

Helping Hawaii's Family Caregivers - the CARE Act

*Legislative Family Caregivers Working Group
September 10, 2015*



Today's Agenda

- **Focus on Transitional Care**
- **Family Caregivers Under Pressure**
- **Caregivers – In Their Own Words**
- **The CARE Act**

Caregiving Roulette

Your odds of becoming a family caregiver or needing care in Hawaii are high

- **Hawaii has the greatest percentage of people over 85 in the nation. The longer you live, the more likely you will need care**
- **62 percent of Hawaii residents age 45-plus expect to be caregivers in the future**



**AARP Public Policy Institute
Across the States 2012**

Significance of Unpaid Care in Hawaii

- 154,000 unpaid family caregivers in Hawaii
- Every year they provide an estimated \$2.1 billion in unpaid care to their loved ones.
- Caregivers spend an annual average of over \$5,531 in out-of-pocket costs
- Physical, emotional, & financial stress are rising

Caregivers under Pressure



Source: 2014 AARP Survey of registered voters 45+

Family Care Getting More Complex

Hawaii's family caregivers are called on to provide increasingly complex types of care at home.

Examples of Complex Caregiving Duties



Source: AARP Study *Home Alone 2012*

Medical and Nursing Tasks

- Managing multiple medications (IV, shots)
- Cooking (special diets)
- Wound care
- Using assistive devices
- Using monitors
- Operating specialized medical equipment

Hospitalization - the Trigger Thrusting Families into Crisis Mode

- **Most families are not prepared to take on caregiving responsibilities after discharge following a significant health event.**
- **The trigger event can come at any age: car or surfing accident, falls, stroke, heart attack ...**
- **Very often, unpaid family or friends are willing to provide care needed at home after discharge – and should be offered timely instruction at the hospital.**

Family Caregivers: In Their Own Words



Families in Crisis at the Hospital

HOSPITALS IN BEST POSITION TO HELP THE CAREGIVER IMMEDIATELY:

- Hospital staff are medically-trained and understand patient's condition and need for post-discharge
- Hospitals are best suited to provide instruction to caregivers in a timely manner
- Hospitals are currently required to inform and instruct the patient of the discharge plan. The CARE Act would include the caregiver in this process, as designated and authorized by the patient
- Hospitals can arm the caregivers with information so that from day one they know what to do until professional help arrives, if at all.

Hawaii's Proposed CARE Act

CARE (Caregiver Advise, Record, Enable) Act would require three things of hospitals:

- **Recordation of designated caregiver on the patient's medical record (if the patient has no caregiver, no requirement for the hospital to find one.)**
- **Advance notice to designated caregiver prior to patient's discharge or transfer to another facility.**
- **Hospitals to offer family caregivers instruction in the tasks needed to be performed at home prior to discharge.**

CARE Act Across the Country

- **Since 2014, 16 states have enacted the CARE Act: Arkansas, Colorado, Connecticut, Illinois, Indiana, Maine, Mississippi, Nevada, New Hampshire, New Jersey, New Mexico, Oklahoma, Oregon, Rhode Island, Virginia and West Virginia**
- **2 more states awaiting governor's signature (CA, NY)**
- **11 others (including Hawaii) and Puerto Rico have introduced the CARE Act**

**No appropriations requested in any CARE
Act legislation nationwide**

Existing Standards and the CARE ACT

Medicare Conditions of Participation and standards from the Joint Commission mention family caregiver involvement but do not require all of the important provisions of the CARE Act.

Some key distinctions:

- **No requirement that each patient be given the opportunity to name a family caregiver and have that information recorded in the medical record.**
- **It is the hospital's decision whether to involve a family caregiver in the discharge process – not the patient's.**
- **When a family caregiver is included, there are no clear standards that the information provided to caregivers should include an offer of instruction and demonstration of aftercare tasks.**

Revised Version of Legislation

- On July 14, LRB was provided with revised version of proposed CARE Act bill for Hawaii.
- This revised bill allows for greater flexibility for hospitals to establish their own policies and processes to give family caregivers the opportunity to receive instruction in aftercare tasks when a loved one is discharged from the hospital.

Hawaii CARE Act - Misconceptions

- **MISCONCEPTION** – The Act would expose hospitals to greater liability for caregiver instruction.

FACT – The Act specifically limits the liability of hospitals complying with the Act and instructing caregivers. Similar protections were developed and agreed to by hospital associations in other states that passed the CARE Act.

- **MISCONCEPTION** – Hawaii’s proposed CARE Act would prevent or delay discharges.

FACT – The CARE Act clearly states that it will not delay the discharge or transfer of a patient if, for example, the family caregiver is unavailable.

Hawaii CARE Act - Misconceptions

- **MISCONCEPTION** – Providing caregiver instruction at discharge will impose excessive costs on hospitals.
- **FACT** – Hospitals already perform discharge planning for patients. Caregivers would now be included in those instructions.
- **MISCONCEPTION** – Hospitals would be responsible for their former patients indefinitely.
- **FACT** – Although it may be good practice, nothing in the Act requires hospitals to follow up once they provide discharge instructions to caregivers.

Hawaii Care Act Facts

- **Supports patient-centered care**
- **Supports caregivers and gives them the right to be included in discharge instructions if they so choose.**
- **Provides consistent opportunity statewide to receive instructions from all acute care hospitals.**
- **Complements Care Transition activities and other professional home services.**
- **Broad support from hospitals in other states.**

Hawaii Voters Support CARE Act

- **Nearly all Hawaii residents age 45-plus (95%) support requiring hospitals to explain and demonstrate medical and nursing tasks family caregivers will perform at home**
- **Among the 95%, 79% strongly support this**

Source: 2014 AARP Survey of registered voters 45+

Mahalo!