

***PALLIATIVE/END OF LIFE CARE
TASK TEAM REPORT TO
THE CALIFORNIA
COMMISSION ON AGING***

**Prepared for
PLANNING FOR AN AGING
CALIFORNIA: AN
INVITATIONAL FORUM
March 8, 2005**

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The Purpose

The purpose of this document is to provide a status report of the work of a stakeholder task team on Palliative/End of Life Care organized around working on implementation of “Planning for an Aging California Population” (Health and Human Service Agency October 2003).

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I. Forward

A. Who is the California Commission on Aging?

The California Commission on Aging (CCoA) was established in 1973 by the Burton Act. It was confirmed in the original Older Californians Act of 1980 and reconfirmed in the Mello-Granlund Older Californians Act of 1996.

The Commission serves as "*the principal advocate in the state on behalf of older individuals, including, but not limited to, advisory participation in the consideration of all legislation and regulations made by state and federal departments and agencies relating to programs and services that affect older individuals.*" As such, the CCoA is the principal advisory body to the Governor, State Legislature, and State, Federal and local departments and agencies on issues affecting older Californians.

B. SB 910—Aging Planning Legislation

California is home to nearly four million people over age 65—the largest older adult population in the nation. This number is expected to more than double over the next several decades as the baby boomers begin reaching this milestone. To address this impending reality, Senator John Vasconcellos wrote Senate Bill 910 (Ch. 948/99, Vasconcellos). The bill mandated that the California Health and Human Services Agency develop a statewide strategic plan on aging for long term planning purposes. On October 14, 2003, the *Strategic Plan for an Aging California Population—Getting California Ready for the Baby Boomers*, was completed with the major support of the CCoA and a plan development task team representing 25 older adult stakeholder organizations supported by 15 state departments. The Governor signed the plan in November 2003. (The Strategic Plan can be reviewed at http://www.calaging.org/works/population_files/population.pdf.)

C. CCoA's Monitoring Role of the Strategic Plan

SB 910 calls for periodic updates so that it can be continuously improved and reflect new circumstances, new opportunities and the changing socio-political environment. The CCoA agreed to assume responsibility for the monitoring and updating the Strategic Plan. In this capacity, the CCoA is responsible for convening stakeholders, holding meetings, and monitoring the progress of priority action items outlined in the Plan. The CCoA will report to the Legislature the progress of the Plan's implementation, and update the Plan's contents to reflect changing priorities and actions. Reports to the Legislature will be on a biennial basis.

The CCoA's approach to monitoring the Strategic Plan's implementation during 2003-2005 includes:

- Encouraging/facilitating work on Strategic Plan implementation by convening nine new stakeholder task teams, facilitating initial meetings and establishing partnerships with two previously formed stakeholder teams.
- Dialoguing with state officials at the March 8, 2005 Forum on the top 15 priorities in the Strategic Plan.
- Distributing and compiling the results of a baseline questionnaire on the Strategic Plan's 15 Priorities. The questionnaire was distributed to private, public and non-profit providers and aging advocates.
- Reporting to the Legislature by May 2005, on the progress of the Strategic Plan.

D. Stakeholder Task Teams

Eleven Stakeholder Task Teams have been charged with identifying and focusing efforts on several of the top priority recommendations, developing action plans to support or achieve implementation of these priorities and identifying necessary amendments or additions to the original Plan. These volunteer Task Teams have been meeting for the period October 2003 through December 2004, though some Task Teams started their efforts later than others. Written reports have been received from all Task Teams—copies are available from the CCoA office. The focus areas for the 11 stakeholder task teams are: Housing, Economic Security, Elder/Financial Abuse, Transportation, Wellness/Prevention, Mental Health, Oral Health, Long Term Care, Palliative/End of Life Care, Assistive Technology, Provider Workforce.

The choices and actions taken by the Task Teams are solely their own and do not necessarily represent the position of the CCoA.

Strategic Plan for an Aging California Population
Report to the California Commission on Aging
March 8, 2005

Palliative/End of Life Care Task Team

II. Background on Palliative/End of Life Care

The time to be strategic about planning for our California aging populations increasing palliative and end of life care needs is *now*. The trends and predictions outlined in the California Health and Human Services: *Strategic Plan for an Aging California Population*, October 2003, will undoubtedly impact California seniors' access and provision of palliative and end of life care services. With the population of seniors in the United States projected to more than double over the next thirty years, the challenges of end of life care will grow more serious. As more people live longer, palliative and end of life care will grow increasingly important. Significant barriers and misconceptions continue to impede access to palliative and end of life care, coupled with inadequate funding and regulatory barriers - the problem becomes catastrophic. Sadly, far too many Americans continue to approach death without adequate medical, nursing, social and spiritual support.

Many strides have occurred in California in recent years to improve end-of-life care and increase access to palliative medicine. California has made some significant accomplishments through both the Legislature and the licensing and regulatory agencies. California is considered among one of the most progressive states in the nation to improve pain and end of life care.

Despite demonstrable strides, much more remains to be accomplished and what is required now is a coordinated, multi-faceted approach to align leadership institutions, organizations and stakeholders to strategically plan next steps. Collaboration will undoubtedly minimize duplication of efforts. Organizations such as the California Coalition for Compassionate Care (Coalition) and the California Hospice and Palliative Care Association have accomplished significant work. The five areas of focus of the California Coalition for Compassionate Care speak eloquently to the areas of most need for palliative and end of life care services: *long-term care, hospitals, consumer education, professional practices and public policy*. The Coalition is a statewide collaboration of 50 organizations representing healthcare providers, consumers and state agencies working to improving end-of-care for Californians since 1999. In addition to the Coalition, which is statewide in focus, over 20 community-based coalitions are working in their local communities to improve end-of-life care. These local coalitions serve as change agents to improve end-of-life care at the grassroots level. See attachment for a summary of the Coalition's accomplishments to date. Furthermore, the Hastings Center Report: *Access to Hospice Care, Expanding Boundaries, Overcoming Barriers*, March-April 2003, highlights eight national recommendations specific to

increasing access to palliative and hospice care which correlate closely to the Coalition's own focus and direction.

Improving end-of-life care in our state requires changing the culture of dying in our society. Changing culture is a complex undertaking that involves societal attitudes, institutional change, professional knowledge, community commitment, ethnic and religious influences, and healthcare policy and funding. Greater success can be achieved when multiple strategies addressing different aspects of culture are pursued simultaneously. Leadership and coordinated direction are paramount to success.

III. Current Status of Palliative/End of Life Care Task Team

The Palliative/End of Life Care Task Team was formed in mid 2004 and met monthly. The Task Team began its work in June 2004, by reviewing the *Strategic Plan on an Aging California* including the full list of Palliative/End of Life Care recommendations. The Task Team worked through a selection process to identify two implementation priorities. The priorities represent what the Task Team members felt could be reasonably accomplished in the current environment. For each of these priorities, an Action Plan was created. As a final step, the Task Team compiled a list of barriers that hinder implementation. Task Team members are listed on page i of this document.

The Task Team realized early that the Strategic Plan held important, but few recommendations on palliative and end of life care. Therefore, the team spent a great deal of time developing important additional recommendations, which can be found in Section V of this report.

In 2005, this Task Team expects to move forward on implementation of priority recommendations and work on removing current barriers and reversing misconceptions.

IV. Palliative/End of Life Care Implementation Priorities and Action Plan

New priorities not included in the original October 2003 *Strategic Plan for an Aging California Population* are shown below in Italics.

Priority	Action Plan
<p>Expand public-private partnerships to support the education and training of health and social service professionals in the specialty of palliative care</p> <ul style="list-style-type: none"> • Create a cadre of academic faculty trained in the principles of palliative care at all of the state’s medical schools and teaching hospitals and schools for related medical professionals (e.g., social workers, nurses, etc.). • Develop Quality of Care Protocols and Indicators for Palliative and End of Life Care, Including Pain Management Not Necessarily Limited to the End-of-Life Timeframe. Establish widespread adoption of one or more of the national guidelines and protocols in a wide range of health care settings. 	<p>The Task Team is working to develop action plans to implement many of these priorities.</p> <p>The action plan for implementation of ‘support the efforts of statewide coalitions ...’ is as follows:</p> <ol style="list-style-type: none"> 1. Provide in-kind support of the efforts of the California Coalition for Compassionate Care (Coalition) as the statewide convener of organizations committed to, and incubator of statewide projected aimed at, improving end-of-life care and palliative medicine. <ol style="list-style-type: none"> a) Each state agency and department involved in health and human services should designate an individual as a representative to the Coalition and make attendance and participation a priority. 2. Increase the capacity of hospitals to provide quality palliative care. <ol style="list-style-type: none"> b) Continue to provide training and mentorship to hospitals interested in establishing palliative care services, including a palliative consult services, palliative care beds, and outpatient palliative services. c) Strengthen and provide resources to the established network of California hospitals providing palliative care services to promote the development of standardized guidelines, protocols, data collection, and quality measurement. 3. Improve the competence of long-term care providers in recognizing, supporting and addressing the end-of-life needs of residents/clients and their loved ones. <ol style="list-style-type: none"> d) Develop new or modify existing training as appropriate to provide basic, but comprehensive end-of-life education for each of the varied settings in which long-term care is provided. e) Develop and implement statewide end-of-life curriculum for certified nurse assistants and similar personnel.

Priority	Action Plan
<p>Expand public-private partnerships to support the education and training of health and social service professionals in the specialty of palliative care (continued)</p> <ul style="list-style-type: none"> • Support the efforts of statewide coalitions, such as the California Coalition for Compassionate Care, seeking to educate the public and health care providers on the purpose and value of hospice care. • <i>Recommend that State of California mandate and fund state run medical schools (UCLA, UCSD, UC-Davis, UCSF, UCI) to develop departments of palliative care within the Division of Medicine.</i> 	<ul style="list-style-type: none"> e) Work with law enforcement community to promote policies and procedures that enhance quality end-of-life care. f) Develop end-of-life resources to assist professionals working with persons suffering from dementia or developmental disabilities. <p>4. Encourage consumers to talk with their loved ones about their end-of-life wishes.</p> <ul style="list-style-type: none"> g) Promote public dialogue about end-of-life issues. h) Normalize advance care planning a component of good preventative healthcare. i) Encourage every person over the age of 55 to name a surrogate decision maker and to have a conversation with that person about their end-of-life preferences. j) Establish competence in palliative medicine as a consumer expectation for the physicians and hospitals from which they receive care. <p>5. Change physician behavior so that advance care planning discussions are a normal part of the physician-patient relationship.</p> <ul style="list-style-type: none"> k) Reimburse physicians for the time necessary to have a quality advance care planning conversation. l) Establish advance care planning as a competence all physicians should possess. m) Develop mentors to role modeling quality advance care planning physician-patient conversations. <p>6. Promote the development of resource and professional competence around diversity and end of life.</p> <ul style="list-style-type: none"> n) Continue to develop resources specific for various cultural communities in California. o) Increase the sensitivity to and competence of professionals working with seniors and people at the end of life in handling diversity issues.

Priority	Action Plan
<p>Expand public-private partnerships to support the education and training of health and social service professionals in the specialty of palliative care (continued)</p>	<p>7. Work with Northern California Pain Initiative (NCPI) and Southern California Cancer Pain Initiative (SCCPI) to improve pain management policy and practices in California. (NCPI is a project of the American Cancer Society devoted to the improvement of pain management. SCCPI is a nonprofit volunteer interdisciplinary organization made up of physicians, nurses, pharmacists, social workers and other professionals dedicated to the relief of cancer pain.)</p>
<p>Restructure Reimbursement Systems for Palliative Care</p> <ul style="list-style-type: none"> • Realign reimbursement systems to cover individuals with certain chronic diagnoses that are not “terminal” but need palliative care. • Reimbursement systems should consider the projected mortality rates for specific diseases and examine the “six month life expectancy” restriction on hospice reimbursement. 	<p>1. Changing care for those at the end of life will require leadership, funding, education and research. In order to substantiate anecdotal evidence that hospice and palliative care services are less costly than mainstream curative medical care, researchers need to look at:</p> <ol style="list-style-type: none"> a) An analysis of whether a case-mix payment system is feasible.⁴ b) Analyses of treatment costs for hospice enrollees of a certain type versus non-hospice patients with the same disease. c) Analyses of varying life spans and related costs. d) Demonstration projects analyzing innovative funding mechanisms. e) Demonstration projects analyzing alternatives to the six-month hospice eligibility requirement. f) Identification of best end-of-life practices in the field and development of practice guidelines.

V. Barriers to Palliative/End of Life Care Priorities Implementation

- While a palliative approach is often appropriate in advanced geriatric illness, only seldom is this course considered, much less followed.
- Too few physicians have any training in the palliative/end of life issues faced by most seniors, and this deficiency is especially telling in the degenerative neurological diseases and other non-cancer illnesses.

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- Medical training and practice in academic institutions is largely compartmentalized along traditional disciplinary lines, which seldom focus on treatment or research at the end stage of disease, or have an interdisciplinary orientation.
 - Academic experts in palliative care often find themselves isolated in departments of Neurology, Oncology, Internal or Family Medicine, were they are viewed as necessary but non-financially productive members.
 - Palliative services, which by their nature are cognitively focused, time consuming and generally non-procedural, are poorly reimbursed.
 - Since most of health care still functions on a modified fee-for-service basis, the cost savings of palliative care interventions may be seen as diminishing rather than enhancing the bottom line. As a result even prominent palliative care opinion leaders often have little sway in hospital or medical hierarchies.
 - In California there are but a few “centers of excellence” in palliative care, and none of the major teaching institutions have a strong program in this area.

VI. Proposed Revisions to the *Strategic Plan for an Aging California Population*

The Palliative/End of Life Care Task Team is recommending changes to the Strategic Plan including the addition of two new recommendations and supplementary materials.

- The Task Team recommends updating the original Strategic Plan Section II, F, 5. to include the following:
 - Expand public-private partnerships to support the education and training of health and social service professionals in the specialty of palliative care

Create a cadre of academic faculty trained in the principles of palliative care at all of the state’s medical schools and teaching hospitals and schools for related medical professionals (e.g., social workers, nurses, etc.).
- The Task Team recommends adding additional background to the original Strategic Plan. The recommended additions are included in Attachment 1.
- The Task Team proposes that a new recommendation be added to the Strategic Plan:
 - State of California Mandate and Fund state run medical schools (UCLA, UCSD, UC-Davis, UCSF, UCI) to develop departments of palliative care within the Division of Medicine.

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- The Task Team recommends adding additional background to the original Strategic Plan related to reimbursement systems. These recommendations are included in Attachment 2.

Attachment 1

**PALLIATIVE/END OF LIFE CARE
RECOMMENDED ADDITIONS TO
STRATEGIC PLAN FOR AN AGING CALIFORNIA**

1.a. Expand public-private partnerships to support the education and training of health and social service professionals in the specialty of palliative care

Neal Slatkin, M.D. and Michelle Rhiner, RN, MSN, NP

Palliative care represents a new paradigm in health care for the majority of U.S. physicians and other health care professionals. During the 20th century the primary focus of medical care was on the diagnosis and treatment of acute illness, the objective usually being cure or life prolongation. The clinical and research concentration on the prevention and treatment of acute illness has been a success by any measure, with the average life expectancy increasing by more than 40% over the past century. However, society and contemporary medicine are now challenged to provide care to an aged and aging population of individuals having multiple medical infirmities, many of whom will succumb to chronic degenerative diseases (e.g. cancer, Alzheimer's disease) or advanced cardio-respiratory conditions. For this rapidly enlarging population of patients, seldom are cures or meaningful life prolongation realistic goals. With the anticipated financial strain that the infirmed elderly will place on governmental budgets, society has a responsibility to ensure that health care resources are invested in practical and problem oriented programs likely to produce tangible good, rather than on technologically based gestures having poorly defined or unrealistic objectives.

The goals of elderly patients for meaningful and dignified care, and of society for equitable and cost-effective solutions, are increasingly finding a common ground in the practice of palliative care. Simply defined, palliative care is focused on the maintenance of comfort and quality of life, the provision of social support, and assistance in planning for end of life. By extension, a core component of palliative care is the development of coherent and well-integrated inter-disciplinary teams, since unlike acute care, success in the management of chronic and advanced disease requires the collaboration of diverse medical and social care disciplines.

1.b. Develop quality of care protocols and indicators for palliative and end of life care, including pain management not necessarily limited to the end-of-life timeframe

Ben Rich, PhD.

Definition of terms

The above charge appropriately reflects a more expansive concept and definition of palliative care, such as the following that has been offered by Dr. Charles von Gunten of the San Diego Hospice: “Palliative care is the relief of pain and suffering.” It is a model of care that is often contrasted to curative or disease-directed interventions. However, emerging models, characterized as “simultaneous care,” recognize that curative and palliative measures can, and often should proceed in tandem, particularly when the patient has months or years of anticipated survival.

Existing standards

There are quite a few clinical practice guidelines and protocols for palliative care (broadly defined as above) that have been promulgated by interdisciplinary panels of prominent experts in the field. Among the first were the Agency for Health Care Policy and Research Clinical Practice Guidelines for acute (1992) and cancer (1994) pain. In 1996, the American Board of Internal Medicine (ABIM) published “Caring for the Dying: Identification and Promotion of Physician Competency,” in which core competencies in end-of-life care were identified and explained. In 1998, the American Medical Association established the Education for Physicians in End-of-Life Care Project (EPEC). Its goal was to create and disseminate a continuing medical education curriculum that would equip all physicians with the core competencies necessary to provide minimally acceptable palliative care to their patients. Both the ABIM and EPEC initiatives are based upon the premise that all physicians, not just pain and palliative care sub-specialists, should be capable of providing competent palliative care.

In 2002, the Last Acts Project published “Means to a Better End: A Report on Dying in America Today.” This report sets forth principles of palliative care, and then evaluates (assigning grades of A through F) the extent to which each state meets 8 separate criteria: advance directive policies; location of death, hospice use, hospital end-of-life services; care in ICUs at the end-of-life; pain in nursing home residents; state pain policies; and palliative care-certified physicians and nurses. California received a “C” grade.

In 2003, the National Consensus Project for Quality Palliative Care issued extensive “Clinical Practice Guidelines for Quality Palliative Care.” The guidelines are organized around eight domains of care: structure and processes; physical aspects; psychological and psychiatric aspects; social,

spiritual, and existential aspects; cultural aspects; care of the imminently dying patient; and ethical and legal aspects.

A good example of a set of indicators for palliative and end-of-life care has been developed by Joseph Fins and colleagues (*Journal of Pain & Symptom Management* 1999; 6:6-15) called the "Goals of Care Assessment Tool (GCAT)." Among the GCAT indicators for a shift in emphasis from disease-directed to palliative therapy are: diagnosis of terminal condition or life-expectancy of less than 6 months; acute decompensation such as ARDS, sepsis, shock, transfer to an ICU; patient expressions of awareness of or wish for impending death; staff identification of patient as dying.

The relationship between clinical practice guidelines and the standard of care

Heretofore, the promulgation of clinical practice guidelines by prominent health care professionals or groups has presaged, rather than constituted, a change in the usual custom and practice of health care professionals in some aspect of patient care. This point is significant because traditionally the standard of care to which physicians or other health care professionals are held is defined and delimited by what other reasonably competent and prudent professionals would do under the same or similar circumstances. There is invariably a lag time between the promulgation of new clinical practice guidelines and their adoption by a majority of health care professionals. Moreover, the mere issuance of clinical practice guidelines, regardless of how much they may be needed or how prestigious the group that develops them, does not necessarily result in changes in professional practice (Lomas, et al., *New England Journal of Medicine* 1989; 321: 1306-1311). Similarly, studies indicate that merely exposing health care professionals to continuing education programs (such as the EPEC seminars or programs offered in response to California Assembly Bill 487) may not consistently result in dramatic changes in practice patterns (Max, et al., *Annals of Internal Medicine* 1990; 113: 885-889).

The problematic nature of motivating health professionals to improve their quality of care in a particular aspect of professional practice has caused courts in an increasing number of jurisdictions to cease to allow the usual custom and practice of health care professionals to define and rigidly set the standard of care. Rather, the usual custom and practice becomes *prima facie* evidence of the standard of care, but that rebuttable presumption can be overcome by evidence, such as national clinical practice guidelines, indicating that the usual custom and practice is inadequate, out of date, and actually detrimental to patient welfare. In other words, the standard of care (when defined as the usual custom and practice) can be shown through such clinical practice guidelines to be substandard. This is arguably what took place in the recent California case of *Bergman v. Chin*, which challenged the quality of pain management provided to a patient with lung cancer. There was expert

testimony offered on behalf of the defendant physician that the pain management he provided to the patient was consistent with the usual custom and practice of similar physicians in California when caring for such patients. However, the jury found more persuasive the expert testimony on behalf of the plaintiff that the AHCPR cancer pain guidelines should constitute the minimal standard of acceptable care and, if they had been followed, would have insured that the patient did not suffer. On this basis, the jury found that the failure of the defendant physician to provide palliative care consistent with those guidelines constituted not simply medical malpractice, but elder abuse.

Ultimately, what is necessary to improve the quality of pain management and palliative care for Californians is the widespread adoption of one or more of the national guidelines and protocols discussed above in a wide range of practice settings, including acute care hospitals, skilled nursing facilities, home health agencies, and hospice programs. All such agencies should be required to demonstrate that their professional staffs have the requisite knowledge, skills, and attitudes to provide care consistent with those guidelines and protocols, and that reliable monitoring mechanisms assure that such care is actually provided. Moreover, mechanisms should be in place to identify departures from those standards and insure that prompt and appropriate remedial measures are instituted.

Attachment 2

PALLIATIVE/END OF LIFE CARE RECOMMENDED ADDITIONS TO STRATEGIC PLAN FOR AN AGING CALIFORNIA REIMBURSEMENT SYSTEMS FOR PALLIATIVE CARE

[To be added to #2 Restructure Reimbursement Systems for Palliative Care: a) Realign reimbursement systems to cover individuals with certain chronic diagnoses that are not “terminal” but need palliative care, and b) reimbursement systems should consider the projected mortality rates for specific diseases and examine the “six month life expectancy” restriction on hospice reimbursement.]

Margaret Clausen

Many Americans, nearing the end of life, suffer needlessly and die badly. In 1982, when Congress enacted the Medicare Hospice Benefit, the program was designed to address the needs of patients with cancer diagnoses, and political considerations demanded budget neutrality. In order to achieve this, provisions were added that require eligible recipients to give up curative care in order to receive hospice services and limit access to the services to those with a prognosis of six months or less to live. Because of the language in the Social Security Act, Medicaid programs follow the same provisions and are plagued by the same barriers.

Since 1982 advances in medical science have blurred the distinction between living and dying as well as distinctions between life-extending and palliative treatments.¹ In order to address the needs of Americans who are living longer with multiple chronic illnesses, improvements are needed to make the system more accessible, less rigid, more accepted by the dying and their families and less financially draining to the health care system.

The Medicare and Medicaid programs are filled with complexities that prevent beneficiaries from fully benefiting from available options. Like Medicare, Medicaid programs lack an innovative, comprehensive plan for providing cost-effective, high-quality care at the end of life. Public policy makers need to reexamine the eligibility requirements in light of the advances in medical care and reimbursement limits of the Medicaid hospice benefit. It is important for Medicaid decision-makers to identify ways to fund palliative care beyond the hospice benefit.²

The current health care delivery system is organized in silos: nursing home, hospital, home and doctor’s office. Under the usual fee-for-service program, doctors, hospitals, and other service providers are paid for each billed service. This arrangement encourages billable services, not continuity of care.³

Changing care for those at the end of life will require leadership, funding, education and research. In order to substantiate anecdotal evidence that hospice and palliative care services are less costly than mainstream curative medical care, researchers need to look at::

- An analysis of whether a case-mix payment system is feasible.⁴
- Analyses of treatment costs for hospice enrollees of a certain type versus non-hospice patients with the same disease.
- Analyses of varying life spans and related costs.
- Demonstration projects analyzing innovative funding mechanisms.
- Demonstration projects analyzing alternatives to the six-month hospice eligibility requirement.
- Identification of best end-of-life practices in the field and development of practice guidelines.

References

¹ The Robert Wood Johnson Foundation, *Financial Implications of Promoting Excellence in End-of-Life Care*, available online at www.promotingexcellence.org, October 2002.

² Austin Bonnie J and Fleisher, Lisa K. *Financing End-of-Life Care: Challenges for An Aging Population*, Academy Health, February 2003.

³ Lynn, Joanne and Adamson David, *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*, Rand Health, 2003.

⁴ Report to the Congress, Medicare Beneficiaries' Access to Hospice, Medicare Payment Advisory Commission, May 2002.