PCHETA and Alzheimer’s Disease

Palliative and hospice care – with a focus on managing and easing symptoms, reducing pain and stress, and increasing comfort – can improve both the quality of care and quality of life for those with advanced dementia.

- Observational studies have shown that as many as half of nursing home residents with advanced dementia have documented pain in the last weeks of life – and about a third have difficulty breathing or swallowing, or suffer from agitation.

- Individuals with advanced dementia who are enrolled in hospice have a lower rate of dying in the hospital, a lower rate of hospitalization in the last 30 days of life, and better symptom management.

- A recent study shows that nursing home residents with dementia who receive palliative care at the end of life, compared with those who do not receive such care, are:
  - up to 15 times less likely to die in a hospital
  - nearly 2.5 times less likely to have a hospitalization in the last 30 days of life
  - up to 4.6 times less likely to have an emergency room visit in the last week of life.

- Families of individuals with dementia who are enrolled in hospice have a greater satisfaction with patient care.

### Percentage of Seniors Receiving Hospice Care at Time of Death, by Condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Alzheimer’s and Other Dementias</td>
<td>48.3%</td>
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<tr>
<td>COPD</td>
<td>39.0%</td>
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<tr>
<td>Cancer</td>
<td>59.5%</td>
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People with Alzheimer’s and other dementias rely heavily on palliative and hospice care at the end of life.

- Of all people living with dementia, 18.6 percent receive hospice care in a given year – a higher percentage than other chronic conditions. Among seniors in hospice care, 1 in every 5 has a primary hospice diagnosis of Alzheimer’s or other dementia.

- In the Veterans Administration health care system, 61.4 percent of dementia patients receive palliative care consultations in the last 90 days of life.

- Nearly half of all people with dementia die in hospice care.
The availability of palliative and hospice care is growing, but the need is growing faster – and the quality of the care remains a concern.

- In 2000, less than one-quarter of U.S. hospitals had a palliative care program. By 2013, that had increased to three-quarters.
- Hospice care is now available in nearly three-quarters of surveyed nursing homes, but less than half of surveyed nursing homes report having some sort of palliative care program.
- Of those nursing homes with a palliative care program, only 42 percent include consultation by a physician certified in hospice/palliative care, and only 28 percent had a designated palliative care director.
- In the 2014-15 academic year, only 265 physicians were trained in hospice and palliative medicine by accredited programs. An expert Task Force concluded that 6,000 more full-time health care professionals are needed to serve current needs in hospice and palliative care programs.

To increase the availability and quality of care, the Palliative Care and Hospice Education and Training Act (PCHETA) (S. 693 / H.R. 1676) would:

- Establish palliative care and hospice workforce training programs for doctors, nurses, and other health professionals.
- Create a national education and awareness campaign to inform patients, families, and health professionals about the benefits of palliative care and available services and supports.
- Enhance research on improving the delivery of palliative care.