

CONTENTS

List of Contributors ix

Preface xv

PART I SOCIETAL AND INSTITUTIONAL ISSUES

- 1 Epidemiology and Health Services Research 3
Chris Feudtner and Kari R. Hexem
- 2 Goals, Values, and Conflict Resolution 26
Carson Strong, Chris Feudtner, M. Karen Ballard, Brian S. Carter,
and Deborah L. Dokken
- 3 Barriers to Integrating Palliative Care and Potential Solutions 56
Patrick M. Jones, Sally Sehring, Dianne Gray, and David M. Steinhorn
- 4 Educational Initiatives 85
Betty Ferrell, Hollye Harrington Jacobs, Jeffrey C. Klick,
John M. Saroyan, Elana E. Evan, Margaret Comeau, Sarah E. Frieibert,
and David Browning
- 5 The Art of Advocacy 114
Devon Dabbs, Lori Butterworth, Mary Jo Gilmer, Brian Greffe,
and Melody Hellsten

PART II THE CYCLE OF CARE

- 6 Decision Making 139
Robert J. Graham, Marcia Levetown, and Margaret Comeau

- 7 **Communication Skills and Relational Abilities** 169
Marcia Levetown, Elaine C. Meyer, and Dianne Gray
- 8 **Psychosocial Needs of the Child and Family** 202
Stacy F. Orloff, Barbara Jones, and Kris Ford
- 9 **Spiritual Dimensions** 227
Dexter Lancot, Wynne Morrison, Kendra D. Koch, and Chris Feudtner
- 10 **Holistic Management of Symptoms** 244
Richard Hain, Lonnie Zeltzer, Melody Hellsten, Susan O. Cohen,
Stacy F. Orloff, and Dianne Gray
- 11 **Bereavement** 275
Stacy F. Orloff, Suzanne S. Toce, Elizabeth Sumner, and Lee Ann Grimes
- 12 **The Other Side of Caring: Caregiver Suffering** 309
Cynda H. Rushton and M. Karen Ballard

PART III SPECIAL CARE ENVIRONMENTS AND PATIENT POPULATIONS

- 13 **Palliative Care in the Neonatal-Perinatal Period** 345
Suzanne S. Toce, Steven R. Leuthner, Deborah L. Dokken,
Anita J. Catlin, Jennifer Brown, and Brian S. Carter
- 14 **Palliative Care in the Pediatric Intensive Care Setting** 387
Kathryn Weise, Marcia Levetown, Carol Tuttle, and Stephen Liben
- 15 **Palliative Care in the Home, School, and Community** 414
Susan M. Huff, Stacy F. Orloff, Janice Wheeler, and Lee Ann Grimes
- 16 **Palliative Care for the Child Who Has a Genetic Condition** 441
Sara L. Perszyk and Brian S. Carter
- 17 **Integrating Palliative Care with HIV Care and Treatment** 465
Nancy Hutton, Cora K. Welsh, and Maureen E. Lyon
- 18 **Integrating Palliative Care with Pediatric Hematology/Oncology** 488
Sarah E. Friebert, Brian Greffe, and Janice Wheeler

Index 521