Altarum Institute Center for Elder Care and Advanced Illness

Agitator’s Guide to Elder Care—Let’s Act!

Reaching the last years of a long life generally entails having multiple chronic conditions, disabilities, and complicated social needs. Our present health and social service systems are fragmented and do not reflect the priorities of elders or their families and caregivers. Caring for frail elders remains one of the neglected public policy issues of our time. For the sake of our elders, families, and communities, we need to realign and transform care for frail elders to emphasize continuity, reliability, meaningfulness, and efficiency.

What to Seek!

▲ Create an elder care advisory group comprising nonprovider elders, family caregivers, and direct care workers in the Centers for Medicare & Medicaid Services (CMS) so that beneficiaries can comment regularly on rules, policy directions, IT infrastructure, Quality Improvement Organization priorities, etc. Provide a small staff to produce a quarterly report with CMS’ public relations staff.

▲ Develop quality measures for planning services for each patient and for enabling self-care. Include status goals of care and priorities of the elderly person and his or her family. Initially require reporting, and eventually penalize poor performance through withholding provider payments.

▲ Demand that the care system for frail elders be longitudinal. In other words, the system should offer care that is “purchased” in large blocks of time, and it should attend to the full package of services (including Older Americans Act, Medicaid, and Medicare). As with private schools, people would generally “buy in” for at least a year, relying on the services tied to a defined geographic area.

▲ Require that elder care service be available around the clock, with records of each elderly person’s plan of care and with the ability to respond to the home (or nursing home) within a few hours.

▲ Provide stipends, health care insurance, respite time, assessment and training, and engagement for family caregivers who provide substantial support to frail elders.

▲ Generate population-based data regarding costs and performance for communities.

▲ Make sure that “meaningful use” criteria in electronic health records enable and require documentation of the likely course of the illness, a person-centered plan of services, an advance care plan, and a time for feedback and revision.

▲ Put material about the disease, its likely course, and the main elements of the care plan on www.mymedicare.gov and in personal health records.

▲ Support decent pay and benefits for direct care workers, such as home health aides.

How to Get Underway!

▲ Go to a candidate forum or debate in the current political campaigns and raise your voice about elder care and caregiver support! Share an experience and describe how the system might have made it better, easier, or more effective.

▲ Get an elder care improvement initiative on the policy agenda of the professional, consumer, disease-based, and volunteer groups to which you belong.

▲ Tell your stories—write responses to blogs, post your story on websites, talk with civic leaders—and tie the challenging experiences to specific aspects of policy and practice.

▲ Visit www.medicaring.org and share your insights on the blog.

The Center for Elder Care and Advanced Illness is led by Dr. Joanne Lynn. To learn more about the ongoing work of the center, please email eldercare@altarum.org or phone 202-776-5100.

Altarum Institute Center for Elder Care and Advanced Illness Vision

To help the United States achieve social arrangements that ensure that, when we must live with serious chronic illnesses associated with advancing age, we can count on living meaningfully and comfortably, at a sustainable cost to our families and society.