Navigating ALS Care

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What People with ALS and Families Need

- As ALS progresses, every patient and family is faced with increased physical care needs
- Options for care
  - Most patients have one main caregiver, supplemented often with additional family members also providing care
  - Sometimes supplemented with private caregivers
  - Some patients do move to long-term care in a nursing home (some may start in assisted living, but the reality of the disease will dictate that people will need nursing-home level of care at some point). However, the vast majority of our patients receive care at home through the end of life

Paying for Outside Care in the Home

- VA benefits
- Long-Term Care Insurance (few people have)
- Medicaid waiver programs
- Paying privately (here in Nebraska right now this type of care is usually $30-$40/hour from a private home care agency)
- Piecing together various funding sources for in-home care through Area Agencies on Aging, state respite program, grants through ALS nonprofits

Disparities in Care

- Higher-income families are usually able to pay for ongoing care in the home
- Lower-income families may qualify for Medicaid/Medicaid waiver that can pay for more care in the home
- Families in the middle struggle the most with the ability to find payment for outside caregivers coming in to assist

Recommendations/Opportunities for Advocacy

- Advocating for a Medicare "waiver" for people diagnosed with ALS that would help to pay for the ongoing, day-to-day care that people need
- Similar to some exceptions that have been made the eliminations of the 5-month waiting period once approved for Social Security Disability (SSDI) and the elimination of the 24-month month waiting period for Medicare once SSDI has been approved
- Encourage/advocate for states to create Medicaid waivers specifically for people with ALS and allow for higher income limits to qualify for Medicaid or create special funding pools to help pay for care

Medicare Advantage Plans

- More and more people are choosing Medicare Advantage plans over traditional Medicare
- For people under 65 receiving Medicare as a result of disability, this may be their only option
- Out of pocket costs may actually be higher because while the premium is lower, many specialty visits and therapies have a co-pay attached to each visit
- Depending on the plan, it may be challenging to find home health agencies willing to accept coverage

Recommendations/Opportunities

- Require Medicare Advantage plans to cover services for people with ALS in a similar manner

Palliative Care/Hospice Care

- True palliative programs that provide assistance with in-home care are limited (especially in the Midwest)
- As hospice is currently structured, Medicare will pay for hospice care OR treatment that is focused on the hospice diagnosis (including provider visits)
- Many patients with ALS and their families want the support and benefits of hospice but do not want to give up the option of meeting with their ALS multidisciplinary care team, their pulmonologist, or discontinue medications they are taking for their ALS

Recommendations/Opportunities for Advocacy

- Define *palliative care* as a specific type of benefit covered by Medicare that comes with an amount of ongoing in-home assistance from a nurse/home health aide/palliative team that is not necessarily short-term or skilled in nature
- Modify Medicare hospice billing structure so that families with ALS can receive the support of both hospice services and the ALS-specific multidisciplinary care (similar to VA pilot with hospice)

Thank you!

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