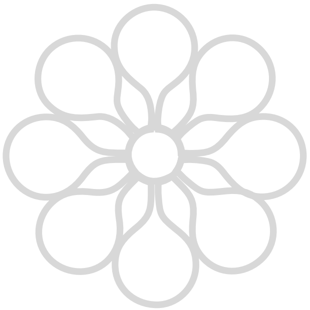
The Palliative Response

F. Amos Bailey, M.D.



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Acknowledgments

The Palliative Response represents the encouragement and support of many individuals who deserve recognition and who, I hope, will be honored by this work. I owe foremost gratitude to the patients who have been my primary teachers over the last 15 years. In the classrooms of their homes and hospital rooms, they have taught me much! It is a great privilege to be invited into a home; it is really being invited into a life. For allowing me that privilege, I thank Ms. M., my first hospice patient about whom I write in the Preface, and the over 2000 people on whom I since have made house calls. Palliative-care inpatients, first at the Balm of Gilead Center at Cooper Green Hospital and now at the Safe Harbor Project at the Birmingham Veterans Administration Medical Center, have all been wonderful educators. It is my honor to pass on their many lessons.

Dr. William Dismukes, Residency Director at UAB Health Systems, planted the seed for this book in 1999 when he asked that all Balm of Gilead patients be assigned to residents, and invited me to devote the final 10–15 minutes of each morning report to palliative care. Suddenly, I had a forum in which to talk about palliative care, and these talks gradually became *The Palliative Response.* My appreciation goes to the residents and medical students assigned to the Cooper Green Hospital Medical Service, who have listened and responded to these talks for the last four years.

My deep appreciation goes to Cooper Green Hospital and its former CEO Dr. Max Michel, who believed that we could create the Balm of Gilead Center as a site of excellence for End-of-Life care and training, and to all my colleagues at the Balm of Gilead and the Birmingham Area Hospice. Together we believed in a vision, and together we nurtured the vision into excellent care in the hospital and hospice of a public health system. Palliative Specialist/Nurse Practitioner Edwina Taylor, RN, CRNP; Project Director James Bolden, MPA, MT (ASCP); Charge Nurse Barbara Sunday, RN; and Community Coordinator Carol Padgett, PhD were instrumental in helping shape the Balm of Gilead into a community of caring at the End of Life.

Dr. Ira Byock and the Robert Wood Johnson Foundation, who selected Cooper Green Hospital and the Balm of Gilead as a demonstration project for Promoting Excellence in End-of-Life care, have offered unwavering support. Their emphasis on dissemination has inspired me to find ways to share the things we have learned and are continuing to learn about palliative care. Dr. Byock's focus on the potential at Life's End for growth in both patients and their caregivers sustains my motivation and guides my interactions.

Carol Padgett has helped organize my material while lending her insights as a keen observer of palliative patients, the human condition, and my interactions with patients, families, staff, and students.

My wife Marci and my children Mandy, Patrick, and Lydia faithfully sent me to my desk to write and faithfully appeared with technical support when the computer went on the fritz. My deepest gratitude, however, is reserved for their moral support, which has made all the difference.

— Dr. F. Amos Bailey,
Birmingham, September 2003

About the Author

In his preface to *The Palliative Response* the author poses the apparent paradox of growth at the end of life. To track the career of F. Amos Bailey is to examine a paradigm of professional growth. This career has taken him from his training as a medical oncologist to a practice in a small Appalachian community to an inner-city public hospital (where he founded the Balm of Gilead, an inpatient hospice facility) to a hospital for veterans. Through those transitions F. Amos Bailey has "morphed" from a simple practitioner of the healing arts into an icon for a new model of medicine's primary mission, the relief of human suffering.

Along the way, Dr. Bailey has become a teacher. He is, however, quite unlike the typical clinical educators who populate the corridors of modern teaching hospitals. Many of them are drawn to their work by a love of the academic environment and a fascination with the process of learning. F. Amos Bailey has been compelled to teach by the desire to advance the mission of palliative care and the need to touch more patients whose suffering needs his balm.

In an era when translation research is a key phrase for priority funding, F. Amos Bailey is perhaps the ultimate "translationalist." He has taken a body of clinically relevant knowledge from multiple domains and demonstrated how to apply it at the bedside in new way. Through this book he shows us how we can be better doctors.

F. Amos Bailey lives and grows in Birmingham with his wife Marci, and their children Mandy, Patrick, and Lydia. He currently practices his art at the VA Medical Center, where he directs the Safe Harbor Palliative Care Project.

— Dr. John I. Kennedy, Jr.

Associate Chief of Staff for Primary Care, Birmingham, VAMC

Professor of Medicine, Division of Pulmonary and
Critical Care Medicine, University of Alabama, Birmingham

Growing Pains

> *Maslow, Erickson, and Piaget each told us*
> *that human development is a lifelong process.*
> *I think it simply turns out that they were right.*
> *—Ira Byock, M.D.*

Growth at the Life's End? Such an idea initially might sound like an oxymoron. Life's End is, after all, a euphemism for Death. What could growth and death have to do with each other? I find part of the answer to that question in the concept of "growing pains." Some children experience pain in their bones at times in their lives when the growth is rapid, sudden and unexpected. When nothing else can explain the pain, we shrug and diagnose "growing pains."

This palliative-care manual is the fruit of "growing pains." In 1989, I moved to Beckley, West Virginia. I had completed training in Medical Oncology and had chosen to practice in a little Appalachian town to test my mettle and ability. Nothing in ten years of training, including a Medical Oncology Fellowship, had prepared me for the immediate turn that my professional life took toward providing care where there can be no cure. A patient, guided by a women's magazine and the wisdom of personal experience, taught me more about caring for the dying than I had learned from mentors guided by medical texts and the tenets of professional practice. Only when I happened upon the *Oxford Textbook of Palliative Medicine* did I recognize that "the suffering paradigm" had been the template over our discussions.

During my first month of private practice in West Virginia, a nurse and social worker asked me to serve as Medical Director for the hospice they hoped to start, assuring me that my duties would include only "signing some papers and writing a few prescriptions for pain medicine." During my second month, I was summoned to the home of Ms. M., who a year earlier had noticed numbness in her right hand. The CT scan had shown a tumor and the biopsy had confirmed its malignancy. Although radiation had held things in check for a few months, the numbness recurred and the repeat scan only confirmed what everyone knew was the recurrence of her cancer and the beginning of the end. Ms. M. read about hospice in "a women's magazine," requested a referral, and identified me as her "new doctor." Following the article's description of hospice care, which she was sure included house calls, Ms. M. was now demanding that her new doctor see her at her home.

With great trepidation, I made my way to her residence. What could I do for her? How could I help her in her own home? In ten years of training, I had received no formal instruction in caring for the dying. I had never referred a patient to hospice and had never heard the words "palliative care." On more than one occasion, I had witnessed patients dying while chemotherapy was being infused into their veins.

Entering Ms. M.'s home, I found a moon-faced bald woman propped in her chair and gazing into her backyard. Ms. M. was gracious and introduced me to her family. I dealt with a few minor adjustments in her medicines. And then she asked me what might happen. She discussed concerns about her children and about unfinished tasks, her interest in meditation and her childhood Catholic faith. She spoke of sadness and fears and, as we ended, told me how much I had helped and asked me to return soon. I visited Ms. M. for the next few months, until she died one cold fall night in her own home surrounded by her family.

I now understand my experience with Ms. M. as one of pain and growth for all who were involved. For me it was an epiphany. Over the next few years, amazed at how much better my dying patients fared at home than in the hospital, I strove to arrange for them to be discharged so that their suffering could be eased; and my clinical interventions in the hospital and clinics became tempered with home-style comfort care. All the while, I remained frustrated at the host of barriers that prevented greater application during hospital care of lessons learned from home care.

I have worked with many teachers since Ms. M. They have included my patients and colleagues in West Virginia, later at the Balm of Gilead Project at Cooper Green Hospital, and now at the Birmingham Veterans Administration Medical Center. This palliative-care manual is a distillation of some of the lessons I am learning.

Life's End can be a time of growth for each of us. Persons who are facing a life-threatening or terminal illness have been "dying" since the day they were born. Now, however, that reality thrusts its way to center stage and demands attention. The dying process can be a time of personal growth for these persons, their families and all with whom they come in contact. Dying persons and their communities grow as they accommodate the changes that are inevitable as death approaches. Palliative care can help each of us to experience personal growth in the light of Life's End. No one can make anyone grow. However, excellent end-of-life care—care that alleviates some of the physical, emotional, social, and spiritual suffering of Life's End—can allow patients, families, and their community of caring to grow and even blossom.

About This Book

As Medical Director of the Balm of Gilead Palliative Care Unit at Cooper Green Hospital, I supervised the General Internal Medicine residents who followed all patients admitted to the unit. The need for basic education in palliative care became clear shortly after the initiation of "palliative work rounds" during the final 15 minutes of the residents' Daily Morning Report. The chapters in this manual are the fruits of this opportunity to introduce new physicians to key dimensions of palliative care.

The manual's topics, designed for presentations of 12–15 minutes, cover management of physical symptoms and emotional, spiritual, and social issues common in end-of-life care. The manual offers guidance for specific palliative roles, such as sharing bad news, conducting a family conference, and making a death pronouncement. Chapters on specific diseases review common symptoms, end-of-life manifestations, and prognostic signs that might prompt referral to palliative care and hospice.

Each chapter opens with annotated **Key Points** from the 12–15 minute discussion and continues with a more detailed **Handout.** Each chapter concludes with **Selected Readings** that direct the student to references for further study on the chapter's topic.

The manual is appropriate as a basic classroom text for students and as a tutorial guide for residents and fellows in Palliative Medicine rotations. Its form facilitates selecting relevant sections for integration into classroom teaching or for review by rounding groups or consulting residents.

Five **Provider Pocket Cards** accompany the manual:

Consider Palliative Medicine outlines the conditions and goals warranting palliative-care consultation.

Analgesic Dosing is an aid for pain management.

Sharing Bad News/Family Conference offers a procedure for speaking with patients and families about realities and decisions associated with Life's End.

Last Hours of Life suggests orders appropriate for patient comfort and family support.

Guidelines for Death Pronouncement leads the physician through the interpersonal and technical aspects of pronouncement, documentation, and follow-up family contacts.

My goal in developing *The Palliative Response* has been to offer a concise and accessible package suitable for palliative-care instruction and review in a variety of settings. My larger hope is that this effort will help bolster the competence, confidence, and commitment of medical providers to integrate *The Palliative Response* into daily clinical practice. I would appreciate feedback and constructive criticism from colleagues so that future revisions will reflect the ongoing refinement of palliative principles and practice.