In this blog for the International Neuro-Palliative Care Society, Suzanne Van Kirk, PhD, MSN, FNP-BC reflects on the challenges of securing appropriate in-home caregiving for her husband, a stroke survivor. She describes a troubling gap between “home health” and “home care”. Routine but essential activities such as G-tube management, bowel regimens, medication assistance, and support with home therapy may be considered “custodial” from one perspective yet restricted as “medical” tasks by “home care” companies.

Drawing on her experience as a long-term care partner, she asks whether liability-driven regulations have unintentionally reduced access to safe, reliable care for people living with chronic neurological conditions. The piece calls for research into the consequences of these restrictions and consideration of alternative models that could provide appropriately trained home caregivers while preserving safety and oversight.

Do Home Care Company Regulations Help or Hinder People Living with Neurological Disease?

During an initial hospitalization, it can be difficult to anticipate the barriers patients and families will encounter as they try to build a meaningful quality of life when they return home. Quality of life after a serious neurological event often looks different from what clinicians imagine during an initial hospitalization. My husband, a brainstem stroke survivor, recently said, “Overall, we have a pretty nice life.” I agree. The stroke itself is not what we dwell on. What we lament is how challenging it can be to manage life with stroke over time. In particular, it has become increasingly difficult to find personal caregivers who will perform tasks frequently needed by those living with neurological limitations. These include G-tube management, bowel training regimens, medication administration, and assistance with home therapy regimens.

Caregivers have shown me documentation on the electronic care plan issued by their “home care” company, strictly forbidding completion of these tasks, and requesting that the caregiver call the company should the family request these tasks be performed. This has become more problematic as states passed regulations for “home care” companies. These companies are numerous, charge an average of $35-$45/hour, but are now considered “non-medical,” leaving clients with no means to complete these routine daily vital tasks. Those with neurological chronic conditions are in the squeeze, unable to secure a “home health” company to complete daily routine tasks according to Medicare definitions of “home health” (part-time/intermittent care/skilled care), and unable to hire a “home care” company willing to complete the care plan tasks. I did find one agency that allows a registered nurse to come to the home to for $125/hour, rather prohibitive financially.

I don't remember ever being informed of this designation, but my husband's care is considered "custodial" and not "skilled nursing" per the Medicare nomenclature. However, "home care" company legal teams, working with state regulators and licensing boards create "medical" skills lists that their caregivers cannot perform. I have thus far not been able to obtain any such list. How can digital stimulation for bowel evacuation simultaneously be a "medical" task and a "custodial" task? Living in the squeeze, sufferers of neurological disease have no recourse but to rely on family members or to hire personally through word of mouth, distributed fliers, and online sites. I was troubled by this turn of events, especially as we always explicitly state required care plan tasks with every company that we engage. A caregiver revealed care plan notes with limitations when the company itself had not disclosed any issues with us. No red flags had been raised during our initial consultation. Insulted and confused, I contacted the inpatient rehabilitation center my husband used after his first stroke, and they confirmed that there really is no one who is expected or able to complete these important tasks in the "home care" realm.

As a care partner to a stroke survivor with a twice daily bowel regimen, 6-7 G-tube gravity fed infusions daily, need for assistance with medication administration orally, and the requirement for set up of equipment and positioning for his home therapy program, I feel trapped, unable to return to work without relying on privately hired caregivers of varying interest, ability, and reliability. Does it make any sense that the staff of a rehabilitation hospital or inpatient setting can successfully train a family member from any previous walk of life or career (plumbing, teaching, law), yet we cannot allow "home care" company employees to perform these tasks with training and oversight? Do we know if these limitations impact health and mortality? Are there missed medications, bowel obstructions, dehydration, and contractures due to these limitations? Does this practice precipitate preventable hospitalizations?

Liability. Liability is the cited reason for this change." Home care" company personnel have reported that they could do "anything" before regulations. Now, they cannot trim nails or instill saline eye drops. They simply cannot complete our care plan. I urge researchers to query the complications of not receiving these crucial and prescribed treatments. Personal literature searches have not revealed research in this area and conversations expose a lack of understanding by some acute care providers about the stratification of care in the community. What is the legal precedent that supported these broad, sweeping regulations? I cannot help but wonder if, like many well-intended policies, we have gone too far and inadvertently restricted the autonomy of care partners while actually endangering the health of those the regulations aim to protect.

Is there a different vision? One in which employees of “home care” companies who might actually be invested in learning skills can train and expand their scope of practice? Can consumers of these companies sign waivers when requesting a higher level of skill? Many people tell me, “The system is failing.” Again, I agree. Help establish the science needed to build better scaffolding around patients and families living with neurological disease. With a system that supports safe, competent care at home, care partners could regain the freedom to work, participate in their communities, and live their own lives with confidence.

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