

Family Caregiver/Caregiving Issues
Relating to Long Term Services & Supports for Family Members with Chronic Conditions
Comments to the Commission on Long Term Care

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August 25, 2013

Recommendations for providing needed support to family caregivers: The Commission on Long Term Care is urged to recognize the need to provide explicit coverage and reimbursement for services and supports directly to family caregivers both in the presence of the family member in need of LTSS, and privately. These services and support must include:

- Covered and reimbursable time to assure that caregivers understand the care-recipient's needs:
 - Extended therapy sessions and/or additional sessions where the physical, occupational, speech, respiratory and/or other therapists explain and demonstrate the treatment and the exercises, services, and/or supports that the family caregiver will be expected to provide and/or assist in providing at home; with billing codes created or designated to allow the therapists to bill and be compensated for their time in these caregiver-related activities
 - Extended sessions and/or additional sessions with physicians and nurses to explain to the caregiver the treatment and medications prescribed, what care and service must be provided, when to call the physician, and how to recognize and manage crises; with billing codes created or designated to allow physicians and nurses to bill and be compensated for their time in these caregiver-related activities
- A separate, dedicated evaluation of family caregivers, performed by a qualified healthcare professional, covered and reimbursable, to determine:
 - If they understand the care-recipient's medical condition and needs,
 - Which care, services and supports they are able to provide, and how they plan to do so
 - Which care, services and supports they are not able to provide, and how they plan to find the needed care that they cannot provide
 - Their current health status and limitations, and implications on their health status of assuming the caregiver's role
 - Their feelings about their situation, psychological and emotional status, and implications of assuming the caregiver's role
 - If they are employed, or wish/need to return to work, what services and supports they need to continue working
 - Their financial situation, their understanding of the costs, and ability to afford the LTSS
 - Billing codes created or designated to allow the physicians and/or healthcare professionals to bill and be compensated for their time in these caregiver-related activities

- Covered and reimbursable time from qualified healthcare professionals to assure that the caregivers are planning, locating, accessing, coordinating, and finding financial sources for the care-recipient's and caregiver's care, services and supports
 - Billing codes created or designated to allow the physicians and other healthcare professionals to bill and be compensated for their time in these caregiver-related activities in-person with or without the care-recipient, by phone and/or email.
- Locally-available LTSS resources for the care-recipient and the caregiver compiled, updated, and made available through phone hotlines and websites to provide a source for ongoing reference and access by family caregivers as well as healthcare professionals
- Ombudsman available 24/7 by phone and email/internet chat for family caregivers to consult their own needs, as well as the needs of the care-recipient.

Signing a form that the caregiver has received a checklist of information is grossly inadequate to assure the understanding and ability of family caregivers to provide the needed care, services and supports.

References. The Commission is to consider the United Hospital Fund's efforts to support caregivers under their recommendations in: "Transitions in Care 2.0: An Action Agenda," which "outlines ten recommendations designed to lay the foundation for health care professionals and administrators to work effectively with family caregivers, make family caregivers part of the care team, and align financing and accreditation policies," at: <http://www.uhfnyc.org/publications/880904> and under their "Next Step in Care" program at: <http://www.nextstepincare.org/>

Also, the Commission is urged to consider the recommendations in the March 2012 report of the Caregiver Pilot conducted in New Jersey by the Hilltop Institute/UMBC: <http://www.hilltopinstitute.org/publications/NewJerseyCarePartnerSupportPilotProgramFinalReport-March2012.pdf>

Background/Credentials of Commenter. Stephanie Mensh found herself thrust into the role of personal caregiver and patient advocate in the same shocking instant that her husband, Paul Berger suffered a severe stroke from a ruptured aneurysm when he was only 36. Stephanie co-authored books on stroke recovery with Paul, including the internationally –acclaimed, "How to Conquer the World With One Hand... And an Attitude," and her own Kindle e-book, "Conquering Aphasia & Stroke for Caregivers, Vol. 2: Stephanie Mensh's Guide for Caregivers." She has made numerous presentations to professional and consumer groups on caregiving and patient advocacy. Stephanie is a volunteer advocate, blogs for Disruptive Women in Healthcare at www.disruptivewomen.net , and writes a monthly column on caregiving for www.strokesurvivor.com e-newsletter. She works professionally for New Editions Consulting, Inc., as a project director on federal disability policy and research. She has served in senior positions providing policy development and advocacy on Medicare and health insurance issues, quality standards, and other federal health policy issues for various national healthcare associations.

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