CHRONIC ILLNESS + CARE

Americans for Better Care of the Dying →

Suggestions for Medicare Reform

AMERICANS FOR BETTER CARE OF THE DYING

June 8, 1999

Attn: Sarah Bianchi
217 Old Executive Office Building
Washington, DC 20502

The Honorable Al Gore
Vice President of the United States
The White House
1600 Pennsylvania Avenue
Washington, D.C. 20510

Dear Mr. Vice President:

Thank you for convening a productive meeting on June 2, 1999, with the Leadership Council of Aging Organizations (LCAO). I participated in the meeting as a recent Board member of the American Geriatrics Society, an LCAO member. I am a hospice and long-term care physician and I also serve as President of Americans for Better Care of the Dying (ABCD).

We applaud your efforts to modernize Medicare and look forward to reviewing the Clinton Administration's Medicare plan shortly. A critical element in modernizing Medicare is changing the program from one that focuses on diagnostic and therapeutic procedures to one that efficiently and adequately supports people with eventually fatal chronic illness. While paying for acute care (i.e. surgical operations) was the most appropriate focus when Medicare was enacted in 1965, the program now has to focus also on the concerns of an older, frail population. Most of us will now spend years disabled with a progressive illness before death, and mostly we will face a mal-adapted health care system which does not know how to provide symptom relief, how to support independence as long as possible, how to help with spiritual and family issues, and even how to avoid the despair that leads some to advocate legalizing suicide. Yet, better care is demonstrably possible within the limits of current spending, but also requires a commitment to innovation and implementation of new service delivery models.

Along with a growing corps of committed researchers and reform-minded citizens, we too are working to update the Medicare program. No one really wants "reforms" that merely allow us to pay less for the current care system. Instead, most Americans are coming to realize that they want a care system that is much more reliable and effective in helping us live with what is usually a few years of our final, fatal illnesses. That reliable care system would be able to *promise* patients and their families health care they can count on. A list of the promises that a worthy care system should be able to make is attached to this letter. It has grown from quality improvement work with a hundred health care institutions across the country (working with the Institute for Healthcare Improvement and with many providers including the Veterans Affairs Health Care System). The care system that could make such promises is one that would be worth the work of real reform!

Two areas are especially ripe for reforms right now: *continuity of care* and *family caregiver support*. Regarding continuity of care, Medicare should both start paying for services that enhance continuity and accountability over time and penalizing those arrangements that ensure discontinuity and lack of accountability. At least for people with serious and eventually fatal conditions, it has to

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be possible for the various sites of care to share responsibility over time (and to be held accountable). If a hospital is not allowed even to recommend outpatient providers, and home care agencies and hospices cannot share staff, for example, then coordination of care across time is impossible (and it is impossible for a clinician in one setting to make any promises to a patient about the care they can expect). The chaos of funding, reporting, and disruption in the wake of the Balanced Budget Act magnifies the problems.

However, this unsettled state of things actually creates an opportunity to initiate some bold new initiatives. For example, Medicare could try out a set of important modifications to the new risk adjustment for Medicare+Choice plans as they affect serious chronic illness that is expected to be fatal. For heart failure, for example, which is the most frequent cause of hospitalization in Medicare, the risk adjusted payments now proposed could start with the discharge from the first hospitalization (instead of starting with the next fiscal year, for survivors only) and could run until death without additional hospitalization required - but ONLY for provider programs that take comprehensive responsibility for the quality of care through all settings. We now have good evidence that programs that combine patient self-management, appropriate medications, pre-emptive early treatment, comprehensive coordination of care, and planning for death are successful in every dimension of importance - family satisfaction, hospital utilization, patient comfort, and costs. Why are they not spreading like wildfire? Because the services needed are not easy to pay for in conventional Medicare (and their success seriously cuts hospital utilization, which is well reimbursed) and because a good reputation is disastrous to capitated plans, because that attracts adverse risks. So, the Medicare reform proposal this year should expand the current demonstration programs in HCFA to include a trial of risk adjusted payments targeted at this opportunity.

Similarly, the administration could move reform substantially ahead by proposing some discounts for services that reflect discontinuity - lower payments for treatment of serious chronic illnesses (cancer, stroke, dementia, heart failure, and lung failure capture about three-quarters of all fatal illnesses now) unless the primary care provider is actually the dominant service provider across time, or unless advance care planning concerning hospitalization and intensive care is discussed and documented, or unless hospitals help ensure that discharged patients have comprehensive continuity care available. Likewise, the continuity that is built into PACE and hospice could provide opportunities for expansion: make it possible to tailor PACE to serve persons with heart failure, for example, or make it possible to serve such patients for longer times in hospice (since prognosis is always too uncertain to ensure meeting the hospice prognosis criterion).

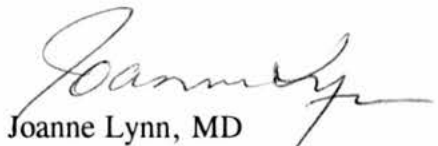
Turning to the question of how better to support family caregivers, while we applaud President Clinton's announcement of a modest tax break for caregivers, we have also found substantial support from a variety of political viewpoints for a proposal that would ensure that family caregivers do not themselves face financial ruin from healthcare costs. A major barrier to family caregiving is the fact that most caregivers are themselves growing older and are facing health problems, and many are women in insecure jobs. If they leave employment, many will lose their health insurance coverage and they will also face serious barriers to re-employment for the rest of their lives, since their prior conditions yield higher premiums for employers. A new benefit to support health care insurance for family caregivers would target especially worthy and needy persons while freeing them up to support their ailing family member.

For example, those who provide unpaid care for a disabled family member could be allowed to "buy in" to Medicare for the time remaining until age 65 at a rate that is not adjusted for prior health status. That proposal could be constrained in one or more of the following ways: the disabled person has to be a Medicare beneficiary, the family member has to be between 55 and 65 years of age and otherwise qualified for Medicare, the "buy in" would start after six months of care for more than 40 hours spread over at least five days each week, the patient would have to be "homebound" or "nursing home eligible," the family caregiver has to have no other way to have health insurance (e.g., from a spouse), and/or the family caregiver has to meet a poverty qualification. The costs could be quite modest, but the ringing endorsement of seeing family caregiving as important for the community would itself honor the endeavor and encourage other social accommodations to support families during end-of-life care.

No one wants just a cheaper version of the care system we have now, at least not when one confronts serious and eventually fatal chronic illness. Even people who are delighted with our system's ability to generate life-saving surgeries and life-enhancing drugs and joint replacements are clear that, once you have a serious illness that will last your lifetime, our care system is not trustworthy. This is the right time to start real reforms. This population of those facing the end of life is large and growing, and care of fatal chronic illness already uses at least half of Medicare's dollars. We don't know enough today to dictate the shape of the best eventual reforms to fit care to this population. However, we can start with incremental changes that change the focus of the debate. We could start seeing serious chronic disease as a public health problem, we could start demanding that medical research and education focus upon it, and we could start the kinds of reforms that will, in aggregate make a substantial difference. We need real leadership in reshaping social resources so that we can count on our care system to do the right things when we need it most. Already, the care system for the end of life is almost entirely a federally funded system. So, we own it and we know that it is hopelessly inadequate. That is an opportunity for leadership.

We are available to answer additional questions regarding these proposals and the data we have to support them. We would be glad to help with legislative language and hearings as your work progresses. Again, thank you for your continued leadership in family caregiver issues and in improving the Medicare program. If you have questions, I can be reached at (202) 467-2222.

Sincerely,



Joanne Lynn, MD
President
Americans for Better Care of the Dying

Cc: Chris Jennings
Sarah Bianchi
Encl: *Promises*

Making Promises: A Vision of a Better System

There are probably a number of ways to construct a vision of a better care system. One that has a special power is to think through the image of a single health care provider talking with a single sick and frightened patient and trying to imagine what that provider could promise -- in a care system that really worked the way it should. For patients with advanced stages of serious illnesses, it is just not possible to promise cure or restoration of health. What would matter to such a patient? Here are the seven promises that really seem to make a difference. In each case, there is a short name for the promise, its core statement, and a few examples of what it might mean to put practices in place to deliver on that promise.

1. ***GOOD MEDICAL TREATMENT:*** *You will have the best of medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.*

    - *Patients will be offered proven diagnosis and treatment strategies to prevent exacerbations and enhance quality of life, as well as to delay disease progression and death*

    - *Medical interventions will be in accord with best available standards of medical practice, and evidence-based when possible*

2. ***NEVER OVERWHELMED BY SYMPTOMS:*** *You will never have to endure overwhelming pain, shortness of breath, or other symptoms.*

    - *Symptoms will be anticipated and prevented when possible, evaluated and addressed promptly, and controlled effectively*

    - *Severe symptoms—such as shortness of breath—will be treated as emergencies*

    - *Sedation will be used when necessary to relieve intractable symptoms near the end of life*

3. ***CONTINUITY, COORDINATION, AND COMPREHENSIVENESS:*** *Your care will be continuous, comprehensive, and coordinated.*

    - *Patients and families can count on having certain professionals to rely upon at all times*

    - *Patients and families can count on an appropriate and timely response to their needs*

    - *Transitions between services, settings, and personnel are minimized in number and made to work smoothly*

Source: ALACE

4. ***WELL-PREPARED, NO SURPRISES:*** *You and your family will be prepared for everything that is likely to happen in the course of your illness.*

    - *Patients and families come to know what to expect as the illness worsens, and what is expected of them*

    - *Patients and families receive supplies and training needed to handle predictable events*

5. ***CUSTOMIZED CARE, REFLECTING YOUR PREFERENCES:*** *Your wishes will be sought and respected, and followed whenever possible.*

    - *Patients and families come to know the alternatives for services, and expect to make choices that matter*

    - *Patients never receive treatments they refuse*

    - *It is usually possible for patients to die at home if they so desire*

6. ***USE OF PATIENT AND FAMILY RESOURCES (Financial, Emotional, and Practical):*** *We will help the patient and family to consider their personal and financial resources and we will respect their choices about the use of their resources.*

    - *Patients and families will be aware of services available in their community and the costs of those services*

    - *Family caregivers' concerns will be discussed and addressed and respite and home aide care will be considered as part of the care plan when appropriate.*

7. ***MAKE THE BEST OF EVERY DAY:*** *We will do all we can to see that you and your family will have the opportunity to make the best of every day.*

    - *The patient is treated as a person, not a disease*

    - *The care team attends to the physical, psychological, social, and spiritual needs of patient and family*

    - *Families are supported before, during, and after the patient's death*