

# Caring for Our Parents

BY SUSAN McDONOUGH

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As someone who has spent nearly her entire professional career in aging services, I was somewhat skeptical that I would find a book about elder care to be informative. However, my skepticism was unfounded. Reading Howard Gleckman's *Caring for Our Parents* convinced me that I should buy this book for all my friends and colleagues. It is a well-written and researched book which would serve as a primer for anyone facing caring for an older adult or plan-

“Today, as many as 44 million Americans care for more than 10 million elderly and disabled friends and relatives.”

ning for his or her own future.

In many instances, those of us in health or elder care believe that we are prepared to deal with the complexities of managing and paying for care for older adults. However, few of us who are in the business have long-term care insurance, and even knowledgeable people find themselves frustrated when trying to arrange care or services for an older adult within their own family or circle of friends.

Gleckman's book provides four distinct perspectives. The first looks at arranging care for older friends or relatives from the viewpoint of the caregiver. The second explores the barriers that disabled younger people encounter when trying to arrange care. The third examines the ways in which people currently pay for long-term care. The fourth provides information on approaches to paying for long-term care in other countries, and here the author offers his own thoughts on the future financing of long-term care.

*Caring for Our Parents* includes real life experiences of people who have taken on the role of caregiver for an older adult, whether for a spouse, parent or grandparent. Mr. Gleckman, like many middle-aged children, found himself acting as a caregiver for his father, mother, and his wife's parents, all within a short period of time. His own frustrating personal experiences add value to this book. Like many, he was confused about how to pay for his father's care. (Studies repeatedly indicate that most Americans believe Medicare will cover their long-term care needs.) Few are well equipped to deal with one specific health event that transforms a vigorous older person into a frail older adult in need of ongoing care.

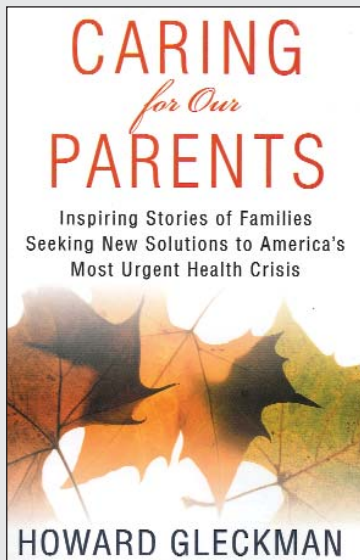
Mr. Gleckman provides a balanced view of long-term care providers in this country. While not singling out Catholic providers, he conveys the frustration

that organizations, particularly those that are not-for-profit, experience when trying to provide the right care at the right time in the right place. Few in Catholic long-term care would argue with the point that the current reimbursement system does not always allow for the flexibility in providing the care we consider to be appropriate. We have all dealt with the frustrations of consumers who have invested in long-term care insurance and found that the insurance they purchased does not cover what they need in the setting they prefer.

Many Catholic long-term care organizations have developed programs that respond to a wide range of care that older adults may need in the course of their aging process, including in-home services, adult day care, assisted living or boarding care, as well as skilled nursing care. Several Catholic organizations, including Alexian Brothers, were early innovators in care models such as PACE (Program of All-inclusive Care for the Elderly), which Gleckman cites as a comprehensive program. He also points to the need to have excellent hospice care, which Catholic health care has long made a priority.

Having worked with the Catholic Health Association and the American Association of Homes and Services for the Aging for several years to advocate for a new approach to long-term care financing, I was delighted to see that the author, having researched different models of care in Europe and Japan, reached a similar conclusion: that the current Medicaid model for long-term care is unsustainable. He further identified the “CLASS Act,” sponsored by the late Sen. Edward M. Kennedy and supported by CHA and the American Association of Homes and Services for the Aging, as offering some real potential.

The author also makes an important point regarding the demographics of



**Caring for Our Parents:**  
Inspiring Stories  
of Families Seeking  
New Solutions to  
America's Most Urgent  
Health Crisis

BY HOWARD GLECKMAN

St. Martin's Press, 2009  
320 pages, \$24.95

[www.us.macmillan.com](http://www.us.macmillan.com)

# Book Reviews

the United States and the current lack of formal and informal caregivers. He believes that the situation will be exacerbated if the United States government continues its current approach to immigration. Today, the author notes, it is increasingly difficult to persuade U.S.-born workers to do these difficult jobs, and approximately 20 percent of the aides in this country are foreign born. Lacking solid alternatives to the current system, these workers will be expected to work even harder in the future and will expect better wages and benefits, thus driving up the overall cost of long-term care, Gleckman notes.

The author does point to some encouraging innovation. Among these are the training programs offered at the Schmieding Center in Arkansas to caregivers for older adults. Another is developing technology that makes it possible for older adults to live longer independently in a variety of settings. He adds his voice to those of millions in this country who understand the need for research to cure Alzheimer's disease, recognizing that dementia care is complicated and costly for both individuals and public reimbursement programs.

*Caring for Our Parents* is an excellent read, accessible for both profession-

als and the general public. My only wish is that the author had been more forceful in suggesting that baby boomers take an active role in ensuring that there is a change in the financing of long-term care. This is not an issue where we baby boomers should sit back and hope that Congress provides for us, or that our 401(k)s will miraculously be sufficient to pay for years of care. Baby boomers, in particular, will find the information useful, whether dealing with a parent in crisis or planning for their own futures. While the boomers are going to live longer with less frailty, they will not be satisfied if the current options are not improved. ■

## Catholic Sisters: The Call to Care

BY SUZY FARREN

*Editor's note: Suzy Farren is the author of Call to Care, The Women Who Built Catholic Healthcare in America (St. Louis, Catholic Health Association of the United States, 1996), a book of stories about the many ways Catholic sisters have been meeting health care needs from the early 18th century through today. Here she reviews two*

*recent books related to that history.*

*Ms. Farren, founding editor of Catholic Health World at the Catholic Health Association, is vice president for communications at SSM Health Care, St. Louis.*

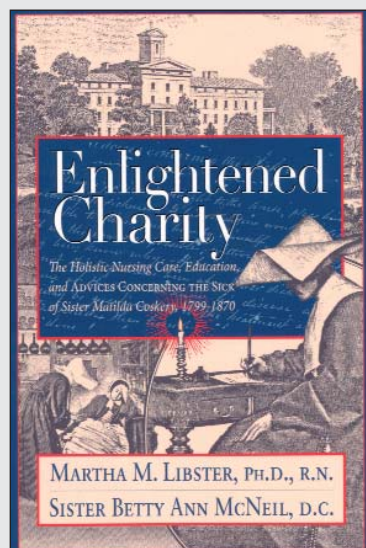
In their scrupulously researched new book, Dr. Martha Libster and Sr. Betty Ann McNeil offer a glimpse into a little-known chapter of American

nursing history. They have extensively documented the story of Sr. Matilda Coskery, a Daughter of Charity and one of the nation's early nurses.

The book stemmed from a happy coincidence. Libster, a psychiatric nurse, was doing research for a book on herbal botanicals, and McNeil, the Daughters of Charity archivist, discussed a 76-page text by Sr. Coskery: *Advices Concerning the Sick*. Much of Sr. Coskery's work centers on care of the insane, a topic that spoke strongly to Libster. This book is the result of their years of collaboration.

For more than a century, the text had lain dormant in the Daughters' archives in Emmitsburg, Md. Speculating that it was never published because it was a "work in progress" with "a number of open spaces on some of the pages," the two delved into the text and in the process, they have filled in some gaps in American nursing history.

Acknowledging that Sr. Coskery's humility posed a challenge, as she would not have allowed herself "to be singled out by name," the collaborators responsible for this volume nonetheless consider her to be the author of the work, and they have pieced together a remarkable amount of information about nursing during what they



### Enlightened Charity – The Holistic Nursing Care, Education, and Advices Concerning the Sick of Sister Matilda Coskery, 1799-1870

BY MARTHA M. LIBSTER, PH.D., R.N.,  
AND SISTER BETTY ANN McNEIL, DC

Golden Apple Publication, LLC, 2009  
528 pages, \$29.95

[www.goldenapplehealingarts.com](http://www.goldenapplehealingarts.com)

describe as a formative, yet heretofore little known, era.

To set the context, they begin with some background. And that is the one criticism I had of the book. Most readers may appreciate the level of detail the book provides, but I found it a bit overwhelming. Founded in 1809, the Sisters of Charity of Saint Joseph (to be renamed the Daughters of Charity in 1850) were the first Roman Catholic sisterhood native to the United States. The sisters started schools and orphanages and cared for the sick in their homes. When Sr. Coskery entered the order in 1827 at the age of 28, the sisters were already established as nurses. Sr. Coskery was described as “small, slight, rather pale with piercing black eyes, a quick and often abrupt manner of speech.” Other descriptions note that she was prone to anxiety and inner conflict. One of her early assignments was to nurse patients at the Maryland Hospital for the Insane.

By 1840, the Sisters opened an asylum for the insane, and with more than a decade of nursing experience, Sr. Coskery was named Sister Servant. There she oversaw the other sisters, and they became known for their humane handling of the insane and for treating patients with kindness rather than force. The authors observe that Sr. Coskery and the Sisters of Charity’s “zealous approach to the care of the insane, some of the most marginalized individuals in society, stemmed from their religious fervor for charitable service to their fellow human beings.”

Much of the book focuses on Sr. Coskery’s text: *Advices Concerning the Sick*. The text is divided into sections, including care of the insane, the field in which Sr. Coskery made her most significant contribution. The authors point out that she taught nurses to treat the insane as rational beings and to provide care that elevated the patients’ self-esteem. The text describes how to create a healing environment and how to offer compassionate care.

Sr. Coskery’s thoughts on nursing care are wonderfully practical, while demonstrating compassion and a concern for patient safety.



Courtesy Daughters of Charity Archives, Emmitsburg, Md.

17th Century Daughter of Charity of St. Vincent de Paul in France

“Always keep a bed or two ready, so that the poor sick may not be kept waiting.”

“If he is faint-like, give him a little wine or toddy.”

“Let every phial or box of medicine have its name on it and the quantity to be given, or serious mistakes will be the consequence ... .”

“Never reproach those suffering from intoxication, for their own thoughts are often more than they can bear ... .”

The authors are quick to reference the inequities of the times. Physicians regarded Sr. Coskery as an “oracle of

wisdom,” yet she could never have become a physician herself. Her own brother earned a medical degree after graduating from school and writing an 11-page thesis on fever. Although her contribution to medicine was far greater, it would be nearly a century (1849) before the first American woman obtained a medical degree.

Sr. Coskery nursed soldiers during the Civil War and continued to provide nursing care almost until her death at 71. In late May 1870, after caring for the poor near Emmitsburg, she became ill herself. She died after a 12-day illness.

*Advices Concerning the Sick* was most likely completed years before Florence Nightingale’s text *Notes on Nursing* appeared in 1860. Libster and McNeil ponder why it was that Ameri-



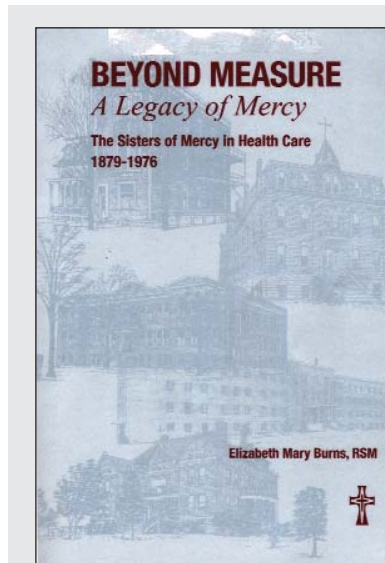
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can nursing adopted the secular model of Florence Nightingale, a British woman, rather than the more spiritual approach of Sr. Coskery and the early Daughters of Charity. After reading this enlightening book, it is a question that gives us pause. ■

Elizabeth Mary Burns has done a wonderful service to the history of Catholic health care. In detailing the ministries of the Sisters of Mercy in Iowa and Michigan over nearly a century, she offers an alluring array of accounts that paint a picture of life in another era. Burns offers brief accounts of every health care facility opened by the Mercy sisters in those two states, beginning in 1879, and each is accompanied by at least one letter or journal entry from a sister who served there.

Many have written about how Catholic health care came to be: how sisters responded to requests to meet the needs in communities across the United States. What we hear less often is what happened when the need was no longer there, or when the times called for a different model of care. In many stories, Burns includes the often emotional departure of the sisters from hospitals where they had served for years. In Dowagiac, Mich., for example, the sisters reluctantly decided to leave the area after many years of operating a sanitarium. This painful decision was made after they learned people in the area were planning to build a new hospital without their help. One sister wrote: "It has certainly brought about a disagreeable feeling, to think that after all the years of service we have rendered to the doctors and citizens ... that we are not more appreciated."

Facility by facility, Burns tells the story of the founding, the operating, and, in some instances, the sisters' departure, using quotes from their letters and journals. She writes of a simpler world than today, but one no less stressful, particularly in regard to



## Beyond Measure — A Legacy of Mercy, The Sisters of Mercy in Health Care 1879-1976

BY ELIZABETH MARY BURNS, RSM

*Gold Leaf Press, 2009*  
*Limited availability*

[www.goldenleafpress.com/inspirational](http://www.goldenleafpress.com/inspirational)

finances. Because the sisters did whatever they could to serve the poor, their financial worries were relentless. One sister decried the rising price of nursery beds. A bed she once paid \$12 for had increased more than 11 times, to \$135 apiece — what with all the “paraphernalia the Public Health requires to be attached to the bed.” And another wrote: “But bills ... seems like we never get any place with them ... I wonder if anyone had such troubles as we do here in Dubuque.”

In fact, life was so difficult for the sisters in Dubuque that one confessed in a letter that she dreamed about how lovely it would be “to just sit in jail and have your meals brought to you, say your prayers and maybe do a bit of knitting. ... Anyway,” she wrote: “the Republicans are in after the elections here in Iowa so things can’t be any worse.”

In 1953, when a mother provincial wrote to deny a request for additional funds from the sister-administrator of a hospital in Fort Dodge, Iowa, she suggested instead, “Let the druggist go, and have the prescriptions sent out and charged to the patients’ bills and have them collected, and get a hold of the situation and do something about your bills.”

In Grayling, Mich., the sisters lived

in the attic of the hospital. Below, “kerosene lamps provided the only illumination, but later electricity was available from seven until nine in the morning on Wednesdays and Saturdays.” And we think we have it tough.

But there were benefits too. In 1890, after the sisters opened a hospital in Manistee, Mich., one wrote in a magazine article, “The exquisite sunsets seen from the hospital fix themselves indelibly on the memory of those who return to their homes as convalescents or cured.” Another entry from their hospital in Grayling, Mich., explains that the sisters “persuaded the lumber camps to provide dairy cattle in exchange for health care.”

In Big Rapids, Mich., a listing of the countries of origin of the patients at Mercy Hospital from the late 1800s witnesses to the influx of immigrants who had come to settle the land: “We have one Negro, two Indians, one Russian, one Spaniard, about four Englishmen; hundreds of French, Swedes, Canadians and Americans, many Irish and Germans. We had some Finns, Lapps, Dutch and Poles; yet they never seem to quarrel about nationalities.” That very same hospital burned to the ground three times, the last in 1918,

when the sisters decided not to rebuild.

Burns' accounts demonstrate the changes over time in religious life, as well. In the late 1950s, the sisters were granted a new benefit: a day off each week. In 1961, a new policy meant sisters no longer needed approval slips to attend overnight professional meetings,

and they could even travel alone to those meetings when necessary.

With the transition from a matriarchal operating model to a business model came a decline in the number of sisters. With fewer sisters and increasing financial pressures, in many instances the sisters transferred their ministries to the laity. The book ends with the for-

mation in 1976 of the Sisters of Mercy Health Corporation, Detroit, which included 17 hospitals.

In her introduction, Burns recounts that tracing the story of the Mercy ministries was an "exciting and rewarding treasure hunt." She has passed that benefit on to her readers. She has indeed given us a treasure. ■

## Neonatal Bioethics

**BY MICHAEL PANICOLA, Ph.D.**

*Dr. Panicola is corporate vice president, ethics, SSM Health Care, St. Louis.*

Based on its title, one might expect to find in Drs. Lantos' and Meadow's book a fairly typical treatment of neonatal bioethics with the main focus on tragic, life-and-death treatment decisions for premature babies occasioned by technological advances in neonatal medicine. To be sure, there is some of this, at least from a historical viewpoint. However, *Neonatal Bioethics* is less a contemporary update to such books as Robert Weir's classic *Selective Nontreatment of Handicapped Newborns* (Oxford University Press, 1984) than it is a probing reflection on neonatal medicine more along the lines of Shannon Brownlee's excellent *Overtreated* (Bloomsbury, 2007).

In *Neonatal Bioethics* Drs. Lantos and Meadow examine medical innovations in neonatology and describe the "iterative, nonlinear and, sometimes, heated process" (p. 8) by which a tentative societal consensus evolved with regard to complex moral, legal, economic and political questions. The book is an easy, fascinating and fairly short read, with the bulk consisting of three chapters that describe distinct eras in the history of neonatal medicine.

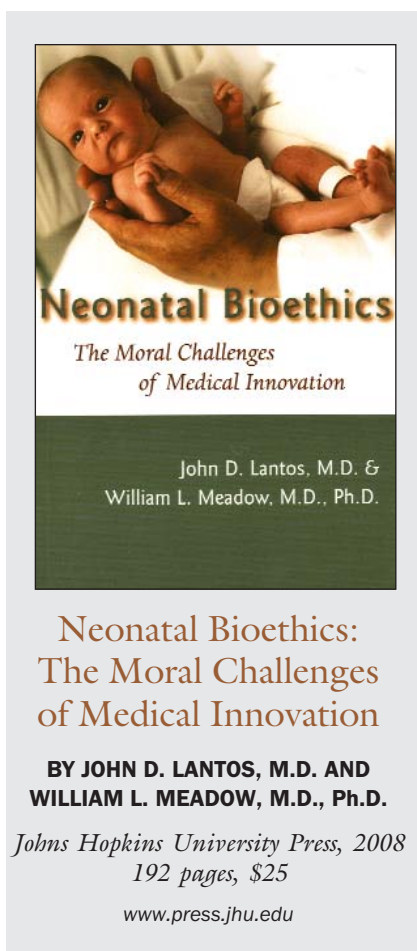
The first is the "Era of Innovation" (1965-1982) during which neonatology had some its most dramatic successes with the regionalization of perinatal care and the introduction of mechanical ven-

tilation and total parenteral nutrition for premature babies. While these innovations made modern neonatal intensive care possible, progress often outpaced moral reflection as parents, physicians and society were for the most part unprepared to grapple with the ques-

tions of which babies should receive the new therapies, when the therapies should be initiated and, even more frightening, when they should be withdrawn.

The second era described in the book is the "Era of Exposed Ignorance" (1982-1992) during which innovations continued (e.g., surfactant and antenatal steroids) but in a less dramatic way as the focus shifted to a refinement of "both the technologies and the societal mechanisms by which the use of the technologies were governed" (p. 85). Unlike the first era, when the prevailing concern was whether physicians were being too zealous in their attempts to "save" premature babies with the new tools at their disposal, this era was dominated by almost the exact opposite concern. With improvements in survival rates among critically ill newborns, yet significant morbidity or disability among some survivors, the concern arose that treatments necessary to save the lives of some impaired newborns were being withheld on quality of life grounds. This concern was fueled by news reports and legal cases, such as that of Baby Doe in Bloomington, Ind., and led to the federal government's intervention into neonatal medicine and the ultimately unsuccessful attempt to create national standards for neonatal treatment decisions.

The third era described in the book is the "End of Medical Progress" (1992-Present) during which no new major innovations in neonatology have materialized and improvements in birth-





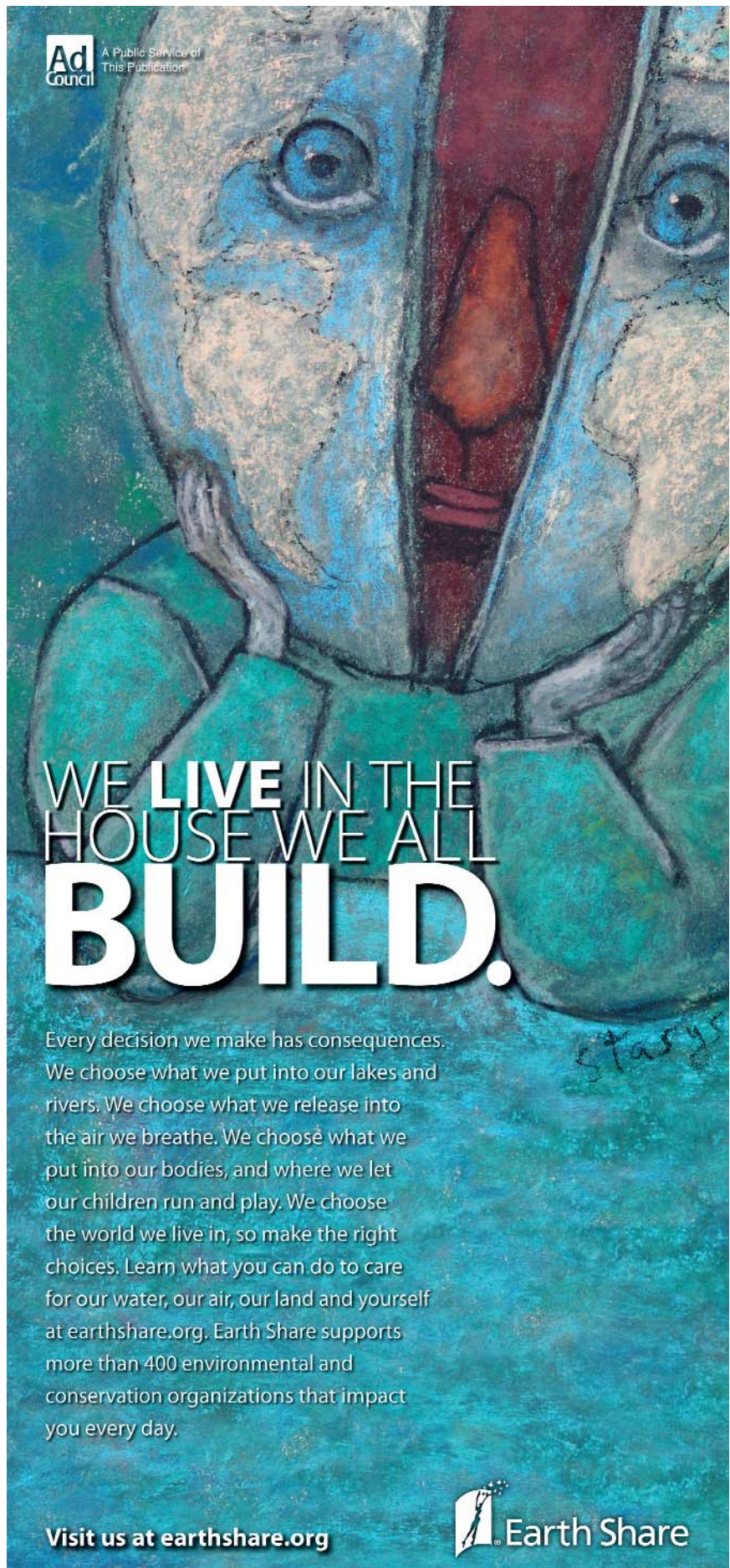
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weight-specific survival rates have come to a halt. Though some lament the lack of progress in this current era, the upside is that it has given physicians a chance to refine prognostic accuracy so that better ethical decisions can be made in the neonatal context, and it has given society a chance to reflect on elements of consensus. The authors summarize this hard-fought societal consensus toward the end of their book.

As a society, we have made a serious commitment to both prenatal and neonatal intensive care. As a society, we have shown a willingness to prohibit some quality of life decisions but to allow others. As a society, we have decided that neither doctors nor parents alone may decide when life-sustaining treatment ought to be withheld or withdrawn. Instead, doctors and parents together must agree to stop treatment or else treatment will continue. This approach is expensive but it saves lives, preserves important moral values and does not seem to have morally intolerable long-term sequelae for individuals, families or society (p. 149).

*Neonatal Bioethics* is an excellent addition to the growing body of literature in health care ethics. In it the authors may not offer simple or definitive answers to the questions they raise. But they do provide insight into how innovation occurs in medicine, how that innovation gives rise to complex issues that stretch across moral, legal, economic and political boundaries, and how societal consensus can be achieved if we have “the courage to allow ourselves doubt” (p.149).

While health care professionals within neonatal medicine will find the book most useful, it has relevance for a much wider audience, including other health care professionals, medical and nursing students and ethicists. ■




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Reprinted from *Health Progress*, November - December 2009.  
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