

Making Promises

A VISION OF A BETTER SYSTEM

Imagine a single health care provider talking with a single sick and frightened patient. What do you think 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 seven promises that can make a difference, along with action guides for clinicians, benefits managers and purchasers, citizens, and policymakers.

Although most improvement requires a vision of a better world and an intention to change, nothing really improves until someone starts making improvement happen. Now, it's up to you. Let's make the end of life a worthy part of living, a time of confidence, reflection, and meaning whenever it can be. Life can be sweet, even when it is constrained by illness and disability. However, life while seriously ill can also be terrifying, painful, alienating, degrading, and impoverishing. What most of us will experience depends upon community commitment and action. Now is the time to start. Every one of us can do something—this week—to get improvement started.

- 1. GOOD MEDICAL TREATMENT:** You will have the best of medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.
 - *Offer patients proven diagnosis and treatment strategies to prevent exacerbations and enhance quality of life, as well as to delay disease progression and death.*
 - *Use medical interventions that are in accord with best available standards of medical practice.*
- 2. NEVER OVERWHELMED BY SYMPTOMS:** You will never have to endure overwhelming pain, shortness of breath, or other symptoms.
 - *Anticipate and prevent symptoms when possible; evaluate and address symptoms promptly, and control them effectively.*
 - *Treat severe symptoms—such as shortness of breath—as emergencies.*
 - *Use sedation when necessary to relieve intractable symptoms near the end of life.*
- 3. CONTINUITY, COORDINATION, AND COMPREHENSIVENESS:** Your care will be continuous, comprehensive, and coordinated.
 - *Be sure patients and families can count on having access to health care professionals at all times.*
 - *Make sure patients and families can count on an appropriate and timely response to their needs.*
 - *Try to minimize transitions between services, settings, and personnel; when transitions are necessary, make sure they go smoothly.*
- 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.
 - *Let patients and families know what to expect as the illness worsens—and what is expected of them.*
 - *Provide patients and families with the 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.
 - *Tell patients and families about the alternatives for services, and encourage them to make choices that matter.*
 - *Never give patients treatments they refuse.*
 - *Help patients who want to live out the end of life at home do so.*
- 6. CONSIDERATION FOR PATIENT AND FAMILY RESOURCES** (financial, emotional, and practical): We will help you to consider your personal and financial resources and we will respect your choices about their use.
 - *Inform patients and families about services available in the community and the costs of those services.*
 - *Discuss and address the concerns of family caregivers. When appropriate, make respite, volunteer, and home aide care part of the care plan.*
- 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.
 - *Treat the patient as a person, not as a disease. What is important to the patient is important to the care team.*
 - *Respond to the physical, psychological, social, and spiritual needs of patients and families.*
 - *Support families before, during, and after a loved one's death.*

Action Guide

FOR CLINICIANS

1. Ask yourself as you see patients, Would I be surprised if this patient died this year? For those “sick enough to die,” learn about the patient’s concerns—often a combination of symptom relief, family support, continuity, advance planning, and spirituality.
2. Ask patients: What do you hope for, as you live with this condition? What do you fear? If you were to die soon, what would be left undone in your life? and How are things going for you and your family? Use the answers to help develop a care plan that reflects the patient’s concerns.
3. Unsure how to ask a patient about advance directives? Try: If at some point you can’t speak for yourself, who should speak for you about health care matters? Follow with: Does this person know about this responsibility? Does he or she know what you want? What *would* you want? Have you written this down? Ask for a copy to add to the medical record.
4. Most clinicians have educational handouts on heart failure, emphysema, cancer and other fatal chronic illnesses. Read these—if they do not mention prognosis, symptoms, and death, exchange them for ones that do. Perhaps recommend books such as *The Handbook for Mortals: Guidance for People Facing Serious Illness* and other resources.
5. Use each episode in the ICU or ER as a “rehearsal.” Ask the patient what should happen the next time. Be sure the patient has all necessary drugs at home and knows how to use them.
6. Can you promise prompt relief from serious symptoms near death? Tell the patient and family what’s possible and make plans together.
7. Very sick people are often most comfortable at home or in a nursing home. Identify programs that are good at home care and send patients to those quality services. Work with these programs to fill the gaps in patient care.
8. Except in hospice, most families never hear from their clinician after a death. Make a follow-up phone call or a visit to console, answer questions, support family caregivers, and affirm the value of the patient’s life. At the very least, send a card!
9. Never tell a patient: “There’s nothing more to be done,” or “Do you want everything done?” Talk instead about the life yet to be lived, and what can be done to make it better (and what might make it worse).
10. Patients and families need to be able to rely upon their care system. Consider what you can promise on behalf of your care system. Pick one of the seven that your patients need to hear and start working with others to make it possible to make that promise! Quality improvement strategies work!

Adapted from a handout by Americans for Better Care of the Dying accompanying the keynote speech by Donald M. Berwick, MD, Institute for Healthcare Improvement, at the ACP-ASIM Annual Meeting, April 22, 1999

Action Guide

FOR BENEFITS MANAGERS AND PURCHASERS

1. Insist upon meaningful measures of quality performance for serious illness.
2. Focus measurement of satisfaction and symptoms on the sickest patients.
3. Provide information and educational materials that help with end-of-life care and related tasks and decision-making.
4. Check with your Employee Assistance Plan (EAP) to assure that it addresses aging, caregiving, and end-of-life issues.
5. Accommodate employees' needs for flexibility in work schedules to address caregiving and care management issues. Offer adequate paid time off through bereavement, family, or medical leave. Consider temporary reassignments during times of grieving or hardship.
6. Review current benefits for adequacy in dealing with serious chronic and eventually fatal illness.
7. Use consumer stories, focus groups and employee feedback as a way to learn how end-of-life care is being delivered and how it can be improved.
8. Sponsor community educational and support groups that bring awareness, understanding and resources to employees and their families.
9. Recognize employees' emotional needs by acknowledging what is going on in their lives, and by providing referrals for assistance and support groups.
10. Encourage employers to offer flexible spending or dependent care accounts within your employee benefits program.

Includes recommendations from the Workplace Task Force of the Last Acts Campaign, July 14, 1999.

FOR CITIZENS

1. Call your local paper's obituary writer. Ask him or her to put into obituaries something about how a person lived during the last years or months. What did the family do?
2. Write a letter to your U.S. Representatives and Senators. Urge them to have government agencies, such as the Health Resources and Services Administration, the Health Care Financing Administration, the Agency for Healthcare Research and Quality, and the Veterans Health Care System, sponsor demonstration programs in end-of-life care.
3. Mobilize local churches or civic and volunteer groups. Together, you can support those who are dying and their families through visits, transportation, meals, and prayer.
4. Talk to your doctors about advance care planning and pain control.
5. Push your local health care system—even if it's only one doctor's office—to get involved in quality improvement efforts.
6. Write to your favorite television or radio show. Ask them to include stories about—or even just to mention people who are facing serious illness and death, and how they and their loved ones manage.
7. Keep pace with what's going on in the field. Start on the web at www.abcd-caring.org, www.medicaring.org, www.growthhouse.org and www.Lastacts.org.
8. Read *Handbook For Mortals: Guidance For People Facing Serious Illness*.
9. Don't quietly accept inept care, for yourself or your loved ones. Raise your voice. Insist on reliability. And when you find good care, publicize it!

Action Guide

FOR POLICYMAKERS

1. Instead of trying to target patients with “a prognosis of less than six months,” target policy toward people who are already quite sick with a condition that will prove fatal. These patients need more than preventive and curative treatments. People who are sick enough to die need continuity, advance care planning, symptom relief, adaptations for disability, family caregiver support, and attention to bereavement and other emotional issues.
2. Change Medicare payment and regulation to encourage continuity across time and settings (hospital, home, physician’s office, and nursing home) for those nearing death.
3. Publish performance report cards for symptom relief and continuity.
4. Provide coverage for prescription medications that are essential for symptom relief.
5. Change language in Medicare statutes and regulations that limits coverage to care that “maintains or improves function.” Medicare must also support care that slows the rate of loss of function or eases suffering for people living with fatal illness.
6. Ensure that people coming to the end of life have reliably good care and an opportunity to choose where to live (e.g., home, nursing home), how aggressively to be treated, and what to do in the time that is left.
7. Embark upon a period of energetic and targeted innovation, aiming to learn how to implement reliable, high-quality, and efficient models of providing care to this especially needy and growing population.
8. Require an annual report on the status of end-of-life care from the Secretary of Health and Human Services, with collaboration from the Surgeon General
9. Support family caregivers, for example, by offering or promoting: insurance coverage (e.g., caregiver eligibility for Medicare); employment security and help with re-employment; coverage for respite help; partial payment for family care when the patient would otherwise need paid care; and, tax breaks.
10. Find out if your state has a task force or commission on end-of-life care, and what you can do to support its work.
11. Review your state laws on pain management and whether they create barriers to effective pain treatment.
12. Guarantee Medicaid funding of palliative care in diverse settings.
13. Expand Medicare hospice eligibility beyond the current six-month survival criteria.
14. Reduce inefficiency in advance directives by combining various right-to-die statutes into one comprehensive act.
15. Develop protocols that allow emergency medical service technicians to withhold CPR in appropriate cases, such as if a patient is wearing a DNR bracelet or has a form posted in the home.