a hospital."

CARE Acts in New Jersey, Oklahoma

Lawmakers in New Jersey and Oklahoma enacted versions of the Caregiver Advise, Record and Enable, or CARE Act, effective in 2014. The law requires hospitals, when a patient is admitted and with his or her consent, to record the caregiver's name; to notify that caregiver before the patient is discharged; and to help prepare the caregiver for the medical or nursing tasks he or she is being asked to perform for the patient at home.

The ultimate aim is to keep patients healthy

Representative Harold Wright Oklahoma

after discharge and to avoid costly readmissions. Nationally, one in five Medicare recipients who leaves a hospital is readmitted within the first 30 days, costing Medicare $17.5 billion a year in additional hospital bills.

The Centers for Medicare and Medicaid Services started penalizing hospitals in 2012 with lower reimbursements for readmissions within a month of discharge as part of the federal government's effort to pay health care providers based on the quality of care they perform.

Oklahoma Senator Brian Crain (R), sponsor of the CARE Act, along with Representative Harold Wright (R), says the law was personal. Both his parents died of Alzheimer's disease within a decade of one another. His father cared for Crain's mother during her illness.

Speaker Vincent Prieto New Jersey

"I see how difficult it is for caregivers. It is a learning process, and there are a lot of things they don't have at their disposal."

"Caregiving was hard on dad," Crain says. "From that standpoint, I have a lot of sympathy for the plight of caregivers who care for loved ones being released from a hospital."

Assembly Speaker Vincent Prieto (D), who sponsored New Jersey's more detailed CARE Act along with Senator Joseph Vitale (D), says he, too, understands the toll caregiving can take. His elderly mother-in-law lives in her own home and is being cared for by his wife.

"I see how difficult it is for caregivers," Prieto says. "It is a learning process, and there are a lot of things they don't have at their disposal. Somebody needs to help them out ... so they can help our elderly be healthy and live to their full potential."

Both lawmakers say their states will benefit from fewer hospital readmissions.

Hospitals' Response

Initially, hospitals in both states had concerns they would be held legally liable if caregivers did not provide proper care and believed the legislation was an unnecessary mandate. New Jersey's association also had concerns that the bill's original provisions could delay a patient's discharge.

Senator Joseph Vitale New Jersey

"We didn't support it because we felt we were doing this already," says Lynne White, spokeswoman for the Oklahoma Hospital Association. But "at the end of the day, we withdrew our opposition," she says. "If we can go the extra step to make our services more patient friendly, that's what we want to do."

New Jersey's hospital association said it took a neutral position after working closely with AARP and the bill sponsors. "It was a very collaborative and productive discussion and we ultimately came up with final language that was beneficial to the patient and that all sides were happy with," says Kerry McKean Kelly, spokeswoman for the association.

Crain and Prieto indicated that hospitals in their states took a softer tone after realizing that the legislation could reduce readmissions and associated penalties. "That was certainly a conversation and selling point we had with the hospital association," Crain says.

In Hawaii, however, lawmakers sponsoring a CARE Act bill were blocked by the Healthcare Association of Hawaii, which took issue with the bill's basic premise. "AARP wants hospitals to train unqualified people to perform complex clinical, medical and nursing tasks," says George Greene, president and CEO of the association. "It makes no sense to force hospitals to do this, and it is not safe for patients."

AARP disagrees. "We can't ignore the fact that right now, family caregivers are cleaning wounds, giving injections, managing complex

FAMILY CAREGIVER AWARDS

To recognize the state elected officials who were integral in creating legislation in 2014 to support family caregivers, AARP honored the following legislators and governors with "2014 Capitol Caregiver" awards.

Senator Hannah-Beth Jackson, California
Assembly Speaker Toni Atkins, California
Assemblywoman Cheryl Brown, California
Governor Dannel Malloy, Connecticut
Senator Terry B. Gerratana, Connecticut
Representative Theresa W. Conroy, Connecticut
Representative Jason Perillo, Connecticut
Representative Valerie J. Longhurst, Delaware
Senator Suzanne Chun Oakland, Hawaii
Senator Rosalyn Baker, Hawaii
Senator Vaneta Becker, Indiana
Senator Ed Charbonneau, Indiana
Representative Edward Clere, Indiana
Senator Patricia Miller, Indiana
Senator Robert Hogg, Iowa
Representative Chip Baltimore, Iowa
Senator Morgan McGarvey, Kentucky
Senator Reginald Thomas, Kentucky
Representative Joni L. Jenkins, Kentucky
Representative Tommy Thompson, Kentucky
Representative Robert A. Johnson, Louisiana
Senator Gale D. Candaras, Massachusetts
Representative Anne M. Gobi, Massachusetts
Representative Christopher M. Markey, Massachusetts
Representative James O'Day, Massachusetts
Senator Sandra L. Pappas, Minnesota
Senator Kathy Sheran, Minnesota
Representative Carly Melin, Minnesota
Representative Dan Schoen, Minnesota
Senator Terry C. Burton, Mississippi
Senator Briggs Hopson, Mississippi
Representative Mark Baker, Mississippi
Representative Bobby Moak, Mississippi
Senator Kate Bolz, Nebraska
Senator Sue Crawford, Nebraska
Senator Robert W. Singer, New Jersey
Senator Joseph F. Vitale, New Jersey
Assembly Speaker Vincent Prieto, New Jersey
Assemblywoman Nancy F. Munoz, New Jersey
Senator Michael Padilla, New Mexico
Representative Tomás Salazar, New Mexico
Governor John Kasich, Ohio
Governor Mary Fallin, Oklahoma
Senator Brian A. Crain, Oklahoma
Representative Harold Wright, Oklahoma
Senator Thomas Alexander, South Carolina
Representative Rebecca Chavez-Houck, Utah
Senator Brian Shiozawa, Utah
Delegate Barbara Evans Fleischauer, West Virginia

medications and much more," says Elaine Ryan, vice president for state advocacy and strategy at AARP.

The hospital group was also concerned that a CARE Act could cost Hawaii's public hospitals millions of dollars in additional staff and liability protection.

Nonetheless, Hawaii Senator Suzanne Chun Oakland (D), the Senate sponsor, says she is not giving up on the bill, particularly since the average Hawaii resident lives so long—the average lifespan is 81 years on the islands, compared to the U.S. average of 78 years.

Caregivers Unprepared

Oklahoma's CARE Act came too late for Kristen, her mother Cheryl and her sister Deidra, who learned through trial and error the complex tasks involving medication management, feeding tubes, wound care and other tasks normally performed by trained health care professionals. "They never showed me anything. We have learned to care for my husband by watching the health providers," Cheryl Mitchem says.

Weeks after 72-year-old Alphus Mitchem was discharged from the hospital the first time, Cheryl says her husband was rushed back with seizures because she and her daughters weren't aware of certain medicines he should have been taking. Since then, she says, at least one other return trip also was triggered by a lack of instruction.

The Mitchems' story illustrates the plight of millions of family caregivers nationwide: Some 46 percent face difficult medical and nursing tasks for which they are unprepared, says Kathy Kelly, CEO of the Family Caregiver Alliance, a national research and advocacy organization.

Family caregiving can also take a personal and financial toll. Many caregivers lose earnings, pensions and Social Security benefits and spend down their savings.

"There are many people who put their personal and financial lives on hold to care for a loved one," Kelly says. "You're providing care for a person who needs it but impoverishing someone else in the process." Those who earn less than $40,000 are at greatest financial risk, she says.

Senator Suzanne Chun Oakland Hawaii

"If we do not make this a top priority, there will be a crisis."

Family caregivers learn quickly that most employer-provided health insurance does not cover long-term care. Neither does Medicare, which helps pay up to 100 days in a skilled nursing facility under certain conditions or part-time home health care. To get Medicaid long-term care coverage, a person must meet specific income and asset criteria that vary from state to state.

Other States Consider CARE Act

Illinois and Kansas are among about a dozen states considering CARE Act legislation.

Elsewhere, legislatures in Delaware, Hawaii, Mississippi and New Mexico formed committees last year to study how their states support family caregivers and how they can help more, while a dozen state legislatures passed a variety of related initiatives. Among them was Rhode Island, which expanded the state's disability insurance program to cover family leave, similar to laws that have been adopted in California, Minnesota and New Jersey in previous years.

In rural and underserved areas, where doctors are often scarce, lawmakers have supported family caregivers by passing legislation that expands nurses' roles. In some of the states, including Kentucky, the laws expand nurse practitioners' scope of practice, enabling them to prescribe certain medications without a collaborative agreement with a doctor. Other states, like West Virginia, now allow nurses to delegate tasks to caregivers.

In Alabama, a state coalition worked to expand its respite care for family caregivers. California, Massachusetts, Mississippi and Wyoming passed laws to protect the interests of vulnerable, incapacitated adults who need guardians.

Increasing Demand

Research leaves no doubt that an aging population will require more care.

A U.S. Department of Health and Human Services study concluded that more than 70 percent of people age 65 and older will need long-term care services for an average of three years. Some 40 percent have a chance of entering a nursing home. Another study in 2010 by AARP found there were seven potential caregivers for each adult over age 80. By 2050, that ratio could drop to three to one.

There has been little action at the federal level. The 2000 National Family Caregiver Support Program provides annual grants to states to support some family caregivers, but funding has stayed at roughly $155 million or less, despite the increasing demand.

In 2010, Congress passed a law to provide training and support for family members who care for post-9/11 military veterans. This pool of family caregivers comprises about 2.6 percent of the whole. Other comprehensive bills are pending but face uncertain odds.

AARP's Reinhard argues that state initiatives "are the first line of defense against institutionalization." They will help family caregivers avoid burnout and care for their loved ones at home and in the community more efficiently and effectively, she says.

However, "substantive action varies tremendously from state to state," says John Schall, CEO of the Caregiver Action Network in Washington, D.C. "Some states have figured out the importance of supporting family caregivers," while others have not.

Hawaii's Senator Chun Oakland wants her state to be in the former category.

"If we do not make this a top priority, there will be a crisis," says Chun Oakland, who proposes that caregiving be taught in schools. "We need to build our capacity, so we do not have our kupuna [elders] and other vulnerable people left with no support."

As state legislatures reset their agendas for the coming year, Reinhard offers this thought for state lawmakers: "You're either a caregiver now or will need one in the future. Caregiving will affect you personally and directly. States need to prepare for the future and at a faster pace than we're doing it now."

FAMILY CAREGIVERS By the Numbers

66%
Portion of family caregivers who are female, 34 percent of whom care for two or more people

19%
Portion who report receiving some training but want more

78%
Portion who report needing more help with at least 14 different caregiving topics

20.4 hours
Average time caregivers spend each week providing care

72%
Portion who live within 20 minutes of their care recipient

$4,570
Annual related expenses for caregivers who live near their loved one

$8,728
Long-distance caregivers' annual related expenses

11%
Those who report that providing care has harmed their own physical health

24 %
Portion who report caregiving has harmed their work performance and shortened their time spent at work

70%
Portion of working caregivers who have made some job change due to caregiving

Sources: AARP, The National Alliance for Caregiving, Gallup Surveys, 2012-2014.

In Brief

AARP Public Policy Institute

CELEBRATING 25 years

Home Alone: Family Caregivers Providing Complex Chronic Care

Susan C. Reinhard, RN, PhD
AARP Public Policy Institute

Carol Levine, MA, and Sarah Samis, MPA
United Hospital Fund

Produced by the AARP Public Policy Institute (PPI) and the United Hospital Fund with support from The John A. Hartford Foundation

In a recent national survey, almost half (46 percent) of family caregivers reported performing medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions. These tasks include managing multiple medications, providing wound care, preparing food for special diets, using monitors, and operating specialized medical equipment. These tasks were in addition to assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Most caregivers said that they received little or no training to perform these medical/nursing tasks.

Family caregivers have traditionally provided assistance with bathing, dressing, eating, and household tasks such as shopping and managing finances. While these remain critically important to the well-being of care recipients, the role of family caregivers has dramatically expanded to include performing medical/nursing tasks of the kind and complexity once provided only in hospitals and nursing homes and by home care professionals. This change has occurred because of the prevalence of chronic conditions in an aging population, economic pressures to reduce hospital stays, and the growth of in-home technology. Formal home care services are short-term and limited.

To document and analyze this major shift, PPI and the United Hospital Fund (UHF) undertook the first nationally representative population-based online survey of 1,677 family caregivers. Caregiver age, socioeconomic status, and education were similar to demographics reported in other national surveys. The care recipients were older (average age 75), mostly female, and mostly Medicare beneficiaries.

This *In Brief* provides highlights of the survey results and recommendations that are fully addressed in the Research Report, *Home Alone: Family Caregivers Providing Complex Chronic Care*, released by PPI and UHF in October 2012. The report explores the complexity of tasks that caregivers provide and challenges the common perception of family caregiving as a set of personal care and household chores that most adults already do or can easily master.

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KEY FINDINGS

Family Caregivers Perform Complicated Medical/Nursing Tasks

The most commonly performed medical/nursing tasks were medication management (78 percent), help with assistive mobility devices (43 percent), preparing food for special diets (41 percent), and wound care (35 percent).

Even though the number of family caregivers saying that they operate medical equipment, such as mechanical ventilators and tube feeding systems, was small (14 percent), 49 percent reported it as hard to do. These family caregivers are performing tasks in a home environment that would challenge even seasoned professionals.

Caregivers Are Responsible for Complex Medication Management

Many family caregivers managed many different kinds of medications. Three out of four (78 percent) family caregivers who performed medical/nursing tasks were managing medications, including administering intravenous fluids and injections.

Almost half were administering five to nine prescription medications a day. Medication management was reported to be difficult because it took so much time, it created anxieties about making a mistake, and some care recipients were uncooperative.

Most family caregivers learned how to manage at least some of the medications on their own. Despite frequent emergency department visits and overnight hospital stays, few family caregivers reported receiving assistance and training from health professionals.

Training Is Limited for Often Challenging Wound Care

More than a third (35 percent) of family caregivers who provided medical/nursing tasks reported doing wound care such as ostomy care and postsurgical dressing changes. While fewer caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as difficult because of fear of making a mistake and discomfort with the level of bodily intrusiveness required.

Family caregivers who deemed wound care difficult received more training from health professionals than did caregivers doing medication management. About a third reported some training by a hospital nurse or physician, and a quarter received training from a home care nurse, but most did not get any training to perform these tasks. Four out of ten family caregivers performing wound care thought more training would help them.

Family Caregivers Feel They Have No Choice

More than half (57 percent) of family caregivers who reported that they felt pressured to take on medical/nursing tasks said they did not feel they had a choice. Of these, many (43 percent) felt they had a personal responsibility (there was no one else to do it, or insurance would not cover it). And some cited pressure from the care recipient (12 percent) or another family member.

Most Care Recipients Do Not Receive Home Visits by Health Professionals

Most care recipients (69 percent) did not have home visits by a health care professional. Of those who did have home visits, roughly seven in ten were visited by a nurse. Twenty-seven percent of caregivers reported no additional help at home.

Family Caregivers Often Serve as Primary Care Coordinators

Family caregivers of chronically ill persons frequently served as care coordinators. More than half (53 percent) of family caregivers who performed medical/nursing tasks coordinated care—twice the rate of those who mainly provided ADL or IADL care.

Very few family caregivers (3 percent) reported working with a care manager from an insurance company or government program or hiring a private geriatric care manager.

Performing Medical/Nursing Tasks May Prevent Nursing Home Placement

Family caregivers who performed medical/nursing tasks were most likely to believe they were making an important contribution, primarily preventing nursing home placement (51 percent). The more medical/nursing tasks they performed, the more likely they were to report this positive effect.

Quality of Life Is Affected

Family caregivers performing medical/nursing tasks were most likely to report feeling stressed and worried about making a mistake. They were also more likely to report talking to so many health care professionals and suppliers as a source of stress. More than half reported feeling down, depressed, or hopeless in the last two weeks, and more than a third reported fair or poor health. These negative impacts increased with the number of the care recipients' chronic conditions.

MAJOR RECOMMENDATIONS

The report highlights an urgent need for both individual and collective action to help family caregivers better cope with handling medical/nursing tasks at home. If adopted, these recommendations should result in consistently improved home care and fewer hospitalizations.

The report notes that no single profession or health care provider is solely responsible for ensuring that family caregivers are trained and supported. This challenge requires the coordinated efforts of all sectors—hospitals, home care agencies, community agencies, nursing homes, hospices, and physician and other clinician practices—and a level of teamwork that challenges attitudes and behaviors firmly entrenched in the current system.

Based on the survey findings, the report recommends the following:

- Because health care professionals' and policymakers' understanding of family caregiving and eligibility of care recipients is typically based on measures of ADLs and IADLs, a consensus-building body should revisit these measures to acknowledge the types of tasks described in this report. The measures commonly used for a half-century no longer adequately capture what family caregivers do.[1] The Institute of Medicine is particularly well suited to this kind of consensus-building effort.
- Individual health care professionals must fundamentally reassess and restructure the way they interact with family caregivers in daily practice. Every health care clinician and social service professional should feel personally responsible for ensuring that patients and families in their care understand how to perform the challenging tasks outlined in this report.
- Health care organizations should support individual professionals and provide resources to ensure that family caregivers' needs for training and support are met.

- Professional organizations should lead and support professionals in their efforts to improve communication with and training for family caregivers.
- Leaders in medical, nursing, social work, allied health professional training, and continuing education should examine their curricula to determine where and how the importance of acknowledging, supporting, and training family caregivers can be added or strengthened. New approaches are needed that blend technical and communication skills. Training must be adapted to respond to changes in the family member's condition or the family caregiver's needs and capabilities.
- Accrediting and standard-setting organizations must take seriously their evaluation of how well institutions incorporate family caregiver needs and require corrective steps to address deficiencies.
- Federal policymakers should proactively consider family caregivers in developing new models of care that focus on coordination and quality improvement. Explicitly including family caregivers in federal funding requirements for new models of care focused on care coordination and quality improvement is an essential first step.
- State policymakers should proactively consider family caregivers in funding and policy development. State governments should incorporate family caregiver assessments in publicly funded programs,[2] including the new demonstrations for people eligible for both Medicare and Medicaid. States should enable registered nurses to delegate medical/nursing care tasks to qualified direct care workers who serve people in their homes.
- Caregiver advocacy and support organizations should include in their service and policy agendas resources that address the needs of family caregivers who have taken on the triple burden of personal care, household chores, and medical/nursing tasks. Caregiver organizations have used ADLs and IADLs in describing their constituents and in advocating for funding and services. They, like their health care professional colleagues, must expand their view to include the special needs of family caregivers who perform medical/nursing tasks.
- Further research is needed around subpopulations of family caregivers performing medical/nursing tasks, such as ethnic or cultural minorities.

Family caregivers are the default providers for the complex care of people with multiple chronic conditions. It is time to clearly spell out the respective responsibilities of health care providers, payers, and family caregivers with transparency and accountability.

Endnotes

[1] S. C. Reinhard, "The Work of Caregiving: What Do ADLs and IADLs Tell Us?" in *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*, ed. Carol Levine (New York, NY: United Hospital Fund of New York, 2004), 181–83.

[2] L. Feinberg and A. Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, 2012).

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AARP Public Policy Institute
601 E Street, NW, Washington, DC 20049
www.aarp.org/ppi.
202-434-3890, ppi@aarp.org

In Brief