CLINICAL MANUAL OF PALLIATIVE CARE FOR ANY SETTING

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Eric L. Krakauer

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Clinical Manual of Palliative Care for Any Setting

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For Paul Farmer and all those who respond responsibly to the suffering of others.

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Contents

List of Abbreviations xiii
Foreword xv
Preface xvii
Acknowledgments xix
List of Contributors xxi

1. What is palliative care? And why a palliative care manual relevant for any setting? 1
Eric L. Krakauer and M. R. Rajagopal
A. Background: A sea of unnecessary suffering 1
B. Definition and scope of palliative care 3
C. Principles of palliative care 4
1. General principles 4
2. Medical ethical principles (Western) most relevant to palliative care 6
3. Contextualizing palliative care 7
4. Practical application of local cultural values and Western ethics 7
D. Approach to the patient in need of palliative care 9

2. Palliative care assessment 12
Eric L. Krakauer and M. R. Rajagopal
A. Principles 12
B. Main steps of palliative care assessment 12
1. History of the present illness(es) 12
2. Review of symptoms 13
3. Social history 13
4. Allergies to medicines 13
5. Current medicines 14
6. Physical examination 14
7. Laboratory testing and diagnostic imaging 14
8. Clinical impression 14
9. Proposed interventions 15

3. Pain assessment and relief 16
Eric L. Krakauer and M. R. Rajagopal
A. Pain definition 16
B. Pain classification and causes 16
1. Classification of pain 16
2. Causes of pain 18
C. Pain assessment 18

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1. Pain history 18
2. Differential diagnosis of pain 19
3. Pain measurement 19
D. Pain relief in adults and children 20
1. General principles 20
2. Pharmacotherapy of pain 21
3. Non-opioid analgesics 23
4. Opioid analgesics 26
5. Adjuvant medicines for pain control 32
6. Invasive procedures for pain relief 35
7. Pain in patients with a history of a substance use disorder 36

4. Assessment and relief of other physical, psychological, social, and spiritual suffering 38
Eric L. Krakauer, M. R. Rajagopal, Guy Maytal, and Trương Nguyễn Xuân Quỳnh
A. Physical symptom assessment and relief: Principles 38
B. Physical symptom assessment and relief: Specific symptoms 39
1. Dyspnea 39
2. Cough 40
3. Nausea/Vomiting 41
4. Diarrhea 43
5. Constipation 43
6. Mouth pain and pain on swallowing 44
7. Weakness/Fatigue 45
8. Fever 45
9. Insomnia 45
10. Pruritus 46
11. Wounds and pressure ulcers 47
12. Hypercalcemia 48
C. Psychological suffering assessment and relief: Principles 49
1. Range of psychological symptoms in people with serious illnesses, their family members, and people who have experienced severe psychological trauma 49
2. Assessing and treating psychological suffering 50
D. Psychological suffering assessment and relief: Specific symptoms 51
1. Adjustment disorder 51
2. Anxiety 51
3. Depressed mood 52
4. Delirium (hyperactive or hypoactive) 53
5. Post traumatic stress disorder (PTSD) 54
6. Prolonged grief disorder 54
E. Palliative care provider well-being 54
F. Social suffering assessment and relief: Principles 55
G. Spiritual suffering assessment and relief 56

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5. **Palliative care for patients with specific conditions** **58**
Eric L. Krakauer, M.R. Rajagopal, Lê Đại Dương, Shekinah Elmore, Temidayo Fadelu, Nahla Gafer, Quách Thanh Khánh, Sarah E. Slater, Thân Hà Ngọc Thể, and Phạm Thị Vân Anh
A. Palliative care for people with cancer 58
1. Principles 58
2. Palliative care and cancer chemotherapy 59
3. Palliative care and radiation therapy 60
4. Palliative care and cancer surgery 60
B. Palliative care for people with HIV infection 61
1. Principles 61
2. Essential components of palliative care for people with HIV infection 61
C. Palliative care for people with multidrug resistant and extensively drug resistant tuberculosis (M/XDR-TB) and for people with serious sequelae of tuberculosis 62
1. Principles 62
2. Essential components of palliative care for people with M/XDR-TB 63
3. When all available treatments for M/XDT-TB have failed 63
4. Patients with serious sequelae of previous TB infection 63
D. Palliative care for people with end-stage lung disease 64
1. Principles 64
2. Opioids for refractory dyspnea 64
3. Dyspnea and anxiety 65
4. Cachexia and end-stage lung disease 65
E. Palliative care for people with end-stage heart failure 65
1. Principles 65
2. Opioids in end-stage heart failure 66
3. Cachexia and end-stage heart failure 66
F. Palliative care for people with dementia 66
1. Principles 66
2. Palliative care services needed by people with dementia 67
3. Palliative care needs of family caregivers 67
G. Palliative care for people with neurologic disorders 68
1. Principles 68
2. Common neurologic disorders that generate palliative care need 68
3. Palliative care services that may be needed by people with neurologic disorders 68
H. Palliative care for frail older people 69
1. Principles 69
2. Palliative care services that may be needed 69
I. Palliative care for people who have experienced severe physical or psychological trauma 70
1. Sequelae of severe physical or psychological trauma 70
2. Medically imperative pain relief and psychosocial support 70

Downloaded from https://academic.oup.com/book/61570 by OUP site access user on 06 November 2025

6. **Palliative care emergencies** **72**
Eric L. Krakauer and M. R. Rajagopal
A. General 72
B. Pain crisis 72
C. Refractory dyspnea of a dying patient 73
D. Massive hemorrhage 73
E. Spinal cord compression 74
F. Seizures 75

7. **Pediatric palliative care** **76**
Rut J. Kiman, Nguyễn Thị Hoàng Quỳnh, and Eric L. Krakauer
A. Principles 76
B. Developmental stages 77
1. Infants (ages 0–1) 77
2. Toddlers (ages 1–3) 78
3. Pre-school age children (ages 3–6) 78
4. School-age children (ages 7–12) 78
5. Adolescents (ages 13–16) 79
C. Assessment and relief of pain in children 80
1. Principles 80
2. Pain assessment 80
3. Pediatric pain assessment tools and pain relief protocols 81
4. Procedure-related pain prevention and relief 83
D. Assessment and relief of other symptoms in children 85
E. Psychological and social support for children 86
F. Bereavement care for children 87

8. **Palliative care nursing** **89**
Julia Downing, Alex Daniels, Maryam Rassouli, and Eric L. Krakauer
A. Overview 89
B. Essential palliative care nursing roles 89
1. Palliative care nursing assessment 89
2. Pain and symptom relief 90
3. Emotional and spiritual support 92
4. Patient advocacy 93
5. Wound care 94
6. Training patients and family caregivers 94
C. Special nursing roles in palliative care 95
1. In hospitals 95
2. In the community 96
3. Nurse practitioners 96

9. **End-of-life care: Medical, ethical, and cultural issues** **98**
Eric L. Krakauer, M. R. Rajagopal, Lê Đại Dương, Guy Maytal, Christian Ntizimira, Hibah Osman, Trương Nguyễn Xuân Quỳnh, Ning Xiaohong, and Jia Zhimeng

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A. Contextually appropriate communication and decision-making with patients or families 98
B. Breaking bad news 101
C. Goals of care 103
D. Optimum use of life-sustaining treatment 103
E. Cardiopulmonary resuscitation (CPR) 104
F. Artificial nutrition and hydration 106
G. Discharge planning 108
H. Preparing family members for the terminal phase 108
I. Bereavement care 109

10. Integration of palliative care into healthcare systems 113
Eric L. Krakauer, M. R. Rajagopal, Richard Harding, Vedaste Hategekimana, Khadidjatou Kane, Hibah Osman, and Jia Zhimeng
A. Policy needs 113
B. Basic structure of integrated palliative care 115
C. Essential Package of Palliative Care 118
D. Quality assessment of palliative care services and training 120
1. Assessment of palliative care services 120
2. Assessment of palliative care training 121

11. Palliative care in humanitarian settings 123
Eric L. Krakauer, Bethany-Rose Daubman, and Tammam Aloudat
A. What are humanitarian settings and humanitarianism? 123
B. Major palliative care needs in humanitarian settings 124

12. Receiving and providing palliative care 127
Lê Đại Dương and Ashla Rani
A. Guidance for doctors practicing palliative care in resource-limited settings 127
B. A patient's advice for palliative care providers 129

Appendix 1: Performance status scales 131
Appendix 2: Safe management of opioid medicines 133
Appendix 3: Brief Pain Inventory 141
Appendix 4: Modified Palliative Outcomes Scale 145
Appendix 5: Advance directives 147
Appendix 6: Infection control when caring for people with HIV infection 149
Appendix 7: Infection control when caring for people with multidrug-resistant tuberculosis 151
Glossary 153
Index 157

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Abbreviations

EPPC	Essential Package of Palliative Care
GA	gestational age
IM	intramuscular
IV	intravenous
NGT	via nasogastric tube
NSAID	nonsteroidal anti-inflammatory drug
PC	palliative care
PPC	pediatric palliative care
PR	per rectum
SC	subcutaneous
WHA	World Health Assembly
WHO	World Health Organization

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Foreword

I still remember vividly the slow and devastating decline of my beloved aunt as her body withered in the wake of esophageal cancer two decades ago in India. I still recall her celebrated surgeon taking me aside, as the only physician in the family, to tell me that despite his heroic efforts, the tumor could not be entirely extricated. There was nothing more that the hospital could offer, and now my aunt should be taken home to die. Those words, that there was nothing more that the healthcare system could offer, continue to ring in my ears. He refused to share this information with my aunt or her family insisting that he did not want to give "bad news" and left it to me to do the job.

Then began the arduous, often secretive, hunt for morphine to dull her excruciating pain. The healthcare system did not offer any care to her or support for our family through those agonizing months. Whatever was needed had to be purchased out of pocket from a fragmented range of private and, often, poorly skilled informal providers. And then a deeply troubling thought struck me: if this was the ordeal that my aunt—member of an upper social class, living in a major city, seeking care from a tony hospital—had to face, how harrowing must be the experience of dying in pain for the countless millions who lived in poverty or in rural areas of the country. To be sure, this situation has not changed much 20 years on, and the large majority of the world's population, in particular its poorest people, continue to suffer because the medical system "has nothing to offer."

It in this context that this manual is nothing short of a godsend for healthcare providers globally and their patients. The manual provides concise, practical guidance for the prevention and relief of suffering, chronic or acute, regardless of whether the underlying medical condition can be cured. It reframes the idea of palliation as essential, regardless of the prognosis and diagnosis. The manual's principles of care not only embrace a biopsychosocial framework, but also highlight the importance of spiritual care. Global in its scope, its underpinning philosophy departs from the usual narrow definition of palliative care by recognizing that people suffer differently in different settings, and it guides clinicians to integrate palliative medicine with local cultural values and practices. It thereby promotes respectful, contextually optimal, and person-centered care. It recognizes the crucial and varied roles of

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families and informal caregivers in caring for the seriously ill and provides guidance on communicating with and supporting family members.

The manual offers useful recommendations on palliative care for patients with many of the specific afflictions that most commonly cause serious suffering of one kind or another, from cancer and major organ failure to drug-resistant tuberculosis and dementia. Looking through this list, it becomes clear just how many people and their families are in need of such care, already a vast number that will only grow as populations age around the world. This manual is designed to be relevant and practical for a wide range of providers in any setting, from high-tech hospital-based specialists to community health workers working with families in their homes. The simple and lucid prose accompanied by clearly outlined guidelines and protocols for addressing a wide range of needs of persons and their families reflect the extensive, front-line experience of the two authors, global leaders in the field who have worked in a diverse range of contexts, and their experience is complemented with contributions from multidisciplinary colleagues around the world. This manual sits alongside the pantheon of its classic predecessors, from the iconic *Where There Is No Doctor* onward, and belongs in the pocket or on the smartphone of every healthcare provider who treats patients with serious illnesses, injuries, or traumatic experiences, regardless of the setting.

—Vikram Patel
Paul Farmer Professor of Global Health, Harvard Medical School
Author of Where *There Is No Psychiatrist*.

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Preface

Palliative care should be accessible by anyone with physical, psychological, social, or spiritual suffering related to any serious illness or condition, including acute physical or emotional trauma, anywhere and anytime. But this imperative has two caveats. First, palliative care never should be regarded as a *substitute* for prevention, early diagnosis, or treatment of preventable or treatable conditions. Efforts to ensure universal accessibility to palliative care should accompany efforts to ensure universal accessibility to the best possible illness prevention and treatment. And palliative care should be *integrated with illness treatment* whenever suffering is present. Second, palliative care should not be defined rigidly as one set of interventions that never varies. Rather, its definition should recognize that people suffer differently in different geographic locations and under different socioeconomic circumstances, and the meanings of illness, dying, and optimum care often vary by culture.

This manual was made possible by the Harvard Medical School Program in Global Palliative Care and its global partners. Together, we have created a network of dedicated palliative care clinicians working either partly or entirely in low- and middle-income settings toward universal access to palliative care. Our manual is designed to enable clinicians in any setting to integrate basic palliative care with illness treatment, regardless of whether the illness is curable or not, and to integrate state-of-the-art symptom relief and psychosocial support with local cultural values. Its focus on practical guidance for low- and middle-income settings, where palliative care is least accessible and suffering most pervasive, makes it unlike other palliative care manuals.

We hope the manual will guide current and future clinicians to relieve the suffering of others and perhaps also guide them toward ways of thinking characterized not just by technological mastery but also by greater openness to others.

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—E. L. K.

Butaro, Rwanda, July 2025

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1

What is palliative care? And why a palliative care manual relevant for any setting?

Eric L. Krakauer and M. R. Rajagopal

A. Background: A sea of unnecessary suffering

The World Health Organization (WHO) has resolved "that palliative care is an ethical responsibility of health systems, and that it is the ethical duty of healthcare professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured."[1] Yet in the age of organ replacement, gene therapy, and immune system manipulation, the developing world remains a sea of unnecessary suffering.[2] Scientific and technological efforts to secure human beings from threats to their well-being, though successful in many ways in high-income countries (HICs), often have instead exacerbated suffering in low- and middle-income countries (LMICs).[3] Western medicine's Cartesian quest for ever more knowledge of and power over the human body and medicine's resultant "rationalization" into specialties focused on one organ or one category of diseases or one technical skill sometimes exacerbates rather than ameliorates suffering.[4,5] Recognition of the inadvertent "adverse effects" of technological medicine; its attention to diseases, organs, and molecules; and its neglect of suffering patients as bio-psycho-social-spiritual beings generated the palliative care movement in the late twentieth century. Yet while the founder of this movement, Dame Cicely Saunders, was keenly aware of the preponderance of suffering in LMICs, the movement defined itself and became concretized into institutions and practices mainly in and for HICs.

WHO has defined palliative care as "an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment

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of pain and other problems, whether physical, psychosocial or spiritual."[6] We agree with the implication that preventing and relieving suffering—responding to suffering—whether physical, psychological, social, or spiritual, is the essence of palliative care. Yet this definition excludes many suffering patients from the purview of palliative care, such as those who do not have an obviously life-threatening illness, and it does not explicitly recognize that the types and severity of suffering vary by geopolitical location, economic situation, and culture.[7–9] Should palliative home-care teams in rural Kerala, where rehabilitation services and pain specialists do not exist, discontinue caring for quadriplegic patients or those with severe congenital anomalies or chronic non-malignant pain, because they are not clearly at risk of dying soon? By violating the definition of palliative care, are these teams and others like them causing confusion or turf wars that will harm efforts to make palliative care universally accessible? Are poor patients with cancer or major organ failure in rural Nigeria, Nepal, or Navajo Nation likely to have the same care needs as White middle-class Bostonians or Britons? Do health and illness, suffering and death, life and after-life have the same meaning everywhere and for everyone within the same context?[10] If not, then palliative care should not be intractably uniform but rather must attend to context: to the needs and values of those it serves.[11] Its goal may be the same everywhere, but it must have many versions to respond optimally to local need. One end, various means.

Until recently, the WHO definition also stated that palliative care "regards dying as a normal process" and never intends to "postpone death." This, too, seems to have been written with HICs in mind. The global poor suffer and die prematurely for lack of access to disease prevention, diagnosis, and treatment that is standard in HICs and accessible by the wealthy even in many LMICs. In the context of the large access and outcome gap between rich and poor, this definition appears to have contributed to a misunderstanding of palliative care as cheaper or second-rate care for the poor.[12] In our view, the dying of a young mother from AIDS, drug-resistant tuberculosis, or cervical cancer who lacked access to prevention, early diagnosis, and treatment should never be regarded as "normal." Where prevention, diagnosis and treatment of serious illnesses like these are not accessible, as in many lower-income settings, it behooves palliative care providers and advocates to enable or seek such access while also striving to integrate palliative care with illness prevention, diagnosis, and treatment.[7,13,14] Thus, palliative care for the affluent in HICs necessarily differs from what it must be in lower-income settings.

While several excellent palliative care manuals edited by eminent experts are available, all assume the availability of medicines and other resources not available in most LMICs and contain extensive information not relevant

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to LMICs.[15–17] It may be difficult for clinicians at the bedside in LMICs to quickly extract from these manuals useful clinical guidance for their context. Our manual aims specifically to enable practicing clinicians in LMICs at all levels of healthcare systems to provide high-quality palliative care. It describes the assessment and treatment of physical, psychological, social, and spiritual suffering using medicines, equipment, and resources that are inexpensive and widely available throughout LMICs. It also guides the integration of palliative care into healthcare systems in LMICs, adaptation of palliative care to local and individual needs, and assimilation of salubrious or meaningful traditions and cultural practices.

B. Definition and scope of palliative care

We define palliative care simply as the prevention and relief of illness-related suffering of adults and children and their families regardless of whether the underlying condition can be cured. It is an essential component of comprehensive care throughout the illness course, including at the end of life; should be provided in any healthcare setting including hospitals, long-term care facilities, community health centers, and in patients' homes; and should be practiced by adequately trained health and social care providers of many kinds: general practitioners; primary care doctors, nurse practitioners, and feldshers; physician specialists in oncology, hematology, geriatrics, pediatrics, family medicine, internal medicine, infectious disease, tuberculosis, pulmonology, cardiology, neurology, disaster medicine, and other specialties that entail care for the seriously ill; clinical officers and assistant doctors; nurses; midwives; social workers and psychologists; community health workers and volunteers; and spiritual supporters. Physician specialists in palliative medicine are needed in LMICs mainly in cancer centers and referral hospitals as palliative care team leaders, consultants for difficult cases, teachers, and implementers. But most palliative care cannot and need not be provided by specialists in LMICs. Our manual is mainly for clinicians who are not palliative care specialists but who care for patients experiencing suffering related to serious ill health or severe psychosocial trauma.

Palliative care entails accompanying and comforting adult and pediatric patients with pain or suffering of any kind related to serious ill health or severe psychosocial trauma by continually assessing, preventing, and relieving their suffering using best available evidence. It optimizes the quality of life and maximizes the dignity of patients and their families. While it should aim to make evidence-based Western medicines and techniques of symptom relief

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accessible to all, including the rural poor, it also should practice cultural humility. Rather than assuming the universality of personhood, personal agency, and individuality as conceived by Western philosophy and the universal applicability Western medical ethics, it should endeavor to understand local ways of thinking, communicating, and decision-making while also never assuming anything about any patient simply because of their place of birth, religion, sex, language, skin color, or ethnicity. Responsible palliative care requires the assessment of each patient's values and, in the case of children, the developmental stage, to provide respectful, people-centered, and culturally, socially, religiously, and developmentally appropriate care. It must practice and strive constantly for openness to others in the widest sense.[5]

C. Principles of palliative care

1. General principles

a. It is the moral responsibility of healthcare professionals to alleviate pain and suffering, whether physical, psychological, or social, irrespective of whether the disease or condition can be cured.
b. Palliative care responds to any suffering, whether acute or chronic, that is not adequately prevented or relieved. Because the most common and severe types of suffering may vary by location, socioeconomic situation, culture, and over time, the populations served by palliative care and its scope also may vary.
c. Palliative care:
    i. Assesses each patient's values and, in the case of children, the developmental stage, to provide respectful, ethical, and culturally, socially, spiritually, and developmentally appropriate care
    ii Is applicable early in the course of serious illness in conjunction with disease-modifying or potentially curative therapies such as chemotherapy for patients with cancer or drug-resistant tuberculosis or antiretroviral therapy for people with HIV/AIDS (Figure 1.1)
    iii. Assists patients to access and adhere to optimum disease treatment if such treatment is desired by the patient and may be more beneficial than harmful according to the patient's values
    iv. Is applicable for people living with long-term physical, psychological, social, or spiritual sequelae from serious health problems such as cancer, or from noxious treatments or severe emotional trauma

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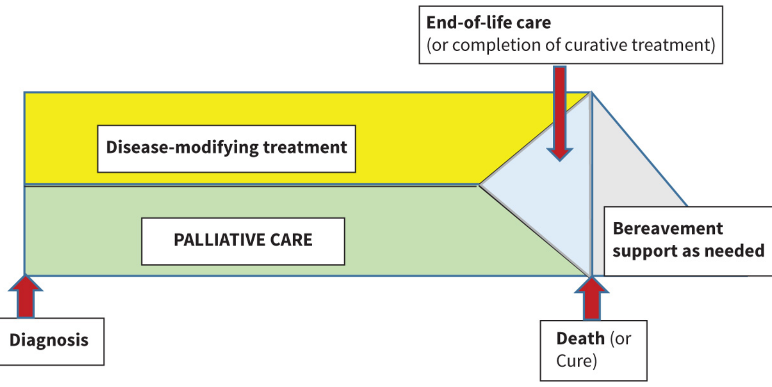

Figure 1.1 Diagram of palliative care throughout the course of illness.

v. Is applicable in the perinatal period for seriously ill, injured, or premature neonates, for fetal demise, and for children with serious congenital health problems
vi. Counsels patients with advanced life-threatening health problems and/or their families, as appropriate, on identifying goals of care and on the potential benefits and harms of life-sustaining treatment
vii. Never intentionally hastens death
viii. Uses any means necessary to protect from suffering any dying patient who wishes relief from suffering, even if sedation is required
ix. Provides personalized bereavement support for adults and children as needed
x. Seeks to mitigate pathogenic effects of poverty and emotional trauma on patients and families and to protect them from financial hardship due to illness or disability
xi. Provides education and assistance in prevention and relief of both chronic and acute pain as needed
xii. Should be integrated into all levels of healthcare systems and into standard responses to humanitarian disasters
xiii. Should be practiced by doctors, nurses, psychologists, social workers, spiritual supporters, community health workers, volunteers, and others, with adequate training
xiv. Should be taught at three levels:
- Basic palliative care training for all medical, nursing, and allied health students and primary care providers

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- Intermediate palliative care training for all medical specialists who care for patients with serious health problems such as cancer, major organ failure, serious neuropsychiatric disease, or severe infant prematurity
- Specialist palliative care training

xv. Is best practiced by an interdisciplinary team that can provide a person-centered response to all forms of suffering
xvi. Encourages active involvement by communities and community members
xvii. Should be accessible by anyone in need, where they are, and when they need it

2. Medical ethical principles (Western) most relevant to palliative care

a. **Non-maleficence**: The clinician has an obligation never to harm the patient and to protect the patient from all types of harm, including harm from stigma, discrimination, or medical interventions that are inappropriate because they are non-beneficial or more harmful than beneficial by the patient's criteria.
b. **Beneficence**: The clinician has an obligation to work for the benefit of the patient.
c. **Autonomy**: The patient, the patient's family, or those designated by the patient have the right to be informed about the diagnosis and prognosis if they wish and to discuss the goals of care with the responsible physician. In many cultures, it is common for patients to defer decision-making to others.
d. **Justice**: The clinician has an obligation to protect the patient from injustices such as denial of care, unfair allocation of available resources, inappropriate interventions, physical or psychological abuse, discrimination, or abandonment.
e. **Non-abandonment**: The patient must never be abandoned even when disease-modifying treatment is no longer beneficial or no longer desired by the patient. Palliative care always should be accessible..
f. **Principle of "double effect"**:
   i. Any interventions may result in bad effects. If desired by a patient, interventions intended purely to provide benefit and that have a reasonable likelihood of benefit may be used even at the risk of foreseeable but unintended side effects.

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ii. This principle is often used to determine the optimal treatment for terminally ill patients when any treatment risks side effects. For example, a terminally ill cancer patient who wishes to be comfortable and who is suffering from severe pain or dyspnea can be treated with an opioid at any dose necessary to assure comfort even at the risk of sedation, hypotension, and respiratory depression.

iii. Four conditions for applying the "double-effect" principle:

The treatment itself must not be immoral.

The sole intention of the treatment must be the good effect, like relief of pain and suffering for terminally ill patients.

The unintended bad effect (causing death) must not be considered as the means to the good effect (comfort).

A treatment that might have severe, unintended side effects (such as death) may be considered only for a proportionally serious reason, such as to relieve severe suffering of a dying patient. In other words, the potential benefits must outweigh the potential bad effects.

3. Contextualizing palliative care

See also Chapters 9 and 10.

a. Palliative care is a response to suffering, and people suffer differently in different clinical, socioeconomic, and cultural contexts.
b. Therefore, palliative care should vary according to local needs and values.

4. Practical application of local cultural values and Western ethics

a. **Giving bad news**: Be careful, gentle, and discrete when giving bad news. Be honest, but do not emotionally overwhelm the patient or family member(s) or insist that they receive medical information if they decline to hear it. Sometimes, the news should be given gradually. Ask the patient or family member if they would like to have someone with them for the discussion, and try to find a private place for the discussion. Never give bad news without being prepared to suggest a care plan. Give the patient or family time to digest the information. Be prepared for emotional responses such as tears or anger.

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b. **Deciding on goals of care**: When the best care plan for a patient is not obvious, efforts should be made to identify the main goal or goals of care. Examples of goals of care:
   i. Treat the disease even if the treatment might have serious adverse effects.
   ii. Focus on comfort.
   iii. Do both at the same time.
   iv. Treat only potentially reversible conditions. Otherwise, focus on comfort.
c. **Recognizing benefits and harms of life-sustaining treatment**: Based on the goals of care, assist patients and families to decide whether to use or not use life-sustaining treatments including cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, non-invasive ventilator support, and artificial nutrition. Assist them to recognize when life-sustaining treatments are likely to be harmful and to provide no benefit.
d. **Do not kill**: Doctors should not intentionally cause the death of a patient. Specifically, a doctor should not participate in euthanasia, physician-assisted suicide, or physician aid in dying.
   i. **Euthanasia**: Intentionally directly causing the death of a patient. This is not acceptable under any imaginable circumstances, including to relieve suffering or to comply with a request from the patient or family. Even the most refractory suffering can be relieved in other ways. Palliative sedation can be used if all other efforts to adequately relieve suffering are unsuccessful (see section on Palliative Sedation).
   ii. **Physician-assisted suicide or physician aid in dying**: Intentionally assisting a patient to end their life by prescribing or otherwise providing for them the means to end their life. This practice, though legal in some places, is generally considered unacceptable or impermissible.
e. **Palliative sedation**: This is permissible sedation to relieve refractory symptoms of a dying patient. It is ethically distinct from euthanasia, physician-assisted suicide, and physician aid in dying, and it is consistent with the principle of double effect. There are two types:
   i. ***Proportionate palliative sedation***: Intentional lowering of a dying patient's level of consciousness via the careful, progressive increase of one or more sedating medicines that are titrated to provide relief of intolerable suffering from refractory symptoms to a degree

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acceptable to the patient using the minimum amount of sedation needed to achieve this goal. The sedating medicine(s) should be added to medicines for symptom control to the extent possible, and the degree of sedation should be proportionate to the patient's suffering in that it should be just deep enough to provide the desired relief.

ii. ***Deep palliative sedation*** or ***palliative sedation to unconsciousness***: Controlled induction of sedation to unconsciousness to relieve severe suffering of a dying patient that is refractory to all reasonable and aggressive interventions including sedation that does not achieve unconsciousness.

D. Approach to the patient in need of palliative care

1. Suffering due to physical and psychological symptoms and to social and spiritual problems is common among patients with cancer, other serious health conditions, and those who have experienced severe psychosocial trauma.
2.. Physical and psychological symptoms can occur at any disease stage and may be due to the disease, adverse effects of treatment, or severe emotional trauma.
3.. Many symptoms (pain, dyspnea, nausea, anxiety) are subjective, and their character and severity cannot be accurately assessed objectively with imaging or laboratory tests. Healthcare workers should believe what the patient says.
4. Symptom assessment:
   a. Should be done at the time of diagnosis and frequently thereafter
   b. Entails history-taking, physical examination, and sometimes also imaging or laboratory testing. Care should be taken to avoid causing or exacerbating discomfort by history-taking and physical examination.
   c. Is especially difficult with patients who cannot communicate clearly such as preverbal children and cognitively impaired adults. In such cases, it may be necessary to rely on reports from family caregivers, on pain assessment tools such as the CRIES Score for infants or the FLACC score for young children (see Chapter 2, Section B), or on physical signs such a grimacing, groaning, agitation, rigidity, or labored breathing.

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5. Any distressing symptom should be treated as intensively and thoroughly as needed to achieve a level of comfort and quality of life acceptable to the patient.
6. Symptom relief:
   a. Can improve a patient's ability to adhere to disease-specific treatments
   b. Is most effective when the cause of the symptom is eliminated. In some cases, symptoms can be relieved by disease-modifying treatments (i.e., antifungal therapy for Candida esophagitis or radiotherapy for cancer patients). However, the symptoms should be treated directly until disease-specific treatments take effect.
   c. Should be provided only with the consent of the patient or family as appropriate, except in an emergency. However, a family member may not prevent a physician from providing symptom relief to an uncommunicative patient if, in the opinion of the physician and one other physician, the patient's suffering may be severe.
7. Social suffering:
   a. Is common among the poor and socially marginalized due to problems such as homelessness, lack of food, physical or mental disability, stigmatization, political, ethnic or sexual violence, geographic isolation, imprisonment, lack of transportation, or lack of funds to pay for the funeral of a family member
   b. Is often a cause of illness
   c. Often makes disease treatment and symptom relief difficult or impossible
   d. Should be assessed as carefully and treated as intensively as physical and psychological suffering

Further Reading

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2
Palliative care assessment

Eric L. Krakauer and M. R. Rajagopal

A. Principles

1. Any severe physical symptom should be treated immediately, using best clinical judgment about the cause, before proceeding with more thorough history-taking, physical examination, or testing (e.g., pain crisis, severe dyspnea, intractable nausea with vomiting). 2. In general, any patient who may need palliative care should be assessed thoroughly. However, care should be taken to avoid or minimize causing discomfort when performing the assessment. In many situations, a focused assessment is adequate based on the patient's current symptoms and illness. For example, if a patient in bed is not short of breath and has severe pain from spinal metastases when asked to sit forward, anterior auscultation of the chest may be adequate.

B. Main steps of palliative care assessment

1. History of the present illness(es)

a. Patient's preferences for receiving and discussing medical information and for making health care decisions
b. Patient's understanding of the illness(es) (if patient agrees to discuss), including:
   i. Diagnosis
   ii. Previous and current treatments
   iii. Likely prognosis
   iv. Any specific fears or concerns
c. Family's understanding of the illness(es) (if the patient declines to discuss and empowers the family to discuss), including:
   i. Diagnosis

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   ii. Previous and current treatments
   iii. Likely prognosis
   iv. Any specific fears or concerns

2. Review of symptoms

a. Current symptoms, beginning with the most distressing one
b. For each symptom:
   i. First occurrence
   ii. Frequency and duration (if not constant)
   iii. Severity on scale of 0–10, at present, on average, and at its worst in past 24 hours
   iv. Characteristics (patient's description of the symptom)
   v. Factors that increase or relieve the symptom
   vi. Impact of symptom on daily activities
   vii. Previous and current treatment(s) and their effectiveness

3. Social history

a. Location of home
b. First-degree family members (spouse or significant other, parents, children, siblings)
c. Members of patient's household (with whom does the patient live?)
d. Financial status of patient and patient's household:
   i. Enough food?
   ii. Adequate shelter?
   iii. Children attending school?
   iv. Able to pay for transportation to receive healthcare?
e. Place of patient's birth
f. Patient's work history
g. History of heavy alcohol use or illicit substance use (highly confidential)
h. Joys and sorrows
i. Patient's evaluation of current quality of life
j. Main source(s) of emotional support

4. Allergies to medicines

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5. Current medicines

a. For each medicine:
   i. Exact dose
   ii. Route of administration (oral, rectal, transdermal, SC, IV, etc.)
   iii. Dosing interval
   iv. Scheduled or as needed

6. Physical examination

a. Vital signs:
   i. Temperature and respiratory rate are always important
   ii. Heart rate, blood pressure, and oxygen saturation only if useful for medical decision-making
b. Basic physical examination with special attention to areas affected by the illness or involved with symptoms
c. Avoid causing discomfort
d. Performance status:
   i. For cancer patients: Eastern Collaborative Oncology Group (ECOG) Scale (Appendix 1)
   ii. For non-cancer patients: Palliative Performance Scale (Appendix 1)

7. Laboratory testing and diagnostic imaging

a. Only if needed for medical decision-making. For example, it may be helpful:
   i. To know the renal function (serum creatinine) to inform decisions about medicines and doses
   ii. To obtain a new CT scan of a patient with cancer and no recent scan to help estimate prognosis and the risk for severe symptoms such as pain, dyspnea, hemorrhage, or bowel obstruction

8. Clinical impression

a. Summary of the major medical problems and types of suffering
b. Differential diagnosis of each symptom (most likely cause)

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c. **Goals of care**:
    i. Any goal(s) of care agreed upon between patient or family and doctor, or statement that goal(s) of care remain unclear

9. Proposed interventions

a. For each medicine:
    i. Exact dose
    ii. Route of administration (oral, rectal, transdermal, SC, IV, etc.)
    iii. Dosing interval
    iv. Scheduled or as needed
b. Any needed social or spiritual supports
c. Plan to address goals of care, including preferred location of care, if not already done.

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3
Pain assessment and relief

Eric L. Krakauer and M. R. Rajagopal

A. Pain definition

The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage."

1. Important aspects of this definition:
   a. Pain is always a personal experience, so a doctor must believe a patient's report of the severity, location, and characteristics of pain unless there is compelling evidence that the patient's report is not true.
   b. Pain may occur even when there is no tissue damage visible on the body surface or with diagnostic imaging (CT, MRI, ultrasound) (e.g., peripheral neuropathic pain related to neurotoxic chemotherapy or diabetes mellitus).
   c. The experience of pain is influenced to varying degrees by biological, psychological, and social factors.

B. Pain classification and causes

1. Classification of pain

For practical purposes, there are three major classes of pain:

a. **Nociceptive pain**: Caused by the stimulation of pain receptors on healthy first-order sensory nerves (nociceptors). There are two subtypes of nociceptive pain:
   i. *Somatic pain*:

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- Caused by stimulation of nociceptors in the skin, soft tissues, muscle, or bone.
- The patient usually can specify the exact location of this pain.
- Patients often describe this pain as sharp, aching, or throbbing.

ii. *Visceral pain*:

- Caused by stimulation of nociceptors in internal organs or hollow viscera. Typical causes include metastatic cancer, obstruction, stretch of an organ's capsule, infection, and non-infectious inflammation.
- The patient often cannot specify an exact location of the pain or describe it clearly. Examples:
  - Malignant bowel obstruction resulting in proximal bowel distention and stimulation of mechano-receptors in the bowel wall
  - Rapid growth of primary or metastatic cancer in the liver resulting in liver capsule stretch and stimulation of mechano-receptors in the liver capsule
  - Cholangitis
  - Gastritis

b. **Neuropathic pain**: Caused by damage to or compression of peripheral sensory nerves (nociceptors) or central nerves from any cause.

i. Usually described as burning, tingling, shooting, or like an electric shock

ii. Often no observable tissue injury

iii. Often "negative symptoms" such as numbness, weakness, or other neurologic deficits

iv. May be associated with **hyperalgesia** (strong pain caused by weak stimulation) or **allodynia** (pain due to stimulus that normally is not painful, such as light touch) in the area innervated by the damaged nerve

v. Examples:

- *Post-herpetic neuralgia*: Peripheral nerve injury due to infection by varicella zoster virus with resultant pain
- *Diabetic neuropathy*: Peripheral nerve injury due to ischemia
- *Toxic neuropathy*: Peripheral nerve injury due to neurotoxic medicines such as antineoplastic agents (e.g., paclitaxel) or antibiotics (e.g., isoniazid)
- *Post-mastectomy pain*: Peripheral nerve injury from surgical cutting
- *Sciatica*: Injury to one or more of the spinal nerves (L4, L5, S1) that form the sciatic nerve, due to compression by a herniated disc, tumor, abscess, or severe osteoarthritis of the spine

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c. **Inflammatory pain**: Healthy nociceptors can be stimulated by inflammation of any cause:
   i. Usually is localizable except in viscera
   ii. May be associated with hyperalgesia or allodynia, but there are no negative symptoms

2. Causes of pain

a. *Actual tissue damage*: From infection, inflammation, neoplasm, ischemia, trauma, invasive medical procedures, medicine toxicity, or other cause
b. *Potential tissue damage*: Recognized disease entities (such as fibromyalgia) that are painful but not associated with observable or measurable tissue damage
c. *Psychosocial factors*:
   i. Mental health disorders such as major depression, anxiety disorders, and substance use disorders can cause or exacerbate physical pain, and physical pain also can be a cause of major depression, anxiety disorders, and substance use disorders
   ii. Other psychological syndromes that predispose patients to chronic pain include somatization disorder, conversion disorder, post-traumatic stress disorder, hypochondriasis, and psychogenic pain disorder
   iii. Severe social stressors such as homelessness, extreme poverty, and stigmatization can predispose to pain by predisposing to mental health disorders
   iv. In some cases, it is impossible to adequately relieve pain without diagnosing and relieving psychological or social problems.

C. Pain assessment

1. Pain history

Ask the patient:

a. About the present illness(es) and any previous health problems (see Chapter 2)
b. About the pain:
   i. Location and any radiation

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ii. First occurrence
iii. Frequency and duration (if not constant)
iv. Severity on scale of 0–10, at present, and on average in the past 3 days
v. Characteristics (patient's description of the pain)
vi. Factors that increase or relieve the symptom
vii. Impact on daily activities
viii. Previous and current treatment(s) and their effectiveness

2. Differential diagnosis of pain

a. Optimum pain treatment often varies depending on the cause(s) of pain.
b. Therefore, whenever the cause of pain is not obvious, the clinician should think about and document a list of possible causes in order of likelihood. In this way:
   i It is less likely that the true cause(s) of the pain will be missed due to a hasty assumption
   ii. If the initial treatment does not provide optimal relief, other potential causes, and treatment options can be considered quickly even when a new clinician or team has assumed responsibility for the patient

3. Pain measurement

See Figure 3.1.

a. The pain severity measurement tool is based on *subjective* self-assessment by the patient:
   i. The pain scores ARE NOT useful to compare pain levels in different patients.
   ii. The pain scores ARE useful to monitor the pain of a single patient over time.

- Useful for most cognitively intact adults and children age 7 or older.
- May require repeated explanation for patients with little education.

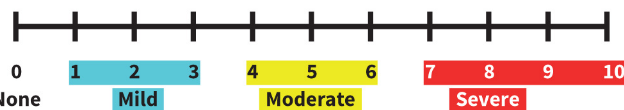

Figure 3.1 Numerical Pain Intensity Scale.

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b. *Brief Pain Inventory* (see Appendix 3) is a tool commonly used in clinical pain research to assess and monitor pain and the impact of pain on the quality of life.
c. *Assessing pain in severely cognitively impaired, mentally ill, semiconscious patients*:
    i. When a patient is unable to quantify, characterize, or communicate about their pain, the clinician should look for the following signs that may indicate the presence of pain:
        - Grimacing
        - Groaning
        - Agitation
        - Muscle rigidity
        - Rapid breathing
    ii. If any of these signs are noted, the possibility of pain should be considered, as should the possibility of other symptoms such as anxiety or dyspnea.
d. *Pediatric pain assessment* (see Chapter 7)

D. Pain relief in adults and children

1. General principles

a. All patients suffering from moderate or severe pain due to any illness, and at any stage of their illness, must be treated to relieve suffering and improve their quality of life unless the patient specifically declines pain relief (very rare).
b. Pain relief is adequate when patients feel no more pain or state that they are comfortable enough to sleep and perform any activities of daily life of which they are capable when not limited by pain.
c. Pain relief should be provided in medical facilities, in the community, and at the home:
    i. Specifically, oral immediate-release morphine must be accessible by patients at home with moderate or severe pain due to any illness.
d. Chronic pain may cause anxiety or depression, and mood disorders such as anxiety and depression may exacerbate pain. Therefore, a palliative care assessment (including psychological assessment) should be done as part of chronic pain assessment (see Chapter 2).
e. Every patient is different. Therefore, an individualized pain treatment plan should be based on the assessment of each patient and on their response to treatment.

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f. Opioid medicines must be stored safely and protected from diversion at all times, including at the place of manufacture or importation; during transport; in hospitals, clinics, and pharmacies; and in patients' homes.

2. Pharmacotherapy of pain

a. Key concepts:
   i. Dosing route:
      - Oral therapy should be used unless the patient is unable to take oral medicine or unless the pain is severe.
      - In case of severe pain, intravenous or subcutaneous therapy should be used to provide rapid relief.
   ii. ***Correct dose***: The dose sufficient to relieve the patient's pain without intolerable adverse effects:
      - To find the correct dose and to minimize adverse effects, the clinician should monitor closely the result of analgesic therapy.
   iii. ***Three-step pain ladder*** (see Figure 3.2):
      - A cancer pain management ladder is useful as a teaching tool and as a general guide to pain relief based on pain severity. However,

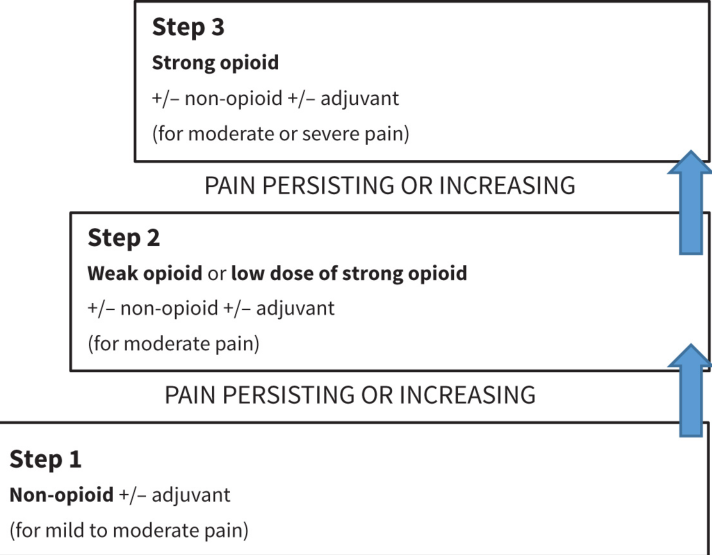

Figure 3.2 Three-step pain relief ladder.
Adapted from World Health Organization. *WHO Guidelines for the Pharmacological and Radiotherapeutic Management of Cancer Pain in Adults and Adolescents*. Geneva: World Health Organization; 2018. https://www.who.int/publications/i/item/9789241550390 [accessed March 17, 2025].

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it cannot replace individualized therapeutic planning based on careful assessment of each individual patient's pain.

iv. Adjuvant pain medicines (see item 5):
- Non-opioid medicines that can help to relieve pain in some situations, either alone or in combination with an opioid or other pain medicine.
- Can be used to minimize the dose of opioid medications needed for adequate analgesia.
- Often useful to treat neuropathic pain and bone pain and when opioid therapy is causing adverse effects such as sedation, delirium, or myoclonus.

b. Dosing:

i. ***Scheduled dosing***: When pain is chronic and moderate or severe, pain medications should be given regularly at fixed time intervals. Before the effect of a dose abates, the next dose should be given.

ii. ***Rescue dosing***: Rescue doses supplement scheduled doses to control *breakthrough pain* (pain flares that may occur despite scheduled doses):
- Most non-opioid pain medications (paracetamol, NSAIDs) have a daily dosing limit and can cause severe toxicity if the maximum dose is exceeded. Therefore, non-opioid pain medicines should not be used to treat breakthrough pain in most cases.
- Adjuvant pain medications should not be used to treat acute breakthrough pain (see item 5).
- Immediate-release oral opioids and injectable opioids are well-suited for rescue dosing.
- In the outpatient setting, the rescue dose typically should be approximately 10% of the total daily opioid dose.

  For example, a patient receiving oral morphine 10 mg every 4 hours:

  Total daily dose: 10 mg × 6 = 60 mg

  Rescue dose: 10% × 60 mg = 6 mg every 2–4 hours as needed
- If breakthrough pain occurs frequently and requires frequent rescue doses, the scheduled doses should be increased.

  For example, if a patient who receives morphine 10 mg orally every 4 hours also requires a rescue dose of 6 mg five times during the day:

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Total rescue dose: 6 mg × 5 times = 30 mg/day;
Thus, the regular scheduled dose can be increased to 15 mg every 4 hours

- If the patient has breakthrough pain that occurs predictably due to washing, walking, or physical therapy, a rescue dose should be given prior to the inciting cause.
  - An oral opioid such as immediate-release morphine should be given at least 30 minutes before the inciting cause.
  - An intravenous opioid such as morphine should be given 10 minutes before the inciting cause. If given subcutaneously, allow 15 minutes.

3. Non-opioid analgesics

See Table 3.1.

Table 3.1 Use of non-opioid analgesics

Analgesics/ Routes	Starting dose	Duration of action/ Dosing interval	Daily maximum dosage	Comments
Recommended analgesics				
Paracetamol (Tablets and oral syrup. Liquid for injection)	Adults: 500–1,000 mg	Every 4–6 hours	4,000 mg	Reduce dose or do not use in patients with liver disease. May be hepatotoxic if recommended dose exceeded.
	Neonates: GA 28–32: weeks: 10–12 mg/kg/ dose orally or per rectum	Every 6–8 hours	40 mg/kg/day	
	Neonates GA ≥33 weeks and term neonates <10 days old: 10–15 mg/kg/dose	Every 6 hours	Maximum 60 mg/kg/day	
	Term neonates ≥10 days: 10–15 mg/kg/dose	Every 4–6 hours	Maximum 75 mg/kg/day	
	Children: 10–15 mg/kg/dose	Every 4–6 hours	Maximum 75 mg/kg/day, up to 4,000 mg/day	

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Table 3.1 Continued

Analgesics/ Routes	Starting dose	Duration of action/ Dosing interval	Daily maximum dosage	Comments
Non-steroidal anti-inflammatory drugs (NSAIDs)				
Ibuprofen (Tablets of 200, 300, 400, 600, 800 mg; Syrup for children. Strength depends on producer)	Adults: 400–800 mg	Every 6–8 hours	Adults: 2,400 mg	Prolonged therapy requires gastrointestinal prophylaxis. Use with caution in patients with severe liver disease due to bleeding risk. Avoid in patients with renal failure.
	Children ≥6 months: 5–10 mg/kg	Every 6–8 hours	Children: Maximum 400 mg/dose and 40 mg/kg/day	
Alternatives NSAIDs				
Diclofenac (immediate release) Oral	Adults: 25–75 mg	Every 12 hours	200 mg	Greater cardiovascular risk than ibuprofen. Prolonged prescription requires gastrointestinal prophylaxis. Use with caution in patients with severe liver disease due to bleeding risk. Avoid in patients with renal failure.
Ketorolac IM/IV	Adults: High initial dose 30–60 mg, followed by 15–30 mg	Every 6 hours	Injection: 120 mg	Danger of gastrointestinal hemorrhage. Gastrointestinal prophylaxis is recommended. Give only a short course (5 days at most).
Oral route	Oral: 10 mg		Oral: 40 mg	Use with caution in patients with severe liver disease due to bleeding risk. Avoid in patients with renal failure.

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Table 3.1 Continued

Analgesics/ Routes	Starting dose	Duration of action/ Dosing interval	Daily maximum dosage	Comments
Meloxicam Oral	Adults: 7.5–15 mg	Every 24 hours	30 mg	Cardiovascular risk may be higher than with ibuprofen. Prolonged prescription requires gastrointestinal prophylaxis. Use with caution in patients with severe liver disease due to bleeding risk. Avoid in patients with renal failure.

a. Prevention of common side effects of NSAIDs:
   i. Avoid NSAIDs therapy in the following situations:
      - History of gastrointestinal hemorrhage or peptic ulcer disease
      - Unidentified pain in the upper stomach
      - Liver disease significant enough to cause elevation of international normalized ratio (INR)
      - Renal insufficiency of any degree
      - Bleeding risk of any cause including, but not limited to, thrombocytopenia, elevated INR, or anticoagulant therapy.
      - Active bleeding of any cause
      - Clotting risk
      - Esophageal stricture or patulous esophagus
   ii. When an NSAID is used for more than a few days, a proton pump inhibitor (e.g., omeprazole) should be used to reduce risk of ulceration of the stomach and duodenum.
   iii. Counsel patients to drink plenty of fluid after taking an oral NSAID and to sit upright or stand for 2 hours after taking.
   iv. If a patient taking an NSAID develops pain in the upper abdomen, NSAID therapy should be stopped immediately.
   v. Avoid combining NSAID with corticosteroid (the combination may increase risk of clotting or gastrointestinal hemorrhage)

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b. Hematemesis, black or bloody stool, or any other evidence of gastrointestinal bleeding is a medical emergency and requires immediate evaluation at a hospital unless the only goal of care of a dying patient is comfort and the patient wishes to remain at home.

4. Opioid analgesics

See Tables 3.2–3.5.

a. Key concepts:
   i. ***Opioid tolerance***: The normal phenomenon in chronic opioid therapy of a fixed dose producing a decreasing analgesic effect over weeks or months. When opioid tolerance develops, a dose increase is needed to maintain stable analgesic effect.
   ii. ***Opioid physical dependence***: The normal phenomenon in chronic opioid therapy of withdrawal symptoms occurring if treatment is stopped suddenly or if the opioid effect is reversed with an opioid antagonist. Because of this normal phenomenon, chronic opioid therapy must be tapered slowly when it is no longer indicated.

Table 3.2 Weak opioids (low dose of a strong opioid is preferred for cancer pain)

Analgesics/Route	Analgesics/ Route	Starting dose	Duration	Comments
Tramadol (often combined with paracetamol)	Oral or intravenous	Adults: 50–100 mg	Every 4–6 hours	Analgesic with similar effects to weak opioid. Side effects common, especially nausea. Maximum dose 400 mg/day Reduce dose or avoid in patients with renal failure. Avoid more than 4 g paracetamol per day.
Codeine (often combined with paracetamol)	Oral	Adults: 30–60 mg	Every 3–4 hours	Requires hepatic conversion to morphine, some patients lack the necessary enzyme. More side effects than other opioids, especially nausea. Ceiling dose (360 mg/ day). Avoid more than 4 g paracetamol per day.

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Table 3.3 Strong opioids

Analgesics/Route	Starting dose	Duration of action/Dosing interval	Comments
Morphine sulfate Immediate-release, oral	Adults: 5 mg	4 hours	May repeat dose or increase by 1.5–2 times if pain not relieved after 45 minutes. Consider giving laxative if multiple doses needed.
	Infant 0–3 months: 0.1 mg/kg	6–8 hours	
	Infant 3–6 months: 0.1 mg/kg	3–4 hours	
	Child >6 months: 0.2–0.5 mg/kg	4 hours	
Morphine sulfate Slow-release, oral	Adults: 10–15 mg	8–12 hours	May increase by 1.5–2 times each day if pain not adequately relieved or if frequent rescue doses needed. Give laxative unless patient has diarrhea.
Morphine chlorhydrate IV or SC	Adults: 2–5 mg	3–4 hours	May repeat dose or increase by 1.5–2 times if pain not relieved 15 minutes after IV dose or 30 minutes after SC dose. Consider giving laxative if multiple doses needed.
	Infant 0–3 months: 0.05–0.2 mg/kg	6–8 hours	
	Infant 3–6 months: 0.05–0.2 mg/kg	3–4 hours	
	Child >6 months: 0.1–0.2 mg/kg	3–4 hours	
Oxycodone Immediate-release, oral	Adults: 5 mg	4 hours	No better than morphine, more expensive. May repeat dose or increase by 1.5–2 times if pain not relieved after 45 minutes. Consider giving laxative if multiple doses needed.
Fentanyl Transdermal patch	Adults and children receiving ≥50 mg oral morphine equivalents per day: 25 mcg/hour	72 hours	Use only for persistent pain, not for breakthrough pain. Do not prescribe for patients with fever, sweating or cachexia. Full effect after 12–18 hours. Clearance not affected significantly by renal failure. Expensive
Fentanyl IV	Adults: 20–50 mcg Children: 1–2 mcg/kg	2 hours	Short duration of action is useful for procedural pain. For constant pain, continuous infusion is recommended. Clearance not affected significantly by renal failure. Expensive

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Table 3.3 Continued

Analgesics/Route	Starting dose	Duration of action/Dosing interval	Comments
Oxycodone Slow-release, oral	10 mg	8–12 hours	**NOT RECOMMENDED** Expensive, no better than slow-release morphine.
Pethidine			**NOT RECOMMENDED** Toxic metabolite, short duration of action.
Methadone			**NOT RECOMMENDED** except by clinicians with **advanced training and expertise in safe use**.

Table 3.4 Opioid equianalgesic doses

Opioid medicine	Oral or per rectum	IV or SC
Morphine	30 mg	10 mg
Oxycodone	20 mg	-
Tramadol	50 mg = 5–10 mg oral morphine	-
Fentanyl	-	0.1 mg (100 mcg)
Codeine	200 mg	120 mg
Pethidine	300 mg	75 mg

Table 3.5 Conversion from injected morphine to fentanyl transdermal patch

Injected morphine (mg/24 hours)	Fentanyl transdermal patch (mcg/hour)
15–30	25
30–48	50
49–65	75
66–80	100
81–98	125
99–115	150
116–130	175
131–148	200

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iii. ***Opioid use disorder*** *(addiction)*: A mental disorder characterized by a problematic pattern of opioid use (such as taking more than prescribed, or compulsive use), serious impairment of social or interpersonal function or of work or academic performance, continued use despite such impairment, or dangerous use of opioid.
iv. ***Pseudo-addiction***: Drug-seeking behavior resulting from inadequate treatment of pain by physicians that resolves when pain is adequately treated. Pseudo-addiction must be distinguished from true addiction, in which drug-seeking behavior continues despite adequate analgesia.

b. Opioid preparations:
   i. Immediate-release oral morphine:
      - The most essential opioid and the most essential palliative medicine
      - Can be provided in either pill or liquid form
      - Must be made safely accessible by outpatients with moderate or severe pain from any illness
      - Other immediate-release oral opioids typically cost more, are no better than morphine, and are not essential
   ii. Injectable morphine:
      - Essential for patients unable to take oral medicines and for severe pain related to any illness
      - While other injectable opioids are not essential for palliative care, ***injectable fentanyl*** is useful especially for patients with renal failure and as premedication to prevent pain during invasive medical procedures.
   iii. Slow-release oral opioids:
      - Most preparations have a duration of effect of 8–12 hours
      - Useful for treating chronic pain because they maintain a more constant blood level of opioid and thus a more constant state of analgesia than short-acting opioids
      - Should be used only with scheduled dosing, never as a rescue dose
      - The pills should never be crushed, and the capsules should never be opened.
      - Typically cost more and are no more effective than oral immediate-release morphine.
   iv. Other preparations:
      - Fentanyl transdermal patch:
         - Useful for some patients unable to take oral medicines

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- Do not use in cachectic patients (poor absorption), febrile patients (rapid and unpredictable absorption), or sweating patients (poor adhesion of patch)
- Available as generic, but expensive

c. Opioid adverse effects/prevention of adverse effects (see Table 3.6):
   i. The risk of serious side effects of opioids is minimal when standard prescribing rules are followed.
   ii. Prescribe the lowest dose of opioid that relieves pain to the degree acceptable to the patient.
   iii. Sleepiness when starting an opioid, or when increasing the dose, is not always due to opioid-induced sedation. Many patients with persistent or frequent pain are sleep-deprived and will go to sleep when their pain is adequately relieved.
      - Normal sleep can be distinguished from sedation by testing the patient's arousability. A normally sleeping patient will be arousable.

d. Discontinuation of opioid therapy:
   i. Opioid therapy should be discontinued:
      - When the patient's pain has resolved.
      - When an alternative type of analgesic therapy is found to be effective.
      - When a patient repeatedly breaks an opioid contract (see Section 7).

b. When opioid therapy of 2 weeks or longer is discontinued, care must be taken to avoid causing opioid withdrawal syndrome. Signs and symptoms of opioid withdrawal syndrome include fever, chills, sweating, nausea, vomiting, painful abdominal cramping, diarrhea, muscle aches, insomnia, runny nose, and hypertension.

c. To avoid this syndrome, the opioid dose should be tapered slowly. Reduce the dose no more than 33% every 2–3 days. If withdrawal symptoms occur, increase the dose again by 33%, and then taper the doses more slowly.

d. Opioid antagonists such as naloxone cause opioid withdrawal symptoms immediately in patients taking opioids chronically and can cause a sudden return of severe pain along with anxiety, agitation, nausea, tachycardia, and occasionally pulmonary edema.

e. When naloxone must be given for a major side effect of opioid therapy such as severe respiratory depression, very small doses

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should be used to reverse the major side effects without completely reversing the analgesic effect and inducing withdrawal. Typical doses are 0.08 mg to 0.12 mg IV every 2 minutes until the desired effect is achieved (see Table 3.6).

Table 3.6 Opioid adverse effects

Adverse effect	Frequency	Prevention/Treatment	Notes
Constipation	Very common	Adults: Stimulant laxative: Bisacodyl 5–10 mg orally 1–2 times per day. Maximum 30 mg/day. Osmotic laxative not as effective: Polyethylene glycol orally 1–2 time per day. Can use both if needed. Children at least 3 years old: Bisacodyl 5 mg orally once/day. Maximum 20 mg/day.	Persists while taking opioid.
Dry mouth	Common	Keep mouth moist with sips or wet sponge	Persists while taking opioid.
Nausea	Common	Usually mild. If severe, give haloperidol 0.5–1 mg orally or IV every 4 hours as needed or scheduled	Usually resolves in a few days.
Sweating	Common	Reassurance	
Sedation	Common	Reassurance	Usually resolves in a few days.
Urinary hesitancy and retention	Common in some populations (see Notes)	Avoid medicines with anticholinergic effects. Treat for benign prostate hypertrophy as appropriate. Consider placing bladder catheter.	Usually in older men with large prostate or in patients with neurologic disease (stroke, neurogenic bladder).
Delirium	Uncommon	See **Chapter 4 for delirium prevention and treatment**	Most common in patients with dementia or other brain disease.
Myoclonus	Uncommon	No treatment if not distressing to the patient. Change to another opioid if possible. If needed, diazepam 2–5 mg orally or IV every 8 hours as needed or scheduled.	Diazepam increases risk of sedation and delirium.
Pruritus (itching)	Uncommon	Change to another opioid if possible.	Usually persists while taking the opioid.

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Table 3.6 Continued

Adverse effect	Frequency	Prevention/Treatment	Notes
Respiratory depression	Very uncommon when dosing guidelines are followed.	Monitor respiratory rate and oxygen (O_2) saturation and give O_2 as needed. No treatment needed if O_2 saturation is normal. If the situation warrants, respiratory depression can be rapidly reversed as follows: Dilute 0.4 mg naloxone into 9 mL saline and give 2–3 mL (0.08–0.12 mg) IV every 2 minutes until respiratory rate returns to normal. Pain crisis may occur. Naloxone effect lasts only 1 hour, so repeat dosing may be necessary. In case of overdose of a slow-release opioid, consider using naloxone continuous IV infusion at an hourly rate of 65% of the dose that produced normal respiration. Continue to titrate to normal respiratory rate.	Sedation always precedes respiratory depression. If a dying patient has refractory pain, the only goal of care is comfort and other modalities of pain relief are not available or acceptable to the patient, some degree of respiratory depression (slowing of respiratory rate) may be an unintentional but acceptable adverse effect of the effort to provide adequate pain relief with opioid therapy (see Chapter 1, Section C2).

5. Adjuvant medicines for pain control

See Table 3.7.

a. Adjuvant medications can, in some cases:
   i. Relieve pain independently
   ii. Enhance the effects of and help to reduce the dosage of opioids
b. Main indications and suggested medicines:
   i. Neuropathic pain:
      - Tricyclic antidepressant (e.g., amitriptyline)
      - Anticonvulsants (e.g., gabapentin, valproate)
      - Local anesthetic (e.g., lidocaine IV or transdermal)
      - Corticosteroid

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Table 3.7 Adjuvant medicines for pain relief

Adjuvant and rout	Dose and administration	Adverse effects
Corticosteroids		
Prednisolone	Adults: 20–80 mg 1 time/day in the morning, orally.	Hyperglycemia Occasionally agitation or psychosis. Increased infection risk. Myopathy with prolonged use. GI bleeding with prolonged use.
	Children: 1 mg/kg 1–2 times/day, orally.	
Dexamethasone	Adults: 4–20 mg/day orally or IV, either once in the morning or twice per day in the morning and early afternoon. Do not give in the evening.	
	Children: 0.3 mg/kg/day × 1–2 times/day, orally or IV	
Tricyclic antidepressants		
Amitriptyline	Adults: Starting dose 10–25 mg orally once/day at bedtime. Maximum dose 100 mg orally at bedtime.	Drowsiness initially. Often postural hypotension, constipation, dry mouth, tachycardia. Life-threatening cardiac toxicity with overdose
	Children: 0.1 mg/kg orally once/day at bedtime. Increase as needed and tolerated every 3–4 days to maximum 2 mg/kg/day	
Anticonvulsants		
Gabapentin	Adults: Starting dose: 100 mg orally every 8 hours or 300 mg orally at bedtime. If no significant adverse effect, increase after 1–2 days to 200 mg orally every 8 hours or 300 mg orally every 12 hours. If no significant adverse effect, increase after 1–2 days to 300 mg orally every 8 hours (minimum effective dose). Maximum dose: 1,200 mg orally every 8 hours. Taper dose slowly over at least 7 days. Reduce dose or avoid in patients with renal failure.	Dizziness, sedation, tremor, nausea. Withdrawal seizures if tapered too rapidly.
Valproate sodium	Adults: Starting dose: 15 mg/kg/day IV in 2 or 3 divided doses. Maximum: 60 mg/kg/day.	Causes drowsiness. Do not use in patients with liver disease. Reduce dose in older patients. Also useful for refractory agitation.

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Table 3.7 Continued

Adjuvant and rout	Dose and administration	Adverse effects
Local anesthetic medicine (sodium channel blocker)		
Lidocaine (for severe neuropathic pain refractory to opioid)	Start with 1 mg/kg IV as a loading dose. If pain relieved, consider starting continuous infusion 1–3 mg/min IV.	Hypotension, cardiac arrhythmia, muscle weakness, confusion.
Anticholinergic medicines (antispasmodic)		
Hyoscine butylbromide	Adult starting dose: 10–20 mg orally 3–4 times/day as needed or scheduled, or 10 mg IV/SC 3–4 times/day Maximum 120 mg/day.	Constipation Dry mouth Tachycardia Urinary retention Does not cross blood–brain barrier, so no sedative or central antiemetic effects.
	Children 6–12 years: 10 mg orally up to 3 times/day, or 0.5 mg IV/SC up to 4 times per day as needed.	
Scopolamine	Adults: 1 mg transdermal patch: 1–2 patches every 72 hours	Constipation Dry mouth Tachycardia Urinary retention Sedation Delirium
Voluntary muscle relaxants		
Diazepam	Adults: 2–10 mg orally or IV 2–4 times/day Children: 0.12–0.8 mg/kg/day orally in 3 or 4 divided doses as needed, or 0.04–0.2 mg/kg IV every 2–4 hours as needed. Maximum 0.6 mg/kg IV in 8 hours.	Drowsiness Delirium
Baclofen	Adults: 5 mg orally 3 times/day. Maximum dose 20 mg 3 times/day	
Bisphosphonates (for bone pain from bone metastases)		
Pamidronate	60–90 mg IV, every 4 weeks	Hypocalcemia. Brief (1–2 days) fever or flu-like symptoms (less often with zoledronate). Risk of adverse effects increases with worsening renal failure.
Zoledronate	4 mg IV, every 4 weeks	

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ii. Bone pain due to metastatic cancer:
  - A corticosteroid (do not use NSAID and corticosteroid together):
  - If considering corticosteroid to relieve bone pain in a patient receiving cancer treatment, ask the oncologist if corticosteroid will interfere with the cancer treatment plan.
  - Bisphosphonate (e.g., zoledronate)

iii. Muscle spasm:
  - Skeletal muscle spasm: Skeletal muscle relaxant (e.g., diazepam)
  - Visceral smooth muscle (cramps): Opioid or anticholinergic (e.g., hyoscine butylbromide)

iv. Malignant tumor causing stretch of liver capsule or bowel obstruction:
  - Dexamethasone (the corticosteroid with least mineralocorticoid effect)

v. Malignant spinal cord compression (emergency):
  - Dexamethasone IV (also consider emergent radiation therapy or surgery)

6. Invasive procedures for pain relief

Patients whose chronic pain is refractory to systemic therapy, or who have serious adverse effects of systemic therapy, may benefit from an invasive procedure if clinicians with adequate training, experience and equipment are available (see Table 3.8).

Table 3.8 Invasive procedures for specific types of pain (examples)

Procedure	Type of pain
Celiac plexus block	Upper abdominal pain from disease of the liver, pancreas, biliary tract, or stomach
Superior hypogastric nerve block	Lower abdominal and internal pelvic pain
Ganglion impar block	Superficial perineal, and anal pain
Epidural therapy with indwelling epidural catheter	Lower body pain (typically only for post-operative patients and patients near the end of life)
Intrathecal therapy with indwelling intrathecal catheter	Lower body pain (typically only for patients near the end of life)
Kyphoplasty	Spinal radiculopathy due to vertebral compression fracture
Vertebroplasty	Spinal radiculopathy due to vertebral compression fracture

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7. Pain in patients with a history of a substance use disorder

a. Principles:
   i. People who frequently take opioids illicitly or who receive methadone maintenance therapy for opioid use disorder (OUD) are likely to have developed **opioid tolerance** and are likely to require higher opioid doses for pain relief than people not taking opioids chronically.
   ii. People taking opioids illicitly and people receiving methadone maintenance therapy also may have greater sensitivity to pain or a lower pain threshold than people not taking an opioid. This phenomenon is called **opioid-induced hyperalgesia**.
   iii. Some patients with a history of a substance use disorder will fear taking opioids or refuse to take them because they fear relapse. This fear should be considered in making treatment decisions.
   iv. There is no clinical reason to fear relapse or to withhold opioids from patients with a history of a substance use disorder if they are dying and suffering from pain or refractory dyspnea.
   v. For people receiving **methadone maintenance therapy**, it is important to note that:
      - Methadone maintenance therapy (once per day) does not provide effective pain relief.
      - Methadone maintenance therapy should continue uninterrupted at the usual dose while pain is treated with other drugs, opioid and/or non-opioid.
      - The risk of serious side effects from opioids is no greater in patients receiving methadone maintenance therapy than in others and probably is lower.
      - It is unlikely that reports of pain in patients receiving methadone maintenance therapy at a stable dose are simply an attempt to obtain more opioids because of addiction.

b. Cancer pain treatment for patients with a history of a substance use disorder who are not near the end of life:
   i. Try to relieve the pain with non-opioids and adjuvant medicines.
   ii. If treatment with non-opioids is not effective, opioids can be used with special precautions to reduce the risk of diversion or non-medical use:
      - Limit amount of medication dispensed to the patient at any one time.

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- Require the patient to adhere to a fixed schedule for renewing the prescription.
- Assess the patient frequently for any evidence of illicit substance use such as fresh injection marks on the skin, suspicious changes in behavior, or changes in adherence to medical therapy. If available, use urine tests to identify what the patient is taking.
- Require the patient to sign a written Opioid Contract (see Appendix 2). The opioid contract should include:
  - A clear description of proper and improper opioid use
  - A commitment by the doctor to continue treating the patient's pain if the patient abides by the Contract
  - A commitment by the patient:
    - To use the opioid properly at all times
    - To safeguard the opioid and not lose it
    - To obtain additional opioid ONLY from the doctor who signs the contract or a designated colleague and ONLY from one pharmacy
    - To submit to routine history-taking and physical examination to assess for any improper opioid use
    - To submit to urine drug testing whenever requested by the doctor
    - To accept the doctor's right to terminate all treatment with controlled medicine if the patient violates the Contract

Further Reading

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4

Assessment and relief of other physical, psychological, social, and spiritual suffering

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A. Physical symptom assessment and relief: Principles

1. Differential diagnosis of symptoms:
   a. Whenever the cause of a symptom is not obvious, the clinician should create a differential diagnosis and document it in the medical record.
   b. Some symptoms may have multiple causes.
2. Symptom treatment:
   a. Decisions about treatment should be based on differential diagnosis and determination of the most likely cause(s) of the symptom.
   b. Many symptom treatments are effective only for symptoms of a specific cause. For example, vomiting has many causes including emetogenic medicines, endogenous emetogenic toxins, viral labyrinthitis, increased intracranial pressure, gastroparesis, bowel obstruction, anxiety, etc. If vomiting is caused only by bowel obstruction, treatment with a dopamine blocker such as haloperidol will have no benefit.
3. Symptom severity:
   a. Treat first the symptom(s) that cause the worst suffering.
   b. If a new patient has a severe symptom, it may be necessary to treat the symptom aggressively before completing the entire palliative care assessment.

B. Physical symptom assessment and relief: Specific symptoms

Table 4.1 Physical symptoms and treatment by cause

Cause	Treatment (starting doses)	Notes
1. Dyspnea		
Pneumonia	Treat with appropriate antimicrobial if consistent with goals of care. Opioid-naïve adult, starting dose: Morphine 2.5–5 mg orally or 1–2 mg IV or SC, every 2–4 hours as needed. If the starting dose does not provide adequate relief, repeat or increase the IV/SC dose every 15 minutes, or the oral dose every 45 minutes. Once the effective dose is found, if dyspnea is persistent, schedule a dose every 4 hours (or give as a continuous IV or SC infusion) and make available an additional rescue dose of 10% of total daily dose every 60 minutes as needed.	Clarify whether invasive and non-invasive ventilatory support are consistent with the agreed-upon goals of care. Morphine or another opioid should be used only if treatment of the underlying cause of dyspnea and ventilatory support are not immediately effective or not consistent with the goals of care. A fan blowing air on the face can provide relief from dyspnea of any cause. Oxygen therapy can provide some relief. However, it is not as effective as morphine.
Aspiration	Aspiration precautions: Avoid thin liquids; patient should eat only when fully awake, sitting upright, and with assistance. Morphine as above.	
Lung cancer or lung metastases	Treat with morphine as above. Consider cancer chemotherapy or radiation therapy if possible and consistent with goals of care.	
Pulmonary embolism	Treat with morphine as above. Consider anticoagulation if consistent with goals of care.	
Cardiogenic pulmonary edema	Diuresis with furosemide. Treat with morphine as above.	
Non-cardiogenic pulmonary edema	Treat with morphine as above.	
Pleural effusion	Consider drainage if consistent with goals of care. Treat with morphine as above.	

(*continued*)

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
Pulmonary hemorrhage	Treat with morphine as above.	
Severe anemia	Treat the cause of anemia, if consistent with the goals of care. Transfuse packed red blood cells, if consistent with the goals of care. Treat with morphine as above.	
Chest muscle weakness (amyotrophic lateral sclerosis, other neurologic diseases)	Treat with morphine as above.	
"Death rattle" (accumulation of secretions in upper respiratory tract)	Hyoscine butylbromide 20 mg, every 6 hours IV or SC around the clock and/or as needed (alternative: glycopyrrolate 0.1–0.3 mg every 6 hours IV or SC around the clock and/or as needed). For associated dyspnea, treat with morphine as above.	
End-stage COPD	Treat aggressively with bronchodilators and steroid. If dyspnea persists despite maximal treatment of COPD, use morphine as above.	When treating with morphine, watch for evidence of worsening hypercapnia (sedation).
End-stage interstitial lung disease	Consider trials of high-dose steroid. Treat with morphine as above.	
2. Cough		
Irritation of bronchopulmonary tree from infection, malignancy, inflammation, fluid accumulation, aspiration	Treat underlying cause if possible. Opioid-naïve patient: Codeine 30 mg every 4 hours orally as needed. If codeine 30 mg is available only in combination with paracetamol, and if the patient has moderate or severe liver disease, use an alternative opioid (such as morphine) that is not combined with paracetamol. If caused at least in part by COPD or asthma, can give oral or IV corticosteroid and taper the dose over days or weeks.	Keep the patient away from any type of dust and smoke (including cigarette smoke).

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
3. Nausea/Vomiting		
Endogenous emetogenic toxin: Inflammatory mediator, emetogenic cytokine, liver failure, renal failure, metabolic derangement. Exogenous emetogenic toxin: adverse effect of medicine, bacterial toxin	First line: Haloperidol 0.5–1 mg 2–4 time/day, orally, IV, or SC, scheduled or as needed Adjuvant: Dexamethasone 4–8 mg/day, in one or two doses, orally or IV scheduled or as needed.	Correct any metabolic derangements if consistent with goals of care. Use steroid with caution in setting of infection, diabetes mellitus, anxiety, agitation. Avoid steroid in setting of GI bleeding.
Chemotherapy, radiation therapy to abdominal area	Ondansetron 4–8 mg oral or IV every 8 hours scheduled or as needed (see Chapter 5, Section A)	
Increased intracranial pressure	Dexamethasone 8–20 mg in one or two doses daily, orally or IV	Give once daily in the morning or twice daily in the morning and in early afternoon. Avoid bedtime dosing. Watch for agitation, anxiety, psychosis, GI bleeding. Increases risk of infection, hyperglycemia.
Anxiety	Haloperidol 0.5–2 mg 2–4 time/day, orally, IV, or SC, scheduled or as needed Diazepam 2–10 mg 3 times/day, orally, IV or SC, around the clock and/or as needed. For chronic anxiety, a selective serotonin reuptake inhibitor (SSRI) such as sertraline, fluoxetine, or citalopram (see Table 4.2).	Avoid diazepam in older patients and patients at risk for delirium. Short-acting benzodiazepines such as alprazolam not recommended due to risk of rebound anxiety.
Gastroparesis	Metoclopramide 5–10 mg, 4 times/day, orally, IV or SC, scheduled or as needed.	Do not combine metoclopramide with haloperidol or other dopamine blockers.
Distension of liver or of hollow viscus due to neoplasm	Dexamethasone 8–20 mg/day in one or two doses, orally or IV.	Give once daily in the morning or twice daily in the morning and in early afternoon. Avoid bedtime dosing. Watch for agitation, anxiety, psychosis, GI bleeding. Increases risk of infection, hyperglycemia.

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
Malignant bowel obstruction	Dexamethasone 8–20 mg/day in one or two doses orally or IV. If effective and prognosis is short (days to 2 weeks), consider maintaining the effective dose. Otherwise, consider tapering to the lowest effective dose. If obstruction appears to be partial, can add metoclopramide 5–15 mg IV or SC every 6–8 hours. If medical therapy is not possible or effective, and if consistent with the patients goals of care, consider: Venting gastrostomy tube for drainage, or Palliative surgical reduction of the obstruction	Typically, there is vomiting with minimal nausea or only very brief episodes prior to vomiting. If possible, avoid nasogastric tube placement for drainage (uncomfortable), or use only for a short time. Give dexamethasone once daily in the morning or twice daily in the morning and in early afternoon. Avoid bedtime dosing. Watch for agitation, anxiety, psychosis, GI bleeding. Increases risk of infection, hyperglycemia.
Non-malignant bowel obstruction	Consider surgical reduction of the obstruction or venting gastrostomy.	Typically, there is vomiting with minimal nausea or only very brief episodes prior to vomiting Avoid nasogastric tube placement if possible (uncomfortable).
Stimulation of vestibular apparatus	Diphenhydramine 12.5–50 mg 3–4 times/day, orally or IV, around the clock or as needed. Hyoscine hydrobromide 1 mg transdermal patch, apply behind ear every 72 hours.	Watch for sedation and delirium.
Severe constipation	See Constipation, below	
	Additional points: • Always ask the patient whether there is constant or long-lasting nausea, or whether there is minimal nausea or nausea lasting only a few seconds or minutes prior to vomiting. • Little nausea prior to vomiting is most consistent with mechanical or functional bowel obstruction and will not be relieved by medicines to treat other causes of nausea. • Adjuvant for nausea of any cause: Diphenhydramine 12.5–50 mg 3–4 times/day, orally or IV, around the clock or as needed. Watch for sedation and delirium.	

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
4. Diarrhea		
Bacterial or parasitic infection; fever or bloody stool	Perform laboratory tests to identify infectious cause of diarrhea, if possible. Treat the underlying cause, confirmed or presumed, with appropriate antibiotics. Replace fluids and electrolytes if consistent with goals of care.	
Idiopathic, no response to antimicrobial treatment, and no fever or bloody stool; radiation enteritis; cancer chemotherapy	Loperamide 4 mg for the first dose, then 2 mg after each loose stool to the maximum of 16 mg/day; or diphenoxylate + atropine (5 mg + 0.05 mg) to maximum of four times per day as needed.	
Fecal impaction/obstipation	Remove fecal impaction Reduce obstipation (see Constipation)	
Laxative overuse	Stop or reduce dose of laxative	
5. Constipation		
Opioid analgesic therapy	Assess for fecal impaction with digital rectal exam unless contra-indicated by severe thrombocytopenia or other bleeding risk. Manually dis-impact as needed. Osmotic laxatives (use only in patients who are well-hydrated): Lactulose syrup 15-45ml in 2–3 times/day orally, maintain 30-90ml/day Polyethylene glycol 110-20gm mixed with fluid once or twice per day Stimulant laxative: Bisacodyl 5–10 mg once or twice daily, orally or as rectal suppository. Enema with natri-phosphate or mineral oil once/day. For severe cases: naloxone 1-3 mg every 8 hours ORALLY as needed.	Most patients with opioid-induced constipation need a stimulant laxative such as bisacodyl. If no bowel movement for more than 3 days, consider using mineral oil enema to soften and lubricate desiccated stool 12–24 hours prior to giving stimulant laxative. Naloxone, when given orally to patients with an intact GI tract, is very poorly absorbed and acts only locally on the GI tract. Thus, ORAL naloxone can treat constipation without reversing the analgesic effect of opioids.
Other constipating medications: anticholinergics, iron, calcium channel blockers	Discontinue constipating medicines if possible. Laxatives and/or enema as above.	

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
Dehydration, inactivity	Rehydrate and mobilize only if consistent with patient's goals of care.	
6. Mouth pain and pain on swallowing		
Oral thrush (Candida)	Antifungal treatment: Not AIDS patient: Fluconazole 100–200 mg orally or IV once daily × 7–14 days; or Itraconazole 200mg orally once daily × 7 days For pain, viscous lidocaine 2%, 15 mL swish and spit before meals and at bedtime (mouth pain), or 15 cc swish and swallow before meals and at bedtime (pain on swallowing). For pain inadequately relieved with topical medicines, add paracetamol or oral or IV morphine until infection resolves.	
Oral and esophagus aphthous ulcer	Apply viscous lidocaine 2% to ulcer before eating; apply topical steroid to ulcer after eating three times per day until resolved. Ulcer >1 cm, consider methylprednisolone 40 mg/day orally for 4 days, taper by 10 mg every 4 days.	
Herpetic ulcers	Treat with acyclovir 400 mg orally 5 times per day for 5 days; or valacyclovir 2 g orally every 12 hours for 1 day. Pain treatment with viscous lidocaine 2% applied to ulcers before eating. For pain inadequately relieved with topical medicines, add paracetamol or oral or IV morphine until infection resolves.	
Esophageal malignancy	Topical and systemic pain treatment as above.	

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Table 4.1 Continued

Cause	**Treatment (starting doses)**	**Notes**
7. Weakness/Fatigue		
Infection, dehydration, anemia, major organ failure, advanced malignancy or advanced AIDS	Treat underlying causes of weakness and fatigue if possible and consistent with goals of care. In patients near the end of life whose weakness or fatigue causes poor quality of life, consider methylprednisolone 20–60 mg orally in the morning; or dexamethasone 4–12 mg orally or IV daily in one or two doses.	Give dexamethasone once daily in the morning or twice daily in the morning and in early afternoon. Avoid bedtime dosing. With any steroid therapy, watch for agitation, anxiety, psychosis, GI bleeding.
8. Fever		
Infection, inflammation, malignancy	Treat the underlying cause of fever if possible and consistent with the goals of care. Paracetamol 500–1,000 mg every 6 hours orally or suppository as needed. Do not exceed 4,000 mg/day. Reduce the dose in patients with liver disease. For severe persistent fever in a dying patient: Dexamethasone 4–16 mg/day in one or two doses orally or IV.	Give dexamethasone once daily in the morning or twice daily in the morning and in early afternoon. Avoid bedtime dosing. With any steroid therapy, watch for agitation, anxiety, psychosis, GI bleeding.
9. Insomnia		
Pain or other physical symptoms, psychological problems such as anxiety or depression or delirium, medicines with psychostimulant effects, poor sleep hygiene	Avoid giving medicines with psychostimulant effects such as steroids late in the day. Treat pain and any other physical symptoms. Treat anxiety, depression, or delirium, if present (see Delirium and Depressed Mood/Anxiety). Both amitriptyline and mirtazapine are effective treatments for anxiety and depression, and both are sedating. Improve sleep hygiene: • Avoid caffeinated drinks late in the day. • Minimize daytime napping. • Quiet activities late in the day. • Minimize nocturnal interruptions, noises and lights.	Avoid benzodiazepines in older patients and any other patients at risk for delirium. In these patients, benzodiazepines may cause paradoxical agitation that is dangerous and difficult to treat.

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
	For older patients and any patient at risk for delirium, if symptom control and sleep hygiene are not effective, use haloperidol 1–2 mg at bedtime orally or IV. In young, cognitively intact patients, can use diazepam 5–10 mg orally at bedtime.	
10. Pruritus		
Dry skin, renal failure.	Emollient lotion.	With antihistamines (chlorpheniramine and diphenhydramine), risk for sedation or delirium. With systemic steroid, watch for agitation, anxiety, psychosis, GI bleeding.
Contact dermatitis	Remove and avoid the allergen. High-potency topical steroid.	
Scabies	Permethrin lotion: apply from head (avoid face) to toes, leave on 8–14 hours, then wash off. Usual adult dose is 20–30 g. Repeat in 1 week. Wash all clothes and bedding and dry in the sun. Do not use for babies >2 months old. If permethrin not available, can use lindane lotion, apply from head (avoid face) to toes, leave on 8–12 hours, then wash off. Usual adult dose 20–50 mL. Wash all clothes and bedding and dry in the sun. Do not use for infants and patients with seizure disorder.	
Eosinophilic folliculitis (HIV/AIDS patients)	High-potency topical steroid. Chlorpheniramine 4 mg orally every 4–6 hours as needed. Metronidazole 250 mg orally every 8 hours for 3–4 weeks.	
Cholestasis	Cholestyramine 4 g orally 1–4 times per day before meals. Ondansetron 8 mg twice per day orally. Biliary stent or percutaneous drain if possible and consistent with goals of care.	
Opioids	Opioid rotation if possible. Chlorpheniramine 4 mg orally every 4–6 hours as needed, or diphenhydramine 12.5–50 mg IV every 4 hours orally or IV	

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
Other causes: HIV, malignancy, uremia	Chlorpheniramine or diphenhydramine as above. Methylprednisolone 20–60 mg/day orally; or dexamethasone 4–20 mg/day in one or two doses orally or IV.	
11. Wounds and pressure ulcers (bed sores)		
Stage 1: Redness in pressured area Stage 2: Skin blisters or small open ulcer	Relieve pressure on bony prominences: soft mattress, reposition patient frequently, heel pads or raise heels off bed. Keep patient dry. Avoid skin trauma from sliding. Treat pain. Clean intact skin with povidone-iodine 10%. Cleanse wound gently with sterile saline. Dress wound with semipermeable membrane dressing (e.g., Tegaderm) or hydrogel dressing (e.g., Duoderm, gauze soaked with sterile hydrogel).	
Stage 3: Skin breakdown, damage to the tissue below the skin. Stage 4: Deep pressure ulcer, damage to the muscle and bone, tendons, and joints.	Relieve pressure on the ulcer: soft mattress, reposition patient frequently, heel pads or raise heels off bed Keep patient dry. Avoid skin trauma from sliding. Treat pain. Cleanse wound gently with sterile saline. Determine goals of wound care: 1. If wound will not heal and/or patient is expected to die soon, goals are to prevent odor and maximize comfort and dignity. Prevent or reduce odor from anerobic bacterial infection with metronidazole powder (crush pills or open capsules) sprinkled on wound 1–3 times per day). If wound is wet or bleeding, use calcium alginate packing or povidone-iodine gauze packing. If wound is dry, use gauze or cotton coated with petroleum jelly (Vaseline or paraffin) or soaked with hydrogel (such as KY jelly).	

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Table 4.1 Continued

Cause	Treatment (starting doses)	Notes
	2. If wound is healable, keep wound moist and clean. Debride as necessary. For most cases, use autolytic debridement with sterile hydrogel soaked packing/dressing. For wounds with thick eschar or extensive necrosis, use surgical debridement. Premedicate for pain. Avoid wet-to-dry dressing as this type of debridement is painful. Dressings should be done as follows: For wet or bleeding wounds, use calcium alginate or foam packing. Then cover with gauze. Change dressing when gauze covering becomes wet. For dry wounds, apply sterile hydrogel to wound (can mix with metronidazole powder if needed to treat anaerobic infection and control odor). Can also use honey or plain yogurt instead of hydrogel. Fill empty space with gauze or cotton coated with petroleum jelly (Vaseline or paraffin) or soaked with sterile hydrogel. Then cover with gauze.	
12. Hypercalcemia		
Cancer (especially squamous cell carcinoma, renal cell carcinoma, and breast, prostate, ovarian cancer), multiple myeloma, primary or secondary hyperparathyroidism, granulomatous disease such as tuberculosis or sarcoidosis.	Hydrate with IV sodium chloride until euvolemic, then IV furosemide Zoledronate 4 mg IV every 4 weeks, or pamidronate 60–90 mg IV every 4 weeks	Symptoms may include delirium, sedation, nausea, vomiting, constipation, abdominal pain, Also causes diuresis and volume depletion.

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C. Psychological suffering assessment and relief: Principles

1. Range of psychological symptoms in people with serious illnesses, their family members, and people who have experienced severe psychological trauma

a. People with serious illnesses and trauma exposure:
   i. Psychological symptoms including anxiety, depression, and delirium are common in people with serious medical illnesses, are major causes of suffering, and should be diagnosed and treated aggressively.
   ii. Major depression may be overlooked in medically ill patients because some symptoms of medical illness are the same as some symptoms of depression. However, unremitting sadness, persistent inability to experience joy, intense feelings of guilt or worthlessness, and suicidal ideation are not normal reactions to medical illness and may indicate major depression.
   iii. Anxiety disorders and depression also occur in patients without serious medical illnesses, including those who have experienced severe psychological trauma. Where psychiatric care is not easily accessible, healthcare providers with at least basic training in palliative care can and should recognize and treat uncomplicated anxiety and depression.
   iv. Post-traumatic stress disorder (PTSD):
      - May occur in susceptible people who experience physical or emotional violence, the unexpected death of a loved-one, or a serious illness.
      - Is characterized by flashbacks, severe anxiety, dissociation, and avoidance or combative behavior.
   v. Patients with complicated or refractory psychiatric problems should be referred to a psychiatrist.

b. Patients' family members:
   i. The emotional and physical strain of caring for a seriously ill family member and the anticipated or actual loss of a family member can result in anxiety and depressed mood.
   ii. Normal bereavement (80–90% of bereaved family members):
      - Disbelief, difficulty accepting the death; preoccupation with thoughts of the deceased; relative disinterest in the rest of the world.

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- Grief gradually declines over weeks or months, gradual acceptance of the loss, reconnection with social life, but waves of sadness may recur, especially on anniversaries and holidays.

iii. Prolonged grief disorder (see also Chapter 9, Section G):
- Persistence for at least 12 months (6 months in children and adolescents) of distressing preoccupation with the deceased, intense emotional pain (such as sadness, guilt, or anger), impaired social functioning and physical health, difficulty accepting the loss, feeling that life is empty or purposeless.
- May occur with or without major depression.
- Requires intervention to help prevent long-term mental and physical illness.

2. Assessing and treating psychological suffering

a. Healthcare providers with at least basic training in palliative care can and should be able to:
   i. Recognize and treat uncomplicated anxiety, depression, and delirium
   ii. Recognize complicated or refractory psychiatric problems and refer for specialist care
   iii. Distinguish normal grief from prolonged grief disorder
   iv. Assist patients and families in developing healthy coping mechanisms
   v. Provide emotional support and improve self-confidence and self-reliance
   vi. Help improve relationships among the patient, family, friends, and peers
   vii. Refer patients or their families to essential social and economic support services

b. Supportive psychological counseling:
   i. Any healthcare provider with at least basic training in palliative care can ask about and explore patients' or family members' fears and concerns, provide supportive listening, and offer encouragement.
   ii. Palliative care teams at hospitals should include a psychologist or social worker who can provide "talk therapy" for patients or family members, assist them to develop effective coping strategies for stressful situations, and provide bereavement support, as needed:

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- Basic bereavement support consists of expressions of condolence, exploration of the bereaved person's coping and social functioning, supportive listening, and reassurance (if appropriate) that unfamiliar thoughts or feelings are a normal part of grieving.

c. Psychological symptoms and treatment by cause (Table 4.1)

D. Psychological suffering assessment and relief: Specific symptoms

Table 4.2 Psychological symptoms and treatment by cause

Cause	Treatment (starting doses)	Notes
1. Adjustment disorder		
Serious illness or injury, loss of function, death of a loved one	Psychosocial supports such as supportive counseling from social worker or psychologist, peer support groups, bereavement support groups. Treatment of anxiety or depressed mood if necessary (see below).	Definition: A maladaptive reaction to an identifiable stressful life event. Symptoms must occur within 3 months of the stressor and persisted for no longer than 6 months. The behavioral or emotional symptoms seem in excess of what would be normally expected from the stressor or there is impairment of social or occupational functioning. Symptoms of depression, anxiety, and disturbed behavior are the most common. It is important to consider cultural values and practices when determining what is normally expected behavior.
2. Anxiety		
Serious illness or injury, chronic physical symptoms, loss of function, death of a loved one, severe social stressors such as extreme poverty or exposure to violence, baseline anxiety disorder	Treat any physical symptoms aggressively. Psychosocial supports such as supportive counseling from social worker or psychologist, peer support groups, assistance with finances, food, safe lodging, transportation. Avoid using benzodiazepines in older patients or patients at risk for delirium. In young, cognitively intact patients, can use diazepam 5–10 mg two to three times per day orally or IV.	Anxiety and depression commonly coincide. Amitriptyline has anticholinergic side effects including sedation, constipation, dry mouth, tachycardia, orthostatic hypotension. It can be stopped without a taper. Sertraline and other SSRIs may cause temporary headache, nausea, or anxiety in the first 1–2 weeks of therapy. To terminate therapy, taper the dose slowly over weeks.

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Table 4.2 Continued

Cause	Treatment (starting doses)	Notes
	For persistent, frequent, or chronic anxiety, a selective serotonin reuptake inhibitor (SSRI). Example: Sertraline 25 mg/day orally. Any SSRI typically takes weeks to work, and the dose should be increased no more often than every 7 days. Usual effective sertraline dose 50–200 mg/day. Alternatives include fluoxetine (starting dose 10 mg orally daily, maximum 80 mg/day) and citalopram (starting dose 10 mg orally daily, maximum 40 mg/day). Amitriptyline 10–25 mg at bedtime orally. Gradually increase dose. Usual effective dose 50–100 mg. Maximum dose 100 mg/day. Takes weeks to work. Risk of life-threatening cardiac toxicity from overdose. Mirtazapine 15 mg/day once at bed time, orally. Gradually increase dose. Usual effective dose 15–45 mg/day.	When treating anxiety with an SSRI or other antidepressant, use a starting dose lower than when treating depression. The effective dose for treating coincident anxiety and depression often is higher than what is needed to treat depression alone. Use only one antidepressant medicine. If it is not effective at maximum dose or if it causes unacceptable adverse effects, try another medicine. If anxiety is refractory to treatment, refer the patient to a psychiatrist if possible.
3. Depressed mood		
Serious illness or injury, chronic physical symptoms, loss of function, death of a loved one, severe social stressors such as extreme pov Serious illness or injury, chronic physical symptoms, loss of function, death of a loved one, severe social stressors such as extreme poverty or exposure to violence, major depressive disorder	Treat any physical symptoms aggressively. Psychosocial supports such as supportive counseling from social worker or psychologist, peer support groups, assistance with finances, food, lodging, transportation.	Depression can be difficult to diagnosis in advanced medical illness such as cancer or major organ failure because typical symptoms of these medical illnesses (such as poor sleep, loss of interests, fatigue, poor concentration, and poor appetite) are similar to those of depression. Feelings of unremitting sadness, persistent inability to experience joy, intense guilt or worthlessness, and suicidal ideation are not typical symptoms of advanced illness and should raise suspicion of major depression.

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Table 4.2 Continued

Cause	Treatment (starting doses)	Notes
	Sertraline 50 mg/day orally. Increase dose no more often than every 7 days. Usual effective dose 50–200 mg/day. May takes weeks to become fully effective, but some benefit often occurs within 2 weeks. Alternative SSRIs include fluoxetine (starting dose 20 mg orally daily, maximum 80 mg/day) and citalopram (starting dose 20 mg orally daily, maximum 40 mg/day) Amitriptyline 10–25 mg at bedtime orally. Gradually increase dose. Usual effective dose 50–100 mg. Maximum dose 100 mg/day. Takes weeks to work. Risk of life-threatening cardiac toxicity from overdose. Mirtazapine 15 mg/day once at bed time, orally. Gradually increase dose. Usual effective dose 15–45 mg/day.	Sadness is normal in the setting of advanced illness, but depression is never normal and should be treated. Anxiety and depression commonly coincide. Notes on antidepressants: Amitriptyline has anticholinergic side effects including sedation, constipation, dry mouth, tachycardia, orthostatic hypotension. It can be stopped without a taper. Sertraline and other SSRIs may cause temporary headache, nausea or anxiety in the first 1–2 weeks of therapy. To terminate therapy, taper the dose slowly over weeks. Use only one antidepressant medicine. If it is not effective at maximum dose or if it causes unacceptable adverse effects, try another medicine. If depression is refractory to treatment, refer the patient to a psychiatrist if possible.
4. Delirium (hyperactive or hypoactive)		
Medicines (especially benzodiazepines, anticholinergics, antihistamines), hypoxia, hypercapnia, renal or liver failure, hypercalcemia, systemic or CNS infection, CNS lesion (ischemia, tumor), psychiatric illness (psychotic disorder, dementia), drug or alcohol withdrawal.	Identify and treat the underlying condition(s) if possible, but treat the symptoms immediately. If possible, place the patient in a quiet room near a window with a clock visible. Reorient the patient frequently, and train family members to reorient and calm the patient. Minimize nocturnal disruptions of sleep. If nonpharmacologic methods are not adequate, give haloperidol 0.5–5 mg orally, IV, or SC every 6–8 hours. Can give more frequently for severe symptoms. For agitation refractory to high-dose haloperidol, can give valproate: starting dose 15 mg/kg/day IV in 2 or 3 divided doses. Maximum: 60 mg/kg/day.	Hyperactive delirium (delirium with agitation) is more dangerous for the patient and others than hypoactive delirium and requires more aggressive treatment. Hypoactive delirium may be mistaken for depression. However, delirium occurs suddenly (over hours or days) and has fluctuating symptoms, whereas depression has a gradual onset over weeks and is usually accompanied by a constant sad mood. For acute dystonia due to haloperidol, discontinue haloperidol and give diphenhydramine 25–50 mg IV or SC every 6 hours until dystonia resolves.

(*continued*)

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Table 4.2 Continued

Cause	Treatment (starting doses)	Notes
5. Post-traumatic stress disorder (PTSD)		
Trauma exposure: Actual or threatened death, serious injury, or sexual violence; witnessing in-person violence to others; learning of trauma to close family member or friend.	Treatment guidelines recommend psychotherapy as first-line treatment. –Pharmacotherapy is reasonable if psychotherapy has failed or is not available, or if symptoms are severe or severely impair social functioning. Pharmacotherapy: First line: Sertraline or fluoxetine (see dosing under Depression) Second line (due to greater adverse effects): amitriptyline (see dosing under Depression)	Definition: A psychiatric disorder that occurs after a trauma exposure, that lasts longer than 1 month, that is not due to a medical condition or substance use, and that is characterized by: Development of intrusive thoughts or dreams Avoidance of trauma-related thoughts or reminders Impaired or distorted cognition, persistently negative emotional state, loss of interest, or social detachment Angry or reckless behavior or marked increase in arousal following exposure to a traumatic event
6. Prolonged grief disorder		
Risk factors include history of mental illness, unanticipated or traumatic loss, loss of a child, history of childhood loss or insecure social attachments, female sex. Death of a spouse is a risk factor also for depression.	See Chapter 9, Section G	

E. Palliative care provider well-being

1. Palliative care providers are at risk for *compassion fatigue* and *burnout* due to regular exposure to tragically ill and suffering patients, death, and grieving family members.
2. The key components of burnout are emotional exhaustion, a distant or indifferent attitude toward work, and reduced sense of personal accomplishment.
3. Other specific symptoms may include decreased empathy, decrease in quality of care, poor morale, physical fatigue, depressed mood, or poor sleep.

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4. Promotion of provider well-being and resilience is an essential part of palliative care:
   a. Resilience is the ability to withstand or recover quickly from difficult or stressful situations.
   b. Resilience can be promoted in various ways:
      i. Regularly scheduled time for sharing emotional reactions to patients, patients' families, and patients' deaths with colleagues, such as at weekly team meetings
      ii. Regular free-time and vacations
      iii. Regular exercise or other activities outside of work
      iv. Palliative care team social events, such as holiday parties
      v. Practicing palliative care part-time, and practicing another discipline (such as internal medicine or oncology) or doing other work (such as administration or research) part-time

F. Social suffering assessment and relief: Principles

See Table 4.3.

1. Social suffering is common among some populations:
   a. People living in extreme poverty
   b. People affected by intolerance or discrimination based on race, sex, religion, or ethnicity
   c. People affected by humanitarian crises
   d. People living with stigmatized conditions such as HIV/AIDS, tuberculosis, or cervical cancer
2. People affected by social suffering also are at heightened risk for physical and psychological illness and suffering.
3. Common types of social suffering and social supports to help relieve them are shown in Table 4.2.
4. Funding for social supports may come from the government agencies in charge of social affairs or from civil society organizations.
5. Ideally, a social worker can assess for social suffering and provide treatment or referrals to relieve it. However, doctors, nurses, psychologists, community health workers, and volunteers also can help to assess and relieve social suffering.

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Table 4.3 Social suffering types and relief

Types	Treatment	Notes
1. Extreme poverty	Food packages Cash payments for rent, food, or school fees for children (tuition, uniform, study materials) Vocational rehabilitation Counseling to help find employment Transportation costs to access healthcare Funeral costs	
2. Inadequate housing	Counseling to help find housing Cash payments for rent	
3. Inadequate food	Food packages (home care) Free meals (hospital)	
4. Stigmatization/ discrimination	Supportive counselling Counseling to help find legal assistance	
5. Social isolation	Arranging for visits from community health worker or local volunteers Assisting patients and estranged family members to reconcile.	

G. Spiritual suffering assessment and relief

Spiritual suffering, such as a loss of faith or a loss of a sense of meaning in life, is common among people with life-threatening or highly stigmatized illnesses (Table 4.4).

Table 4.4 Spiritual suffering types and interventions

Types	Interventions	Notes
Loss of a sense of meaning in life	"Dignity therapy": Encourage the patient to recount life story for one or more palliative care providers, includes achievements and sorrows. Consider offering to record the story and make a transcript for the patient to review and use as desired. Family meetings at which family members recount the patient's achievements. Explore for meaningful tasks that are feasible for the patient, such as preparing a legacy or memory box for children or grandchildren, writing letters or making videos for children or grandchildren. Assist the patient to resolve any conflicts with family members or friends by asking for forgiveness, granting forgiveness, expressing pride or affection.	

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Table 4.4 Continued

Types	Interventions	Notes
Loss of faith, or questioning why God or gods have allowed the illness and suffering to happen	Provide a consistent presence to ensure that the patient does not feel abandoned and to enable the patient to speak about spiritual concerns. Invite local volunteer spiritual counselor such as trained monks, priests, nuns, Imams, or traditional healers to visit patients who request spiritual support.	To minimize the risk of harm to the patient, potential volunteer spiritual counselors should be screened for unhelpful misconceptions about serious illnesses (such as that cervical cancer is due to witchcraft or divine punishment) and trained about common fears and sensitivities of patients.

Further Reading

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5

Palliative care for patients with specific conditions

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A. Palliative care for people with cancer

1. Principles

a. A palliative care assessment should be done at the time of diagnosis of cancer:
   i. Any distressing symptoms should be treated immediately.
   ii. Once any distressing symptoms have been relieved, the assessment should be completed by exploring the patient's or family's understanding of the illness and the patient's social history and values, and efforts should be made to reach agreement on the goals of care (see Chapter 2).
b. Palliative care is not an alternative to cancer treatment. Instead, palliative care and cancer treatment should be integrated and provided simultaneously (see Figure 1.1):
   i. Palliative care can improve adherence to and completion of cancer treatment by relieving cancer symptoms or adverse effects of treatment and by providing needed psychosocial supports.
   ii. Cancer treatments, including chemotherapy, radiation therapy, and surgery, can themselves be palliative by relieving symptoms such as pain, dyspnea, or hemorrhage.
c. Many patients and families can benefit from assistance and guidance in weighing the potential benefits and harms of cancer treatment in the context of the patient's values and the family's financial situation.

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d. If cancer treatment is deemed non-beneficial or more harmful than beneficial, or if it is no longer desired by the patient, palliative care may become the only beneficial type of care:
    i. When patients go home from the hospital at the end of life, every effort should be made to arrange for the patient to receive palliative care in the community.
e. Cachexia is common in patients with end-stage cancer due to a catabolic state. Artificial nutrition typically provides no benefit and may worsen suffering by increasing ascites, pleural effusions, peripheral edema, or respiratory secretions.

2. Palliative care and cancer chemotherapy

a. Common adverse effects of cytotoxic chemotherapy include, nausea, vomiting, diarrhea, constipation, mucositis (mouth pain), fatigue, and peripheral neuropathy:
    i. Typically, medicines should be given before or along with chemotherapy to prevent or minimize adverse effects.
    ii. When chemotherapy results in symptoms that are not adequately controlled by these pre-medications, treatment should be provided as in Chapters 3 and 4.
b. Immunotherapy with immune checkpoint inhibitors can result in acute or chronic autoimmune reactions that may occur weeks or months after treatment:
    i. The most common immune-related adverse events are pneumonitis (causing dyspnea and sometimes life-threatening respiratory failure), colitis (causing abdominal pain and diarrhea), hepatitis, and thyroiditis.
    ii. Other possible immune-related adverse events include endocrinopathies, myocarditis, nephritis, cytopenias (anemia or neutropenia or thrombocytopenia), arthritis, dermatitis, neuropathies, and uveitis.
    iii. Immune-related adverse events usually respond quickly to cessation of immunotherapy and initiation of steroid therapy. However, steroid therapy also reduces the anti-cancer effect of immune checkpoint inhibitor therapy. Thus, difficult decisions often must be made that balance the patient's comfort and immediate safety against the benefits of a potent anti-cancer immune response.

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3. Palliative care and radiation therapy

a. Radiation therapy can both relieve and cause a variety of symptoms:
   i. **Symptom relief**: Radiation therapy is a crucial palliative care modality because of its effectiveness in treating painful bone metastases, dyspnea due to malignant airway obstruction, symptomatic malignant spinal cord compression, hemorrhage, and other cancer-related symptoms:
      - An important part of palliative care for cancer patients is recognizing when to refer for radiation therapy to optimize symptom relief.

   ii. **Symptom causation**: Radiation therapy can cause inflammation of any tissue and thereby result in, for example, symptomatic dermatitis, oral mucositis, pneumonitis, esophagitis, colitis, proctitis, vaginitis or cystitis:
      - Topical or systemic steroid sometimes relieves pain and other symptoms from radiotherapy-induced inflammation.
      - Other symptomatic treatments can be applied as in Chapters 3 and 4.

4. Palliative care and cancer surgery

a. Palliative surgical procedures can be considered in the appropriate situation if consistent with the goals of care and if there is a reasonable likelihood of greater benefit than harm according to the patient's values. Examples include:
   i. Diverting colostomy or ileostomy for malignant large bowel obstruction refractory to medical treatment or for rectovaginal or vesicorectal fistulas
   ii. Small bowel resection for malignant small bowel obstruction refractory to medical treatment
   iii. Venting gastrostomy tube placement for malignant gastric outlet obstruction or malignant small or large bowel obstruction refractory to medical treatment
   iv. Feeding gastrostomy or jejunostomy placement
   v. Gastrojejunostomy tube placements for malignant gastric outlet or proximal small bowel obstruction
   vi. Pyloric stenting for malignant gastric outlet obstruction
   vii. Esophageal stenting for malignant obstruction
   viii. Amputation for painful osteosarcoma

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ix. Resection of disfiguring neoplasms
x. Placement of indwelling pleural drain for recurrent, symptomatic pleural effusion
xi. Placement of indwelling peritoneal drain for recurrent, tense ascites causing pain or dyspnea
xii. Spinal decompression for spinal cord compression or cauda equina syndrome
xiii. Intraoperative celiac plexus block for painful malignancies of the upper abdomen that are unresectable

B. Palliative care for people with HIV infection

1. Principles

a. A palliative care assessment should be done at the time of diagnosis of HIV infection.
b. Palliative care and anti-retroviral therapy should be integrated and provided simultaneously (see Figure 1.1):
   i. Palliative care can improve adherence to anti-retroviral therapy by relieving adverse effects of treatment and providing needed psychosocial supports.
   ii. Anti-retroviral therapy is itself palliative by preventing and relieving symptoms associated with opportunistic infections.
c. Psychological and social suffering is common among people living with HIV infection for several reasons:
   i. HIV infection remains highly stigmatized.
   ii. People with preexisting social problems such as substance use disorders, poverty, or imprisonment are at high risk of acquiring HIV infection.

2. Essential components of palliative care for people with HIV infection

a. Relief of symptoms of HIV infection and HIV-related conditions
b. Relief of adverse effects of antiretroviral therapy
c. Regular supportive counseling as needed, even for patients who are medically stable on anti-retroviral therapy
d. Social supports as needed

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e. Treatment of substance use disorders
f. Help to obtain legal assistance, as needed
g. Universal precautions by healthcare personnel
h. Training in infection control and harm reduction for the patient and the patient's family caregivers (see Appendix 6).

C. Palliative care for people with multidrug resistant and extensively drug resistant tuberculosis (M/XDR-TB) and for people with serious sequelae of tuberculosis

1. Principles

a. All M/XDR-TB patients should receive palliative care assessment at the time of diagnosis or first contact.
b. Palliative care and treatment of M/XDR-TB should be integrated and provided simultaneously (see Figure 1.1).
c. Palliative care integrated into treatment of patients with M/XDR-TB:
   i. Can reduce suffering and improve quality of life of patients
   ii. May help patients to adhere to long and noxious treatment and thus also increase the likelihood of treatment completion and cure and reduce mortality
   iii. May also help protect public health:
      - By improving treatment adherence
      - By improving infection control in the home through close follow-up
   iv. May also provide financial risk protection for patients' families and reduce costs for public healthcare systems
d. For these reasons, integration of palliative care into M/XDR-TB treatment programs is medically and morally imperative.
e. Psychological and social suffering is common among people with M/XDR-TB for several reasons:
   i. TB remains highly stigmatized.
   ii. Preexisting social problems such as substance use disorders, poverty, homelessness, and imprisonment are risk factors for acquiring MDR-TB.

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2. Essential components of palliative care for people with M/XDR-TB

a. Regular supportive counseling, even for patients who are medically stable on treatment
b. Treatment of substance use disorders
c. Help to obtain legal assistance, as needed
d. Continuous reinforcement of the need for infection control
e. TB clinicians should receive basic palliative care training.
f. Directly observed therapy (DOT) providers and community health workers (CHWs) should be taught to recognize and report when patients with TB need palliative care intervention.
g. Specialized treatment centers for people with M/XDR-TB should have a multidisciplinary palliative care team, and prisons that house people with M/XDR-TB should have at least one physician and nurse with basic palliative care training.

3. When all available treatments for M/XDT-TB have failed

a. Home-based palliative care should be provided with appropriate attention both to the well-being of the patient and to infection control.
b. Inpatient care focused entirely on palliation (hospice care) should be available on a voluntary basis (patients should not be forced against their will to enter or remain in a TB hospital or hospice).

4. Patients with serious sequelae of previous TB infection

Those with serious sequelae of previous TB infection, such as chronic obstructive, restrictive, or interstitial lung disease and resultant chronic dyspnea, may need ongoing palliative care (see Section D).

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D. Palliative care for people with end-stage lung disease

1. Principles

a. A palliative care assessment should be done at the time of diagnosis of end-stage lung disease or when the patient has dyspnea at rest or with minimal exertion:
   i. The assessment should include exploration of the patient's or family's understanding of the illness and the patient's social history and values, and efforts should be made to reach agreement on the goals of care (see Chapter 2).
b. Palliative care is not an alternative to treatment of end-stage lung disease. Instead, palliative care and lung disease treatment should be integrated and provided simultaneously (see Figure 1.1).
c. For patients with end-stage lung disease, if invasive or non-invasive ventilator support would not be beneficial according to the patient's values, or would be more harmful than beneficial, palliative care may become the only beneficial type of care.
d. When patients go home from the hospital at the end of life, every effort should be made to arrange for the patient to receive palliative care in the community.

2. Opioids for refractory dyspnea

a. Opioids are highly effective to relieve dyspnea that is refractory to treatment of the underlying cause
b. For patients with dyspnea at rest or with minimal exertion, careful opioid therapy can prevent or relieve dyspnea and anxiety and may improve exercise tolerance without causing respiratory depression, an increase in pCO_2, or a decrease in pO_2 (see Table 4.1).
c. In the setting of end-stage lung disease and dyspnea, morphine therapy for opioid-naïve patients should be started at half of the usual starting dose for pain: 2.5 mg orally every 4 hours as needed, or 1 mg IV/SC every 4 hours as needed.
d. If dyspnea is constant, morphine also can be scheduled every 4 hours, and a rescue dose can be ordered as needed for breakthrough dyspnea.

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3. Dyspnea and anxiety

a. In patients with end-stage lung disease, anxiety typically is due to dyspnea, and anxiety typically resolves if the dyspnea is adequately treated and honest assurance of ongoing palliative care is provided. Therefore, benzodiazepines are not first-line medicines for treating anxiety in patients with end-stage lung disease and should be prescribed only:
   i. If anxiety persists after dyspnea is well-controlled
   ii. If the patient was already taking a benzodiazepine for a preexisting anxiety disorder

4. Cachexia and end-stage lung disease

Cachexia is common in patients with end-stage lung disease due to a catabolic state. Artificial nutrition typically provides no benefit and may worsen dyspnea by increasing respiratory secretions.

E. Palliative care for people with end-stage heart failure

1. Principles

a. A palliative care assessment should be done at the time of diagnosis of end-stage heart failure or when the patient has dyspnea or chest pain at rest or with minimal exertion:
   i. The assessment should include exploration of the patient's or family's understanding of the illness and the patient's social history and values, and efforts should be made to reach agreement on the goals of care (see Chapter 2).
b. Palliative care is not an alternative to treatment of end-stage heart failure. Instead, palliative care and heart failure treatment should be integrated and provided simultaneously (see Figure 1.1).
c. For patients with end-stage heart failure, if cardiopulmonary resuscitation (CPR) or ventilator support would not be beneficial according to the patient's values, or would be more harmful than beneficial, palliative care may become the only beneficial type of care. In this situation, the patient should be protected from CPR and other non-beneficial procedures.

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d. When patients go home from the hospital at the end of life, every effort should be made to arrange for the patient to receive palliative care in the community.

2. Opioids in end-stage heart failure

a. Opioids are highly effective to relieve dyspnea or chest pain that is refractory to aggressive treatment of the underlying cause (see Table 4.1)
b. In patients with end-stage heart failure, if aggressive diuresis, ionotropic support, and afterload reduction does not relieve dyspnea promptly, and if cardiac assist devices (such as a left ventricular assist device) will not be used, opioid therapy should be initiated.

3. Cachexia and end-stage heart failure

Cachexia is common in patients with end-stage heart failure due to a catabolic state. Artificial nutrition typically provides no benefit and may worsen dyspnea by increasing pulmonary edema, ascites, pleural effusions, peripheral edema, or respiratory secretions.

F. Palliative care for people with dementia

1. Principles

a. Dementia onset usually is slow and typically begins with memory impairment.
b. Other typical symptoms include cognitive impairments (agnosia, apraxia, aphasia), personality changes, emotional lability, behavioral disturbances, psychosis (delusions or paranoia).
c. In advanced dementia, patients lose the ability to perform basic tasks such as walking, toileting, or feeding themselves.
d. As function is lost, and especially if there is emotional lability or agitation, caring for someone with dementia can be extremely physically and emotionally stressful for family caregivers.

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2. Palliative care services needed by people with dementia

a. Assessment and relief pain or other physical symptoms:
   i. Patients with late-stage dementia may not be able to communicate. Thus, symptom assessment must be done using signs. For example, signs of pain may include grimacing, groaning, agitation. Signs of dyspnea may include rapid respiratory rate, labored breathing, use of accessory breathing muscles, sweating, gasping.
b. Assessment and treatment psychological symptoms such as agitation, delusions, or comorbid depression
c. Optimization of the patient's safety without severely compromising quality of life (prevention of accidents such as falls, burns, or wandering away from home)
d. Provision of appropriate, low-stress stimulation and activities and orientation cues (clocks, calendars, frequent verbal reorientation)
e. Protection from life-sustaining treatments that are likely to be more harmful than beneficial. These may include cardiopulmonary resuscitation, invasive and non-invasive mechanical ventilation, hemodialysis, artificial nutrition, and antibiotics:
   i. Antibiotics for common infections such as pneumonia may be harmful by prolonging a quality of life that is unacceptably poor according to the patient's values.
f. Discontinuation of medicines that no longer have clear benefits

3. Palliative care needs of family caregivers

a. Assistance with feeding, washing, or toileting the patient
b. Emotional support from community health workers
c. Assessment for and treatment of anxiety or depression
d. Assuring the safety of caregivers of patients who become agitated or violent
e. Social supports such as food packages for family caregivers living in poverty

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G. Palliative care for people with neurologic disorders

1. Principles

a. Many disorders causing weakness or paralysis engender severe persistent suffering in low- and middle-income countries (LMICs) where social supports and rehabilitation services may be limited or absent.
b. Severe neurologic disorders may occur suddenly. Others may progress rapidly, and other may entail slow decline.
c. Survivors of stroke or spinal cord injury often are confined to four walls with poor quality of life and are at risk for recurrent urinary tract infections, pressure ulcers, malnutrition, depression, and avoidable death.
d. Many patients may lose the ability to communicate well either due to physical disability or cognitive impairment.
e. Where adequate rehabilitation services, neurologic care, and social supports are not accessible, such patients and their families should receive care from clinicians with palliative care training both in hospitals and in the community.

2. Common neurologic disorders that generate palliative care need

a. Stroke
b. Traumatic brain injury
c. Spinal cord injury
d. Brain injury from encephalitis or meningitis
e. Brain tumor or metastases
f. Parkinson's disease and other neurodegenerative disorders
g. Multiple sclerosis and other neuroinflammatory conditions
h. Amyotrophic lateral sclerosis and other motor neuron disease
i. Perinatal neurologic injury

3. Palliative care services that may be needed by people with neurologic disorders

a. Frequent visits and emotional support for patient and family
b. Assistance with mobility

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c. Provision of canes, walkers, wheelchairs, and other such devices
d. Assistance with exercises to avoid contractures and maximize independence
e. Assistance with washing or feeding
f. Counseling on prevention of falls, pressure ulcers, or aspiration
g. Social supports such as food packages and materials for tube feeding
h. Assessment for and treatment of pain and dyspnea
i. Assessment for and treatment of depressed mood

H. Palliative care for frail older people

1. Principles

a. Persons older than 60 years often have chronic illnesses that create a need for palliative care.
b. Even in the absence of an advanced chronic illness, many older people are frail and suffer physically, psychologically, socially, or spiritually. Typical types of suffering include:
   i. Pain from injuries due to falls
   ii. Adjustment disorder or depression related to loss of function or loss of a spouse
   iii. Social isolation
   iv. Extreme poverty
   v. Loss of a sense of meaning of life
c. Supports are needed to help frail older patients to remain at home safely.

2. Palliative care services that may be needed

a. Counseling on prevention of falls
b. Provision of canes or walkers
c. Social supports, such as food packages
d. Treatment of depressed mood
e. Assistance to obtain glasses or hearing aids
f. Emotional support from frequent visits by community health workers or mobile palliative care teams and surveillance by clinicians at the nearest community health center.

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I. Palliative care for people who have experienced severe physical or psychological trauma

See also Chapter 11.

1. Sequelae of severe physical or psychological trauma

a. Inadequate relief of acute pain and inadequate treatment of those suffering the effects of severe psychological trauma increase morbidity and mortality.
b. Failure to adequately relieve acute pain due to trauma or postoperative pain has been shown to increase the risk for:
    i. Cardiovascular adverse events including arrhythmias, myocardial infarction, congestive heart failure, hemorrhage, and stroke
    ii. Deep vein thrombosis and pulmonary embolism
    iii. Atelectasis and pneumonia
    iv. Hypercatabolic state and tissue wasting
    v. Compromised immune function and increased risk of infection
    vi. Anxiety, depression, impaired sleep, and demoralization
    vii. Development of persistent chronic pain (especially common after limb and breast amputations)
a. Severe psychological trauma, due, for example, to critical illness or experiencing violence, has been shown to increase risk for mood disorders including PTSD, other anxiety disorders, and depression:
    i. Supportive counseling should be easily accessible to patients and family members in intensive care units.

2. Medically imperative pain relief and psychosocial support

a. Pain from physical trauma always should be treated promptly and as aggressively as necessary until the patient reports adequate relief:
    i. In emergency departments, post-anesthesia care units, and intensive care units, when patients are hypotensive and in moderate or severe pain, efforts should be made to safely stabilize blood pressure using fluid resuscitation, blood, or vasopressors to enable safe opioid therapy.

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b. Standard palliative care assessment includes assessment for exposure to violence or other emotionally traumatic events:
   i. Many patients will be reluctant to speak about emotional trauma, but it should be suspected when a patient was a soldier in a war or has lived in a place where political, ethnic, gender-based, or interpersonal violence is or was common.
   ii. When exposure to violence is suspected, assessment for mood disorders is especially important.
   iii. Supportive counseling, ideally by a social worker or psychologist, should be made accessible to patients and family members with a trauma history.
   iv. To minimize the risk of traumatizing seriously ill patients or their family members, care should be taken to deliver bad news in a supportive manner (see Chapter 9, Section A).

Further Reading

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6

Palliative care emergencies

Eric L. Krakauer and M. R. Rajagopal

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A. General

Appropriate response to palliative care emergencies typically requires a physician to remain at the bedside for long periods and/or to return frequently to the bedside to gain and maintain control of distressing symptoms. This may require shifting the care of other patients and other responsibilities to other staff members.

B. Pain crisis

1. Pain crisis, defined as intolerable pain causing a patient to suffer severely, requires immediate and aggressive intervention.
2. In most cases of pain crisis, a strong opioid such as morphine should be given intravenously every 15 minutes until pain is adequately controlled. The effect of IV morphine will be evident within 15 minutes (see Chapter 2):
   a. For an opioid-naïve adult, the starting dose could be morphine 3 mg IV.
   b. If the patient reports no relief after 15 minutes, the dose should be doubled.
   c. If the patient reports partial but still inadequate relief, the original dose (3 mg IV) should be repeated.
   d. This process should continue until pain is adequately controlled or unacceptable adverse effects occur.
3. If the required doses of morphine are high enough to risk serious adverse effects such as sedation, hypotension, or respiratory depression:
   a. Consider adding adjuvant medicines (see Table 3.7).
   b. Consider interventional procedures such as nerve block, if available and consistent with the agreed-upon goals of care based on the patient's values (see Table 3.8).

c. Further opioid therapy should be guided by the patient's values, by agreed-upon goals of care, and by the principle of double effect (see Chapter 1).

C. Refractory dyspnea of a dying patient

1. In case a dying patient develops dyspnea that is refractory to treatment of the underlying cause, a strong opioid such as morphine should be given intravenously every 15 minutes until dyspnea is adequately controlled. The effect of IV morphine will be evident within 15 minutes:
   a. For an opioid-naïve adult, the starting dose is morphine 1-2 mg IV.
   b. If the patient reports no relief after 15 minutes, the dose should be doubled.
   c. If the patient reports partial but still inadequate relief, the original dose (1-2 mg IV) should be repeated.
   d. This process should continue until dyspnea is adequately controlled or unacceptable adverse effects occur.
2. If the patient is unable to communicate, the degree of dyspnea should be assessed based on respiratory rate, presence or absence of labored breathing, use of accessory respiratory muscles, presence or absence of sweating. Blood gases and oxygen saturation are not useful for assessing comfort or distress.
3. If the required doses of morphine are high enough to risk serious adverse effects such as sedation or hypotension, further treatment should be guided by the patient's values, by agreed-upon goals of care based on the patients values, and by the principle of double effect (see Chapter 1).

D. Massive hemorrhage

1. Massive hemorrhage may or may not cause severe physical distress:
   a. Pulmonary hemorrhage and massive hemoptysis can result in sudden or severe dyspnea.
   b. Patients with serious coronary artery disease may develop severe chest pain during exsanguination.
2. Massive hemorrhage is almost always extremely emotionally distressing for the patient, for family members, and even for some clinicians.

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3. Massive hemorrhage often can be anticipated, and preparations should be made:
   a. Staff and family members should be informed of the possibility of massive hemorrhage, and the plan for managing it should be explained. In some cases, the patient also should be informed and assured that plans exist to maximize comfort.
   b. A large supply of dark towels and at least two large basins should be placed near the patient.
   c. Intravenous access should be maintained to enable rapid administration of medicines for comfort.
   d. Intravenous morphine and diazepam should be readily available in large quantities.
4. When massive hemorrhage occurs:
   a. Provide verbal reassurance to the patient, any family members present, and to staff members.
   b. Treat severe dyspnea as in Section C.
   c. Treat pain crisis as in Section B.
   d. Even if pain and dyspnea are not present initially, be prepared for these symptoms to develop as the patient exsanguinates and to treat them aggressively with scheduled and/or as-needed morphine.
   e. Instruct nurses (or family caregivers) that blood should be collected in large basins lined with dark towels, covered, and removed when the towels are soaked.

E. Spinal cord compression

1. Spinal cord compression:
   a. Is a common complication of malignant metastases to the vertebrae or spine
   b. Can result in paraplegia and loss of bladder and bowel control, all of which severely reduce the quality of life
   c. Is a medical emergency because the longer the spinal cord compression persists, the less likely the effects can be reversed. The compression should be relieved within a few hours of symptom onset, if possible.
2. Patients at risk for spinal cord compression should be monitored closely for back pain, neurologic deficits in the legs, and bladder and bowel problems (incontinence or inability to void/defecate).

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3. If symptoms consistent with spinal cord compression occur:
   a. High-dose dexamethasone should be given immediately: 20 mg IV once, followed by 5 mg IV every 6 hours.
   b. MRI of the spine should be done immediately. If MRI is not available, CT of the spine should be done immediately.
   c. Consultation from specialists in neurosurgery and radiation oncology should be requested emergently, if possible.
4. If MRI or CT studies show spinal cord compression, treatment with surgical decompression or radiotherapy should be started emergently if consistent with the goals of care agreed upon between the patient/family and the responsible physician.

F. Seizures

1. Seizure prevention is a standard part of palliative care. Anticonvulsant therapy should be continued or initiated when the risk of seizure is more than minimal, even when the only goal of care is comfort:
   a. It often is unclear how much discomfort a patient experiences during and after a seizure, but it should be assumed that significant discomfort is likely enough to warrant seizure prophylaxis and treatment.
2. When seizure occurs, abortive therapy, typically with diazepam or another benzodiazepine, should be given emergently and aggressively regardless of the goal(s) of care.

Further Reading

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7
Pediatric palliative care

Rut J. Kiman, Nguyễn Thị Hoàng Quỳnh, and Eric L. Krakauer

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A. Principles

a. Children are not just little adults. While the general principles of palliative care apply to both adults and children, pediatric palliative care (PPC) requires attention to physical, developmental, psychosocial, ethical, spiritual, and relational phenomena that are unique to children (see Table 7.1.

Table 7.1 Pediatric palliative care: differences from adult palliative care

- Prognosis, life expectancy, and functional outcome often are less clear.
- More frequent need to integrate palliative care with intensive disease-modifying or life-sustaining treatments due to unclear prognosis.
- Care often requires a dual focus on growth/development and potential for death.
- Greater emotional burden for family members and clinicians because serious and life-threatening illnesses are not commonly considered normal conditions for children.
- Parents and siblings are at greater risk of prolonged grief disorder.
- Patients undergo continual developmental change: physical, hormonal, cognitive, expressive, and emotional.
- Patients have changing informational, recreational, social, and educational needs, and modes of coping with stress. Thus, child life specialists, play therapists, and behavioral specialists can greatly enhance palliative care for children.
- Patients' diagnoses sometimes are not clear: they may have congenital anomalies of uncertain type or rare genetic conditions.
- Some genetic conditions may affect multiple children in a family and create a sense of guilt in parents.
- Expertise is needed both to discern a child's emotional and cognitive development and to communicate in a manner appropriate for the child's emotional and cognitive development: to provide the most appropriate amount and kind of information about the illness and to elicit the child's preferences for care.

b. A very wide range of pediatric illnesses generate a need for PPC (see Table 7.2). Thus, PPC should be integrated into all sectors and all levels of child healthcare, and it should be integrated with many types of potentially curative and life-sustaining treatments, such as treatment of leukemia and pediatric critical care.

Table 7.2 Populations that need pediatric palliative care

Population	Examples
Children with acute life-threatening conditions from which recovery may or may not be possible	Any critical illness or injury, severe malnutrition
Children with chronic life-threatening conditions that may be cured or controlled for a long period but that may also cause death	Malignancies, major organ failure, multidrug-resistant tuberculosis, HIV/AIDS
Children with progressive life-threatening conditions for which no curative treatment is available	Spinal muscular atrophy, Duchenne's muscular dystrophy
Children with severe neurologic conditions that are not progressive but may cause deterioration and death	Static encephalopathy, spastic quadriplegia, spina bifida
Neonates who are severely premature or have severe congenital anomalies	Severe prematurity, anencephaly, congenital diaphragmatic hernia, trisomy 13 or 18
Children undergoing painful procedures	Bone marrow biopsy, lumbar puncture, wound debridement or dressing changes, phlebotomy
Family members of a fetus or child who dies unexpectedly	Fetal demise, hypoxic-ischemic encephalopathy, overwhelming sepsis in a previously healthy child, trauma from motor vehicle accident, burns, . . .

B. Developmental stages

Based on childrens' development at different stages, it is possible to understand their needs, their understanding of death, their ways of grieving, and their reactions to physical and psychological hardship. However, children proceed at different speeds through the many developmental milestones. Thus, palliative care providers should become adept at assessing the unique developmental stage and needs of each child and at responding appropriately. Children who have grown up with chronic illness, interacting with clinicians and hospitals, tend to have a more mature understanding of illness, death, and dying than do children of their age who have been healthy most of their lives.

1. Infants (ages 0–1)

a. Children at this age:
   i. Communicate nonverbally at this age.
   ii. Need as much consistency as possible in caretakers, setting, and daily routine.

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   iii. Will understand and be affected by the (showed) sadness of the parents or caretakers.
b. Adults should use simple language, terms, voice, and tone that show love, and touch and caress.

2. Toddlers (ages 1–3)

a. Children at this age:
   i. Continue to need as much consistency as possible in caretakers, setting, and daily routine.
   ii. Will be affected by the sadness of the parents or caretakers.
   iii. Feel anxious when separated from parents.
   iv. Have no concept of death.
b. Adults should give simple explanations, be clear and consistent, and prepare the child just before a medical procedure.

3. Pre-school age children (ages 3–6)

a. Pre-schoolers:
   i. Understand the world by interweaving fact and fantasy ("magical thinking").
   ii. Need as much consistency in daily routine as possible.
   iii. Understand death as reversible: a "temporary departure" or "long sleep."
   iv. Are egocentric and are likely to feel responsibility for their illness and for the sadness or death of a parent. Thus, it is important to explore the child's understanding of the cause of death, correct misconceptions, and dispel guilt.
b. When a parent dies, the child may interpret the sadness of the surviving parent or caretaker as disappointment in the child's behavior. Thus, it is important to explain simply that the child is loved and that the parent or caretaker is sad about the death.

4. School-age children (ages 7–12)

a. School-age children:
   i. Think concretely and lack; abstract reasoning.
   ii. Begin to understand cause and effect.

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   iii. Begin to understand death as irreversible and that all living things die.
   iv. May ask questions about life, death, or afterlife, and may show curiosity about funerals.
   v. May see treatments as punishments. Thus, reassure the child that treatments are not punishments.
   vi. Wish to understand and control what is happening around them. Caregivers should offer choices to give the child a sense of control.
   vii. May return quickly to their usual activities and to being with best friends after a parent's death. Such activity helps the child to cope with the loss.
b. Evaluate for fears of abandonment, destruction, or body mutilation. Invite the child to share their thoughts, fears, and sadness when they are ready.
c. Be truthful and open about treatments or about a parent's illness or death without giving too much detail.

5. Adolescents (ages 13–16)

a. Adolescents:
   i. Are capable of abstract thoughts. Cultural specificity begins at this age.
   ii. Undergo dramatic physical change and are very self-conscious.
   iii. Begin to challenge parental values and separate from parents by developing peer group identity.
   iv. Have a concept of death similar to that of adults: cessation of bodily functions.
   v. May think that death cannot happen to them due to their egocentrism, and they may take dangerous risks to confirm their control over mortality.
   vi. May have very complex relationships with and feelings toward both a dying parent and a surviving parent. This may make communication and grieving more difficult. They may turn to a non-parental adult to share sadness. It is important for an adolescent to have an adult with whom they can remember a dead parent, whether that adult is the surviving parent or another adult.
   vii. Are at risk for developing depression. Signs may include guilt feelings, suicidal ideation. Depression requires treatment.
2. Allow adolescents to express anger.
3. Allow privacy and reasonable independence. Maintain access to peers.
4. Provide clear, honest, direct explanations.

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C. Assessment and relief of pain in children

1. Principles

a. Classification and causes of pain are similar in adults and children (see Chapter 3, Section B).
b. Assessment of pediatric pain:
   i. The most reliable measure of a patient's pain is the patient's report. However, children may feel pain even when they don't outwardly express that they are in pain. Infants and younger children may be unable to report pain. In these situations, assessment should be based on caregiver report and observation.
   ii. Pain assessment instruments specific for the patient's age should be used.

2. Pain assessment

a. Begin with direct observation of the child and reports from parents or other adult caregivers:
   i. Notice body position, spontaneous movements, level of arousal, and interaction with others.
   ii. In preverbal children, pain can be indicated by crying, irritability, withdrawn or depressed affect, tense body position, facial grimacing, or fearfulness.
b. Ask even very young children if and where they hurt before trying to examine them.
c. Physical examination, or even anticipation of physical examination, can cause a child to start crying. Once the child is frightened and crying, it is difficult or impossible to determine areas of tenderness and to complete the physical exam. To reduce the child's fear, ask them to tell you as soon as something hurts.
d. Neuropathic pain may have associated motor or sensory changes.

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3. Pediatric pain assessment tools and pain relief protocols

NOTE: Clinical judgment is needed for each patient and situation

a. Neonates and infants to age 6 months: See Figure 7.1.

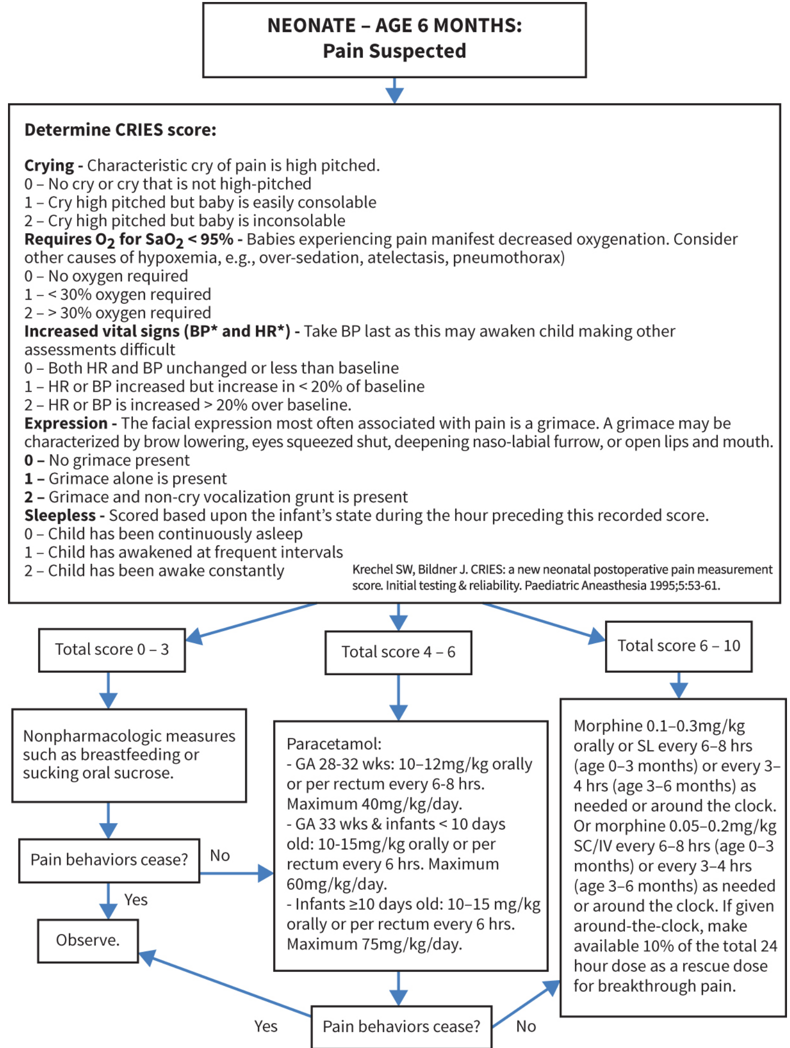

Figure 7.1 Pain assessment and relief algorithm for neonates and infants to age 6 months.

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b. Age 6 months to 7 years (preverbal or impaired linguistic ability): See Figure 7.2.

Table 7.3 FLACC pain intensity assessment

Pain intensity	FLACC Pain Intensity Scale
Mild	1–3
Moderate	4–6
Severe	>7

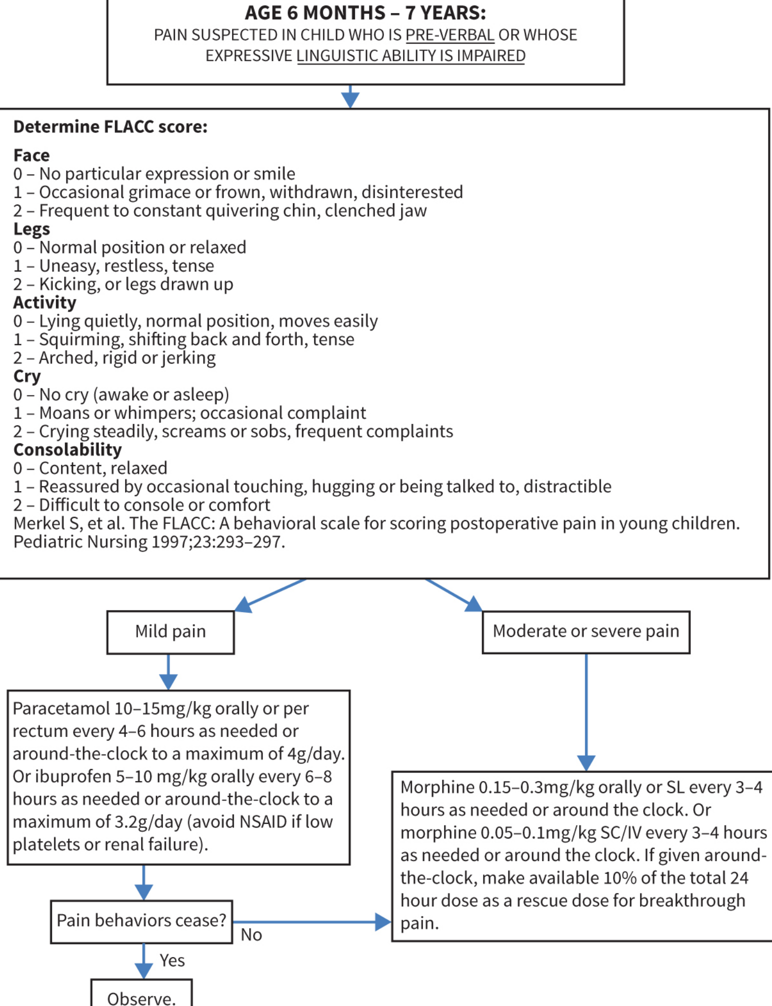

Figure 7.2 Pain assessment and relief algorithm for children age 6 months to 7 years who are preverbal or have impaired linguistic ability.

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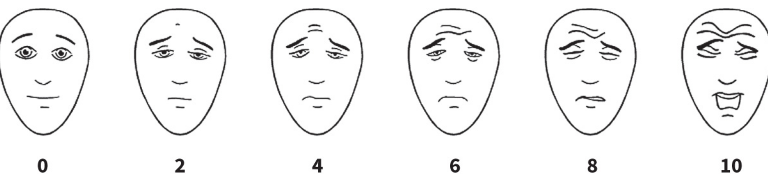

0–2 No pain or minimal pain
4 Mild pain
6 Moderate pain
8–10 Severe pain

Figure 7.3 Faces Pain Scale-Revised (FPS-R) for assessment of pain severity in verbal children ages 3–7 years.

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c. Ages 3–7 years (verbal): Faces Pain Scale-Revised (FPS-R):
   i. Explain to the child, “These faces show how much pain you might have. This face (point to the face furthest to the child’s left) shows no pain. The faces show more and more pain (point to each of the faces from left to right) until you get to this one (point to the face at far right) that shows a lot of pain. Now please point to the the face that shows how much pain you have.“ See Figure 7.3.
   ii. Treat verbal children ages 3–7 years as above based on severity.
d. See Chapter 3, Tables 3.1 and 3.3, for details of pain control in children age > 7.

4. Procedure-related pain prevention and relief

a. For quick and minimally invasive procedures such as phlebotomy, simple non-pharmacologic techniques such as distraction or relaxation can be used before, during, and after the procedures to minimize pain and its associated fear and distress. Topical analgesia also can be used, if available.
b. For more complex procedures, such as burn dressing changes, systemic analgesic medication should be used, either non-opioid or opioid such as morphine. Intraoperative and postoperative pain usually require morphine.

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Table 7.4 Procedure pain control in children

Procedure	Neonates	Older children
Heel lancing	Sucrose 24% 02–03 mL for preterm infants and 1–2 mL for term infants orally, 2 minutes prior to procedure, maximum dose: 0.5 mL for 27–31 weeks, 1 mL for 32–36 weeks, 2 mL for ≥37 weeks	
Blood sampling and intravenous cannulation	Sucrose as above EMLA cream 0.25–1 g topically 60 minute prior to procedure Dose/site: 0.25 g (0–12 months), 0.5 g (1–11 years) Maximum dose (multiple sites): 1 g (0–3 months), 2 g (3–12 months), 10 g (1–5 years), 20 g (6–11 years) Caution in patient with methemoglobinemia or preterm age	EMLA cream
Nasogastric tube placement	Sucrose as above	Apply local anesthetics such as lubricant gel containing lidocaine to tip of tube prior to placement
Vaccination	Sucrose as above	EMLA cream
Lumbar puncture	Sucrose as above EMLA cream Midazolam 0.1mg/kg IV if an infant is restless Morphine 0.05–0.1 mg/kg IV or fentanyl 0.5–3 mcg/kg IV if an infant is intubated	EMLA cream Midazolam 0.1 mg/kg IV For children requiring multiple lumbar punctures, general anesthesia should be offered
Endotracheal intubation	Fentanyl 0.5–3 mcg/kg IV and midazolam 0.1 mg/kg	Morphine 0.05–0.1 mg/kg or fentanyl IV and midazolam 0.1 mg/kg IV
Chest tube insertion	Local anesthesia using lidocaine 1% subcutaneous 2–4 mg/kg Morphine 0.05–0.1 mg/kg IV	EMLA cream Subcutaneous infiltration of buffered lidocaine Midazolam 0.1 mg/kg IV and Morphine 0.05–0.1 mg/kg IV General anesthesia should be considered for extremely agitated patients
Chest tube removal	EMLA cream	Morphine 0.05–0.1 mg/kg IV
Bladder catheterization		Apply lidocaine 1% or 2% lubricant gel to the urethral mucosa
Dressing changes in a burned child		Morphine 0.05–0.1 mg/kg IV, +/− midazolam 0.1 mg/kg IV Consider general anesthesia for the initial dressing changes and for the subsequent procedures if child is very distressed
Bone marrow aspiration/ biopsy		Use a local anesthetic such as buffered lidocaine or lidocaine Midazolam 0.1 mg/kg IV Morphine 0.05–0.1 mg/kg IV

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D. Assessment and relief of other symptoms in children

Table 7.5 Non-pain symptom relief in children

Symptom	Palliative medications (select based on clinical situation)	Dosage and administration
Dyspnea	Morphine sulfate orally or morphine chlorhydrate IV	As in Chapter 3, Table 3.3
	Lorazepam	0.025–0.1 mg/kg orally/SC/ IV every 4 hours as needed for anxiety refractory to treatment with morphine
Constipation	Bisacodyl	3–11 years: start with 5 mg once or twice per day. Maximum 30 mg/day 12 years and older: 5–15 mg once or twice per day. Maximum 30 mg/day
	Glycerin suppository	1 suppository per rectum once per day
	Sorbitol	5–10 mL orally every two hours until stools
	Pediatric Fleets enema	Once per day as needed
Diarrhea	Loperamide	13–20 kg: 1 mg three times per day orally as needed 20–30 kg: 2 mg two times per day orally as needed > 30 kg: 2 mg three times per day orally as needed
Nausea/ vomiting	Diphenhydramine (as an adjuvant to other anti-emetics, or for nausea caused by vestibular sensitization)	1 mg/kg orally/IV every 6 hours as needed. Maximum 50 mg/dose.
	Dexamethasone: • For nausea caused by emetogenic toxins, metabolic derangements, malignant bowel obstruction, malignant liver capsule stretch	0.3 mg/kg/day orally or IV
	• For nausea caused by cerebral edema with increased intracranial pressure	1 mg/kg/day divided into 3 doses (every 8 hours)
	Metoclopramide (for nausea caused by gastroparesis or ileus)	0.2 mg/kg orally every 8 hours as needed. Maximum 10 mg/dose
	Ondansetron (for nausea caused by cancer chemotherapy or radiation therapy)	0.15 mg/kg orally every 8 hours as needed

(*continued*)

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Table 7.5 Continued

Symptom	Palliative medications (select based on clinical situation)	Dosage and administration
	Lorazepam (for nausea caused by anxiety)	0.025–0.1 mg/kg orally/IV every 8 hours as needed. Maximum 2 mg/dose
	Haloperidol (for nausea caused by emetogenic toxin)	0.5–2 mg orally or IV every 6 hours as needed or scheduled.
Fever	Paracetamol	See Chapter 3, Table 3.1.
	Ibuprofen	
Sweats	Cimetidine	Neonate: 5–20 mg/kg/day orally in divided doses every 6–12 hours Infant: 10–20 mg/kg/day orally in divided doses every 6–12 hours Child: 20–40 mg/kg/day orally in divided doses every 6–8 hours
Insomnia	Lorazepam	0.025–0.1 mg/kg orally/SC/IV at bedtime. Maximum 2 mg/dose.
	Amitriptyline	Child older than 2 years: Begin with 0.1 mg/kg orally at bedtime. Increase as needed and tolerated every 3–4 days to maximum 0.5 mg/kg
Anxiety	Lorazepam	0.025–0.1 mg/kg orally/IV every 6 hours as needed. Maximum 2 mg/dose
Delirium	Haloperidol	0.5–2 mg orally or IV every 4 hours as needed
Fatigue/ weakness (at the end stage)	Methylprednisolone	1 mg/kg once or twice per day orally with food or IV
Terminal respiratory secretions (“death rattle”)	Hyoscine butylbromide	Age 6–12 years: 0.5 mg IV/SC up to 4 times per day as needed

E. Psychological and social support for children

Providing psychological and social support for children with serious illness or facing the dying process can help them cope with powerful feelings such as anxiety and distress.

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a. Disclose child's medical condition in a manner appropriate for the child's developmental stage and in a simple but straightforward way. Avoid hiding the illness or lying to the child.
b. Discuss with the child the treatments and life changes they may experience.
c. Encourage the child to express any thoughts or feelings, and provide support through regular play, art therapy, or counseling appropriate for the developmental stage.
d. Help the child become familiar with any new treatment environment or new living schedule. Try to keep the changes as small as possible, and encourage routine activities that the child can maintain while receiving disease treatments and palliative care.
e. Maintain the child's existing social relationships (school, friends, teachers, relatives) as much as possible and help the child to build new relationships, such as with other children in the hospital or with doctors, nurses, social workers.

F. Bereavement care for children

Appropriate care for children who experience the serious illness or death of a parent or sibling can facilitate their grieving and promote long-term well-being.

a. It is important for grieving children to continue age-appropriate activities. Family time and daily routines should be protected (if possible).
b. Children should be encouraged to tell a trusted adult everything they hear about the parent's or sibling's illness or death. It is important to be honest with children without overwhelming them. In general, children's questions should always be welcomed.
c. Meaningful items may help children to grieve, make sense of the loss, develop and maintain a sense of identity and roots, and maintain a spiritual connection to their dead parent or sibling. Such items may include gifts from the deceased, diaries, written family stories, audio or video recordings, or memory boxes containing photos, letters, jewelry or other meaningful souvenirs.

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Further Reading

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8

Palliative care nursing

Julia Downing, Alex Daniels, Maryam Rassouli, and Eric L. Krakauer

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A. Overview

Nurses often spend more time than doctors with seriously ill patients and their families and may become better acquainted with their illness understandings, values, hopes, and fears. Nurses also are well positioned to appreciate patients' symptoms and the effectiveness of symptom management. For these reasons, nurses have crucial roles in hospital-based, outpatient, and home-based palliative care and in inpatient and home-based hospice (end-of-life) care.

B. Essential palliative care nursing roles

1. Palliative care nursing assessment

a. Every patient with palliative care needs should be assessed by a nurse at the first inpatient, outpatient, or home encounter.
b. Palliative care nursing assessment typically should include:
    i. Reviewing and documenting physical and psychological symptoms including pain, dyspnea, nausea, vomiting, diarrhea or constipation, anxiety, insomnia (see item 2)
    ii. Exploring and documenting the patient's, family's, or caregivers' understanding of the illness, including:
        - Diagnosis
        - Previous or current major treatments
        - The reason for coming to the hospital or clinic
    iii. Reviewing the history of previous illnesses, including major treatments
    iv. Obtaining or expanding and documenting the social history, including the patient's values, hopes, and any fears about the illness or being in the hospital; becoming familiar with the patient as a person

v. Exploring spiritual values or needs
vi. Reviewing and documenting allergies to medicines
vii. Reviewing and documenting current medications, including doses and dosing intervals, and any traditional medicines
viii. Assessing performance status using a scale such as the Palliative Performance Status (PPS) or the Eastern Collaborative Oncology Group (ECOG) performance status scale (see Appendix 1)
ix. Performing physical examination:
- Minimize discomfort to the patient during the exam
- Assess for wounds

x. Creating a nursing problem list
xi. Creating a nursing care plan

c. The nursing assessment should be documented in the medical record, and the responsible physician should be alerted immediately about any moderate or severe symptoms or other clinical problems that may require urgent attention.
d. Nursing assessment is an ongoing process:
i. Obtaining or expanding the social history, getting to know the patient, and providing emotional support, should be part of routine care.
ii. Any new or worsening symptoms or psychosocial concerns should be recognized and documented every day or every visit.

2. Pain and symptom relief

a. If the nursing assessment reveals severe pain or any other severe symptoms, further assessment should be deferred and the symptom adequately treated or reported immediately to the responsible physician (see Chapters 3, 4, and 7).
b. Rescue dosing of morphine or other medicines (see Chapter 3). A nurses duties typically should include
i. Determining when a rescue dose is needed
ii. Administering rescue doses or advising family members when to provide them, as appropriate
iii. Documenting their use, including the dose and time (this is crucial so that the prescriber will be aware of how many rescue doses were needed)
iv. Documenting the effect of each rescue dose
v. Communicating with the prescriber if the patient's pain, dyspnea, or other symptoms are still not controlled despite repeated rescue doses

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c. Subcutaneous (SC) dosing:
   i. When patients are unable to take medicines orally, do not have a feeding tube, and do not have or want an intravenous catheter, some medicines can be given easily SC. This method is especially useful for home care.
   ii. SC catheters are easy to place (see below).
   iii. Medicines can be given via a SC catheter either intermittently and/or as a continuous infusion with an infusion pump.
   iv. Nurses may teach family members to give intermittent SC doses safely.
   v. Technique for SC catheter insertion:
      - Where a subcutaneous infusion set is not available, a 23- or 25-gauge winged (butterfly) needle can be used.
      - The SC catheter should be placed only in certain sites (see Figures 8.1 and 8.2)
      - Avoid:
         - The abdominal area if there is abdominal distension
         - The supraclavicular area
         - The subclavicular area if the patient is cachectic and has COPD, due to the risk of pneumothorax
         - Areas where there is edema, broken skin, infection, or inflammation; tumor involvement; bony prominences; or skin folds
         - Recently irradiated areas
      - If the patient is restless or confused and thus at risk of pulling out the catheter, the upper back is the best site.
      - Wear examination gloves, sterilize the placement site.
      - Grasp the skin between the thumb and index finger. Insert the needle at a 45-degree angle to the skin (if the patient is cachectic this may need to be 30 degrees).
      - Then remove the metal needle and tape the plastic catheter firmly in place.
      - Document the date and time that the catheter is inserted—this may be in the individuals' notes, or carefully written on the tape.
   vi. The catheter site should be checked regularly every day for redness, tenderness, or other signs of infection or dislodgement.
   vii. SC catheters may remain in place for 7 days or longer if there is no evidence of infection or dislodgement and if it continues to function.

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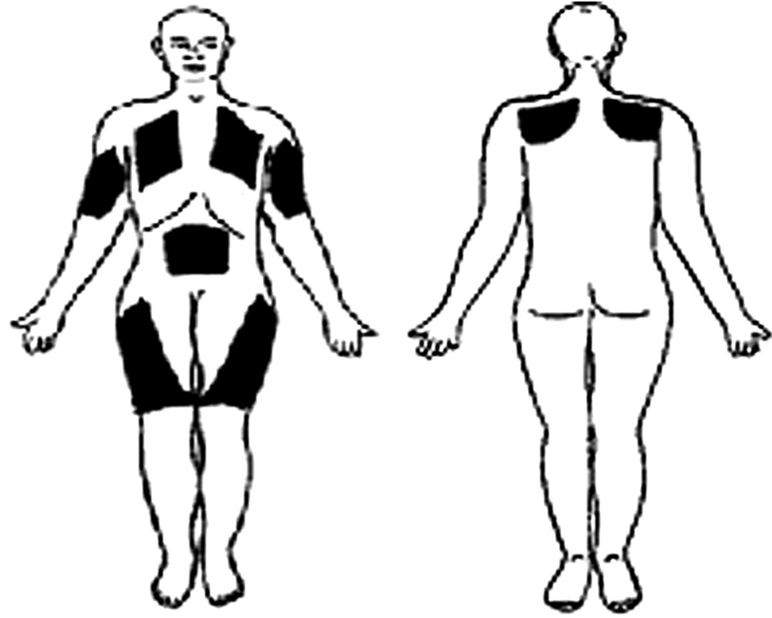

Figure 8.1 Suggested sites for inserting catheter for subcutaneous infusion in adolescents and adults.

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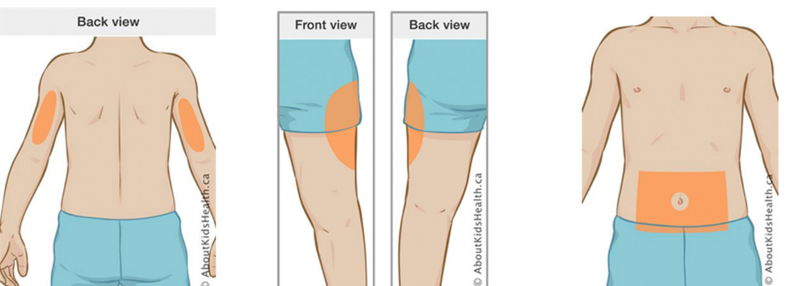

Figure 8.2 Suggested sites for inserting catheter for subcutaneous infusion in children.

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3. Emotional and spiritual support

a. If the nursing assessment reveals fears about the illness or being in the hospital, the nurse should provide attentive listening and assuage fears and provide assurances of care without offering false hope.

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b. If a nursing assessment reveals a lack of knowledge or misunderstanding about the illness or treatment, help the patients or families to understand physicians' explanations of the diagnosis, treatment options, and prognosis; correct any misconceptions; or inform the responsible physician of the need for more discussion.
c. Patients and family members often speak to the nurse about their concerns and about what physicians have said. Therefore, the nurse should be present when a physician speaks with the patient or family so the nurse knows what has been said, can provide emotional support if there is bad news, can clarify any misconceptions, and can help to ensure consistent messaging.
d. If the nursing assessment reveals spiritual distress, the nurse should provide attentive listening and, if the patient requests or gives permission, seek to arrange a visit from an appropriately trained spiritual supporter (see Table 4.4).
e. When a patient dies, the nurse can provide guidance and bereavement support for family members.

4. Patient advocacy

a. Nurses have a crucial role in assuring their patients receive the best possible care by assisting doctors to understand patients' needs and assisting patients to access the best care:
   i. Nurses may have a chance to become more familiar with a patient than would a doctor, and they can convey to the doctor important information about a patient's medical history, values, illness understanding, needs, hopes, and fears.
   ii. Many patients and their families are unfamiliar with the medical system and do not know how to find or request the care they need. Nurses can provide important counseling to help patients negotiate the healthcare system.
b. In hospitals that have a palliative care consultation service, nurses can recommend which patients on their ward would benefit from palliative care.
c. Nurses have a crucial role in informing the responsible physician when a symptom such as pain is not well controlled or when a patient or family needs more information or more discussion of the care plan.

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5. Wound care

a. Nurses commonly have primary responsibility for wound care such as dressing changes, controlling foul odor, and reporting the status of wounds to the doctor as appropriate (see Table 4.1).
b. Prevention of pressure ulcers is also a crucial responsibility of nurses:
   i. Minimize pressure on bony prominences:
      - By arranging or advocating for pressure-reducing mattresses or mats
      - By regularly changing the position in bed or chairs of patients at high risk for pressure ulcers, or by training family members when and how to change the patient's position

6. Training patients and family caregivers

a. Training patients and/or family caregivers to attend to the patient's specific needs is an essential role of nurses:
   i. In any setting, family caregivers commonly need training and reassurance to provide the necessary care in the home.
   ii. In many settings where there is a shortage of clinical staff, family caregivers also must stay with the patient in the hospital and provide most of the hands-on care. In these situations, nurses
      - Provide the patient's prescribed medicines to the family caregiver and instruct the caregiver on how to give the correct dose of each medicine at the correct time.
      - Train the family caregivers the safest ways:
         - To feed the patient with **aspiration precautions** (see Chapter 9, Section F)
         - To bathe the patient
         - To transfer the patient between bed and chair
         - To assist the patient with toileting
         - To keep the patient's mouth moist and clean
         - To regularly reposition the patient to prevent pressure ulcers and facilitate comfortable breathing
         - As appropriate, to give artificial nutrition via gastrostomy, jejunostomy, or nasogastric tubes
b. In any setting, prior to discharge of the patient to home, the nurse should train the family caregivers to safely provide all necessary care for

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the patient. This care may include any or all of the above. In addition, it may be important to provide:

i. Training to safely give injections via SC or IV catheters
ii. Training to recognize signs of significant changes in the patient's condition such as bleeding, difficulty breathing, and reduced responsiveness
iii. Information or guidance on follow-up appointments or referrals

C. Special nursing roles in palliative care

In some settings, nurses also have important roles in coordinating inpatient or outpatient palliative care and, where allowed by government regulations, in independently treating pain and other symptoms.

1. In hospitals

a. Nurses may serve as coordinators of inpatient palliative care consultation teams.
b. Within a hospital ward, a nurse or nurse leader may serve as palliative care liaison by reviewing daily the patients on the ward, identifying any patients in need of palliative care, and so informing the palliative care team.
c. Nurse discharge planners can help to ensure continuity of care and thus that vulnerable patients do not experience suffering by falling out of the healthcare system. Specific discharge plans that nurses may make might include:
    i. Assuring that transportation is available and affordable
    ii. Arranging for palliative care to be provided in the community or at home
    iii. Transferring the necessary clinical information to the community-based clinicians who will assume responsibility for the patient's care while following guidelines on confidentiality
d. **Nurse navigators** based in hospitals or clinics may:
    i. Facilitate communication among patients' clinicians
    ii. Contact patients to remind them of appointments and to ensure they have transportation
    iii. Monitor symptoms

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iv. Assist patients or family caregivers by:
- Clarifying language related to medical treatment
- Offering emotional support
- Identifying or recommending resources that may be helpful to the patient or family
- Advocating for the patient within the healthcare team
- Helping patients become familiar with the healthcare system.

2. In the community

a. Nurses based at district hospital or community health centers are indispensable to make palliative care accessible in the community and in patient's homes.
b. Nurses at community health centers:
   i. Should be made aware of patients in need of palliative care in their community, either by a hospital staff member when the hospital discharges a patient to that community, or by community health workers
   ii. Should supervise community health workers, who can act as the eyes and ears of the staff at the community health center and report any inadequately treated suffering
   iii. Should visit patients at home as needed
   iv. Should train family caregivers to care for the patient appropriately at home

3. Nurse practitioners

Including advanced practice nurses, nurse specialists, midwives, and feldshers.

a. In some settings, nurses with advanced or specialized training may assume responsibility for diagnosing and treating palliative care problems, in both inpatient and outpatient settings.
b. **Palliative care nurse practitioners**:
   i. In some places, specialized training in pain control or more generally in palliative care is available for nurses.
   ii. These nurse practitioners may be able to provide comprehensive palliative care and, depending on local regulations, to independently prescribe, carry, or dispense morphine and other palliative medicines.

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c. Other nurse practitioners:
   i. Training programs for nurse practitioners in any discipline that entails treating patients with serious illnesses (including primary care, oncology, geriatrics, pediatrics, gynecology, surgery, HIV/AIDS, and tuberculosis) should include required training in basic palliative care.
   ii. This training should enable the nurse practitioner to independently provide basic palliative care with supervision from or collaboration with a physician. This care might include:
      - Assessing for and identifying specific palliative care needs (see Chapter 2)
      - Treating physical and psychological symptoms as allowed by local regulations, or providing treatment recommendations to the patient's physician (see Chapters 3 and 4)
      - Prescribing morphine or other opioids for pain if allowed by local regulations (see Chapter 3)
      - Discussing and seeking agreement on goals of care (see Chapter 9)
      - Planning for safe discharge of patients from the hospital

Further Reading

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9

End-of-life care

Medical, ethical, and cultural issues

Eric L. Krakauer, M. R. Rajagopal, Lê Đại Dương, Guy Maytal, Christian Ntizimira, Hibah Osman, Trương Nguyễn Xuân Quỳnh, Ning Xiaohong, and Jia Zhimeng

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A. Contextually appropriate communication and decision-making with patients or families

See also Chapter 10, Section A.

1. Patients and families have a wide variety of preferences about communicating and decision-making with their doctors or clinicians:
   a. Preferences for sharing medical information and medical decision-making vary widely across cultures, but they also may vary widely **within** cultures:
      i. Thus, **serious efforts should be made to understand local culture and practices**. However, **no assumptions about preferred ways to communicate should be made based on appearance, language, religion, ethnicity, national origin, gender, level of education, or economic status** (see Box 9.1 and Box 9.2).
      ii. Preferences for sharing medical information and medical decision-making should be elicited as part of the social history (see Chapter 2, Section B) and confirmed in advance of sharing new information or decision-making. Specifically, it should be clarified:
         - With whom should information be shared, and with whom should it not be shared
         - Who will participate with the clinician in medical decision-making
   b. Depending on patients' preferences, their autonomy can be respected:
      i. By speaking and sharing decision-making only with them if they so prefer

   ii. By speaking and sharing decision-making only with designated others if they so prefer

c. Every effort should be made to:
   i. Share medical information and engage in medical decision-making privately: only with the appropriate persons, but including all appropriate persons
   ii. Keep information about the patient confidential beyond those appropriately included in information-sharing or medical decision-making

Box 9.1 Example of cultural context: Vietnam

Lê Đại Dương, MD, MS

Filial piety—obedience to and respect for elders—is an important traditional value in Vietnam. And, traditionally, people identify more as belonging to a family than as individuals. For many patients and families in Vietnam, these values and traditions influence expectations about appropriate communication and decision-making in healthcare settings. Specifically, filial piety traditionally entails ensuring that elders are well fed and cared for, and, based on this tradition, many family members feel obligated to insist on invasive life-sustaining treatments for elders at the end of life even when such treatments probably will cause harm and provide no benefit. In light of these traditions and dilemmas, we use and teach the following guidance for communicating medical information and medical decision-making with patients or families in Vietnam:

- Start by exploring who should be included in the discussion. Some patients might defer decision-making to one or more family members.
- Exploring the patient's or family's understanding of the diagnosis, treatment options, and likely prognosis. If they are unaware of the situation, try to use terms that are easily understandable by the patient or the family.
- Clarify politely each family member involved in the discussion (relationship to the patient, role in the family).
- Vietnamese rarely discuss their own emotions, so observe the patient and family members for clues about what they may be feeling and acknowledge them.
- Typically, healthcare decisions are made collectively by the patient and extended family.
- Acknowledge the main family caregivers (typically women) and actively involve them in the conversation.
- Inquire "what matters the most" to the patient or family to explore their values.

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- If the family asks that a cognitively intact patient not be given medical information:
  - o Politely request permission to give the patient an opportunity to assent or ask to be included in the discussion.
  - o If the family does not agree, avoid negotiating with them in front of the patient.
  - o Ask to meet separately with either the main family decision-maker or the whole family.
  - o Explore the reason for the family's reluctance to inform the patient of the situation. Most of the time, it is an attempt to protect the patient from potential emotional harm from learning the truth.
  - o Offer appreciation of the family's wish to protect the patient from harm.
  - o Gently explain the potential harms from concealing the truth:
    - Unnecessary suffering from interventions that the patient might have refused.
    - Inability of a patient to attend to important unfinished business (closure with loved ones, legacy, will, funeral plans) if the patient does not know about a short prognosis.
    - Lingering doubt among family members about whether they made the best decisions for the patient.
  - o Express your intention to support the family to make the best decision for patient and to avoid regret after the patient's death.
  - o If possible, negotiate a plan to discuss decisions with the patient and family together.
  - o Consider including colleagues who can help with challenging emotions (social worker, nurse, psychologist)

Box 9.2 Example of cultural context: Rwanda

Christian Ntizimira, MD, MMs-GHD

In Ikinyarwanda, the language of Rwanda, it is said that "when you are healthy, you belong to yourself, but when you are sick you belong to your family." In Rwandan culture, patient autonomy entails active family involvement. The family takes care of a sick member not only at home but also in the hospital. As in many low- and middle-income countries, a family caregiver accompanies the patient to the hospital and stays with the patient, sleeping in a nearby rented room, in a hospital courtyard, sometimes under the patient's bed. It is expected that the family provides food, hygiene, transportation, financial support, and emotional accompaniment. And the extended family typically will gather for sharing of important information and medical decision-making.

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The tight intertwinement of patient and family in Rwanda often manifests as shared distress about an ominous diagnosis or prognosis between patient and family. This distress also may be complicated and exacerbated by the history of the genocide against the Tutsis in 1994. But because of the cultural "stoicism" in Rwanda, the sensitivity of mentioning the genocide, and the stigma of mental illness, recognition of emotional distress requires discernment of behavioral and linguistic nuance, and efforts to provide emotional support require great delicacy.

A culturally sensitive model for discussion of bad news and medical decision-making near the end of life in Rwanda may include the following:

- Clarify with the patient and family who should be present, and document this in the medical record. In organizing the meeting, honor diverse definitions of "family."
- Acknowledge the distress that may be experienced in the setting of the patient's illness.
- During the family meeting, enable all participants to be introduced.
- Try to identify the primary decision-maker or individual significantly influencing decisions within the family unit, often referred to as the "Lion" or "Lioness."
- Once the primary decision-maker is identified, the process of advanced care planning may commence, emphasizing collaborative decision-making and prioritizing the quality of life for both the patient and the family members.

B. Breaking bad news

1. It is important to communicate bad news well because:
   a. The patient can be emotionally injured if it is done badly
   b. The patient–physician relationship is strengthened when done well
   c. When the clinical situation and prognosis are understood by patients or families, they may be able to:
      i. Make important and realistic plans
      ii. Begin the grieving process that is necessary for long-term health
2. Before communicating bad news:
   a. Determine whom the patient would like to receive the information (sometimes, the patient may prefer not to be involved).
   b. Think in advance about what to say.
   c. Allow adequate time.

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d. If possible, find a private place where the discussion will not be interrupted, and turn off mobile phones not being used as part of the discussion.
e. Sit down so that you are at eye level with the patient or family.
f. Inquire how much the patient (or family) wants to know.
g. Prepare yourself for a broad range of reactions including anger, sadness, tears. Remember that any anger expressed toward you may have nothing to do with you and that it may be helpful for the patient or family, or indicative of their trust in you, that they express strong emotions.
h. Be prepared to offer facial tissues.
i. Always be prepared to provide or suggest next steps in caring for the patient. **Never give bad news without knowing what care will or can be provided next.**
j. Assess the patient's (or family's) ability to comprehend information and the amount of detail they wish to hear.

3. Communicating bad news:
   a. Politely explore the patient's or family's understanding of the illness and prognosis.
   b. If there are misconceptions, and the true situation is worse, begin slowly to correct any misconceptions by first stating gently that the situation is not quite so good. This enables the patient or family to prepare themselves for bad news.
   c. Deliver the bad news clearly and concisely, avoiding medical jargon:
      i. Express empathy.
      ii. Pause after each item of bad news to enable the patient or family to comprehend it and compose themselves. Sometimes, a pause of one or more minutes may be needed.
   d. Avoid talking too much.
   e. Listen patiently to any questions or comments.
   f. Be prepared for the patient or family to express powerful emotions such as sadness or anger and to continue listening patiently without becoming defensive:
      i. Just listening to expression of emotions, acknowledging or naming them (e.g., "I see that you are quite upset"), and expressing condolence can be helpful for the patient or family and may help to build trust.
      ii. However, if you feel physically threatened, leave immediately.
   g. Ask the patient or family politely whether they feel they have understood the news or whether you should explain again or in a different way.

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h. Provide suggestions, based on understanding of the patient's values, for the next steps in care of the patient, including:
   - Any suggested tests or treatments (disease-modifying or palliative)
   - Any suggested changes in goals or preferred location of care
i. Offer any available psychosocial or spiritual support.
j. Provide a way for the patient or family to have further questions answered.

C. Goals of care

1. Whenever there is a major change in the patient's condition, and especially if the patient appears to be dying, it is necessary for the patient's physician to review the goal(s) of care with the patient or family and to suggest any changes in goals of care based on the patient's values and condition:
   a. To discuss of goals of care, proceed as when breaking bad news, as outlined in Section B
   b. Consider asking the patient or family to review the patient's values (what matters most to the patient). Then suggest the goals of care based on the clinical situation and the patient's values.
   c. Encourage the patient or family to ask questions, request clarification, or present different opinions.

D. Optimum use of life-sustaining treatment

1. Life-sustaining treatments such as cardiopulmonary resuscitation (CPR), mechanical ventilation, non-invasive ventilator support, hemodialysis, and artificial nutrition can provide great benefit for some patients. But in others, especially in those near the end of life, they often provide no benefit or result in much more harm than benefit. However, many families insist on intensive life-sustaining treatments even when they seem to be harmful and non-beneficial because they think that "intensive care" is the best care or because they feel a cultural or religious responsibility to demand everything to keep their family member alive. As a result, many vulnerable patients suffer unnecessarily near the end of life:
   a. Physicians must understand these perspectives when they discuss goals of care with patients or families.

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2. The principle of "non-maleficence" is crucial in considering optimum use of life-sustaining treatment. Stated most simply, the principle states that clinicians should "do no harm." They may not always be able to cure or control a patient's disease, but they must never harm the patient unless there is a reasonable expectation that the benefit of what they do will outweigh the harm:
   a. Use of CPR or mechanical ventilation near the end of life often causes harm without any reasonable expectation of benefit based on the patient's own values.
   b. It is often helpful for clinicians to explain to family members the importance of **protecting** the patient from harm by avoiding harmful, non-beneficial interventions.
3. Use of an *advance directive*, as shown in Appendix 5, is useful to help assure that the patient's values are honored and that all clinical staff are aware of the goals of care.

E. Cardiopulmonary resuscitation (CPR)

1. Like any medical treatment with potential adverse effects, CPR should be used only if:
   a. There is a medical indication
   b. There are no absolute contraindications
   c. The likelihood and significance of potential benefits outweigh the risk and severity of potential harms in the context of the patient's values.
2. Indications for CPR are potentially reversible cardiac and/or respiratory arrest.
3. Absolute contraindications include:
   a. Declined by a patient with decision-making capacity
   b. Unanimously declined by the surrogate decision-maker(s) of a patient who lacks decision-making capacity or who defers decision-making to the family
   c. Non-reversible cardiac arrest
4. If a decision has been made not to provide CPR, this should be documented in the medical record in a way that informs all members of the patient's treatment team of this plan:
   a. Ideally, an **advance directive**, as shown in Appendix 5, should be completed in this situation. One copy should be placed in the medical record, and another copy should be given to the patient or family.

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5. Imminently dying patients:
    a. CPR is relatively contraindicated for a patient who is imminently dying.
    b. CPR should be provided only if there is a compelling reason to implement an invasive life-sustaining procedure on a dying patient.
    c. It may be possible for a physician to decline to offer CPR if the following three caveats are met:
        i. In the opinion of the patient's physician, the patient will die imminently regardless of whether CPR is provided.
        ii. There is no compelling reason to implement CPR.
        iii. The Chairperson of the department agrees the CPR should not be offered.
    d. If CPR will not be offered:
        i. The patient or family should be informed that CPR will not be offered.
        ii. This plan and the communication with the patient or family should be described in the medical record.
        iii. Psychosocial support should be made available to the patient or family from a social worker or psychologist.
6. Patients who are not deemed to be imminently dying but for whom CPR would be more harmful than beneficial based on the patient's values:
    a. If a patient's physician determines that CPR would be more harmful than beneficial in the context of the patient's values, the physician should:
        i. Explain to the patient or family, as appropriate, that "doing no harm" is a fundamental principle of medicine
        ii. Express regret that the disease process cannot be reversed
        iii. Suggest that the patient be **protected** from the harm of CPR
    b. Psychosocial support should be made available to the patient or family from a social worker or psychologist.
    c. If the patient or family continues to insist that CPR be initiated in event of cardiac or respiratory arrest:
        i. Consultation from a hospital ethics committee should be sought whenever such a committee exists.
        - All hospitals with an intensive care unit should establish an ethics consultation committee composed of hospital staff members from multiple disciplines (doctors, nurses, social workers, or psychologists) and at least two community representatives:

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ii. Discussion of goals of care with the patient or family should be resumed whenever there is a significant change in the patient's condition.
iii. CPR should be initiated in the event of cardiac or respiratory arrest.

7. CPR of doubtful or no benefit:
 a. It is never acceptable to merely appear to perform CPR. CPR always must be performed according to established protocols. Deception is never justifiable.
 b. Whenever CPR is provided, it must be clear who is the CPR team leader. The CPR team leader should be:
  i The ICU/critical care specialist doctor who is present at the bedside
  ii. If there is no ICU/critical care specialist doctor at the bedside, the doctor at the bedside with the most expertise in CPR
 c. If the CPR team leader decides at any time that continuing CPR is no longer indicated, the CPR team leader should order that CPR be stopped and death pronounced.
 d. Early termination of CPR should be considered if:
  i. The patient has advanced dementia, end-stage cancer, or end-stage major organ failure, and either
   - The EKG shows either asystole or pulseless electrical activity, or
   - A pulse and blood pressure cannot be restored in 10–15 minutes, or
   - The patient had another cardiac arrest within the previous week.

F. Artificial nutrition and hydration

1. There is evidence that artificial nutrition and hydration does not improve the quality or quantity (length) of life for patients with advanced dementia or end-stage cancer and often for patients with other end-stage major organ failure:
 a. Patients with these end-stage conditions develop a catabolic state involving consumption of body fat and muscle and inability to assimilate oral or artificial nutrition. Therefore, artificial nutrition provides no physiologic benefit for patients with these conditions.
2. Artificial nutrition and hydration, like more invasive life-sustaining treatments, often are harmful for dying patients. Artificial nutrition and hydration may harm dying patients by:

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a. Causing or worsening respiratory secretions resulting in coughing, choking, or dyspnea
b. Worsening pleural effusions or pulmonary edema resulting in dyspnea
c. Worsening ascites resulting in pain or dyspnea
d. Worsening peripheral edema or anasarca resulting in immobility and skin breakdown with pain and infection risk
e. Creating a need for chemical or physical restraints to prevent the patient from pulling out feeding tubes or intravenous lines and thereby increasing risk of agitation or delirium

3. For the above reasons, it is easier to assure the comfort of a dying patient who is relatively volume-depleted than a dying patient who is well-hydrated:
   a. Typically, the only uncomfortable symptom of volume depletion in a dying patient is dry mouth, and this can be relieved easily with frequent use of oral swabs or a sponge.
4. Because providing nutrition symbolizes love or devotion and is emotionally very important for many people, withholding or withdrawing artificial nutrition and hydration near the end of life often requires careful discussion between doctors and family members:
   a. It may be difficult for family members to accept that artificial nutrition and hydration provide no medical benefit for the patient and may harm the patient, and therefore that they can best show their love for the patient by **protecting** the patient from this treatment.
5. Oral nutrition should never be withheld from a patient who indicates a wish to eat:
   a. Oral nutrition always should be offered.
   b. If the patient is at risk for aspiration, aspiration precautions should be taken. These include:
      i. Positioning the patient fully upright prior to offering food
      ii. Making sure the patient remains fully awake and alert when eating
      iii. Providing foods with the consistency that is most easy to swallow safely: thickened liquids and pureed foods. Avoid thin liquids
6. Most patients with end-stage dementia, cancer, or major organ failure have little or no appetite. They should *never* be forced to eat as this may cause either physical or emotional suffering:
   a. Clinicians should explain gently to families that loss of appetite is normal at the end of life.
   b. Appetite stimulants rarely are effective in this situation and may cause harm.

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   c. In some cases, a steroid medicine can improve appetite, energy, and mood for some days or weeks. But this should be considered only if there are no clear contraindications.

G. Discharge planning

1. When planning for a patient to be discharged home from the hospital at the end of life, the hospital physician should:
   a. Anticipate what symptoms may occur or worsen before the patient dies.
   b. Make plans for how to prevent or relieve any anticipated symptoms.
   c. Inform the community health center closest to the patient's home about the patient's condition and discuss how to respond to any anticipated symptoms, if possible.
   d. Provide the community health center closest to the patient's home with contact information for virtual consultation in case it is needed.
   e. Establish a plan for ongoing prescription of any controlled medicines such as morphine. This may require discussion with a physician at the district hospital closest to the patient's home.
2. If the patient's physician believes that the patient cannot receive adequate care at home or is likely to develop symptoms that cannot be well controlled at home, the physician should propose and try to arrange inpatient end-of-life care at the healthcare facility closest to the patient's home that has staff with adequate training in palliative care to meet the patient's needs (ideally, the nearest community health center or district hospital). In this way:
   a. The patient can be near home and still have access to inpatient palliative care. Family members can visit easily but do not need to take time away from work or other family responsibilities.
   b. Patients do not need to remain in expensive, overcrowded central-level hospitals to assure good symptom control at the end of life.

H. Preparing family members for the terminal phase

i. Clinicians should explain to family members what they might see or hear in the terminal phase so that the terminal phase is less shocking or upsetting to them. Common manifestations of dying include:

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a. **Audible respiratory secretions**: This is often more troubling to family members than to the patient. However, it can be treated with hyoscine butylbromide IV (see Chapter 3) and/or furosemide.
b. **Gasping respirations**: Many patients breathe in gasps at the end of life. If the patient does not appear to be laboring to breath, the family should be assured that such a breathing pattern does not indicate suffering. However, if a rapid respiratory rate or evidence of laboring suggest that the patient may be experiencing dyspnea, morphine should be given IV (see Chapters 3 and 5).
c. **Terminal agitation**: The family can be instructed to touch the patient and speak reassuringly to the patient. If this does not calm the patient, treatment with haloperidol IV is warranted (see Chapter 3).

I. Bereavement care

1. Grief:
   a. A painful mental state generated by a significant loss such as the death of a close family member or friend.
   b. May vary greatly in content, quality, intensity, and duration among cultures and among grieving persons within a culture.
   c. Common emotions associated with grief:
      i. Sadness about the loss
      ii. Anxiety about the future without the deceased
      iii. Guilt about not doing enough and about surviving
      iv. Anger about others not doing or caring enough and sometimes at the deceased
      v. Shame about feeling vulnerable or about uncontrollable emotions
   d. Painful emotions may mix with some pleasurable ones:
      i. Enjoyment in recalling happy times or funny anecdotes
      ii. Pride in honoring the deceased
      ii. Relief from caregiving burden or worry
2. Bereavement: The state of grieving the loss of a loved one.
3. Mourning: The behavioral expression of grief that often is culturally and socially determined.
4. Normal (uncomplicated) grief (80–90% of the bereaved):
   a. Variable in duration: days to months
   b. Characteristics:
      i. Sense of disbelief, difficulty accepting the death

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    ii. A mix of emotions, often intense and unfamiliar
    iii. Preoccupation with thoughts and memories of the deceased
    iv. Some loss of interest in previous interests
  c. Distress declines over time
  d. The griever:
    i. Gradually accepts the loss
    ii. Reconnects with life in the absence of the bereaved
    iii. Sustains self-esteem and sense of purpose
    iv. Continues to be productive
    v. Continues to experience waves of sadness—especially at the time of holidays, anniversaries, and other reminders of the deceased.
    vi. The waves of sadness diminish in intensity and frequency over time.
5. Complicated grief (10–20% of the bereaved):
  a Lack of adjustment to the loss
  b. Lack of return to full engagement with life
  c. Increased risk of developing prolonged grief disorder, major depression, suicidal thinking, and medical problems
  d. Risk factors:
    i. Close or dependent relationship to the deceased
    ii. Death of a child
    iii. Poor social supports or social isolation
    iv. Past history of mental illness
    v. Past history of separation anxiety
    vi. Traumatic childhood experiences such as abuse or neglect
    vii. Unanticipated death—lack of preparation
    viii. Having a strained relationship with the deceased
    ix. Other major current stressors, including financial difficulties
  e. Death of a spouse is a risk factor for depression.
6. Depression in bereavement:
  a. Should be treated as any other depressive episode (see Chapter 4, Section B)
  b. Incidence of major depression in first year after death of a spouse is 4–6 times the incidence in the general population.
7. Prolonged grief disorder:
  a. Definition:
    i. Pervasive yearning or longing for the deceased, or persistent preoccupation with the deceased, often accompanied by:

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- Emotional distress, including bitterness or anger about the loss
- Difficulty accepting the loss
- A feeling that part of oneself died with the deceased
- Avoidance of reminders of the loss
- Feelings of intense loneliness or that life is meaningless that lasts beyond cultural norms (typically longer than 6 months) and causes disruption in functioning

ii. Significant disruption in social or professional functioning due to symptoms

iii. Symptoms persist at least 1 year after the death of the loved one (6 months in children and adolescents)

b. Without treatment, prolonged grief disorder may lead to poor quality of life, impaired sleep, major depression, substance use (alcohol, tobacco, illicit drugs), increased risk of cancer or heart disease, and suicide.

c. Treatment:

i. Psychotherapies that include cognitive behavior therapy (CBT) may be effective in reducing symptoms. These therapies:

- Promote acceptance of the reality of the loss
- Promote development of goals and attainment of satisfaction in life without the loved one
- Can be provided to individual patients or in a bereavement group

ii. Other therapeutics strategies may include:

- Psychoeducation: Informing patients that the thoughts, behaviors, and feelings of prolonged grief disorder can improve with treatment
- Helping patients to recognize and reduce avoidance behavior
- Supporting patients to reengage with friends, set goals, and create new sources of joy, meaning, and fulfillment
- Addressing any mistaken belief that the grieving person contributed to death
- Helping the patient to prepare for anniversaries and holidays

iii. Pharmacotherapy with selective serotonin re-uptake inhibitors alone have not been shown to provide benefit for prolonged grief disorder, but they may provide additive benefit when combined with grief-focused therapy.

iv. Treat depression if present (see Table 4.2).

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10 Integration of palliative care into healthcare systems

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A. Policy needs

1. Palliative care policies are crucial to enable the implementation and scale-up of high-quality palliative care training and services. Ideally, these policies should include:
   a. *National Palliative Care Policy*, calling for universal access to palliative care as a medical and moral imperative and a necessary step toward universal health coverage (UHC)
   b. *National Palliative Care Strategic Plan*, including financing plans, specific goals, timelines, and plans for monitoring and evaluation
   c. Palliative care sections in national policies or strategic plans on noncommunicable diseases, cancer, primary healthcare, elder care, tuberculosis, and humanitarian crisis response
2. The World Health Assembly Resolution 67.19 (2014) on "Strengthening of palliative care as a component of comprehensive care throughout the life course" should be used as a basis for national palliative care policies (https://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf)
3. Several documents from the World Health Organization (WHO), based on the World Health Assembly Resolution, provide detailed guidance for creating national palliative care policies:
   a. Planning and implementing palliative care services: A guide for programme managers (https://www.who.int/publications-detail-redirect/planning-and-implementing-palliative-care-services-a-guide-for-programme-managers)
   b. Integrating palliative care and symptom relief into primary health care: A WHO guide for planners, implementers and managers

(https://iris.who.int/bitstream/handle/10665/274559/9789241514477-eng.pdf?sequence=1)

   c. Integrating palliative care and symptom relief into paediatrics: A WHO guide for health care planners, implementers and managers (https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-paediatrics)
   d. Integrating palliative care and symptom relief into the response to humanitarian emergencies and crises: A WHO guide (https://www.who.int/publications/i/item/9789241514460)

4. Many policymakers, public health officials, hospital and clinic leaders, and clinicians may not be familiar with the meaning and importance of palliative care. Thus, anyone with training or experience in palliative care should be prepared to:
   a. Advocate for palliative care to respond effectively to the physical, psychological, social, and spiritual suffering of patients
   b. Provide advice for policymakers, public health officials, hospital and clinic leaders, and clinical colleagues on palliative care policy and implementation and on palliative care for specific patients
5. **Contextualizing palliative care** based on culture and needs of specific populations:
   a. Palliative care is a response to suffering, and people suffer differently in different clinical, socioeconomic, and cultural contexts:
      i. Certain health problems or social problems are more common in some regions and less common in others.
      ii. The meanings of life, death, afterlife, health, illness, comfort, suffering, caring, self, family, and community may vary between cultural or linguistic groups.
   b. Therefore, palliative care should vary according to local needs and values. This includes:
      i. How patients and family members are addressed, how information is communicated, and how treatment plans are discussed and made
      ii. How patients are examined
      iii. How palliative care interventions are prioritized
   c. In some settings and situations, it may be meaningful or comforting to the patient if a traditional healer designated by the patient or family is invited to participate in the patient's care:
      i. If this is done, care should be taken to minimize the risk of harm to the patient. This may require open discussion or negotiation with the traditional healer about what traditional and scientific

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medicine can offer and how the two can be combined to maximize benefit and minimize harm to the patient.

d. Assumptions should never be made about any patient's beliefs, values, or wishes simply because of their place of birth, religion, sex, language, skin color, or ethnicity. It is necessary to work to understand the particulars of each patient's beliefs, values, hopes, and fears (see Chapter 9, Section A).

B. Basic structure of integrated palliative care

1. Palliative care and the Essential Package of Palliative Care should be accessible at every level of the healthcare system (see Section C).
2. Any doctor from any level of the healthcare system with at least basic palliative care training may provide palliative home care, including:
   a. Physician-specialists in any field working in hospitals
   b. General doctors working at district hospitals or community health centers
3. Nurses and social workers from any level of the healthcare system with at least basic palliative care training also may provide palliative home care, ideally in collaboration with a doctor with at least basic palliative care training.
4. Prompt and effective communication between levels of the healthcare system is necessary to assure safe and smooth movement of patients between levels.
5. Efforts should focus on assuring the following network of palliative care services and human resources:
   a. Central-level hospitals (national, regional, and provincial hospitals):
      i. Interdisciplinary palliative care team consisting of:
         - Full-time doctor with at least intermediate-level palliative care training (70–140 hours). As soon as possible, the team leader should be a palliative care specialist or subspecialist
         - Other full-time or part-time doctor(s) with at least intermediate-level palliative care training (70–140 hours)
         - Nurses with at least basic-level palliative care training (35–70 hours)
         - Psychologist and/or social worker with at least basic palliative care training (35–70 hours)

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    ii. Inpatient and outpatient palliative care services:
        - Palliative care initiation and treatment planning for patients with newly discovered palliative care needs (see Chapters 3 and 4)
        - Palliative care for patients with severe symptoms, both chronic and acute
        - Consultation to any department or ward in the hospital
        - Discharge planning for patients returning home at the end of life
        - Outpatient pharmacy must stock and dispense oral immediate-release morphine by prescription

b. District hospitals:
    i. Small palliative care team consisting of:
        - At least one full-time or part-time doctor with intermediate-level palliative care training (70–140 hours)
        - Other full-time or part-time doctor(s) with at least basic-level palliative care training (70–140 hours)
        - Nurses with at least basic-level palliative care training (35–70 hours)
        - Part-time psychologist or social worker
    ii. Inpatient and outpatient palliative care services:
        - Palliative care initiation and treatment planning for patients with newly discovered, uncomplicated palliative care needs
        - Palliative care for patients with chronic or acute symptoms that are too severe or complex to be treated in the community but not severe or complex enough to require central-level care
        - Consultation to any department or ward in the hospital
        - Discharge planning for patients returning home at the end of life
        - Hospital pharmacy must stock and dispense oral immediate-release morphine by prescription if no other pharmacy in the district stocks and dispenses it

c. Community health centers:
    i. Doctor or assistant doctor with at least basic-level palliative care training (35–70 hours)
    ii. Nurse(s) with basic-level palliative care training (35–70 hours)
    iii. Outpatient palliative care services:
        - Palliative care initiation and treatment planning for patients with uncomplicated palliative care needs
        - Continuation of palliative care begun in a hospital

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- Supervision of community health workers
- Surveillance for uncontrolled symptoms
- Home visits as needed
- Prescription refills
- Referral to higher level for patients whose suffering cannot be adequately controlled at community level

iv. Inpatient hospice care for at most one patient at any one time if there is a nurse present 24 hours, if the family is unable to care adequately for the patient at home, and if the symptoms are well controlled

d. Home care:

i. Community health workers who visit patients as often as every day, as needed, and who serve as the "eyes and ears" of the clinician(s) responsible for palliative care at the community health center or other healthcare facility

ii. Home visits by the doctor or nurse responsible for palliative care at the community health center or district hospital as needed

6. Standard operating procedures (SOPs) for communication and transfers between levels:

a. Whenever a patient receiving palliative care will be transferred from one level of the healthcare system to another, a clinician at the institution from which the patient will be transferred should:

i. Contact a clinician at the institution that will receive the patient within 24 hours before the transfer to give a verbal summary of the reason for the transfer and the palliative care needs

ii. Write a summary of the case to be sent with the patient to the receiving institution. The summary must include:

- Brief medical history, including major diagnoses and current treatments
- Palliative care needs
- Reason for transfer
- Current goals of care
- All current medicines, including doses and dosing regimen
- Medicine allergies

b. When a patient will be transferred from a hospital to home, a clinician at the hospital should:

i. Contact a clinician responsible for palliative care at the community health center or other healthcare facility closest to the patient's home within 24 hours before the transfer to give a verbal summary of the reason for the transfer, the palliative care needs,

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and the recommended frequency of visits by a community health worker

ii. Write a summary of the case, as above

iii. If the clinician responsible for palliative care at the community health center closest to the patient's home believes that adequate palliative care cannot be provided at the patient's home, the clinician at the hospital should instead pursue transfer to the district hospital nearest to the patient's home

7. Nursing homes:
   a. Nursing homes provide inpatient nursing care for a variety of patients, including those with palliative care needs. Therefore, all nursing homes should have:
      i. A doctor with at least basic training in palliative care available on site or on call at all times
      ii. At least one nurse with at least basic training in palliative care on duty at all times
   b. All items in the Essential Package of Palliative Care should be accessible for patients in nursing homes (see Section C).

C. Essential Package of Palliative Care

1. The following **interventions**, **medicines**, and **equipment** must be available at all levels of the healthcare system (all hospitals and community health centers):
   a. Interventions:
      i. Prevention and relief of pain and other physical suffering
      ii. Prevention and relief of psychological suffering
      iii. Prevention and relief of social suffering
      iv. Prevention and relief of spiritual suffering
   b. Medicines:
      i. Amitriptyline, oral
      ii. Bisacodyl oral
      iii. Dexamethasone, oral and injectable
      iv. Diazepam, oral and injectable
      v. Diphenhydramine oral and injectable
      vi. Fluconazole, oral
      vii. Fluoxetine oral
      viii. Furosemide, oral and injectable
      ix. Hyoscine butylbromide, oral and injectable

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x. Haloperidol, oral and injectable
xi. Ibuprofen oral
xii. Lactulose oral
xiii. Loperamide, oral
xiv. Metoclopramide, oral and injectable
xv. Metronidazole, oral—to be crushed for topical use
xvi. Omeprazole oral
xvii. Paracetamol, oral
xviii. Petroleum jelly

c. Equipment:
i. Pressure reducing mattress (inexpensive mat filled with foam, air, or water)
ii. Nasogastric drainage and feeding tube
iii. Urinary catheters
iv. Adult diapers (or cotton and plastic to make adult diapers)

2. In addition to the above, the following medicines and equipment should be available at all hospitals, including district hospitals. Where permitted and safe, they also should be available at community health centers:
   a. Medicines:
      i. Morphine, oral immediate-release and injectable
   b. Equipment:
      i. Opioid lock box
3. Hospitals that provide care for children also should have available:
   a. Pediatric formulations of paracetamol, ibuprofen, morphine, diazepam
   b. Topical anesthetic ointment for preventing pain from procedures
   c. Injectable ketamine for preventing pain from brief procedures or dressing changes
4. Hospitals that provide cancer treatment also should have available ondansetron oral and injectable.
5. Efforts should be made to obtain the following **social supports** for patients and their primary family caregiver if they live in extreme poverty:
   a. Cash transfers to cover housing, children's school tuition, transportation to healthcare facilities, or funeral costs
   b. Food packages
   c. In-kind support (blanket, sleeping mat, shoes, soap, toothbrush, toothpaste)

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6. Efforts should be made to facilitate visits to patients in hospitals by local volunteer spiritual supporters when **spiritual support** is requested by the patient (see Chapter 4, Section D).

D. Quality assessment of palliative care services and training

1. Assessment of palliative care services

a. Quality measurement is important:
   i. To help ensure that palliative care services improve patient outcomes and are well-regarded and to determine which could be improved
   ii. To recognize whether palliative care is being implemented well and to what extent it is being made accessible to all in need
b. When planning a quality assessment, it is important to clarify whether the focus will be service implementation or clinical effectiveness (patient outcomes):
   i. Implementation measurements assess whether and how palliative care is being scaled-up (e.g., acceptability, reach, sustainability)
   ii. Clinical measurements assess how well palliative care benefited patients and families (e.g., symptoms, satisfaction, trust, timeliness)
c. The WHO publication on "Assessing the development of palliative care worldwide"[2] provides a set of pragmatic and foundational indicators that can be used for implementation assessment (https://www.who.int/publications/i/item/9789240033351)
d. Optimal assessment of palliative care clinical effectiveness (patient and family outcomes) requires consideration of the setting of care (e.g., hospital, home, hospice), patient population (e.g., pediatric, limited social capital, non-cancer diagnoses), burden of measurement (e.g., routinely collected vs. additional effort for staff or burden for patients), need for research ethics committee approval and informed consent, and temporal factors (e.g., concurrent with clinical care, retrospective):
   i. In resource-limited settings, clinicians may feel that they lack time or expertise for quality measurement. However, tools are available that can be used both for clinical care and for assessment of patient outcomes.An example is the Palliative Outcomes Scale (https://pos-pal.org/; see Appendix 4 and Herce, in the Further Reading list).

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   ii. A reasonable initial strategy combines routinely collected clinical data, administrative data, and interviews with healthcare experts.

2. Assessment of palliative care training

a. Effective palliative care training can transform trainees' thinking and behaviors:
   i. Promote perception of patients as not just biological but also emotional and social beings embedded in families and communities
   ii. Enhance recognition of suffering and skills and commitment to relieving it
b. When designing palliative care training, educators should consider the goals of training (e.g., changing thinking and attitudes, imparting skills, and changing behavior), who are the learners (e.g., undergraduate medical students, practicing physicians), curricular design (e.g., in-person, virtual, full-days, one or more hours per week), and teaching methods (e.g., lectures, discussions, role-play)
c. A cultural adaptation process may be needed to contextualize palliative care curricula and training:
   i. Develop content in the local language, or translate and adapt an existing curriculum for the local culture and clinical setting, always in collaboration with local clinicians.
   ii. Consider inviting cultural leaders to develop or adapt relevant parts of the curriculum, such as psychosocial and spiritual assessment and support.
   iii. Seek support for the training from respected clinical leaders.
d. There are few validated and culturally adapted training assessment tools, but some training assessment tools have been published (see Tsao et al. 2023). Assessment may include:
   i. Changes in palliative care knowledge from baseline to post-training
   ii. Changes in palliative care–related attitudes from baseline to post-training
e. If possible, obtain follow-up data from trainees in the years after training to assess:
   i. Duration of any improvements in palliative care–related knowledge and attitudes
   ii. If and how the trainees are practicing or teaching palliative care.

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11

Palliative care in humanitarian settings

Eric L. Krakauer, Bethany-Rose Daubman, and Tammam Aloudat

A. What are humanitarian settings and humanitarianism?

1. **Humanitarian settings** are large-scale emergencies or crises that:
   a. Threaten the health or well-being of community groups or societies
   b. Have multiple causes:
      i. *Geologic or climatic hazards* such as earthquakes, major storms, floods
      ii. *Epidemics of life-threatening infections*
      iii. *Violent political or ethnic conflict*
      iv. *Famine*, often related to conflict or climatic hazards
   c. Often entail mass displacement of populations related to any of these events
   d. Often result in massive physical, social, spiritual, and psychological suffering and high death tolls
   e. Are most calamitous in regions that are impoverished or have weak healthcare systems:
      i. Risk = Hazard × Vulnerability
2. Humanitarianism definition and principles:
   a. **Humanitarianism** (also called humanitarian response) can be defined as **action to prevent and relieve human suffering** caused by large-scale emergencies or crises wherever it occurs, to protect life and health, and to ensure respect for the human being:
      i. Palliative care is an essential part of response to humanitarian emergencies and crises because its focus is prevention and relief of suffering regardless of whether the underlying condition is curable or not.

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b. Several humanitarian principles serve as a basis for the International Committee of the Red Cross and have been adopted by most humanitarian actors as a basis for humanitarian response:
   i. *Humanity*: Preventing and alleviating human suffering wherever it may be found, protecting life and health, ensuring respect for the human being, promoting mutual understanding . . . and peace
   ii. *Impartiality*: Making no discrimination as to nationality, race, religious beliefs, class, gender, or political opinions; endeavoring only to relieve suffering, giving priority to the most urgent cases of distress
   iii. *Neutrality*: Taking no sides in hostilities or engaging at any time in controversies of a political, racial, religious, or ideological nature
   iv. *Independence*: Maintaining autonomy to be able at all times to act in accordance with the principles of humanity, impartiality, and neutrality

B. Major palliative care needs in humanitarian settings

1. Relief of acute pain due to:
   a. Traumatic injury
   b. Surgery (relief of operative and postoperative pain)
   c. Loss of access to medicines or other treatments for chronic conditions
2. Relief of chronic pain due to chronic illness such as cancer
3. Relief of other acute or chronic physical symptoms such as:
   a. *Dyspnea* due to infection, aspiration, traumatic injury, or decompensation of chronic lung or heart disease
   b. *Vomiting* due to acute infection or chronic disease such as cancer, autonomic dysfunction, or renal or liver failure
   c. *Diarrhea* due to acute infection or chronic disease such as inflammatory bowel disease
4. Psychological first aid:
   a. Provision of supportive care to people in distress who have recently been exposed to a crisis event. The care involves assessing immediate needs and concerns, ensuring that immediate basic physical needs are met, providing or mobilizing social support, and protecting from further harm.
5. Relief of *psychological symptoms* such as anxiety or depression

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6. *Triage*:
   a. The principles of humanitarianism explicitly require a focus both on saving lives and on prevention and relief of human suffering, regardless of the type of humanitarian crisis or the types of suffering it causes.
   b. For this reason, palliative care is an essential part of all triage categories (Table 11.1). Specifically:
      i. Palliative care should be integrated as much and as soon as possible into treatment of patients triaged in the immediate/red category.
      ii. The *medical ethical principle of non-abandonment* requires provision of palliative care for any patient triaged into the expectant/blue category.
      iii. Palliative care typically is needed by patients triaged into the yellow or green categories. Patients without significant physical symptoms often are experiencing psychological or social distress.
7. End-of-life care:
   a. For patients whose lives cannot be saved, pain and symptom relief and psychological support for patient and family are imperative.
   b. Efforts should be made to provide as peaceful and dignified a death as possible.

Table 11.1 Triage categories and the role of palliative care

Category	Colour code	Description
1. Immediate	Red	Survival possible with immediate treatment
		Palliative care should be integrated with life-sustaining treatment as much as possible.
2. Expectant	Blue	Survival not possible given the care that is available
		Palliative care is required
3. Not red or green,	Yellow	Not in immediate danger of death, but treatment needed soon. Monitor for decompensation.
		Palliative care and/or symptom relief may nevertheless be needed immediately.
4. Minimal	Green	Will need medical care at some point after patients with more critical conditions have been treated.
		Symptom relief may be needed.

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Further Reading

International Committee of the Red Cross (ICRC). *Fundamental Principles of the Red Cross and Red Crescent Movement*. Geneva: International Committee of the Red Cross (ICRC); 1986. https://www.icrc.org/en/fundamental-principles

World Health Organization (WHO), War Trauma Foundation, and World Vision International. *Psychological First Aid: Guide for Field Workers*. WHO: Geneva, 2011. https://www.who.int/publications/i/item/9789241548205

World Health Organization (WHO). *Integrating Palliative Care and Symptom Relief in Responses to Humanitarian Emergencies and Crises: A WHO Guide*. Geneva: World Health Organization, 2018. https://www.who.int/publications/i/item/9789241514460

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12

Receiving and providing palliative care

Lê Đại Dương and Ashla Rani

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A. Guidance for doctors practicing palliative care in resource-limited settings

Lê Đại Dương

Palliative care is relatively new in most low- and middle-income countries (LMICs). Few patients in need have access to palliative care, and even when it is available in some places, many patients suffer for weeks, months, or years before they find or are referred to a clinician or team that provides good-quality palliative care. Furthermore, clinicians with some training or experience in palliative care may feel competent to treat pain and other physical symptoms but less able to relieve psychological, social, or spiritual suffering. However, in my experience as a palliative care physician in Vietnam, palliative care is needed by most patients with advanced chronic illnesses, greatly improves the quality of life of those who receive it, and can be deeply meaningful and satisfying for those who practice it.

Building meaningful patient relationships with patients and their families is an essential part of good palliative care. As part of our standard palliative care assessment, we explore patients' narratives and experiences, their suffering, sorrows, joy, and achievements. The interest we show in the patient as a person generates the trust that itself can be therapeutic. And, with this knowledge, we can help patients review their lives, find pride and meaning in their experiences, and decide how to leave legacies for loved ones. These palliative care tasks, and the comfort they bring to patients, give me joy and keep alive my passion for caregiving. Obtaining patients' social and personal histories also promotes clinicians' openness to diverse cultures and spiritual beliefs and broadens their perspectives on illness, death, and dying.

Simple palliative care interventions, like providing oral morphine to relieve pain or addressing patients' fears and concerns, can greatly reduce suffering and can enable patients to escape from agony and isolation to comfortable engagement with their families. Distressed families can be comforted by

assistance in making difficult decisions and assurances that they are providing good care for their loved one. These are palliative care victories, small but priceless and life-changing.

Practicing palliative care also has challenges. We regularly encounter harsh realities of illness, suffering, death, and grief. These encounters can evoke personal reflection on loss and mortality and may affect emotional well-being. Palliative care may not be well understood or respected in the healthcare community and in society in general. In addition, practicing in resource-limited settings often means that much-needed medicines, equipment, staff, and expert advice are not always available. Policies and regulations conducive to palliative care may be inadequate or may not yet exist. And these shortages and regulatory inadequacies make it more difficult to assure comfort and a peaceful end-of-life journey for patients. To weather these challenges, promote resilience, and enable others to experience the great rewards of practicing palliative care, I offer the following advice for doctors considering palliative care in resource-limited settings:

- Embrace compassion:
  - Compassion is the cornerstone of palliative care. Foster empathy for patients, families, and yourself.
  - Practice being present for patients. Meet patients and families where they are. Sit at eye level to enhance connection.
  - Prioritize self-care. Establish regular routines and celebrate daily achievements.
  - Engage in debriefing sessions with colleagues to reflect on patient care, share experiences, and offer mutual emotional support.
- Be creative:
  - Solve problems using creativity and flexibility. Explore new approaches to patient care, like using alternative medication delivery methods.
  - Gather evidence from literature, collaborate with colleagues, and engage in interdisciplinary teamwork.
- Advocate for change:
  - Familiarize yourself with frameworks, guidelines, and policy documents from local, national, international institutions, and organizations like the World Health Organization (WHO) and the United Nations (UN) to support advocacy.
  - Use quantitative data (patient-reported outcomes) and qualitative data such as stories of patients to push for palliative care integration into healthcare policies and systems.

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- Be bigger than the sum:
  - Seek help from colleagues, mentors, and peer networks when facing challenges.
  - Foster a respectful and supportive team environment with nurses, pharmacists, therapists, and social workers to promote patient-centered care and reduce burnout.
- Keep learning and educating:
  - Engage in local and regional palliative care networks for clinical and academic growth, networking, and staying updated on best practices.
  - Pursue travel scholarships for international conferences or clinical observations to gain a sense of professional community and foster collaboration and new thinking.
  - Educate colleagues, patients, and families to raise awareness and build capacity in palliative care through training initiatives.

B. A patient's advice for palliative care providers

Ashla Rani

My name is Ashla Rani, a software professional from Kerala, India. At the age of 28, I fell off a moving train. I woke up after 2 days in an intensive care unit, paralyzed in all four limbs. My spinal cord was injured at C5–6 level. The hospital and its staff fixed my broken bones and provided physiotherapy to enable me to sit up in a wheelchair and work on my laptop. They ignored my symptoms, broken life, and suffering. They reduced me to a "case of quadriplegia" and my mother to a "bystander," depriving us of our identities and dignity. They talked about me, but not to me. They had no interest in my life after discharge.

What I needed was acknowledgment as a person and treatment with dignity. I needed information and the ability to participate in decision-making. I also needed relief of uncomfortable symptoms, including constipation; emotional support; and social and vocational rehabilitation.

My world was confined to my room. I existed; I had no life. There was no purpose to my existence; I was in an existential crisis. I searched for a place where I could get care and also do some productive work with my limited abilities. One of my friends found Pallium India in a newspaper article 4 years later. Pallium India accepted me as a patient even though my diagnosis was not "life-threatening," and my life then began to change for the better.

I got my identity as a person back; so did my mother. I was listened to, spoken to, and became a part of the decision-making process. My mother

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and I felt supported emotionally. Rehabilitation was not only physical but also emotional, social, and vocational so that I could earn a living. At Pallium India, I grew from a care recipient to a care provider. I felt loved and valued.

For my life to be meaningful, I had to give something back, not only to receive. Someone asked me what gave me the most happiness during my 10 years at Pallium India. On reflection, I found that it was when someone shared their experiences in the most vulnerable time of their lives. It was palliative care that empowered me to listen to them. I found it a huge privilege.

In high-income countries, a serious disability or illness may not cause the extent of suffering that it often does in low- and middle-income countries (LMICs). All suffering related to serious illness, injury, or emotional trauma, including disabilities, can and should be relieved by palliative care where other resources to address the suffering are lacking. It would be unethical to walk away from some kinds of suffering because of a definition formulated without extensive input from LMICs.

I hope you will consider, doctor, that your primary goal should not be just to fix a broken body, manage a disease, or practice a specific specialty, but also to attend to and relieve the singular suffering of each patient, of each Other whom you encounter.

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APPENDIX 1

Performance status scales

For patients with a malignancy: The Eastern Cooperative Oncology Group (ECOG) Performance Status Scale.

Grade	ECOG Performance Status
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature (e.g., light house work, office work)
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair
5	Dead

Developed by the Eastern Cooperative Oncology Group, Robert L. Comis, MD, Group Chair.

Oken M, Creech R, Tormey D, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group. *Am J Clin Oncol.* 1982;5:649–655. This material is not covered by the terms of the Creative Commons license of this publication. For permission to reuse, please contact the rights holder.

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For patients who do not have a malignancy: The Palliative Performance Scale (PPS)

PPS level	Ambulation	Activity level and evidence of Disease	Self -care	Intake	Conscious level
PPS 100%	Full	Normal activity and work **No evidence** of disease	Full	Normal	Full
PPS 90%	Full	Normal activity and work **Some evidence** of disease	Full	Normal	Full
PPS 80%	Full	Normal activity and work *with* effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable normal activity and work **Significant** disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance	Normal or reduced	Full or confusion
PPS 50%	Mainly sit/lie	Unable to do any work **Extensive** disease	Considerable assistance	Normal or reduced	Full or drowsy or confusion
PPS 40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
PPS 30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Reduced	Full or drowsy +/- confusion
PPS 20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal sips	Full or drowsy +/- confusion
PPS 10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma
PPS 0%	Dead	-	-	-	-
Instructions: PPS level is determined by reading left to right to find a "best horizontal fit." Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, "leftward" columns take precedence over "rightward" columns.					

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APPENDIX 2

Safe management of opioid medicines

Adapted from:
Joranson D, Maurer M, Mwangi-Powell F (eds.). *The African Palliative Care Association Model Guidelines for Ensuring Patient Access to, and Safe Management of, Controlled Medicines*. Kampala: African Palliative Care Association, 2010.
Note: These guidelines, adapted for this manual from the African Palliative Care Association, require further adaptation for other settings but can inform efforts to create the necessary guidelines in any setting.

Guide for hospital ward staff

Hospital staff members, including pharmacists, nurses, and doctors, should receive training in the handling of controlled medicines. Some topics need to be emphasized. Many patients in need of palliative care leave hospitals and return home for continued care. Strong opioids like morphine in tablet and liquid form are often used, and health staff or patients/families may need to carry these opioids into patients' homes for continued pain control.

Palliative care teams may visit patients while carrying these opioids and administer them or leave a supply to use at home. This section provides guidance about how health staff on wards can meet the basic requirements of the *1961 Single Convention on Narcotic Drugs* that was signed by virtually every country: https://www.unodc.org/pdf/convention_1961_en.pdf

Ward supplies of scheduled medicines

Records to be kept

Article 34(b) of the Single Convention requires that hospitals keep records of the quantities of controlled drugs manufactured and of each individual acquisition and disposal of drugs. Such records shall respectively be preserved for a period of not less than 2 years.

Therefore, these guidelines recommend that the following should be available on the hospital ward to meet the Single Convention requirements for record keeping and to account for their use; however, it is up to the discretion of each country to decide how to keep such records.

a. Ward Scheduled Medicines Register
b. Ward Ordering Book (Figure A.1).

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WARD:_______________.			NO. 00123	
DRUG	FORM	STRENGTH	QUANTITY REQUESTED	QUANTITY SUPPLIED
MORPHINE	SOLUTION	5MG IN 5 ML	3 × 150 ML	3 × 150 ML
Requested by:	date:			
Supplied by:	date:			
Checked by:	date:			
Collected by:	date:			
Received on ward by:	date:			

Figure A.1 Sample of ward opioid order book.

All records should be kept in an immovable locked cupboard for 2 years from the date of last entry. There should be one book for each type of opioid (e.g., one for morphine and another for fentanyl).

Within each book there should be separate sections for various forms of the medicine (e.g., morphine oral liquid 5 mg/mL, morphine oral liquid 10 mg/mL, morphine injectable 10 mg/mL).

New record books should be available from the pharmacy.

Storage of scheduled medicines

The Single Convention does not have specific storage requirements for Schedule I and II drugs. Each country has the discretion to implement national laws and regulations to meet the fundamental requirements of the Single Convention to ensure access and control diversion of Schedule I and II drugs. These guidelines recommend the following with regard to storage of Schedule I and II medicines in hospital wards. However, each country should establish requirements that are suited to its prevailing conditions.

- Schedule I/II medicines should be stored in a specified and secure locked cupboard or lockbox.
- The keys for the cupboard or lockbox should be kept by the pharmacist-in-charge (if there is a pharmacy on the ward) or the ward leader.
- Procedures should be in place to allow for 24-hour access in case of emergencies (e.g., accidental spillage that could lead to interrupted supply to patients).

Ward ordering of Schedule I/II medicines from the pharmacy

These guidelines offer the following recommendations for ward ordering of medicines from the pharmacy:

1. Persons to order these medicines should be defined and approved by the medical director. The appropriate person may be the ward leader or a senior nurse.
2. Authorized staff must submit their names and sample signatures to the pharmacy.
3. When the stock level falls to a minimum, new stock should be ordered from the pharmacy using the ward ordering book (Figure A.1).

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4. Ward ordering books should be kept on the ward. New ward ordering books should be obtained from the pharmacy.
5. Fill out in the order book the medicine and its form, strength, and quantity, and submit it to the pharmacy.
6. Each form and strength of the medicine is ordered on a separate page.
7. The person making the order of medicines should sign and date the order.
8. Staff authorized to collect these medicines should be specified and agreed by the pharmacist-in-charge, senior nurse, and medical director.
9. The person collecting the medicines should sign the Ward Ordering Book and the pharmacy medicines register.
10. The receiving ward nurse-in-charge should check the medicines and then sign the ordering book to indicate that the medicines were received.

Administering Schedule I/II medicines on the ward

These guidelines offer the following recommendations with regard to administering Schedule I/II medicines on the ward:

1. These medicines are only administered following prescription by an authorized prescriber (doctor and, in some settings, also a clinical officer or nurse practitioner).
2. Prescriptions may be written in duplicate—one copy to remain in the pharmacy and another in the patient's ward file. However, a prescription may also be entered into the written or electronic medical record.
3. If these medicines are not kept on the ward, the nurse should take the prescription or treatment card/sheet to the pharmacy and obtain them.
4. If the ward stocks the required medicines, the nurse should carefully check the details of the prescription:
   - Medicine and form (e.g., solution, tablets, injection)
   - Dose
   - Prescriber's name and signature
   - Date and times of administration
   - Patient's age
   - Any allergies and drug interactions the patient may have.
5. If any of the above details are missing or unclear, the nurse should attempt to contact the prescriber or another doctor.
6. In all cases, the nurse should record giving the medicine including:
   - Form and strength
   - Quantity
   - Nurse's name and signature,
   - Date and the time of administration
7. An entry must be made in the written or electronic medicine record.
8. In some settings, the patient or relative could be asked to sign for receiving the medicine in the medicine record book.
9. When patients keep tablets and solutions by their bedside:
   - The nurse should check and document the quantity both on a label and in the medical record and also write on the label the patient's name, medical record number or birthdate, and the directions for taking the medicine.
   - Another member of staff should check and confirm this information.
   - Each day the nurse must check that the patient has taken the medicine as prescribed. The doctor should be informed, a record made in the patient's medical record, and the patient (or family caregiver) counseled if the medicine was taken inappropriately.

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10. When the medicines are kept centrally or in the case of injections:
    - In some settings, another nurse may be required to check the medicine, form, and quantity before it is given.
    - The time of administration should be recorded.
    - If the patient does not take the medicine, the reason should be recorded in the patient's medical record.
    - If a nurse must dispose of an opioid, another nurse or a pharmacist should observe when it is discarded, and both should make a note in the medical record confirming the medicine and amount discarded.
    - On discharge, the nurse should advise the prescriber of any medicines the patient still has.

A guide for home care teams

Home care teams may need to carry legal Schedule I/II medicines (opioids) for patients who are at home. The teams need to adhere to national laws and regulations pertaining to handling of Schedule I and II medicines. The following section provides guidance both for policymakers and home care teams.

Patient medical records

Article 34(b) of the Single Convention on Narcotic Drugs requires that hospitals keep records of the quantities of controlled drugs manufactured and of each individual acquisition and disposal of drugs. Such records should be preserved for a period of not less than 2 years. These guidelines also recommend the following for home care teams:

1. Home care teams should keep separate records for each patient. These should include a section for medication, which can also be the prescription itself.
2. A record should be kept of each dose of each medicine given to the patient.
3. The total quantity to be dispensed to the patient should be written in words and figures to prevent any discrepancies.
4. Written records should be securely kept under lock and key and a person responsible for the key nominated.
5. Patient records must be kept for at least 2 years after the patient dies or is discharged from the program.

Prescribers of Schedule I and II medicines

Article 30 (b)(i) of the Convention does not specify who may or may not prescribe, other than to say that a "medical prescription" is required for the supply and dispensation of drugs to individuals. These guidelines offer the following recommendations with regard to prescribing:

1. Check national laws and regulations and follow accordingly; however, registered doctors, dental surgeons, and veterinary doctors are typically allowed to prescribe.
2. In some settings, it may be beneficial and safe if specially trained nurse practitioners and clinical officers are allowed to prescribe.

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3. The authorized prescriber's name and signature should be given to the pharmacy. Identification should be checked by the pharmacy. Any new health worker should ensure that his or her name and written or electronic signature are submitted to the pharmacy.

Who can dispense Schedule I and II medicines

1. National laws and regulations should be followed about who can dispense these medicines. However, it typically is a pharmacist, pharmacy technician, doctor, or nurse providing palliative home care.
2. Wherever possible, any dispensing should be checked and confirmed by another member of the home care staff in the written or electronic medical record.

How these medicines should be stored

All medicines should be kept in a secure locked cupboard or lockbox at all times, except during the home visits when they are carried in the health worker's medicine bag.

Medicine bags

a. Need to have a complete list of the contents for each day or visit, including the quantities of medicines and any equipment. This list should be entered into a written or electronic medical or pharmacy record.
b. On any given day, the contents may vary depending on the needs of the patients to be visited.
c. The contents should include:
    - A "standard medicines bag" containing medicines that are not designated to particular patients but frequently are needed.
    - A "daily medicine bag" containing any medicines needed for patients to be seen that day and not included in the standard medicine bag and required in case of need.
d. Any Scheduled I or II medicines dispensed should be documented in the patient's written or electronic medical record.
e. Any Scheduled I or II medicines carried but not dispensed on a given day must be returned to the pharmacy's locked cupboard or lockbox and the amount recorded in the written or electronic medical or pharmacy record.

On the first home visit

1. The health worker should:
    a. Ask to see any medicines (including traditional medicines) that the patient is currently taking.
    b. Explain carefully to the patient or family caregiver:
        i. What each medicine is for
        ii. How it should be taken
        iii. Possible adverse effects (e.g., constipation) and how to manage them
2. The patient or family caregiver should be asked to sign for receipt of the medicines.

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3. It is recommended that the patient and family caregiver be given a chart (medicines chart) detailing the medicines and how they should be taken (Table A.1). This should include:
   - Medicines they were previously taking which the team would recommend they continue
   - The date of the next planned visit

Following visits

1. The pharmacy should record details of Schedule I/II medicines dispensed in the Scheduled I and II in the written or electronic pharmacy record.
2. Any Schedule I/II medicines dispensed (including those for the extra bags) should be returned and secured.
3. The team member returning (and collecting) the medicines from the pharmacy should sign the pharmacy Schedule I/II medicines register.
4. Any medicines that are no longer required should be recorded during the visit at which they are stopped and the reason specified.
5. The patient's medication chart should be checked and amended as necessary.
6. The pharmacy records and the patient's medical records should be kept in a secure place, available for inspection, for at least 2 years from when the patient dies or is discharged from the program.

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Table A.1 Medication record for home care teams

Patient Name:__________ Patient No.:__________									
Date prescribed	**Date stopped**	**Medicine, form and strength**	**Dose and Directions**	**Quantity left**	**Quantity supplied**	**Reason prescribed/ stopped/ dose change**	**Person who prescribed**	**Signature of pre- scriber**	**Signature of patient/ relative**
12/02/10		**Morphine solution 5 mg/ 5 mL**	**5 mg q4h and 10 mg at night**	**New**	**105 mL × 5 mg in 5 mL (also in words)**	**For pain**			
12/02/10		**Senna Tabs 7.5 mg**	**2 at night**	**New**	**18 tabs**	**To prevent constipation**			
12/02/10		**Amitriptyline tabs 25 mg**	**1 at night**	**New**	**14 tabs**	**Nerve pain**			
12/02/10		**Ibuprofen 200 mg tabs**	**2 tabs q8h**	**New**	**32 tabs**	**Bone pain**			

Medication Record for Home Care Teams (Adapted from the Uganda Ministry of Health Guidelines for Handling Class A drugs, 2001). African Palliative Care Association.

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APPENDIX 3

Brief Pain Inventory

Date: ☐☐/☐☐/☐☐ Study Title: (used when needed)

(date) (month) (year)

Patient's name:
Study Code: (used when needed) ☐☐☐☐ Study Number: (used when needed)

Brief Pain Inventory

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

☐ Yes ☐ No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

Front Back

Front Back
Right Left Left Right

3. Please rate your pain by ticking the one box that best describes your pain at its worst in the past 24 hours.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

No pain — pain as much as you can imagine

4. Please rate your pain by ticking the one box that best describes your pain at its least in the past 24 hours.

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☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

No pain — pain as much as you can imagine

5. Please rate your pain by ticking the one box that best describes your pain on the average.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

No pain — pain as much as you can imagine

6. Please rate your pain by ticking the one box that tells how much pain you have right now.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

No pain — pain as much as you can imagine

7. What treatments or medications are you receiving for your pain?

____

8. In the past 24 hours, how much relief have pain treatments or medications provided? Please tick the one box that shows how much relief you have received.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
No relief										Complete relief

9. Tick the one box that shows how much pain, in the last 24 hours, has interfered with your:

A. General activity

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

Does not interfere — Completely interferes

B. Mood

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

Does not interfere — Completely interferes

C. Walking ability

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

Does not interfere — Completely interferes

D. Normal work (including work outside the home and housework)

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10

Does not interfere — Completely interferes

E. Relations with other people

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☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10 Does not interfere … Completely interferes
F. Sleeping
☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10 Does not interfere … Completely interferes
F. Enjoyment of life
☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 10 Does not interfere … Completely interferes

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APPENDIX 4

Modified Palliative Outcomes Scale

Patient no. ________________	Possible responses
Ask the patient	
Q1. Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	0 (No pain) 5 (Worst/overwhelming pain)
Q2. If you have physical symptoms other than pain, how much have these symptoms bothered you in the last 3 days?	0 (Not bothered at all) 5 (Overwhelmingly distressing)
1. Lack of energy or fatigue	0–5
2. Mouth problems (dryness, soreness)	0–5
3. Shortness of breath	0–5
4. Nausea or vomiting.	0–5
5. Lack of appetite	
6. Others:	0–5
____	0–5
____	0–5
____	
Q3. Have you been feeling worried (anxious) in the past 3 days?	0 (Not at all) 5 (Overwhelming worry)
Q4. Have you been feeling sad (depressed) in the past 3 days?	0 (Not at all) 5 (Overwhelming worry)
Q5. Over the past 3 days, have you felt rejected or stigmatized because of your illness?	0 (Not at all) 5 (Overwhelmingly)
Q6. Over the past 3 days, have you felt supported emotionally by your family or friends?	0 (Not at all) 5 (Yes, fully supported emotionally)
Q7. Over the past 3 days, have you been concerned about lack of money to meet basic needs of you or your family? (Examples of basic needs: treatment, food, school fees, transport, rent.)	0 (No, not at all) 5 (Yes, overwhelming concern)
Q8. Over the past 3 days, have you felt at peace?	0 (No, not at all) 5 (Yes, all the time)
Q9. Have you had as much information as you wanted about your illness?	0 (Not at all) 5 (As much as wanted)

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Patient no. ________________	Possible responses
Q10. Among these or any other concerns, what have been your main concerns over the past 3 days?	1. ____________ 2. ____________ 3. ____________
Ask the family carer	
Q11. Have you had as much information as you wanted about the patient's illness?	0 (None) 5 (As much as wanted) N/A (None wanted)
Q12. Do you and the family have all the practical support you need to care for the patient (for example nursing care or advice on caring)?	0 (Not at all) 5 (Have all needed support)
Q13. Have you been feeling worried (anxious) in the past 3 days?	0 (Not at all) 5 (Overwhelming worry)
Q14. Have you been feeling sad (depressed) in the past 3 days?	0 (Not at all) 5 (Overwhelming worry)
Q15. If you have any physical symptoms caused by caregiving, how much have these symptoms bothered you in the last 3 days?	0 (Not bothered at all) 5 (Overwhelmingly distressing)
1. Pain	0–5
2. Lack of energy or fatigue	0–5
3. Difficulty sleeping	0–5
4. Others:	
____________	0–5
____________	0–5
____________	0–5
Q16. Over the past 3 days, have you been concerned about lack of money to meet basic needs of you or your family? (Examples of basic needs: treatment, food, school fees, transport, rent.)	0 (No, not at all) 5 (Yes, an overwhelming concern)

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APPENDIX 5

Advance directives

1. Advance directives enable clinicians to know how to respond in case of sudden deterioration of the patient's condition.
2. Optimum care requires:
   - That the patient's values be explored as soon as a palliative care need is identified.
   - That a specific surrogate decision-maker is clearly identified who will speak for the patient if the patient loses decision-making capacity or declines to participate in medical decision-making.
   - That the understanding of the medical situation by the patient, surrogate decision-maker, or family be explored and that any misunderstandings be corrected.
   - That the goal(s) of care be agreed upon with the patient, surrogate decision-maker, or family based on understanding of the clinical situation and the patient's values.
   - That decisions be made about use of invasive life-sustaining treatment such as cardiopulmonary resuscitation (CPR), mechanical ventilation, non-invasive ventilator support, hemodialysis, and artificial nutrition (see Chapter 9).
3. Two types of advance directive are recommended for patients with serious chronic illnesses:
   a. Advance directive 1: Life-sustaining treatment

<table>
<tr><td colspan="2">Advance directive 1: Life-sustaining treatment</td></tr>
<tr><td colspan="2">Regarding the care of ______________________________ (write name of patient), I affirm that I have been informed about the potential benefits and harms of cardiopulmonary resuscitation (CPR), endotracheal intubation, and mechanical ventilation, and I direct the treating team as shown below.
I understand that I can change or revoke my directions at any time.</td></tr>
<tr><td>A</td><td>Cardiopulmonary resuscitation (CPR)
In case of cardiac or respiratory arrest:
☐ Do not resuscitate ☐ Attempt resuscitation</td></tr>
<tr><td>B</td><td>Intubation/mechanical ventilation
In case of respiratory failure:
☐ Do not intubate or mechanically ventilate; instead focus care on comfort
☐ Intubation or mechanically ventilation are acceptable</td></tr>
<tr><td>C</td><td>Signed in Section C by:
☐ The patient ☐ Parent or guardian of a child patient ☐ Family member representing the family
Signature: _________________________ Date: _________________
Print name of the signer: _______________ Mobile of signer: __________________</td></tr>
</table>

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Advance directive 1: Life-sustaining treatment	
D	Signature of doctor Signature confirms that this form accurately reflects discussion with the Section C signer. Signature: ______________________ Date: ________________ Print name of the signer: _______________________
E	Signature of Department Chairperson or Hospital Director Signature: ______________________ Date: ________________ Print name of the signer: _______________________
The comfort of every patient should be maximized.	

b. **Advance directive 2: Surrogate decision-maker**

Advance directive 2: Surrogate decision-maker	
Patient's name: _________________________________ I affirm that I wish to appoint _____________________________ (name of surrogate decision-maker) to receive all medical information and to make all medical decisions on my behalf if I am unable to make or communicate medical decisions or if I decline to make medical decisions. I understand that I can change or revoke at any time my choice of surrogate decision-maker.	
A	Signature of patient: Signature: ____________________ Date: ________________
B	Signature of Surrogate Decision-maker: Signature: ____________________ Date: ________________ Print name of the signer: _________________ Mobile: ___________________
C	Signature of doctor: Signature: ______________________ Date: ________________ Print name of the signer: _______________________
D	Signature of Nurse: Signature: ______________________ Date: ________________ Print name of the signer: _______________________
The comfort of every patient should be maximized.	

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APPENDIX 6

Infection control when caring for people with HIV infection

A. General

1. HIV is present in blood, blood-containing fluids, and most bodily fluids including vaginal discharge, semen, cerebrospinal fluid, peritoneum fluid, articular membrane fluid, amniotic fluid.
2. HIV is not present in tears, sweat, urine, or non-bloody emesis.
3. Blood and body discharge should be assumed to contain HIV and Hepatitis B and C virus.
4. Risk of HIV infection to caregivers is very low when universal precautions are taken.

B. Universal precautions

1. Purpose: Minimize exposure to blood and body fluids
2. Use of protective barriers:
   a. Wear gloves, masks, gowns, eye protection whenever contact with blood or body fluids is anticipated.
3. Hand hygiene:
   a. Wash hands with water and soap for more than 10 seconds and dry with single-use towel.
   b. Then use of hand sanitizer with 50–95% ethyl or isopropyl alcohol.
4. Environmental control:
   a. Clean visible blood/fluid with towel and discard.
   b. Disinfect the area with intermediate-level disinfectants such as1:100 dilution (500 ppm) of hypochlorite.
5. Sharps management:
   a. Do not recap needles.
   b. Safely dispose of sharps after use.
   c. Use puncture-resistant containers.
   d. Monitor containers for overfilling.
   e. Ensure that adequate numbers of containers are available wherever sharps are used.
   f. Incinerate sharps containers when full.
6. Instructions for home care:
   a. When the patient's clothes or sheets have blood or other bodily discharge on them, they must be separated from that of the others in the family and washed with bleach solution.

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APPENDIX 7

Infection control when caring for people with multidrug-resistant tuberculosis

1. Special care must be taken when caring for people with multidrug-resistant or extensively drug resistant tuberculosis (M/XDR-TB) to protect healthcare providers from becoming infected.
2. When a patient with active M/XDR-TB is sent home, care also must be taken to protect family members and community members from becoming infected.
3. Essential infection control methods include all of the following:
   a. Training in infection control for all healthcare providers.
   b. Use by the patient of a surgical mask whenever outside the bedroom and whenever family members or caregivers are present.
   c. Use of N95 masks by all family members and healthcare providers when with the patient.
   d. Thorough handwashing by the patient and all contacts.
   e. A separate bedroom for the patient.
   f. Open windows whenever possible.

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Glossary

Accompaniment – Visiting patients regularly and faithfully; the opposite of *abandonment*.

Acute pain – Pain that is temporary, usually sudden in onset, and usually has an obvious cause such as a surgery, injury, or infection.

Adherence to treatment – The ability of a patient to complete or maintain a treatment regimen as prescribed to obtain the best possible treatment outcome.

Advance care planning – A practice of discussing and clarifying over time a patient's understanding of their illness, their values and preferences for care near the end of life, or how medical decisions should be made if the patient loses decision-making capacity.

Advance directive – A document that specifies either:
- A patient's values or preferences for care near the end of life
- How medical decisions should be made if the patient loses decision-making capacity.

Beneficence – Doing good, or acting in a way that does good for others.

Bereavement support – Psychological or spiritual counseling or other emotional support for a person grieving after the death of a loved one.

Children – Persons up to their 18th birthday/age of 18 years.

Community health workers (CHWs) – Members of the community where they work, should be selected by the community, should be answerable to the community for their activities, should be supported by the health system but not necessarily be a part of it, and have shorter training than professional health workers.

Complicated grief – Persistence for at least 6 months of distressing preoccupation with the deceased, impaired social functioning and physical health, difficulty accepting the death, and feeling that life is empty or purposeless.

Developmental stages – Age ranges in which most children can do specific sets of increasingly complex tasks because they have specific sets of increasingly refined functional skills.

Dignity – The quality, state, or feeling of being worthy, honored, or esteemed.

Disease-modifying therapies – Therapies intended to cure or control specific diseases.

Double agency – Having two main motivations at the same time.

Euthanasia – Intentionally and directly causing the death of a patient (unethical and illegal).

Frailty – A state of weakness, fragility, and vulnerability that typically results from advanced age or disease.

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Goals of care – The main aims or foci of care such as "cure," "comfort," "prolong life but also maximize quality of life," etc.

Health – A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.

Hospice – An organization or institution devoted entirely to providing inpatient or outpatient palliative care for patients nearing the end of life.

Informed consent – The process of informing the patient or family about the diagnosis and potential treatments in a way that is understandable (if they wish to know) and assisting them to decide on the best treatment.

Integrated health services – Health services that are managed and delivered in a way that ensures people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation, and palliative care services at the different levels and sites of care within the health system and according to their needs throughout their life course.

Integration into health systems – The building of a new feature into existing health systems.

Interdisciplinary team – People from different disciplines with different training and skills working together to achieve what each of them alone could not.

Life-sustaining treatment – Treatments designed to prolong life or stave off death such as cardiopulmonary resuscitation, mechanical ventilation, hemodialysis, artificial nutrition and hydration, etc.

Noncommunicable disease (NCD) – A disease or medical condition that is non-infectious and non-transmissible among people, such as heart disease, stroke, cancer, diabetes, and chronic lung disease.

Non-maleficence – Not doing harm or harming others.

Palliative care – The prevention and relief of suffering of any kind—physical, psychological, social, or spiritual—experienced by adults and children living with serious health problems using best available evidence. It is a people-centered accompanying of patients and their families throughout the illness course, including at the end of life, that optimizes quality of life and maximizes dignity. It is an essential component of comprehensive care for persons with serious health problems that should be accessible at all levels of the healthcare system and in patients' homes. Accordingly, specialized palliative care should be provided at major general hospitals and cancer centers; intermediate-level palliative care should be provided by specialists in internal medicine, family medicine, pediatrics, oncology, hematology, and other disciplines based in hospitals; and basic palliative care should be provided by primary care providers in the community.

Palliative care—basic (generalist) – Basic assessment for physical, psychological, social, or spiritual suffering, and relief of easily relievable suffering, and referral, if possible, to intermediate or specialist palliative care providers for relief of more complex or refractory suffering.

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Palliative care—intermediate – Prevention, assessment, and relief of easily preventable or relievable suffering, or of more complex or refractory suffering, as part of specialist care for patients with serious health problems.

Palliative care—specialized – Prevention, assessment, and relief of suffering of any kind and of any severity or level of complexity by healthcare workers with extensive training in palliative care.

Palliative care specialist – A physician, nurse, or other clinician with specialist training or extensive experience in palliative care whose work is mainly in palliative care.

Palliative care specialized service – An interdisciplinary team whose members have specialized training or extensive experience in palliative care; that has expertise in preventing and relieving complex or refractory suffering of all kinds experienced by adults and children living with serious health problems in one or more settings (inpatient, outpatient, home care); and that can provide palliative care training and consultation.

Palliative care team – An interdisciplinary group, whose members have at least basic training in palliative care, designed to prevent and relieve suffering of any kind experienced by adults and children living with serious health problems in one or more settings (inpatient, outpatient, home care).

Palliative care unit – Within an inpatient healthcare institution, a location, room, ward, or cluster of beds devoted to palliative care where an inpatient palliative care team works.

Palliative sedation – Sedation to relieve refractory symptoms of a dying patient (allowed).

Patients values – What matters most or is most important to a patient. Examples may include avoidance or relief of any suffering, spending time with loved ones, being at home, adherence to religious or cultural rituals, etc.

People-centered – Focused on the patient as a whole that includes biological, psychological, social, and spiritual dimensions, not just on specific diseases or organ systems. Also attending to the patient's family.

Physician-assisted suicide or physician aid in dying – Intentionally assisting a patient to end their life by prescribing or otherwise providing for them the means to end their life.

Primary healthcare (PHC) – Essential healthcare based on practical, scientifically sound, and socially acceptable methods and technology. It is the central function and main focus of a country's health system, is essential for the overall social and economic development of the community, and is the first level of contact with the national health system; it brings healthcare as close as possible to where people live and work. It should be universally accessible to individuals and families in the community, and it should be affordable.

Quality of life – A person's self-perceived level of general well-being or level of health, comfort, and happiness.

Serious health problems – Illnesses, disabilities, or symptoms, either chronic or acute, that significantly impair the patient's quality of life or ability to perform typical activities of daily life. Examples include cancer and major organ failure; life-threatening or

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debilitating infections such as HIV/AIDS, multidrug-resistant tuberculosis, or Ebola; serious injuries; serious congenital abnormalities or severely low birthweight; and multiple coexisting morbidities.

Serious congenital health problems – Serious health problems that are either present at birth or develop in the perinatal period. Examples include serious anatomic or physiologic abnormalities and perinatal traumatic injury.

Shared decision-making – A process whereby healthcare professionals and a patient or their surrogate decision-makers discuss and clarify the diagnosis and prognosis and the patient's values and then try to come to agreement about the goals and specific plans of care.

Social suffering – Suffering from social problems, such as extreme poverty, inadequate housing, inadequate food, stigmatization, discrimination, or social isolation.

Social support – Actions to relieve social suffering, such as providing food packages for patients and families with inadequate access to nutrition, transportation to healthcare appointments for those who cannot afford it, or school tuition for families of patients who cannot afford it; efforts to arrange for free or affordable healthcare for families at risk of financial catastrophe due to out-of-pocket payments; and frequently visiting the socially isolated or stigmatized.

Spiritual suffering – Suffering from spiritual problems, such as a crisis or loss of faith or loss of a sense of meaning in life.

Spiritual support – Actions to relieve spiritual suffering, such as religious counseling for crises of faith or loss of a sense of meaning in life, religious ritual to absolve guilt, or assistance with life review.

Suffering – The state of undergoing physical, emotional, social, or spiritual pain, distress, or misery due to illness, injury, loss, or deprivation.

Universal health coverage (UHC) – Health coverage that provides people with the health services they need while protecting them from exposure to financial hardship incurred in obtaining care. Health services are broadly defined to include

- Health promotion initiatives (such as anti-tobacco policies or emergency preparedness)
- Disease prevention activities (such as vaccination)
- Provision of treatment, rehabilitation and palliative care (such as symptom relief and end-of-life care) of sufficient quality to be effective.

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Index

For the benefit of digital users, indexed terms that span two pages (e.g., 52–53) may, on occasion, appear on only one of those pages.

Tables, figures, and boxes are indicated by an italic *t*, *f*, and *b* following the page number.

adjustment disorder, 51*t*, 69
advance directive, 104, 147
agitation, 9, 20, 30, 33*t*, 39*t*, 66, 67, 107, 109
allodynia, 17, 18
amitriptyline, 32, 33*t*, 39*t*, 51*t*, 85*t*, 118, 139*t*
anemia, 39*t*, 59
antihistamine, 39*t*, 51*t*
anxiety, 9, 18, 20, 30, 38, 39*t*, 49, 50, 51*t*, 64, 65, 67, 70, 85*t*, 86, 89, 109, 110, 124
aphthous ulcer, 39*t*
artificial hydration, 106–8
artificial nutrition, 8, 59, 65, 66, 67, 94, 103, 106–8, 147
ascites, 59, 61, 66, 107
aspiration, 39*t*, 69, 94, 107, 124

baclofen, 33*t*
bereavement, 5*f*, 5, 49, 50, 51, 51*t*, 87, 93, 109–11
birth, prematurity, 6, 76
bisacodyl, 31*t*, 39*t*, 85*t*, 118
bisphosphonate, 33*t*, 35
bowel obstruction, 14, 17, 35, 38, 39*t*, 60, 85*t*
breaking bad news, 101–3

cachexia, 27*t*, 59, 65, 66
cancer, xv, 1–2, 4, 6, 7, 9, 10, 14, 17, 35, 39*t*, 51*t*, 58–61, 106, 107, 111, 113, 119, 124
  cancer pain, 21–22, 26*t*, 27*t*, 35, 36
  cervical cancer, 2, 55, 56*t*
  chemotherapy, curative, 59, 85*t*
  chemotherapy, palliative, 39*t*, 59, 85*t*
  radiation therapy, palliative, 39*t*, 60, 85*t*
  surgery, palliative, 60–61
cardiopulmonary resuscitation, 104–6
caregivers, xv–xvi, 9, 62, 66, 67, 74, 79, 80, 89, 94–95, 96, 99, 100*b*, 119, 135, 137, 138, 149, 151
chlorpheniramine, 39*t*
chronic obstructive pulmonary disease (COPD), 39*t*, 91
cimetidine, 85*t*
citalopram, 39*t*, 51*t*
codeine, 26*t*, 28*t*, 39*t*
communication, patient-doctor, 95, 98–99, 99*b*, 105
community health centers, 3, 96, 115, 116–17, 118, 119
community health workers, xvi, 5, 55, 63, 67, 69, 96, 117
compassion, 54, 128
congenital anomalies, 1–2, 76*t*, 77*t*
constipation, 31*t*, 33*t*, 39*t*, 51*t*, 59, 85*t*, 89, 129, 137, 139*t*
contextually appropriate care, xv–xvi, 1–3, 98–99, 99*b*–100*b*, 114–15
cough, 39*t*, 107
culture, 98, 100*b*, 100–1, 109, 114–15

delirium, 22, 31*t*, 33*t*, 39*t*, 49, 50, 51*t*, 85*t*, 107
dementia, xvi, 31*t*, 51*t*, 66–67, 106
depression, 18, 20, 39*t*, 49, 50, 51*t*, 67, 68, 69, 70, 79, 110, 111, 124
developmental stages of childhood, 76, 76*t*, 77–79
dexamethasone, 32, 33*t*, 54, 55, 74, 85*t*, 118
diarrhea, 27*t*, 30, 39*t*, 59, 85*t*, 89, 124
diazepam, 31*t*, 33*t*, 35, 39*t*, 51*t*, 74, 75, 118, 119
differential diagnosis of symptoms, 14, 19, 38
diphenhydramine, 39*t*, 51*t*, 85*t*, 118
discharge planning, 94–95, 96, 97, 108, 116, 129, 136
district hospitals, 96, 108, 115, 116, 117, 118
dyspnea, 7, 9, 12, 14, 20, 36, 39*t*, 58, 59, 60, 61, 63, 64–65, 66, 67, 69, 73, 74, 85*t*, 89, 90, 107, 109, 124
  terminal, 36, 39*t*, 64–65, 67, 73, 109

emetogenic toxin, 38, 39*t*, 85*t*
Essential Package of Palliative Care, 115, 118–20

Downloaded from https://academic.oup.com/book/61570 by OUP site access user on 06 November 2025

ethics, 1, 4, 6–9, 76, 105, 120, 125, 130

family caregivers, 9, 62, 66, 67, 74, 79, 80, 89, 94–95, 96, 100*b*, 119, 135, 137, 138, 151. *See also* caregivers
fatigue, 39*t*, 51*t*, 54, 59, 85*t*, 145
fecal impaction, 39*t*
fentanyl, 27*t*, 28*t*, 29, 84*t*, 134
  injectable, 27*t*, 28*t*, 29, 84*t*
  transdermal, 27*t*, 28*t*, 29
fetal demise, 5, 77*t*
fever, 27*t*, 30, 33*t*, 39*t*, 85*t*
fluconazole, 39*t*, 118
fluoxetine, 39*t*, 51*t*, 118
food insecurity, 10, 13, 51*t*, 56*t*, 67, 69, 119, 145
frail elders, 69
furosemide, 39*t*, 109, 118

gabapentin, 32, 33*t*
gastroparesis, 38, 39*t*, 85*t*
gastrostomy, 39*t*, 60, 94
geriatrics, 3, 69, 97. *See also* frail elders
glycerin suppository, 85*t*
goals of care, 5, 6, 8, 15, 39*t*, 58, 60, 64, 65, 72–73, 75, 97, 103, 104, 106, 117
grief, 50–51, 51*t*, 76*t*, 87, 93, 109–11, 128. *See also* bereavement

haloperidol, 31*t*, 38, 39*t*, 51*t*, 85*t*, 109, 119
heart failure, 65–66, 70, 71
hemorrhage, 14, 23*t*, 25, 39*t*, 58, 60, 70, 73–74
HIV/AIDS, 2, 4, 39*t*, 55, 61–62, 71, 77*t*, 97, 149
home care, 1–2, 56*t*, 91, 115, 117, 136–38, 139*t*, 149, 151
housing insecurity, 10, 18, 56*t*, 62, 119
humanitarian crises, 55, 113, 125
humanitarian crises, triage, 125, 125*t*
humanitarianism, 5, 55, 114, 123–25
hydrogel, 39*t*
hyoscine butylbromide, 33*t*, 35, 39*t*, 85*t*, 109, 118
hyperalgesia, 17, 18, 36
hypercalcemia, 39*t*, 51*t*

imaging, 9, 14, 16
immunotherapy, 59
increased intra-cranial pressure, 38, 39*t*, 85*t*
infection control, 62, 63, 149, 151
insomnia, 30, 39*t*, 85*t*, 89
interstitial lung disease, 39*t*, 63
itching, 31*t*, *See also* pruritis

kyphoplasty, 35*t*

laboratory tests, 9, 14, 39*t*
lactulose, 39*t*, 119
lidocaine, 32, 33*t*, 39*t*, 84*t*
lidocaine/prilocaine cream, 84*t*
life-sustaining treatment, 5, 8, 67, 76*t*, 76, 99*b*, 103–4, 106, 125*t*, 147
loperamide, 39*t*, 85*t*, 119
lorazepam, 85*t*

methadone maintenance therapy, 27*t*, 36
methylprednisolone, 39*t*, 85*t*
metoclopramide, 119
metronidazole, 119
midazolam, 84*t*
mirtazapine, 39*t*, 51*t*
morphine, xv, 22, 26*t*–28*t*, 39*t*, 64, 72, 73, 74, 81*f*, 82*f*, 83, 84*t*, 85*t*, 90, 96, 97, 108, 109, 116, 119, 127–28, 133, 134*f*, 134, 139*t*
  immediate release oral, 20, 23, 27*t*, 29, 116, 119
  injectable, 23, 27*t*, 28*t*, 29, 39*t*, 72, 73, 74, 84*t*–85*t*, 109, 119
  slow-release oral, 27*t*
mucositis, 59, 60
myoclonus, 22, 31*t*

naloxone, 30–31, 31*t*, 39*t*
nausea, 9, 12, 26*t*, 30, 33*t*, 39*t*, 51*t*, 59, 85*t*, 89, 145
  non-steroidal anti-inflammatory drugs (NSAIDS) xiii, 22, 23*t*, 25, 35, 82*t*
nurse practitioners, 3, 96–97, 135, 136
nursing, 3, 5, 55, 63, 74, 87, 89–90, 91, 92–93, 94–97, 100, 105, 115, 116, 117, 118, 129, 133, 134, 135, 136, 137, 145

omeprazole, 25
ondansetron, 39*t*, 85*t*, 119
opioid physical dependence, 26–29, 30
opioid tolerance, 26, 36
opioid use disorder, 36
opioids, 7, 21, 21*f*, 22, 23, 26–31, 26*t*–27*t*, 32, 33*t*, 35, 36, 37, 39*t*, 64, 66, 70, 72, 73, 83, 97, 119, 133, 134*f*, 134, 136
  adverse effects, 22, 26, 26*t*, 30–31, 31*t*, 36
  equianalgesic dosing, 28*t*

Downloaded from https://academic.oup.com/book/61570 by OUP site access user on 06 November 2025

respiratory depression, 30–31, 31*t*, 64, 72
safe supply chain
oral thrush (oral candidiasis), 39*t*
oxycodone, 27*t*–28*t*

pain, xv, 1–2, 3–4, 5, 7, 9, 12, 14, 16–23, 21*f*, 25, 26*t*, 27*t*, 29, 30, 31*t*, 32–35, 33*t*, 35*t*, 36–37, 39*t*, 49–50, 58, 59, 60, 61, 67, 69, 70–71, 72–74, 80–83, 81*f*, 82*t*, 82*f*, 83*f*, 84*t*, 85*t*, 89–91, 93, 95–97, 106–8, 109–11, 118–20, 124–25, 127–29, 133, 139*t*, 141, 145
assessment, adults, 9, 16–20, 141
assessment, children, 9, 20, 80, 81–83, 81*f*, 82*f*, 83*f*
breakthrough, 22, 23, 27*t*, 81*f*, 82*f*
classification, 16–18
crisis, 12, 31*t*, 72–73, 74
definition, 16
inflammatory, 18
measurement, 19–20
neuropathic, 17
nociceptive, 16
procedure–related, 83, 84*t*
somatic, 16–17
visceral, 17
pain treatment
adjuvant medicines, 21–22, 32–35, 33*t*, 36, 39*t*, 72, 85*t*
children, 9, 19, 20–37, 23*t*, 27*t*, 31*t*, 33*t*, 50, 76, 80–83, 82*t*, 82*f*, 83*f*, 84*t*, 85, 85*t*, 119
invasive procedures, 18, 29, 35, 35*t*, 83, 99*b*, 105, 106, 147
non–opioids, 21–22, 23–26, 23*t*, 36, 83
opioids, 7, 21–22, 23, 26–31, 26*t*–28*t*, 31*t*, 32, 33*t*, 35, 36, 37, 39*t*, 64, 66, 70, 72, 73, 83, 97, 119, 133, 134*f*, 136
and substance use disorders, 13, 18, 36–37, 51*t*, 61, 62, 63, 111
palliative care
assessment, 12–15
community health centers, 3, 69, 96, 108, 115, 116, 117–18, 119
and culture, 1–2, 4, 6, 98, 100*b*, 109, 114, 121, 127
emergencies, 10, 26, 35, 70, 72–75, 123, 134
essential package, 115–20
ethics, 1, 3–4, 6–9, 98–99, 105, 120, 125
in humanitarian crises and emergencies, 10, 26, 55, 72–75, 113, 125
implementation, 113, 114, 120
inpatient, 63, 89, 95, 96, 108, 116, 117, 118
integration, 2–3, 62, 113–22, 128
neonatal, 5, 23*t*–26*t*, 81, 81*f*, 84*t*, 85*t*
nursing, 5, 89–97
outpatient, 22, 29, 89, 95, 96, 116
pediatric, 76–88, 119, 120
policies, 113–15, 128
and primary care, 3, 5, 97
quality assessment, 120–21
standard operating procedures, 117
palliative home care, 56*t*, 91, 115, 117, 136–38, 139*t*, 149
palliative outcomes scale, 120, 145
pamidronate, 33*t*, 39*t*
paracetamol, 22, 23*t*, 26*t*, 39*t*, 81, 82*t*, 85*t*, 119
patient advocacy, 2, 93, 96, 114, 128
performance status, 14, 90, 131
peritoneal drain, 61
petroleum jelly, 39*t*, 119
physical examination, 9, 12, 14, 37, 80, 90
pleural drain, 61
pleural effusion, 39*t*, 59, 61, 66, 107
pneumonia, 39*t*, 67, 70
polyethylene glycol, 31*t*, 39*t*
policy, 113–15
post–traumatic stress disorder (PTSD), 18, 49, 51*t*, 70
poverty, xv, 5, 18, 51*t*, 55, 56*t*, 61, 62, 67, 69, 119
prednisolone, 33*t*
pressure–reducing mats/mattresses, 39*t*, 94, 119
pressure ulcers, 39*t*, 68, 69, 94
prolonged grief disorder, 50, 51*t*, 76*t*, 110, 111
pruritis, 31*t*, 39*t*
pseudo–addiction, 29
psychological first aid, 124
psycho–social support, xvii, 51*t*, 58, 61, 70–71, 103, 105, 121
pulmonary edema, 30, 39*t*, 66, 107
pulmonary embolism, 39*t*, 70

radiation therapy, adverse effects, 39*t*, 60, 85*t*
renal failure, 23*t*, 25, 26*t*, 27*t*, 29, 33*t*, 39*t*, 51*t*, 82*f*, 124
rescue dose, 22–23, 27*t*, 29, 39*t*, 64, 81*f*, 82*f*, 90
resilience, 55, 128

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respiratory secretions, 39*t*, 59, 65, 66, 85*t*, 107, 109

scabies, 39*t*
scopolamine, 33*t*
sedation, 5, 7, 8–9, 22, 30, 31*t*, 33*t*, 39*t*, 51*t*, 72, 73, 81*f*
seizure, 33*t*, 39*t*, 75
selective serotonin re–uptake inhibitors (SSRIs), 39*t*, 51*t*, 111
self–care, 128, 131
sertraline, 39*t*, 51*t*
social history, 13, 58, 64, 65, 89, 90, 98
social isolation, 56*t*, 69, 110
social suffering, 10, 55, 56*t*, 61, 62, 118
social supports, 51*t*, 55, 61, 67, 69, 86–87, 110, 119, 124
sorbitol, 85*t*
spinal cord compression, 35, 60, 61, 74–75
spiritual suffering, xvii, 38–57, 56*t*, 114, 118, 127
spiritual supporters, 3, 5, 15, 56*t*, 93, 120
stigma, 6, 10, 18, 55, 56*t*, 56, 61, 62, 101*b*, 145
still birth. *See* fetal demise
subcutaneous injection / infusion, xiii, 14, 15, 21, 23, 27*t*, 31*t*, 33*t*, 39*t*, 84*t*, 91, 92*f*, 97
substance use disorders, 13, 18, 36–37, 51*t*, 61, 62, 63, 111

tramadol, 26*t*, 28*t*
trauma, physical, xvii, 18, 39*t*, 68, 70, 77*t*, 124
trauma, psychological, xvii, 3–4, 5, 9, 49–50, 51*t*, 70, 71, 130
tuberculosis, xvi, 2, 3, 4, 39*t*, 62–63, 77*t*, 97, 151

valproate, 32, 33*t*, 51*t*
vertebroplasty, 35*t*
vomiting, 12, 30, 38, 39*t*, 59, 85*t*, 89, 124, 145

World Health Organization (WHO), xiii, 1, 2, 21*f*, 113–14, 120, 128
wounds, 39*t*, 77*t*, 90, 94

zoledronate, 33*t*, 35, 39*t*

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