

Physician Aid in Death and Long Term Care Across Settings

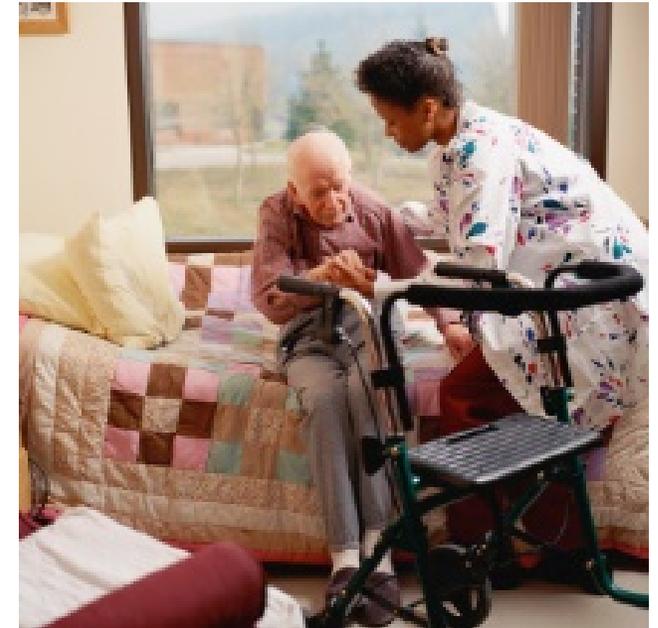
Cheryl Phillips, M.D., AGSF

President and CEO – Special Needs Plan Alliance

Washington, D.C.

Long Term Care – Many Settings

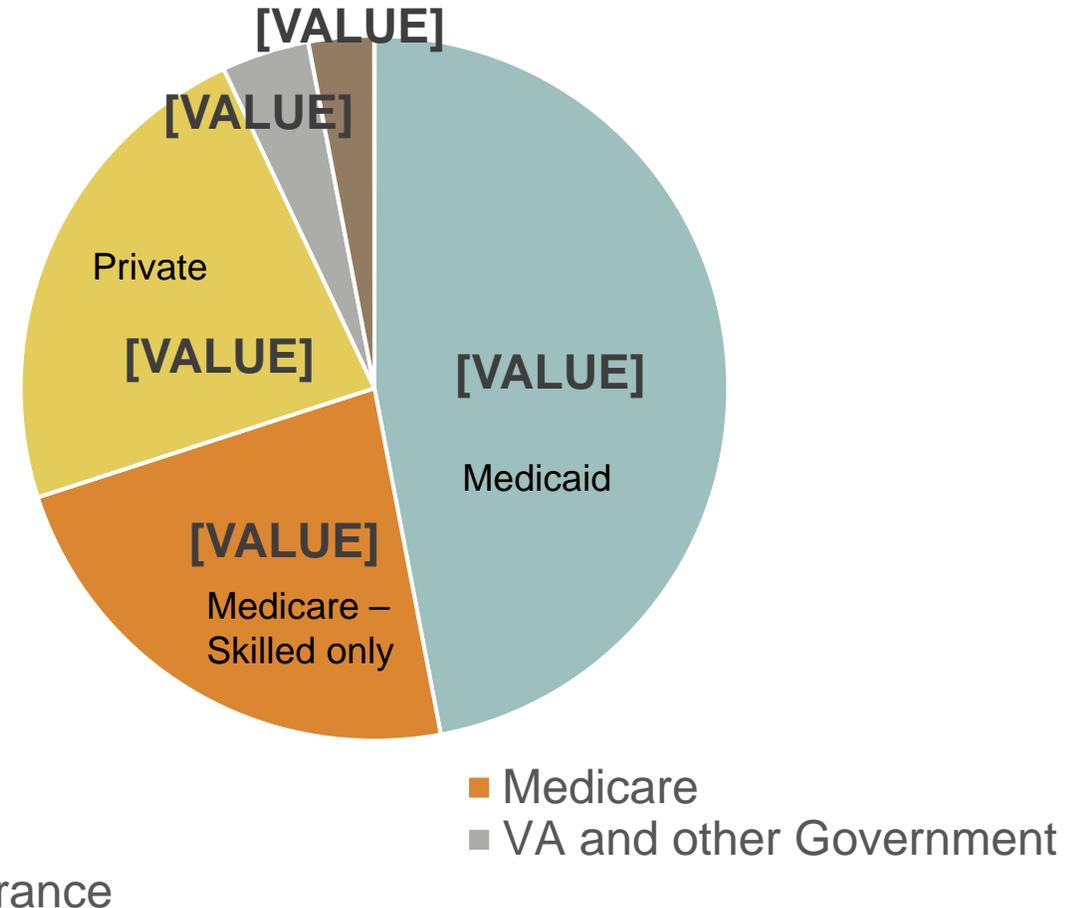
- Medicare Post-acute Skilled – limited and defined services)
 - SNF (typically rehab)
 - Home Health
 - In-pt rehab
 - Long-term care hospital
- Custodial (long stay) nursing home
 - Government (county, VA, veterans home)
 - Private-pay
 - Medicaid
- Assisted living (majority private pay)
- Home and community-based services (HCBS)
- Long Term Services and Supports (LTSS) includes custodial, residential and HCBS
 - Majority of services are private pay
 - States moving to managed Medicaid LTSS



LTC is Expensive

- Average nursing home (long stay) = \$84 K per year
- Average Assisted Living = \$44 K per year
- In-home care average \$150/ 8 hrs – average annual spend it \$46 K per year

- **OVERALL – LTC costs \$275 billion/year**



Significant Burden of Dementia and Cognitive Impairment



- 50-70% of residents in long stay nursing homes and assisted living have documented dementia
- Cognitive impairment is thought to be much higher
- Rates in home and community services for LTC are unknown



Policy Challenges Facing LTC

- Long term services and supports (including long stay nursing home) serves more than 12 mill people and is expected to grow another 18% in 2 years.
- States are moving quickly to Managed LTSS (managed Medicaid for LTSS)
 - States are facing increasing budget challenges and desire to cut back on Medicaid benefits (eg: Indiana)
 - LTSS services are typically funded under “waivers” and are not typically part of Medicaid “essential benefits”
 - Medicaid “reform” likely to involve block grants – further limiting states \$\$
- Medicare only pays for “skilled services” – and not “daily support services” or personal care



Work Force – Who is there to Provide the Care?

- Direct care work force: a 50% increase in workers needed by 2030 just to keep up with existing demand (PHI – 2010)
- Licensed providers (doctors, nurses, therapists, social workers): FEW are prepared in palliative or geriatric care
- Minimal staff in most care settings – few with palliative care training
- Family and other personal caregivers:
 - Value of uncompensated care is estimated at \$450 billion annually
 - Doesn't fully count lost employment opportunities, retirement savings, and other caregiver losses
 - Few resources for families to even KNOW how to provide advanced illness and symptom care



PAD in Long Term Care Settings

- Data virtually non-existent
- Oregon reportedly has had 2 cases in a NH since the law was enacted
- California does not required “location of ingestion” – so no reliable data available
- Anecdotally – most nursing homes have policies against PAD (fear licensing and certification)
- How to measure potential subtle, or overt, family pressure is unknown
- Waiting lists for many Medicaid-covered LTSS services are very long (some private-pay settings, such as assisted living, may also have LONG waiting lists)
- For every opening in subsidized senior housing – there are 10 senior waiting. Most will die before they are accepted.



So – what does all this mean?

- Individuals in long term care often face SIGNIFICANT financial barriers
- Families are ill-prepared to manage care – financially or otherwise
- Most people fear institutional care
- Perceptions of “being left alone to die in pain” are common
- All these create potential for subtle (and not-so-subtle) pressures by family and the individual that “ending it quickly” is a better option
- Few have actually had a discussion of FULL options – care to address symptoms, options to manage end-of-life, care plans that fully reflect personal care and support wishes.
- **“Does PAD for individuals in LTC reflect individual autonomy – or merely the perceived best option in a badly flawed system of care?”**



Policy and Research Gaps

While LTSS is getting some “press” – primarily because of the managed Medicaid aspects – little is known about this population, in terms of their views, their access to, and the incentives for PAD.

Our policy focus for PAD has been for younger people with more predictable courses (eg: cancer) - there is little, if any, attention to the “oldest old” who are trying to grapple with frailty and lack of available support systems and care.

It is hard to imagine PAD in this population until the underlying challenges of access to services are addressed.

