COH-PPRC

Index/Order Form of Materials

The purpose of the COHPPRC is to disseminate information and resources to assist others in addressing pain management, palliative care, quality of life and cancer survivorship. The COHPPRC, established in 1995, is a central source for collecting a variety of materials including pain assessment tools, patient education materials, quality assurance materials, palliative care resources, research instruments and other resources.

If you have materials that may be useful to others related to these topics you are invited to contribute them. Please contact Celeste Radell or Betty Ferrell, RN, PhD, FAAN at the City of Hope for a materials submission form so that you will be properly credited for your contribution.

Note: Most items or item information is downloadable on our website: http://prc.coh.org.

Please feel free to copy this index of materials and distribute to whomever you feel would benefit from this service.
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CITY OF HOPE PAIN & PALLIATIVE CARE RESOURCE CENTER
Index of Materials

Under each section, materials are organized under the following categories:

- City of Hope Publications
- Recommended Publications
- Educational Materials/Curriculum
- Guidelines/Clinical Pathways
- Other Organizational Links
- Key References
- Position Statements/Standards

I. Quality of Life and Cancer Survivorship

Section Description: This section includes City of Hope publications and figures of the City of Hope Quality of Life conceptual models. The section also includes City of Hope Publications related to Quality of Life in specific populations of ovarian cancer, breast cancer, cancer survivors, and Hematopoietic cell transplantation.

For more information on measurement tools, refer to Section IX. Research Instruments/Resources.

Quality of Life Models – all of the models include a list of references (see online PRC for links to models)

- Quality of Life Breast Cancer Model
- Quality of Life Cancer Survivor Model
- Quality of Life Ovarian Cancer Model
- Quality of Life Family Caregiver Model
- Quality of Life Effect of Fatigue
- Quality of Life Hematopoietic Cell Transplant (Bone Marrow Transplant)
- Quality of Life Ostomy Model
- Quality of Life Pain-Impact Model

City of Hope Publications


Recommended Publications


37. From Cancer Patient to Cancer Survivor: Lost in Transition
     Website: http://books.nap.edu/catalog.php?record_id=11468#toc. Read online FREE!

**Educational Materials/Curriculum**

1. Cancer Survival Toolbox - National Coalition for Cancer Survivorship
   - The Cancer Survival Toolbox is a free, self-learning audio program that has been developed by leading cancer organizations to help people develop important skills to better meet and understand the challenges of their illness. You can read or listen to the Toolbox in English and Spanish or download the files to read or listen later. Chinese transcripts are also available. Website: http://www.canceradvocacy.org/toolbox/.

2. Coping with Cancer: Supportive and Palliative Care - National Cancer Institute

3. Facing Forward – Life after Cancer Treatment – National Cancer Institute
   - This booklet shares what the NCI has learned from cancer survivors about life after cancer including practical ways of dealing with common problems and guidelines for managing your physical, social, and emotional health. Also available in Spanish. Website: http://www.cancer.gov/cancertopics/life-after-treatment.

4. Pink Ribbon Survivors Network - Rocky Mountain Cancer Centers
   - This network hosts three online libraries that serve as resources for breast cancer survivors, caregivers, healthcare providers and referring physicians. Website: http://www.pinkribbonsurvivorsnetwork.org/

5. R.A. Bloch Cancer Foundation & Bloch Cancer Hotline
   - There are over 300 up to date cancer support organizations listed supporting specific types of cancer, organizations offering financial aid, blogs, a cancer checklist, patient matching services, meditation, transportation and more. Website: http://blochcancer.org/

6. Survivorship: During and After Treatment – American Cancer Society
   - Tips on staying active and healthy during and after cancer treatment. You can also get information on dealing with the possibility of cancer recurrence, and find inspiration and hope in stories about other people whose lives have been touched by cancer. Website: http://www.cancer.org/Treatment/SurvivorshipDuringandAfterTreatment/index.

**Guidelines/Clinical Pathways**

1. Long-Term Follow Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers - CureSearch
   - The Long-Term Follow-Up Guidelines were developed as a resource for clinicians who provide ongoing healthcare to survivors of pediatric cancer. Website: http://www.survivorshipguidelines.org.

2. NCCN Clinical Practice Guidelines – National Comprehensive Cancer Network
   - NCCN Guidelines have become the most widely used guidelines in oncology practice and have been requested by cancer care professionals in over 115 countries. There has also been substantial international interest in translating the guidelines into a variety of languages. Select NCCN Guidelines have been translated into Chinese, German, Italian, Japanese, Russian, and Spanish. Website: http://www.nccn.org/professionals/physician_gls/f_guidelines.asp.

3. The National Action Plan for Cancer Survivorship – Centers for Disease Control and Prevention & Lance Armstrong Foundation
   - Developed to identify and prioritize cancer survivorship needs that will advance cancer survivorship in national, state, and community-level public health organizations. Website: http://www.cdc.gov/cancer/survivorship/what_cdc_is_doing/action_plan.htm.
I. Quality of Life and Cancer Survivorship

A. Lung Cancer

Section Description: This section includes City of Hope publications and other resources and publications related to quality of life in lung cancer care.

City of Hope Publications


I. Quality of Life and Cancer Survivorship

B. Ovarian Cancer

Section Description: This section includes City of Hope publications and other resources and publications related to quality of life in patients with ovarian cancer.

City of Hope Publications


I. Quality of Life and Cancer Survivorship

C. Breast Cancer

Section Description: This section includes City of Hope publications and other resources and publications related to quality of life in breast cancer patients.

City of Hope Publications


II. Spirituality

Section Description: This section includes City of Hope publications and other resources relating to spirituality in health care including articles relating to cross-cultural topics. There is a listing of tools for assessing spirituality and spiritual concerns, links to organizational position statements relating to spirituality, and recommended publications.

City of Hope Publications


**Recommended Publications**

1. Spirituality in Healthcare

2. Principles and Practice of Palliative Care and Supportive Oncology, 4th Edition, esp. Section II: #54 Spirituality

   Website: http://www.amazon.com

5. Making Health Care Whole: Integrating Spirituality into Patient Care

   Website: http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199332342


   Website: www.chausa.org/workarea/DownloadAsset.aspx?id=2147485267


12. Psychology, Religion, and Spirituality
      DOI: 10.1007/978-0-387-87573-6.

    - Tanenbaum. (2009). Tanenbaum Center for Interreligious Understanding. ASIN: B0033T7O8Q.

    DOI: 10.1177/0898010810327212.


    DOI: 10.1177/0269216309327212.


18. The Nature of Suffering and the Goals of Nursing
      Website: http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780195333121


**Educational Materials/Curriculum**

   - An interactive CD inviting patients and families to learn about the practical, emotional, spiritual, and medical issues faced by those dealing with advanced illness. The CD is available through the Instructional Media Center at Michigan State University. For ordering information call (517) 353-9229 or [http://www.completingalife.msu.edu/](http://www.completingalife.msu.edu/).

2. Core Curriculum for Holistic Nursing - American Holistic Nurses Association  
   - Nurses are increasingly aware of the need to blend technology, mind, and spirit in creating optimal circumstances for healing. Barbara Dossey, a pioneer and leader in the field, has created a core curriculum that will provide a blueprint for what it means to be a holistic nurse. Order online at [http://www.jblearning.com/catalog/9781284035834/](http://www.jblearning.com/catalog/9781284035834/).

3. FACIT Questionnaires  
   - Functional Assessment of Chronic Illness Therapy, (FACIT), manages questionnaires that measure health-related quality of life for people with chronic illnesses. The first questionnaire, The Functional Assessment of Cancer Therapy-General (FACT-G), was developed and validated over 10 years ago, and has been used in hundreds of studies worldwide. Since then over 40 questionnaires have been developed and selected questionnaires translated into over 45 different languages. There are three questionnaires relating to spirituality: the FACIT-Sp (Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being), FACIT-Sp-12 (12-item Spiritual Well-Being Scale), FACIT-Sp-Ex (Spiritual Well-Being, Expanded version). Website: [http://www.facit.org/FACITOrg/Questionnaires](http://www.facit.org/FACITOrg/Questionnaires).

4. Fast Facts and Concepts - Palliative Care Network of Wisconsin (PCNOW)  
   - Taking a Spiritual History #19  
   - Music Therapy #108  
   - Physicians and Prayer Requests #120

5. Interfaith Care for the Ill – Mobile Application  
6. GWish SOERCE: Educational and clinical resources in spirituality, religion, and health.
   - An amazing array of resources on spirituality, religion, and health. Supported by a grant from The John Templeton Foundation, GWish created SOERCE to build the online infrastructure to support medical educators and other health professionals in their quest to teach about spirituality and health by providing educational materials and resources. SOERCE covers an array of topics including spiritual assessment, end of life care, palliative care, spiritual distress management and interventions, articles on major faith traditions, educational modules, presentations, and videos. Website: http://www.gwumc.edu/gwish/soerce/about.cfm.

7. Marie Curie Cancer Care - London: Marie Curie Cancer Care

8. Pain Care Fast Facts: 5-Minute Clinical Inservice - UW Health, University of Wisconsin Hospital & Clinics, Madison, WI
   - Pain, Suffering and Spiritual Assessment
   - Website: http://prc.coh.org/pdf/Suffering-FF%2011-06.pdf

9. Passport to Comfort: Reducing Barriers to Pain & Fatigue Management – City of Hope, Duarte, CA
   - This model addresses patient, professional and system barriers to the relief of pain and fatigue and is based on established guidelines developed by the National Comprehensive Cancer Network (NCCN). An NCI supported program. Most available in English and Spanish. Website: http://prc.coh.org/Pt-familyEd.asp, #17.
   - Patient Spiritual Care Card
   - Spirituality Card

10. The Clinical Social Work Spiritual Care Lecture Series – City of Hope, Duarte, CA
    - Lecture series designed with the overall goal of providing training to clinical oncology social workers to develop their skills in identifying and responding to various spiritual care concerns in the cancer and palliative care population. Website: http://prc.coh.org/Clin%20SW%20Spiritual%20Care.pdf

Other Organizational Links
- American Holistic Medical Association http://www.holisticmedicine.org/
- American Holistic Nurses Association http://www.ahna.org/
- Canadian Society for Spirituality & Social Work http://w3.stu.ca/stu/sites/spirituality/index.html
- Can’t Believe I Have Cancer http://cantbelieveihavecancer.org/
- Chaplains on Hand –Providing Spiritual Comfort Chaplainsonhand.org
- HealthCare Chaplaincy Network - Helps people faced with distress of illness and suffering to find comfort and meaning http://www.healthcarechaplaincy.org/
- Strengthening the Spirit http://www.cancercare.org/publications/56-strengthening-the-spirit
- Tanenbaum Center for Inter religious Understanding https://www.tanenbaum.org/
- The Importance of Spirituality in Cancer Care http://www.integrativeoncology-essentials.com/2012/08/spirituality-and-cancer/

Position Statements/Standards
1. American Holistic Nurses Association (AHNA) Position Statements

2. Hospice and Palliative Nurses Association (HPNA) Position Statements
3. National Comprehensive Cancer Network. (NCCN)
   You must log in to access these documents. Registration is free:
   - Palliative Care: http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf

III. Palliative Care
   Section Description: This section includes book order forms, curriculum materials from a home care palliative education project, instruments used in end-of-life care, course syllabus on End-of-Life Care Content Guidelines, and position statements from professional organizations. Additional information on other resource centers on end-of-life care and information on educational programs such as the End-of-Life Nursing Education Consortium (ELNEC) is also available.

City of Hope Publications


**Recommended Publications**

1. *Principles and Practice of Palliative Care and Supportive Oncology, 4th Edition*

2. *Tarascon Palliative Medicine Pocketbook*

3. *Death and Dying: Life and Living, 7th Edition*

4. *Grief and Loss: Theories and Skills for Helping Professionals, 2nd Edition*

5. *Handbook of Health Social Work, 2nd Edition*

6. *Conversations in Palliative Care: Questions and Answers with the Experts, 3rd Edition*

7. *Living With Dying: A Handbook of End-of-Life Care for Practitioners*

8. *Making Health Care Whole: Integrating Spirituality into Patient Care*

9. *Reflections of a Loving Partner: Caregiving at the End of Life*

10. *Palliative Care: Transforming the Care of Serious Illness*


14. **Living with Grief: Diversity and End-of-Life Care**
   - Yearly book published by the Hospice Foundation of America. Each year addresses a different topic relating to grief.
   - Topics include:
     - Cancer and End-of-Life Care
     - Diversity and End-of-Life Care
     - Children and Adolescents
     - Before and After Death
     - Ethical Dilemmas at the End of Life
     - After Sudden Loss


18. **Palliative Care Nursing: Quality Care to the End-of-Life, 3rd Edition**

19. **Counseling Individuals with Life-Threatening Illness**

20. **The End of Life Advisor**


22. **Communication as Comfort: Multiple Voices in Palliative Care**

23. **Handbook of Bereavement Research and Practice: Advances in Theory and Intervention**


25. **Hospice and Palliative Nursing: Scope and Standards of Practice, 4th Edition**


29. Living Through Loss: Interventions Across the Life Span

30. A National Framework and Preferred Practices for Palliative and Hospice Care Quality
     Website: http://www.rwjf.org/content/dam/farm/reports/reports/2006/rwjf13081.

     Website: http://www.zondervan.com/9780310258957.

32. Ambiguous Loss: Learning to Live with Unresolved Grief

33. Healing after Loss: Daily Meditations for Working Through Grief
     Website: http://www.amazon.com/.

34. Oxford University Press Books
   Oxford Textbook of Palliative Social Work
     Website: http://www.amazon.com/Oxford-Textbook-Palliative-Social-Work/dp/0199739110

   Oxford Textbook of Palliative Nursing

   Oxford Textbook of Palliative Medicine, 4th Edition

   The Nature of Suffering and the Goals of Nursing
     Website: http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/.

Please check the Oxford University Press Health & Medicine section for many more books.
Website: http://global.oup.com/academic/category/medicine-and-health/?cc=us&lang=en/.

**Educational Materials/Curriculum**

1. BioMed Central (BMC) Palliative Care
   - An online journal publishing research articles after full peer review.
     Website: http://www.biomedcentral.com/content/pdf/1472-6939-3-3.pdf
   - Consensus Guidelines on Analgesia and Sedation in Dying Intensive Care Unit Patients
     Website: http://www.biomedcentral.com/content/pdf/1472-6939-3-3.pdf
   - Family Meetings in Palliative Care: Multidisciplinary Clinical Practice
     Website: http://www.biomedcentral.com/content/pdf/1472-684X-7-12.pdf.
   - Quality of Life at the End of Life
     Website: http://www.hqlo.com/content/pdf/1477-7525-5-51.pdf.
   - Sedation in Palliative Care – a critical analysis of 7 years experience.
     Website: http://www.biomedcentral.com/content/pdf/1472-684X-2-2.pdf.
2. Care of the Dying Patient - Video Listing
   - This project, funded by the Project on Death in America, is a listing of more than 250 videos recommended for use in palliative care education. Compiled by Marianne Matzo, RN, PhD, FAAN.
   - Website: http://prc.coh.org/pdf/Care%20of%20Dying%20Video%20List%20.pdf.

3. CARES: A Tool for the Care of the Dying - City of Hope, Duarte, CA
   - CARES is acronym for Comfort, Airway, Restlessness, Emotional support, and Self care to organize the most common needs and education requirements to support the dying patient and their family.

4. Center to Advance Palliative Care (CAPC)
   - Excellent resource for palliative care issues.
     - CAPCconnect™ Forum
       - Many project listings from hospitals, outpatient clinics, long-term care, and more.
       - Website: http://www.capc.org/forums/.

5. Between a Rock and a Hard Place: Clinical Ethics in Action
   - Clinical Ethics Case Study Series by Dr. David Seres on behalf of the International Clinical Ethics Section (ICES) of the American Society for Parenteral and Enteral Nutrition.

   - An interactive CD inviting patients and families to learn about the practical, emotional, spiritual, and medical issues faced by those dealing with advanced illness. The CD is available through the Instructional Media Center at Michigan State University. For ordering information call (517) 353-9229 or http://www.completingalife.msu.edu/.

7. Core Curriculum for the Advanced Practice Hospice and Palliative Nurse
   - The goal of the curriculum is to provide a foundation of knowledge from which APNs can practice palliative care including advanced skills, management of complex life-limiting, progressive issues and special clinical issues.

8. Education in Palliative and End-of-Life Care (EPEC)
   - Ordering information and description of a train the trainer program designed to educate physicians in the essential clinical competencies in end-of-life care. Program supported by a grant from the Robert Wood Johnson Foundation.
   - Website: http://www.epec.net.

   - A comprehensive national education program to improve end-of-life care by nurses. Information available on the American Association of Colleges of Nursing (AACN) website.
   - Website: http://www.aacn.nche.edu/ELNEC/.

10. End of Life Online Curriculum, US Veterans Administration and SUMMIT, Stanford University Medical School
    - An online learning tool on palliative care, hospice care, and bereavement. Contains case discussion, defines terms, and generally does a good job of education.
    - Website: http://endoflife.stanford.edu/M00_overview/intro_lrn_overv.html.
    - Contains the following modules:
      - Bereavement
      - Communication
      - Dyspnea
      - Home Hospice
      - Opioid Conversion
      - Overview of Palliative Care
      - Palliative Sedation
      - Prognostication
      - Transition to Death

11. End-of-Life Professional Caregiver Survey - Yale School of Nursing
    - This is an excellent tool for use to assess staff knowledge about palliative care.
    - Website: http://nursing.yale.edu/end-life-professional-caregiver-survey.
12. Fact Sheets - American Psychological Association (APA)
   - Culturally Diverse Communities and End-of-Life Care
   - End-of-Life Care

13. Fact Sheets - International Association for the Study of Pain (IASP), Seattle, WA
   - Pain and Symptom Management During the Final Days of Life
     Website: http://www.iasp-pain.org/AM/Template.cfm?Section=Home&Template=/CM/HTMLDisplay.cfm&Conten
     tID=7198.

    Over 270 one-page synopsis on topics important to palliative and end-of-life care.
    Website: http://www.mypcnow.org/#!fast-facts/c6xb
    - Cancer Related Fatigue #173
    - Dyspnea at End of Life #27
    - Emergency Department Management of Hospice Patients #246
    - Initiating a Hospice Referral from the Emergency Department #247
    - Neuroexcitatory Effects of Opioids: Patient Assessment #57
    - Opioid Poorly Responsive Cancer Pain #215

15. Instruments Used in End-of-Life Care Education, City of Hope, Duarte, CA
    - A collection of instruments currently in use by City of Hope investigators to assess staff knowledge and needs to
      improve end-of-life care. Curriculum Survey for Nursing Schools; Clinical Nurse Survey; Home Care/Hospice
      Agencies; Home Care Nurses and HHAs; for Nurses; Knowledge Assessment for HHA’s; Chart Audit Tool;

16. Palliative Care Quiz for Nursing
      of an instrument to measure nurses' knowledge of palliative care. Journal of Advanced Nursing, 23(1), 126-137.

17. Palliative Sedation Resources
    - Kirk, T. W., & Mahon, M. M. (2010). National Hospice and Palliative Care Organization (NHPCO) position
      statement and commentary on the use of palliative sedation in the imminently dying terminally ill patients.
    - Hospice and Palliative Nurses Association Position Statement on Palliative Sedation.
      Website: http://www.hpna.org/PicView.aspx?ID=707
      Website: http://www.aahpm.org/positions/sedation.html.
    - Palliative Sedation: When and How? - The University of Texas, MD Anderson Cancer Center
      Website: http://jco.ascopubs.org/content/30/12/1258.full

18. Quality Care at the End of Life Survey – City of Hope, Duarte, CA
    - This survey was designed based on the National Consensus Project for Quality Palliative Care guidelines and used at
      the City of Hope as a tool for assessing quality care. Users are invited to adapt and use it in their own institutions to
      assess the quality of care provided and to measure the institution's performance in comparison with national guidelines.
      Website: http://prc.coh.org/pdf/Quality%20Care%20at%20the%20End%20of%20Life%20Survey.pdf.

19. TIPS Sheets - Hospice and Palliative Nurses Association (HPNA)
    - TIPS for Communicating with Seriously Ill Patients (also Spanish Version)
    - TIPS for Nearing Death Awareness (also Spanish Version)
    - TIPS for Recognizing Behaviors Indicating Patient has Pain (also Spanish Version)
    - TIPS for Recognizing Pain in Patients with an Inability to Communicate Verbally (also Spanish Version)
    - TIPS for Respecting the Patient and Family Cultural Beliefs (also Spanish Version)
    - TIPS for Talking with Dying Patients (also Spanish Version)
    Website: http://www.hpna.org/DisplayPage.aspx?Title=TIPS
Guidelines/Clinical Pathways

1. Clinical Practice Guidelines for Quality Palliative Care, 2nd Edition
   - The National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care were developed by leaders in the field who examined other national and international standards with the intent to promote consistent, accessible, comprehensive, optimal palliative care through the health care spectrum. Within the guidelines there are eight domains to the provision of palliative care. Website: http://www.nationalconsensusproject.org/Guideline.pdf.

2. Consensus Statement: Palliative and Supportive Care in Advanced Heart Failure
   - The statement is the result of a consensus conference in which experts and leaders in the field worked to define the important knowledge gaps with regards to palliative care and advanced heart failure. The statement outlines future research objectives that can guide this field of study. Website: http://www.sciencedirect.com/science/article/pii/S1071916403007152.

3. End-Stage Renal Disease Workgroup Report - Recommendations to the Field
   - Clinicians and researchers working with end-stage renal disease (ESRD) can now access an important palliative care resource online. The report presents the methods, findings, recommendations and products of the ESRD Workgroup sponsored by the Promoting Excellence in End-of-Life Care Project. Website: http://www.mywhatever.com/cifwriter/content/41/downloads/esrd_full_report.pdf.

4. Guidelines for the Assessment of Bereavement Risk in Family Members of People Receiving Palliative Care
   - These Centre for Palliative Care guidelines aim to assist providers of services to families of dying people to identify family members at risk of complicated bereavement outcomes based on best available evidence. Website: http://prc.coh.org/BereavGuidelines.pdf.

5. National Framework and Preferred Practices for Palliative and Hospice Care Quality
   - This National Quality Forum report endorses a framework for palliative and hospice care that is intended to be the first step in developing a comprehensive quality measurement and reporting system for palliative care and hospice services and preferred practices designed to improve palliative and hospice care. Website: http://www.qualityforum.org/Publications/2006/12/A_National_Framework_and_Preferred_Practices_for_Palliative_and_Hospice_Care_Quality.aspx.

6. Promoting Excellence in End-of-Life Care
   - Advanced Practice Nurses (APNs) convened to hold a conversation on the state of palliative care advanced practice nursing in the United States, to identify gaps in and barriers to that practice and to develop strategies for the future. The report on this important gathering of APNs working in the field of palliative care is available on the Promoting Excellence in End-of-Life Care website at http://www.promotingexcellence.org/.
   - A special series of articles describing the experiences and exciting results of 22 innovative projects funded by Promoting Excellence in End-of-Life Care have been published in The Journal of Palliative Medicine. The articles, edited by Ira Byock, Promoting Excellence Director, are included in the Innovations section of the journal. Begins in 2003, Volume 6, Number 2. Website: http://www.promotingexcellence.org/jpm/index.html.

7. Psychosocial Care: Hospice Palliative Care Program Symptom Guidelines
   - This guideline is adapted for interprofessional primary care providers working in various setting and provides recommendations for assessing and addressing psychosocial issues of adult patients who are facing a progressive life limiting illness. Website: http://www.fraserhealth.ca/media/psychosocial%20care.pdf.

Other Organizational Links

Advancing Expert Care: HPNA, HPNF, HPCC  http://advancingexpertcare.org/
American Academy of Hospice and Palliative Medicine  http://www.aahpm.org
American Hospice Foundation  http://www.americanhospice.org/
American Journal of Nursing  http://www.AJNonline.com
American Society for Pain Management Nursing  http://www.aspnm.org
Americans for Better Care of the Dying (ABCD)  http://www.abcd-caring.org/
Association of Death Education and Counseling (ADEC)  http://www.adec.org
Position Statements/Standards

1. A Position Statement from American Nursing Leaders
   - Advanced Practice Nurses Role in Palliative Care Position Statement

2. American Academy of Hospice and Palliative Medicine
   - Access to Palliative Care and Hospice
   - Clinical Practice Guidelines for Quality Palliative Care
   - Palliative Sedation Website: http://www.aahpm.org/positions/default/index.html.

3. American Nurses Association (ANA) Position Statements
   - Euthanasia, Assisted Suicide, and Aid in Dying
   - Forgoing Nutrition and Hydration
   - Nursing Care and Do-Not-Resuscitate Decisions
   - Privacy and Confidentiality

4. American Society of Pain Management Nurses (ASPMN) Position Statements
   - Pain Management at the End-of-Life
   - The Use of “As Needed” Range Orders for Opioid Analgesics in the Management of Pain

5. Hospice and Palliative Nurses Association (HPNA) Position Statements
   - Artificial Nutrition and Hydration in End-of-Life Care
   - Complementary Therapies in Palliative Care Nursing Practice
   - Evidence-Based Practice
   - Legalization of Assisted Suicide
   - Pain Management
   - Palliative Sedation
   - Spiritual Care
   - Value of Nursing Assistant in Palliative Care
   - Value of Hospice and Palliative Care Nursing Certification
   - Value of Professional Nurse in Palliative Care

6. NHPCO Task Force Statement on Ethics of Hospice Participation in Research
   - This task force statement discusses the important of hospices’ potential contributions to research and describes ways
     in which characteristics of hospice patients, and hospices’ structure, create ethical challenges that may limit these
     contributions. It concludes by proposing ways in which hospices and national professional organizations can begin to
     overcome some of these challenges.
     Website: http://www.liebertonline.com/doi/pdfplus/10.1089/109662101753381566.

7. Oncology Nursing Society (ONS) and Association of Oncology Social Work (AOSW) Joint Position Statement
   - Palliative and End-of-Life Care
     Website: http://www.ons.org/Publications/Positions/EndOfLife.

8. Oncology Nursing Society (ONS) Position Statements - 28 Position Statements
   - Access to Quality Cancer Care
   - Cancer Pain Management
   - Nurse’s Responsibility to the Patient Requesting Assistance in Hastening Death
     Website: http://www.ons.org/publications/positions/.
III. Palliative Care
   D. Palliative Surgery

Section Description: This section includes City of Hope publications and other resources and publications related to palliative surgery.

City of Hope Publications


**Recommended Publications**

1. The M.D. Anderson Surgical Oncology Handbook, 5th Edition  
   - Website: http://www.amazon.com


18. Surgical Palliative Care: A Resident’s Guide


23. Surgical Palliative Care (Supportive Care)

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### Other Organizational Links

- Canadian Association of Psychosocial Oncology: [http://www.capo.ca/](http://www.capo.ca/)
- COS Multidisciplinary Education in Oncology: [http://www.cos.ca](http://www.cos.ca)
- Palliative Care Quality Network: [http://www.pcqn.org/](http://www.pcqn.org/)
- Society of Surgical Oncology: [http://www.surgonc.org/](http://www.surgonc.org/)

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### III. Palliative Care

#### E. Communication

*Section Description: This section includes City of Hope publications and other resources relating to communication in palliative care and end-of-life*

**City of Hope Publications**


**Recommended Publications**

1. Communication in Palliative Nursing

2. New Challenges in Communication with Cancer Patients


4. Dying with Comfort: Family Illness Narratives and Early Palliative Care


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9. Communication as Comfort: Multiple Voices in Palliative Care  

**Educational Materials/Curriculum**

1. Communication Cards for Patients and Their Care Team - City of Hope, Duarte, CA  
   - Pain assessment tools include phrases in English, Spanish, Chinese, Armenian and Korean.  
   - Website: [http://prc.coh.org/pdf/CommCards.pdf](http://prc.coh.org/pdf/CommCards.pdf)

2. End-of-Life Care: Improving Communication Skills to Enhance Palliative Care  
   - Learn the differences between hospice and palliative care, and how to communicate with patients and families to learn their end-of-life wishes. CE credits offered by Medscape Nurses without fee for this Web-based continuing education program. (One time-free registration required to access Medscape.) Website: [http://www.medscape.com/viewprogram/12632](http://www.medscape.com/viewprogram/12632).

3. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering  
   - This monograph lays the foundation for future innovative research in the area of patient-centered communication in oncology as well as other illness settings. Highlights include: conceptualization of patient-centered communication into six key functions; emphasis on research that examines the relationship between patient-centered communication and patient health outcomes; detailed discussion of potential mediating and moderating mechanisms of the association between communication and patient outcomes; and identification of specific research priorities that would guide NCI in planning future research initiatives in this important area.  
   - Website: [http://appliedresearch.cancer.gov/areas/pcc/communication/monograph.html](http://appliedresearch.cancer.gov/areas/pcc/communication/monograph.html)

**Other Organizational Links**

- Communicating with Patients: [http://www.aha.org/advocacy-issues/communicatingpts](http://www.aha.org/advocacy-issues/communicatingpts)
- Palliative Care Communication Institute: [http://www.pccinstitute.com/](http://www.pccinstitute.com/)
- Also on Facebook: [https://www.facebook.com/pccinstitute?ref=aymt_homepage_panel](https://www.facebook.com/pccinstitute?ref=aymt_homepage_panel)
- Also on Twitter @pallcarecomm: [https://twitter.com/search?q=palliative%20care%20communication%20institute&src=typd](https://twitter.com/search?q=palliative%20care%20communication%20institute&src=typd)
IV. Pain and Symptom Management

A. Pain Assessment Tools (Also see Section IX. Research Instruments/Resources)

Section Description: This section includes various tools to assess pain. Specifically, pocket reference cards, rating scales, assessment packets, chart forms, database tools, home health flow sheets, chart documentation packets, and tools for infant and pediatric pain assessment are among the resources available.

Recommended Publications

1. Pain Assessment and Pharmacologic Management


Pain Assessment Tools

1. Communication Cards for Patients and Their Care Team, City of Hope, Duarte, CA

2. Fast Facts and Concepts – Palliative Care Network Of Wisconsin (PCNOW)
   Over 200 Fast Facts, a PDA version and a Discussion Blog. Website: http://www.mypcnow.org/#!fast-facts/c6xb
   - Cultural Aspects of Pain Managements, 2nd ed., #78
   - Pediatric Pain Assessment Scales, #117
   - Pain Assessment in the Cognitively Impaired #126
   - Pseudoaddiction, 2nd ed., #69
   - Insomnia Assessment and Treatment Website: http://prc.coh.org/pdf/Insomnia-FF-1-07.pdf.
   - Pain, Suffering and Spiritual Assessment Website: http://prc.coh.org/pdf/Suffering-FF%2011-06.pdf.

3. Home Health Pain Management Flow Sheet - University of Wisconsin Hospitals & Clinics, Madison, WI
   - A one-page pain management flow sheet to be used in the home care setting. Website: http://prc.coh.org/pdf/HH-pain-mgmt.pdf.

4. Pain Assessment Packet/Chart Forms
   - Nursing Assessment and Care Plan - City of Hope, Duarte, CA
     Comprehensive pain assessment tool for use in initial evaluation of patients referred to a pain service. Website: http://prc.coh.org/pdf/Nurs-Assess.pdf.
   - Pain Rating Scales – InteliHealth
     The three pain rating scales included are: 0-10 visual analog scale, Wong-Baker Faces rating scale and the verbal scale. Website: http://www.intelihealth.com/article/the-purpose-of-pain-scales.

5. Pain Assessment Packet/Chart Forms - Dartmouth-Hitchcock Medical Center, Lebanon, NH
   - Initial Pain Rating Tool & Pain Flow Sheet
     Website: http://prc.coh.org/pdf/initial_pain_rating_dartmouth.pdf.
   - Post-Operative Pain Management Needs Assessment
     A tool to assess the nurse’s knowledge and attitude regarding pain management. Website: http://prc.coh.org/pdf/Post-op_Dart.pdf.
6. Pain Management – United States Department of Veterans Affairs
   - Clinical Tools and Resources
     Website: http://www1.va.gov/PAINMANAGEMENT/Clinical_Resources.asp.

7. Pain Scales in Multiple Languages
   - The British Pain Society has produced a series of pain scales in multiple languages (Albanian, Arabic, Bengali, Chinese (simplified), Chinese (traditional), Greek, Gujarati, Hindi, Polish, Punjabi, Somali, Swahili, Turkish, Urdu, Vietnamese, and Welsh). Website: http://www.britishpainsociety.org/pub_pain_scales.htm.

8. Psychosocial Pain Assessment Form - City of Hope, Duarte, CA
   - Developed by Shirley Otis-Green, MSW, LCSW. This 8-page assessment and guided interview form measures the impact of pain on five domains; economics, social support, activities of daily living, emotional problems, and coping behaviors as perceived by the interviewer, patient and significant other.
   - Psychosocial Pain Assessment Forms in Spanish (for adults and children/adolescents):

   - Overview, Criteria for Evaluation, Comparison Grid, Comparison of Tool Items with AGS Persistent Pain
   - Guidelines, Review References
   - Abbey Pain Scale (Abbey) (Abbey, J., et al.)
   - Certified Nurse Assistant Pain Assessment Tool (CPAT), (Cervo, F., et al.)
   - Checklist of Nonverbal Pain Indicators (CNPI), (Feldt, K.)
   - Disability Distress Assessment Tool (Dis DAT) (Regnard, C., et al.)
   - Discomfort Behavior Scale (DBS) (Stevenson, K., et al.)
   - Discomfort Scale-Dementia of the Alzheimer’s Type (DS-DAT), (Hurley, A., et al.)
   - Doloplus 2, (Wary, B and the Doloplus Group)
   - Elderly Pain Caring Assessment 2 (EPCA-2) (Morello, R., et al.)
   - Face, Legs, Activity, Cry and Consolability Pain Assessment Tool (the FLACC), (Merkel, S. I., et al.)
   - Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID) (Husebo, B. S., et al.)
   - Nursing Assistant-Administered Instrument to Assess Pain in Demented Individuals (NOPPAIN), (Snow, A. L., et al.)
   - Pain Assessment in Advanced Dementia (PAINAD) Scale, (Warden, V., et al.)
   - Pain Assessment for the Dementing Elderly (PADE), (Villaneuva, M., R., et al.)
   - Pain Assessment in Noncommunicative Elderly Persons (PAINE) (Cohen-Mansfield, J., et al.)
   - Pain Assessment Scale for Senior’s with Severe Dementia (PACSLAC), (Fuchs-Lacelle, S. K., et al.)
   - Pain Behaviors for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICE) (Tsai, P., et al.)
   Website: http://prc.coh.org/PAIN-NOA.htm.

IV. Pain and Symptom Management
B. Pharmacology/Policies and Procedures
   Section Description: Includes pain management reference cards, algorithm packets, along with flow sheets to record pain assessment and management as well as meperidine usage guidelines.

For more information see Section VI.B. Patient and Family Education
City of Hope Publications


**Recommended Publications**

1. Pain Assessment and Pharmacologic Management
   - Sections III (Nonopioid Analgesics), IV (Opioid Analgesics), and V (Adjuvant Analgesics).

   - Section 10.1 The Management of Pain, pages 587-800.


**Educational Materials/Curriculum**

1. Case Studies and Faculty Guides – Wisconsin Cancer Pain Initiative
   - Cancer Pain Role Model Program - Includes 7 case studies and faculty guides for each to use in teaching basic pharmacology principles related to pain
     - Website: http://prc.coh.org/pdf/cancer_pain_role_model_program.pdf
   - Home Care - Includes 5 case studies and faculty guides for each to use in teaching basic pharmacology principles related to pain.
2. Fast Facts and Concepts – Palliative Care Network of Wisconsin (PCNOW)
Website: http://www.mypcnw.org/#!fast-facts/c6xb.

Over 270 Fast Facts, a PDF version and a Discussion Blog. More than 40 Fast Fact sheets related to pain issues.
- Bisphosphonates for Bone Pain, #113
- Calculating Opioid Dose Conversions, #036
- Choosing an Oral Opioid Combination Product, #051
- Controlled Release Oxycodone, #080
- Converting to/from Transdermal Fentanyl, #002
- Cultural Aspects of Pain Management, #078
- Epidural Analgesia, #085
- Gabapentin for Neuropathic Pain, #049
- Intrathecal Drug Therapy for Pain, #098
- Is it Pain or Addiction, #068
- Ketamine Use in Palliative Care, #132
- Meperidine for Pain: What’s all the Fuss? #071
- Methadone for Neuropathic Pain, #171
- Methadone for the Treatment of Pain, #075
- Methadone: Starting Dosing Information, #086
- Morphine and Hastened Death, #008
- Neuroexcitatory Effects of Opioids: Treatment, #058
- Non-Tricyclic Antidepressants for Neuropathic Pain, #187
- Once Daily Oral Morphine Formulations, #166
- Opioid Allergic Reactions, #175
- Opioids and Nausea, #25
- Opioid Dose Escalation #020
- Opioid Infusion Titration Orders, #072
- Opioid Infusions in the Imminently Dying Patient, #054
- Opioid Use in Renal Failure, #161
- Opioid Withdrawal, #095
- Oral Opioid Orders—Good and Bad Examples, #074
- Oral Oxymorphone, #181
- Oral Transmucosal Fentanyl Citrate, #103
- Pain Management in Nursing Homes: Analgesic Prescribing Tips, #089
- Parenteral Lidocaine for Neuropathic Pain, #180
- Patient Controlled Analgesia in Palliative Care, #092
- Phantom Limb Pain, #212
- PRN Range Analgesic Orders, #70
- Radiopharmaceuticals for Painful Osseous Metastases, #116
- Short-Acting Oral Opioid Dosing Intervals, #018
- Steroids in the Treatment of Bone Pain, #129
- Subcutaneous Opioid Infusions, #028
- Sublingual Morphine, #053
- Tapentadol, #228
- The Legal Liability of Under-Treatment of Pain, #063
- The Lidocaine Patch, #148
- Topical Opioids for Pain, #185
- Treatment of Pain in Patients Taking Buprenorphine for Opioid Addiction, #221
- Vertebroplasty and Dyphoplasty for Vertebral Compression Fractures, #202
- Why Patients Do Not Take Their Opioids, #083
- Writing Discharge/Outpatient Opioid Prescriptions, #094
Website: http://www.eperc.mcw.edu/EPERC/FastFactsandConcepts

3. Health and Nutrition Facts for You – UW Health, University of Wisconsin Hospital & Clinics, Madison, WI
More than 2,200 topics are available, from medication instructions to nutrition information.
- 4% Topical Lidocaine Website: http://prc.coh.org/pdf/TopLid11.pdf
- Coping with Pain Website: http://prc.coh.org/pdf/Coping-FF%205-10.pdf
- Establishing Pain Relief Goals Website: http://prc.coh.org/pdf/Goals-FF%205-10.pdf
- Intravenous Lidocaine for Perioperative Pain Website: http://prc.coh.org/FF%20LidoIVPer12-10.pdf

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- IV KetAMINE for Perioperative Analgesia  
  Website: http://prc.coh.org/pdf/Ketamine5-10.pdf
- Management of Opioid Induced Constipation  
  Website: http://prc.coh.org/pdf/OpioidIndConst9-11.pdf
- Multimodal Analgesia  
  Website: http://prc.coh.org/pdf/FF%20MA-11.pdf
- Opioid-Induced Nausea  
  Website: http://prc.coh.org/pdf/Nausea-FF%203-10.pdf
- Opioid Withdrawal  
  Website: http://prc.coh.org/pdf/OpWith-FF%209.pdf
- Oral Transmucosal Fentanyl Citrate – OTFC (ACTIQ')  
  Website: http://prc.coh.org/pdf/Actiq-FF%2012-09.pdf
- Patient Controlled Epidural Analgesia (PCEA)  
  Website: http://prc.coh.org/pdf/PCEA.pdf
- PRN Range Analgesic Orders  
  Website: http://prc.coh.org/pdf/PRN-FF%208-09.pdf
- The Correct Way to Write “Titrate to Comfort” Orders  
  Website: http://prc.coh.org/pdf/Titrate5-10.pdf
- Transdermal Fentanyl  
  Website: http://prc.coh.org/pdf/TransFen11.pdf
- Transitional Analgesia  
  Website: http://prc.coh.org/pdf/TranAna11.pdf
- Transverses Abdominis Plane (TAP) Block  
  Website: http://prc.coh.org/pdf/FF-TAPBlock01-11.pdf
- Urine Drug Testing (UDT)  
  Website: http://prc.coh.org/pdf/UDT-FF-10.pdf

Website: http://www.uwhealth.org/healthfacts/

4. Patient Contracts/Agreements
   Website: http://www.elsevier.com/wps/find/bookdescription.advertisers/722199/.

5. Two-Sided Pain and Symptom Management Cards – City of Hope Division of Nursing Research and Education
   - Pain Management Guidelines
     Website: http://prc.coh.org/NRE%20PM%20Guidelines.pdf
     Website: http://prc.coh.org/NRE%20PC%20SYM%20MGMT.pdf

Guidelines/Clinical Pathways
1. Achieving Balance in Federal & State Pain Policy
   - Evaluation guide presents a framework that has been developed by the Pain & Policy Studies Group (PPSG) to understand and to evaluate policies at the federal and state level.

2. Palliative Care and Pain Management - Memorial Sloan-Kettering Cancer Center, New York, NY

3. Care of the Patient Receiving Conscious Sedation - Canadian Society of Gastroenterology Nurses & Associates

4. Cleveland Clinic Guide to Pain Management – Michael Stanton-Hicks, MD
   - In The Cleveland Clinic Guide to Pain Management, Dr. Michael Stanton-Hicks presents critical information about the scientific studies and progress in regulating and managing pain and how a healthy mind-body relationship can change the experience of chronic pain.
   Website: http://chhealth.clevelandclinic.org/books/pain-management.

5. Conscious Sedation/Analgesia for Adults Policy and Procedure – Pain Management Educator/Consultant Chris Pasero
   - Developed by Christine Pasero, RN, BSN, MHSAC, a Pain Management Consultant, this guideline is intended to assist in developing a policy and procedure to help insure safe administration of conscious sedation.
   Website: http://prc.coh.org/html/Paserosedation.htm.

6. Core Curriculum for Pain Management Nursing - American Society of Pain Management Nurses (ASPMN)
7. Opioid Treatment Guidelines - Journal of Pain
   - Clinical Guidelines for the Use of Chronic Opioid Therapy in Chronic Noncancer Pain – American Pain Society and the American Academy of Pain Medicine
     Website: http://www.jpain.org/article/S1526-5900(08)00831-6/abstract
     Website: http://www.jpain.org/article/S1526-5900(08)00832-8/abstract
     Website: http://www.jpain.org/article/S1526-5900(08)00830-4/abstract.

8. Pain Management - California Board of Registered Nursing
   - The Nurse’s Role in Pain Management
     Website: https://medical.wesrch.com/User_images/Pdf/MS1_1225761426.pdf

   - Continuous Infusions, PCA via Epidural Catheters, Pediatric Patients Receiving Epidural Analgesia, Narcotic Control, Nursing Care of the Patient Receiving TENS, Subcutaneous Infusion/PCA, Application and Destruction of Fentanyl Transdermal Patches and other procedures.

    - Packed with a wealth of updated information in an easy-to-use format with concise information about appropriate drug selection, dosing variation among patient populations, rapid treatment of breakthrough pain, and side effect minimization.
    Website: http://www.americanpainsociety.org/library/content/apprinciplesofanalgesicuse.html.

11. Protocols for Practice: Creating a Healing Environment - American Association of Critical Care Nurses (AACN)
    - Pain Management in the Critically Ill
      Website: http://ccn.aacnjournals.org/cgi/content/full/23/2/99
    - Interventions to Decrease Family Anxiety
      Website: http://ccn.aacnjournals.org/cgi/content/full/22/6/61
    - Family and Pet Visitation in the Critical Care Unit
      Website: http://ccn.aacnjournals.org/cgi/content/full/23/5/62.

12. Reflex Sympathetic Dystrophy/Complex Regional Pain Syndrome (RDS/CRPS), 2nd Edition
    - Download guidelines from Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)

13. Resources to Help Organizations Implement Standards of Pain Management - WHO Pain & Palliative Care Communications Program
    - Index of issues from Cancer Pain Release from 1988 through 2009. Many excellent articles on pain management and palliative care for both adults and pediatrics.
      Website: http://whocancerpain.wisc.edu/?q=node/189.

14. Society of Critical Care Medicine Guidelines
    - Clinical practice guidelines for the sustained use of sedatives and analgesics in the critically ill adult.
    - Guidelines and levels of care for pediatric intensive care units

Other Organizational Links
Agency for Healthcare Research and Quality http://www.ahrq.gov/
American Society of Pain Management Nurses http://aspmn.org/
Be Med Wise http://bemedwise.org/
International Association for the Study of Pain http://www.iasp-pain.org
Low Cost Prescription Drugs: Patient Assistant Programs http://www.thelivingweb.net/lowcost_prescription_drugs.html
National Cancer Comprehensive Network http://www.nccn.org/
National Consensus Project for Quality Palliative Care http://www.nationalconsensusproject.org/
Pain & Policy Studies Group - University of Wisconsin http://www.painpolicy.wisc.edu/

Key References
2. Common Regional Nerve Blocks - University of Wisconsin Hospital & Clinics
   - Quick guide developed by UWHC Acute Pain Service Website: http://prc.coh.org/ComRegNB.pdf.

Position Statements/Standards
1. American Society for Pain Management Nursing
   - Use of Placebos for Pain Management
     Website: http://www.aspmn.org/pdfs/Use%20of%20Placebos.pdf.
2. California Board of Registered Nursing
   - Conscious Sedation
     Website: http://www.rn.ca.gov/pdfs/regulations/npr-b-06.pdf.
3. International Association for the Study of Pain (IASP)
   - Guidelines

IV. Pain and Symptom Management
C. Complementary, Alternative, and Integrative Approaches
   This section includes several handouts for complementary pain management strategies at home. Books and journal articles on a variety of complementary and integrative techniques for pain and symptom management in addition to journal articles relating to complementary and integrative approaches are included.

City of Hope Publications


**Recommended Publications**


16. Integrative Oncology

17. The Mindfulness Solution to Pain: Step-by-Step Techniques for Chronic Pain Management


28. Enhancing Cancer Care: Complementary Therapy and Support
   Website: http://www.amazon.com/Enhancing-Cancer-Care-Complementary-Therapy/dp/019929755X.


33. Psychosocial Nursing Care Along the Cancer Continuum, 2nd Edition
   - Chapter 32: Complementary and Alternative Medicine: Moving Toward Integrative Cancer Care
   Website: http://www.amazon.com/Psychosocial-Nursing-Along-Cancer-Continuum/dp/1890504572.

34. Nurses Herbal Medicine Handbook, 3rd Edition


48. Women and Pain: Why It Hurts and What You Can Do

49. Choices in Healing: Integrating the Best of Conventional Complementary Approaches to Cancer

**Educational Materials/Curriculum**

1. Academy for Guided Imagery
   - Interactive guided imagery self paced audio/video/DVD study course

2. Coping Skills for Bone Marrow Transplantation and Relaxation and Imagery

3. Core Curriculum for Holistic Nursing - American Holistic Nurses Association
   - Nurses are increasingly aware of the need to blend technology, mind, and spirit in creating optimal circumstances for healing. Barbara Dossey, a pioneer and leader in the field, has created a core curriculum that will provide a blueprint for what it means to be a holistic nurse.

4. ECaP (Exceptional Cancer Patients)
   - Bernie Siegel, MD started ECaP more than 3 decades ago. ECaP uses *Carefrontation* which helps patients interpret their drawings, dreams and images to express their feelings about the healing process. The physical, spiritual, and psychological benefits that emerge strengthen the immune system, a direct response to the power of the Mind-Body Connection. There are also a listing of Dr. Siegel's articles and books and a blog post where he answers patients questions.
   - Website: [http://berniesiegelmd.com/](http://berniesiegelmd.com/).

5. Fast Facts and Concepts - Palliative Care Network of Wisconsin (PCNOW)
   - Guided Imagery for Anxiety #211
   - Insomnia: Non-Pharmacological Treatments #104
   - Music Therapy #108

6. Treatment Guidelines - American Cancer Society (ACS)
   - Complementary and Alternative Methods and Cancer
   - Website: [http://www.cancer.org/treatment/treatmentsandsideeffects/complementaryandalternativemedicine/complementaryandalternativemethodsandcancer/index](http://www.cancer.org/treatment/treatmentsandsideeffects/complementaryandalternativemedicine/complementaryandalternativemethodsandcancer/index)
Other Organizational Links
Academic Consortium for Complementary & Alternative Health Care  http://www.accahc.org/
Academy of Integrative Health & Medicine  http://aihm.org/
American Academy of Medical Acupuncture  http://www.medicalacupuncture.org/
American Art Therapy Association  http://www.arttherapy.org/
American Holistic Nurses Association  http://www.ahna.org/
American Music Therapy Association  http://www.musictherapy.org
Arizona Center for Integrative Medicine  http://integrativemedicine.arizona.edu/
Association for Applied and Therapeutic Humor  http://www.aath.org/
Healing Beyond Borders  http://www.healingtouchinternational.org/
NIH Senior Health Complementary Health Approaches  http://nihseniorhealth.gov/cam/toc.html
Simonton Cancer Center  http://www.simontoncenter.com
The Center for Health & Healing  http://www.healthandhealingny.org/

Key References
1. Complementary Pain Management Information
   - Complementary Pain Management Bibliography
     Website: http://prc.coh.org/pdf/Complementary%202005.pdf.

2. Complementary Pain Management Resource List
   Website: http://prc.coh.org/pdf/Complementary%20Alternative%20List.pdf
   - Music as Medicine Bibliography
     Website: http://prc.coh.org/pdf/music_as_medicine_bib.pdf.

Position Statements/Standards
1. American Holistic Nurses Association (AHNA)
   - Position Statements
     Website: http://www.ahna.org/Resources/Publications/PositionStatements/tabid/1926/Default.aspx

2. California Board of Registered Nursing
   - Complementary and Alternative Therapies in Registered Nursing Practice
V. Special Populations
A. Family Caregiving

Section Description: This section includes publications regarding the experiences of family caregivers in caring for a loved one in pain or at the end-of-life.

City of Hope Publications


**Recommended Publications**

1. Cure’s 2014 Cancer Guide

2. Principles and Practice of Palliative Care and Supportive Oncology, 4th Edition, esp. Part C #52 caregiving in the Home
   - Website: http://www.amazon.com/Principles-Practice-Palliative-Supportive-Oncology/dp/145112127X.

3. What You Need to Know as a Cancer Caregiver


     Chapter 21: Caregivers in Palliative Care
     Chapter 22: Families and Family Conferencing
     Chapter 26: The Why's and Wherefores of Support Group
     Chapter 27: Social Work and Technology: The Software and Hard Drive of Patient and Family Care
     Chapter 37: Palliative Social Work with Older Adults and Their Families
     Chapter 43: Social Work and Child Life: A Family’s Journey with Childhood Cancer

11. Help Wanted: Caregiver

    Website: http://www.amazon.com/American-Cancer-Society-Complete-Caregiving/dp/094423500X.

    Website: http://www.oup.com/us/catalog/general/subject/Psychology/Health/?view=usa&ci=9780195146011

    Website: http://hospicefoundation.org/hfa/media/Files/Hospice_TheDyingProcess_Docutech-READERSPREADS.pdf


22. Reflections of a Loving Partner: Caregiving at the End of Life

23. Dying with Comfort: Family Illness Narratives and Early Palliative Care
24. The Survivorship Net: A Parable for the Family, Friends, and Caregivers of People with Cancer  

25. Passages in Caregiving: Turning Chaos into Confidence  
   Website: http://www.amazon.com

     Section I: Principles of Patient and Family Assessment  
     Section III: Supporting Families in Palliative Care  

27. The Caregiver’s Path to Compassionate Decision Making: Making Choices for Those Who Can’t  

28. Cancer Journey: A Caregiver’s View From the Passenger Seat  
   Website: http://www.caregivercancerjourney.com./


33. Family Carers in Palliative Care: A Guide for Health and Social Care Professionals  
     Website: http://www.amazon.com/Family-Carers-Palliative-Care-professionals/dp/0199216908.

34. Caregiving in the U.S.  
   - Pew Research Internet Project  
     Website: http://www.pewinternet.org/2012/07/12/main-report-14/.


38. Supporting Family Caregivers


40. Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework


44. A Family Caregiver Speaks Up: It Doesn't Have To Be This Hard


51. The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent


56. When the Focus Is on Care  

57. Breast Cancer Husband How to Help Your Wife (and Yourself) Through Diagnosis, Treatment, and Beyond  


62. Caregiving and Loss: Family Needs, Professional Responses  
   - Hospice Foundation of America  
     Website: http://store.hospicefoundation.org/product.php?productid=45.

63. Caregiving: The Spiritual Journey of Love, Loss, and Renewal  

**Educational Materials/Curriculum**

1. And Thou Shalt Honor  
   - A PBS Series, forums and support for caregivers, patients, and health care professionals.  
     Website: http://www.pbs.org/thoushalthonor/caregivers/index.html

2. APA Caregiver Briefcase – American Psychological Association  
   - This Briefcase provides psychologists at all levels of training and experience with information about: how caregiving affects all of us; facts about family caregiving; common caregiving problems; how to identify and reach caregivers; roles psychologists have in working with family caregivers; assessment tools and effective interventions; conducting caregiver research; educating and teaching about caregiving; advocating for family caregivers; resources for diverse populations and age groups. Website: http://www.apa.org/pi/about/publications/caregivers

3. Averting the Caregiving Crisis: Why We Must Act Now (October 2010)  
   - Rosalynn Carter Institute for Caregiving  
4. Family Caregivers in Cancer: Roles and Challenges - National Cancer Institute
   Website: http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/healthprofessional/page1/AllPages

5. Fast Facts and Concepts - Palliative Care Network of Wisconsin (PCNOW)
   - Over 270 Fast Facts, a PDA version and a Discussion Blog.
   - Asking about Cultural Beliefs in Palliative Care #216
   - Broaching the Topic of a Palliative Care Consultation with Patients and Families, 2nd Ed. #42
   - Grief in Children and Developmental Concepts of Death #138
   - Helping Surrogates Make Decisions #226
   - Hospice Referral: Moving from Hospital to Home #139
   - Implementation of a Family Presence During Resuscitation Protocol #233
   - Information for Patients and Families About Ventilator Withdrawal, 2nd Ed. #35
   - Preparing for the Family Meeting #222
   - Responding to Emotion in Family Meetings #224
   - Teaching the Family What to Expect When the Patient is Dying #149
   - The Family Meeting: Causes of Conflict #225
   - The Family Meeting: End of Life Goal Setting and Future Planning #227
   - The Family Meeting: Starting the Conversation #223
   - What Do I Tell the Children, 2nd Ed. #47
   Website: http://www.eperc.mcw.edu/EPERC/FastFactsandConcepts.

6. Help for Cancer Caregivers
   - Help for Cancer Caregivers, a new resource, helps cancer caregivers manage their own health and wellness needs. It is an interactive, personalized web tool that gives the right information at the right time to help lessen stress throughout the caregiving experience. Website: http://www.helpforcancercaregivers.org/.

7. Home Alone: Family Caregivers Providing Complex Chronic Care

8. Navigating Cancer Caregiver Survey
   - Navigating Cancer surveyed 326 cancer caregivers through an online survey in October 2010. The survey results revealed significant emotional, financial and physical strain on the cancer caregiver community, as well as a lack of comprehensive resources to support their needs. Website: https://www.navigatingcancer.com/groups/caregivers-support-group/

9. Orientation to Caregiving: A Handbook for Family Caregivers of Patients with Serious Illness
   - A handbook on what to expect as a family caregiver. This handbook is a product of the Caregivers Project, a collaboration between the UCSF Osher Center for Integrative Medicine & UCSF Department of Neurological Surgery. Website: http://cancer.ucsf.edu/_docs/crc/Caregiver_GEN.pdf.

10. Partners in Healing
    - This site provides practical tools, encouragement and inspiration to those wanting to be a source of healing for a loved one. Book, instructional DVD, and CD. Focuses on simple massage and touch techniques that caregivers can use for their loved ones. Website: http://partnersinhealing.net/.

11. Standards for Social Work Practice with Family Caregivers of Older Adults

Other Organizational Links

Aging Parents and Elder Care http://www.aging-parents-and-elder-care.com/

AARP: Caregiving Resource Center http://www.aarp.org/relationships/caregiving-resource-center/

American Cancer Society (ACS):
Caring for the Patient with Cancer at Home
Listen with Your Heart

American Chronic Pain Association

American College of Physicians Ethics, Professionalism and Human Rights Committee:
Information Resources for Physicians Supporting Family Caregivers

Assisted Living Directory

Be the Match: Bone Marrow Donor

CANCER Care
Caregiving

Cancer Hope Network

Cancer.Net: Caregiver Support

Cancer Support Community
Frankly Speaking About Cancer

Caregiver Action Network

Caregiving.com

Caregiver Resource Center

Caring.com

Families Facing Cancer: Emotional & Practical Support

Family Caregiver Alliance

Family Caregiver Support Network

Full Circle of Care

International Palliative Care Family Carer Research Collaboration

Joe’s House: A Lodging Guide for Cancer Patients

Leukemia & Lymphoma Society:
Long-Distance Caregiving
Caregivers’ Guide for Bone Marrow/Stem Cell Transplant: Practical Perspective

Lotsa Helping Hands

National Alliance for Caregiving

National Cancer Institute:
- Caring for the Caregiver booklet
- Coping with Cancer: For Caregivers, Family, Friends
- Deep Water: Making Sense of a Cancer Diagnosis (YouTube)
- Facing Forward: Life After Cancer Treatment
- Family Caregivers in Cancer: Roles & Challenges

http://www.cancer.org
http://www.cancer.org/Treatment/UnderstandingYourDiagnosis/TalkingaboutCancer/ListenwithYourHeart/index
http://theacpa.org/
http://www.assisted-living-directory.com/
http://www.marrow.org/
http://www.cancercare.org/
http://www.cancercare.org/tagged/caregiving
http://www.cancerhopenetwork.org/
http://www.cancer.net/coping/caregiving
http://www.cancersupportcommunity.org/
http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Frankly-Speaking-About-Cancer
http://caregiveraction.org/
http://www.caregiving.com
http://www.aarp.org/home-family/caregiving/
http://www.caring.com/
http://familiesfacingcancer.org/
http://www.caregiver.org/caregiver/jsp/home.jsp
http://www.caregiversupportnetwork.org/default.asp?id=1
http://www.centreforpaillacare.org/index.php/research/ipcfrcrc/
http://www.joeshouse.org/
http://www.lls.org/diseaseinformation/forcaregivers/longdistanceare giving/
http://www.lls.org/resourcecenter/suggestedreading/adultpatiente ntcaregivers/caregiving/caregiversguideforbonemarrow
http://www.lotsahelpinghands.com/
http://www.cancergov/cancertopics/coping/familyfriends
http://www.cancergov/cancertopics/coping/life-after-treatment
http://www.cancergov/about-cancer/coping/family-friends/family-caregivers-pdq
Factors to Consider in Caregiver Assessment
When Someone You Love Has Advanced Cancer
When Someone You Love Has Completed Cancer Treatment
When Someone You Love Is Being Treated for Cancer
Caring for the Caregiver

National Comprehensive Cancer Network (NCCN)
Patient and Caregiver Resources
Navigating Cancer and Blood Disorders
Patient Resource Net
Patient Resource Cancer Guide
Resources and Links for Patients and Families
Rosalynn Carter Institute for Caregiving
Today's Caregiver
Well Spouse Association

Key References from Comprehensive Cancer Centers
The following comprehensive cancer centers have family caregiver support and/or resource pages.

1. The Cancer Institute of New Jersey, Robert Wood Johnson Medical School – New Brunswick, New Jersey
   Website: http://www.cinj.org/
   - Caregiving Links
     Website: http://www.cinj.org/education/caregiving.

2. City of Hope National Medical Center – Duarte, California
   Website: http://www.cityofhope.org
   - Sheri & Les Biller Patient and Family Resource Center
     Website: http://www.cityofhope.org/patient_care/Biller-Center

3. MD Anderson Cancer Center – University of Texas, Houston, Texas
   Website: http://www.mdanderson.org/
   - Family-Centered Care
   - Patient and Caregiver Support Line
   - Patient and Family Support
4. **Memorial Sloan-Kettering Cancer Center – New York, New York**  
   Website: [http://www.mskcc.org/mskcc/html/44.cfm](http://www.mskcc.org/mskcc/html/44.cfm)  
   - Counseling & Support for Caregivers & Families  
     Website: [http://www.mskcc.org/cancer-care/counseling-support/caregivers-families](http://www.mskcc.org/cancer-care/counseling-support/caregivers-families)  
   - A Guide for Caregivers  

5. **Norris Cotton Cancer Center – Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire**  
   Website: [http://cancer.dartmouth.edu/](http://cancer.dartmouth.edu/)  
   - Patient & Family Support Services  
     Website: [http://cancer.dartmouth.edu/pf/cancer_care/support_services.html](http://cancer.dartmouth.edu/pf/cancer_care/support_services.html)  
   - Caring for Someone with Cancer Group  
     Website: [http://cancer.dartmouth.edu/support_services/caring_someone_cancer_group.html](http://cancer.dartmouth.edu/support_services/caring_someone_cancer_group.html)  
   - Shared Decision Making  
     Website: [http://cancer.dartmouth.edu/pf/cancer_care/shared_decision.html](http://cancer.dartmouth.edu/pf/cancer_care/shared_decision.html)

6. **The James – Ohio State University Comprehensive Cancer Center, Columbus, Ohio**  
   Website: [http://cancer.osu.edu/](http://cancer.osu.edu/)  
   - Patient and Caregiver Support Groups  
     Website: [http://cancer.osu.edu/patientsandvisitors/cancerinfo/support/support%20groups/pages/index.aspx](http://cancer.osu.edu/patientsandvisitors/cancerinfo/support/support%20groups/pages/index.aspx)

7. **Roswell Park Cancer Institute – Buffalo, New York**  
   Website: [http://www.roswellpark.org/](http://www.roswellpark.org/)  
   - Role of Caregivers  
     Website: [https://www.roswellpark.org/media/audio/role-caregivers-s-sharcot](https://www.roswellpark.org/media/audio/role-caregivers-s-sharcot)  
   - BMT Orientation and Caregiver Program  

8. **Sidney Kimmel Comprehensive Cancer Center – Johns Hopkins University, Baltimore, Maryland**  
   Website: [http://www.hopkinsmedicine.org/kimmel_cancer_center/](http://www.hopkinsmedicine.org/kimmel_cancer_center/)  
   - Being a Caregiver  
     Website: [http://www.hopkinsmedicine.org/healthlibrary/conditions/adult/home_health_hospice_and_elder_care/being_a_caregiver_85,P00602/](http://www.hopkinsmedicine.org/healthlibrary/conditions/adult/home_health_hospice_and_elder_care/being_a_caregiver_85,P00602/)  
   - Caregivers Video Series: Walking on Eggshells  

9. **University of Michigan Comprehensive Cancer Center – Ann Arbor, Michigan**  
   Website: [http://mcancer.org/](http://mcancer.org/)  
   - Thrive: Focusing on the Caregiver  
     Website: [http://www.cancer.med.umich.edu/files/winter10-thrive.pdf](http://www.cancer.med.umich.edu/files/winter10-thrive.pdf)  
   - Living with Cancer  
     Website: [http://www.hopkinsmedicine.org/healthlibrary/conditions/adult/home_health_hospice_and_elder_care/being_a_caregiver_85,P00602/](http://www.hopkinsmedicine.org/healthlibrary/conditions/adult/home_health_hospice_and_elder_care/being_a_caregiver_85,P00602/)  
   - Caring for the Caregiver FAQ  
     Website: [http://www.cancer.med.umich.edu/news/pro05fall05.shtml](http://www.cancer.med.umich.edu/news/pro05fall05.shtml)  
   - Caregivers benefit from cancer support programs  

10. **UW Carbone Cancer Center – University of Wisconsin, Madison, Wisconsin**  
    Website: [http://www.uwhealth.org/cancer-for-researchers/uwccc/28373](http://www.uwhealth.org/cancer-for-researchers/uwccc/28373)  
    - Caregiver Tips  
      Website: [http://www.uwhealth.org/healthfacts/B_EXTRANET_HEALTH_INFORMATION-FlexMember-Show_Public_HFFY_1105110081585.html](http://www.uwhealth.org/healthfacts/B_EXTRANET_HEALTH_INFORMATION-FlexMember-Show_Public_HFFY_1105110081585.html)  
    - Caregiver Role Strain  
      Website: [http://www.uwhealth.org/healthfacts/B_EXTRANET_HEALTH_INFORMATION-FlexMember-Show_Public_HFFY_1126663367681.html](http://www.uwhealth.org/healthfacts/B_EXTRANET_HEALTH_INFORMATION-FlexMember-Show_Public_HFFY_1126663367681.html)
11. UCSF Helen Diller Family Comprehensive Cancer Center – University of California, San Francisco, California  
   Website: http://cancer.ucsf.edu/  
   - Ida & Joseph Friend Cancer Resource Center  
     Website: http://cancer.ucsf.edu/crc/  
   - Osher Center for Integrative Medicine  
     Website: http://www.osherc.ucsf.edu/  

12. Vanderbilt-Ingram Cancer Center – Vanderbilt University, Nashville, Tennessee  
   Website: http://www.vicc.org/  
   - The Hope Connection: Talk with someone who’s been there  
     Website: http://www.vicc.org/hope/  
   - Stress within the Family or Couple  
     Website: http://www.vicc.org/cancercare/symptoms/counseling/stress.php  
   - Cancer Supportive Care Clinic  
     Website: http://www.vicc.org/clinics/support/  

V. Special Populations  
B. Pain Management, Palliative, and Long-Term Care in the Elderly  
*Section Description:* This section includes Clinical Practice Guidelines on the Management of Pain in the Elderly from the American Geriatric Society and the American Medical Directors Association. Book order forms are available that address pain management in the elderly and in the long-term care setting.  

**City of Hope Publications**  

**Recommended Publications**  
1. Geriatric Palliative Care  
     Website: http://www.Amazon.com  
5. Evidence-Based Geriatric Nursing Protocols for Best Practice, 4th Edition  


23. **Pain in Older People**  

24. **Pain Management for Older Adults, A Self Help Guide**  

### Educational Materials/Curriculum

1. **Detecting Discomfort in Dementia: Focus on Behaviors** – Alliance of State Pain Initiatives (ASPI), Madison, WI  
   - An educational video toolkit to help nursing assistants understand their role in providing good care for cognitively impaired residents in pain. Includes a 13 minute DVD and a booklet *Tools for Inservice Education*.  
   Website: [http://trc.wisc.edu/](http://trc.wisc.edu/).

2. **Pain Care Fast Facts: 5-Minute Clinical Inservice** – UW Health, University of Wisconsin Hospital & Clinics, Madison, WI  
   - Assessing Pain in the Nonverbal or Cognitively Impaired  
   Website: [http://prc.coh.org/pdf/Assess%20Cog%2009-09.pdf](http://prc.coh.org/pdf/Assess%20Cog%2009-09.pdf)

### Guidelines/Clinical Pathways

1. **Clinical Practice Guideline: Pain Management in the Long-Term Care Setting**  
   - Published by the American Medical Directors Association (AMDA). The guideline is directed toward the entire interdisciplinary team - as well as patients and their families - in order to achieve effective pain management.  

2. **The Management of Persistent Pain in Older Persons**  
   - Clinical Practice Guidelines from the American Geriatrics Society.  

3. **State of the Art Review of Tools for Assessment of Pain in Nonverbal Older Adults**  
   - Herr, K., Bursch, H., & Black, B.  
   Website: [http://prc.coh.org/PAIN-NOA.htm](http://prc.coh.org/PAIN-NOA.htm)  
   - Overview, Criteria for Evaluation, Comparison Grid, Comparison of Tool Items with AGS 2002 Persistent Pain Guidelines, Review References  
   - Abbey Pain Scale (Abbey J, et al.)  
   - Certified Nurse Assistant Pain Assessment Tool (CPAT), (Cervo, F., et al.)  
   - Checklist of Nonverbal Pain Indicators (CNPI), (Feldt K)  
   - Disability Distress Assessment Tool (Dis DAT) (Regnard, C., et al.)  
   - Discomfort Behavior Scale (DBS) (Stevenson, K., et al.)  
   - Discomfort Scale-Dementia of the Alzheimer’s Type (DS-DAT), (Hurley A, et al.)  
   - Doloplus 2, (Wary B and the Doloplus Group)  
   - Elderly Pain Caring Assessment 2 (EPCA-2) (Morello, R., et al.)  
   - Face, Legs, Activity, Cry and Consolability Pain Assessment Tool (the FLACC), (Merkel SI, et al.)  
   - Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID) (Husebo, B.S., et al.)  
   - Nursing Assistant-Administered Instrument to Assess Pain in Demented Individuals (NOPPAIN), (Snow AL, et al.)  
   - Pain Assessment in Advanced Dementia (PAINAD) Scale, (Warden V, et al.)  
   - Pain Assessment for the Dementing Elderly (PADE), (Villaneuva MR, et al.)  
   - Pain Assessment in Noncommunicative Elderly Persons (PAINE) (Cohen-Mansfield, J., et al.)  
   - Pain Assessment Scale for Senior's with Severe Dementia (PACSLAC), (Fuchs-Lacelle SK, et al.)  
   - Pain Behaviors for Osteoarthritis Instrument for Cognitively Impaired Elders (PBOICE) (Tsai, P., et al.)
Other Organizational Links

AARP (American Association of Retired Persons) http://www.aarp.org
Administration on Aging http://www.aoa.gov/
Advancing Excellence in America's Nursing Homes http://www.nhqualitycampaign.org/
AgingCare.com: Connecting caregivers http://www.agingcare.com/
Aging with Dignity http://www.agingwithdignity.org
Aging Parents and Elder Care http://www.aging-parents-and-elder-care.com/
Alzheimer’s Association http://www.alz.org/
Alzheimer’s Disease Education & Referral (ADEAR) http://www.nia.nih.gov/alzheimers
American Assisted Living Nurses Association http://www.alnursing.org/
American Association for Long Term Care Nursing http://ltcnursing.org/
American Chronic Pain Association http://www.theacpa.org/
American Geriatrics Society http://www.americangeriatrics.org
American Society on Aging http://www.asaging.org
Care Force: Excellence in Care Management http://www.careforce.com/
Caregiver Action Network http://www.caregiveraction.org/
Caregiving.com http://www.caring.com/
Caring.com http://www.clinicalgeriatrics.com
Geriatric Pain http://www.geriatricpain.org/Pages/home.aspx
Gerontological Advanced Practice Nurses Association http://www.gapna.org/
Gerontological Society of America http://www.geron.org/
In the Face of Pain http://inthefaceofpain.com/
Long Term Care Planning Network http://www.ltcplanningnetwork.com/
National Association Directors of Nursing Administration in Long Term Care http://nadona.org/
National Gerontological Nursing Association http://www.ngna.org/
National Institute on Aging http://www.nih.gov/nia/
Nurses Improving Care for Healthsystem Elders http://nicheprogram.org/
Organ Procurement and Transplantation Network http://optn.transplant.hrsa.gov/
Palliative Care for Seniors, Care Givers and Families http://www.hydrotherapybathing.com/resources/palliative-care-for-seniors/
Rheumatoid Arthritis (RA) Learning Center http://healthtools.aarp.org/learning-center/rheumatoid-arthritis
SeniorNet http://www.seniornet.org
StopPain.org http://www.stoppain.org/
V. Special Populations

C. Pediatrics

Section Description: This section covers perinatal through young adults and includes City of Hope publications, recommended books, studies, informational articles, and pamphlets as well as policy statements from professional organizations on pediatric topics. Topics include pain & symptom management, palliative and hospice care, spirituality, ethics, advance directives, grief & bereavement. Additional sections include educational materials and related organizational links.

Additional assessment tools for pediatrics can be found under the Section IX. Research Instruments/Resources.

City of Hope Publications


Recommended Publications


2. Wong’s Essentials of Pediatric Nursing, 9th Edition

3. Palliative and End of Life Care for Children and Young People: Home, Hospice, Hospital


20. Textbook of Interdisciplinary Pediatric Palliative Care

21. A Gift of Time: Continuing Your Pregnancy When Your Baby’s Life is Expected to Be Brief


57. Oxford Textbook of Palliative Nursing

Section VI: Pediatric Palliative Care:
- Chapter 55: Symptom Management in Pediatric Palliative Care
- Chapter 56: Pediatric Hospice and Palliative Care
- Chapter 57: Pediatric Care: Transitioning Goals of Care in the Emergency Department, Intensive Care Unit, & In Between
- Chapter 58: End-of-life Decision-Making in Pediatric Oncology

     Website: http://www.amazon.com/.


62. Pediatric Hematology Nurse: Scope & Standards of Practice  


77. Palliative Care for Children and Families: An Interdisciplinary Approach


87. Hospice Care For Children, 3rd Edition

88. Empty Arms: Coping After Miscarriage, Stillbirth and Infant Death

89. Living with Grief: Children and Adolescents
1. **APHON’s Foundations of Pediatric Hematology/Oncology Nursing: A Comprehensive Orientation & Review Course**
   This course is designed to provide participants with an overview of nursing issues involved in caring for children and adolescents with cancer and blood diseases. A course evaluation form and posttest are provided to assist in measuring the effectiveness of the program. Website: [http://apps.aphon.org/Store/ProductDetails.aspx?productId=407](http://apps.aphon.org/Store/ProductDetails.aspx?productId=407)


3. **NHPCO Standards for Pediatric Palliative and Hospice Care for America’s Children - National Hospice and Palliative Care Organization**
   - Standards of Practice for Pediatric Palliative Care and Hospice is designed to supplement NHPCO’s Standards of Practice for Hospice Programs. The standards set clinical and organizational precedence for hospice and palliative care programs providing care to infants, children, adolescents, and their families in the home, hospital, and other settings. These standards can be used to create a template for organizational best practice and to provide safe, effective, high-quality care for children and their families facing life-threatening illness. Website: [http://www.nhpco.org/quality/nhpco's-standards-pediatric-care](http://www.nhpco.org/quality/nhpco's-standards-pediatric-care)

4. **Essentials of Pediatric Oncology Nursing: A Core Curriculum, 3rd Edition - Association of Pediatric Oncology Nurses**
   - Written and edited by the top experts in the field of pediatric hematology/oncology nursing, the Core Curriculum covers every component of the job. Website: [http://www.amazon.com/Essentials-Pediatric-Hematology-Oncology-Nursing/dp/0966619331](http://www.amazon.com/Essentials-Pediatric-Hematology-Oncology-Nursing/dp/0966619331).

5. **Fast Facts and Concepts - Center to Advance Palliative Care (CAPC)**
   - Grief in Children and Developmental Concepts of Death #138
   - Pediatric Pain Assessment Scales #117

6. **Initiative for Pediatric Palliative Care (IPPC)**
   - IPPC curriculum materials are available—free of charge—through their website. The modules are designed to facilitate individual clinician learning and strengthen an institution’s programs and services. The six modules include: Engaging with Children and Families; Relieving Pain and Other Symptoms; Analyzing Ethical Challenges in Pediatric End-of-Life Decision Making; Responding to Suffering and Bereavement; Improving Communication and Strengthening Relationships; and Establishing Continuity of Care. Website: [http://www.ippcweb.org/curriculum.asp](http://www.ippcweb.org/curriculum.asp).

7. **A Lion in the House - LION**

8. **Capturing a Short Life**
   - Capturing a Short Life is a beautiful, intimate and life-affirming documentary about families dealing with infant loss. It explores how critical it is to remember and celebrate the beautiful babies who are only with us for a moment, and how impossible it is to forget them. Website: [http://www.capturingashortlife.com/home/](http://www.capturingashortlife.com/home/).

9. **Health Facts for You - UW Health, University of Wisconsin Hospital & Clinics, Madison, WI**
   - Pediatrics, Parenting
     Website: [http://www.uwhealth.org/healthfacts/parenting/](http://www.uwhealth.org/healthfacts/parenting/)
   - EMLA Cream (for needle sticks)
     Website: [http://www.uwhealth.org/healthfacts/pain/5706.html](http://www.uwhealth.org/healthfacts/pain/5706.html)
   - Intranasal Analgesia Prior to Insertion of Nasogastric Tube
- Sucrose Analgesia for Infants  
  Website: http://prc.coh.org/SucAnal.pdf

- Topical Lidocaine – L.M.X.4  
  Website: http://www.uwhealth.org/healthfacts/B_EXTRANET_HEALTH_INFORMATION-FlexMember-Show_Public_HFFY_1126663168419.html

- Where Do You Hurt? – Pediatric (also in Spanish)  
  Website: http://www.uwhealth.org/healthfacts/pediatricsparenting/where-do-you-hurt.html

- Health Facts for You  
  Website: http://www.uwhealth.org/healthfacts/

10. Pain of Circumcision and Pain Control - Circumcision Information and Resource Pages (CIRP)  
   - This website indexes material on the pain of neonatal male circumcision, its effects, and attempts to control circumcision pain. Website: http://www.cirp.org/library/pain/.

11. Pediatric Pain & Symptom Management Algorithms for Palliative Care  
   - A pocket-sized book that has dozens of symptom management algorithms for hospice and palliative care. This is a book with core information needed for medical professionals working with pediatric hospice, home care, palliative care resource teams, oncology services, and long-term care facilities.  

**Guidelines/Clinical Pathways**

1. CRIES Tool - Judy Bildner, Neonatal Clinical Nurse Specialist; University Hospital & Clinics, Children's Hospital, Columbia, MO  
   - Behavioral assessment tool for pain in neonates. Includes self-learning module and documentation forms.  
   Website: http://prc.coh.org/pdf/CRIES.pdf.

2. FLACC Scale (Face, Legs, Activity, Cry, Consolability) - CS Mott Children's Hospital, University of Michigan Medical Center  

3. Neonatal Pain, Agitation, & Sedation Scale (N-PASS) - Hummel & Puchalski  
   - The N-PASS is a valid and reliable clinical pain/agitation and sedation tool for neonates. Nurses find the N-PASS easy to use clinically, facilitating documentation and management of pain and sedation.  
   Website: http://www.anestesiaarianimazione.com/2004/06c.asp.

   - A compendium of evidence based research for pediatric practice.  

5. Pediatric Nurses' Knowledge and Attitudes Survey Regarding Pain – © Manworren  
   - Instrument to access pediatric nurses' knowledge and attitudes regarding pain in children. Answer key also provided.  
   Contact: Renee Manworren, PhD, ARPRN, PCNS-BC, Division of Pain and Palliative Medicine, Connecticut Children’s Medical Center, University of Connecticut School of Medicine, 282 Washington Street, Hartford, CT 06106  

6. Pediatric Nurses Knowledge and Attitudes Survey (PNKAS) – © Manworren and Shriners Hospitals  
   - The PNKAS survey pertains to pediatric pain in burns, orthopedics and spinal cord injuries. Answer key also provided.  

7. Paediatric Pain Profile - Institute of Child Health, University College, London and Royal College of Nursing Institute  
   - The Paediatric Pain Profile (PPP) is a behaviour rating scale for assessing pain in children with severe physical and learning impairments.  
   Website: http://www.ppprofile.org.uk/.

8. Pediatric Palliative & End-of-Life Care Resource  
   - This valuable resource is the product of a partnership between APHON and the Children's Oncology Group Nursing Discipline and provides important information for pediatric hematology/oncology nurses who are caring for critically and terminally ill children.  
   Website: http://apps.aphon.org/Store/ProductDetails.aspx?productId=34.
   Website: http://www3.us.elsevierhealth.com/WOW/
   - Translations of the Wong-Baker Faces Pain Rating Scale.
     Website: http://prc.coh.org/Ref%20Man%20Wong-Baker.pdf.

Other Organizations Links
American Academy of Pediatrics http://www.aap.org
Association of Pediatric Hematology/Oncology Nurses http://www.aphon.org
Association of Pediatric Oncology Social Workers http://www.aposw.org
Bandaides and Blackboards http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/
Child/Adolescent Health http://www.ahrq.gov/child/
Children’s Hospice International http://www.chionline.org
Compassion Books for Children http://www.compassionbooks.com/categories/For-Children/
Compassionate Friends: Supporting Family After a Child Dies http://www.compassionatefriends.org
CureSearch for Children’s Cancer http://www.curesearch.org/
Cure SMA (Spinal Muscular Atrophy) http://www.curesma.org/sma/about-sma/
End of Life Nursing Education Consortium (ELNEC) http://www.aacn.nche.edu/ELNEC/
Griefnet.org http://www.griefnet.org/support/sg2.html
Initiative for Pediatric Palliative Care. http://www.ippcweb.org/
International Children’s Palliative Care Network http://www.icpcn.org.uk
Kidsaid - 2 Kids, 4 Kids, By Kids http://kidsaid.com/
Liam’s Foundation for Pediatric Palliative Care http://liamsfoundation.org/foundation.html
Loving Touch (Infant Massage) http://www.lovingtouch.com/
Make a Wish Foundation http://www.wish.org
National Children’s Cancer Society http://www.thenccs.org/aboutNCCS
National Hospice and Palliative Care Organization Pediatric Hospice http://www.nhpco.org
Organ Procurement and Transplantation Network http://optn.transplant.hrsa.gov/
Pediatric Art Therapy for Children with Cancer http://www.tracyskids.org/
Post Pals http://www.postpals.co.uk/
What is Pediatric Palliative Care http://getpalliativecare.org/whatis/pediatric/

Position Statements/Standards
1. American Academy of Pediatrics (AAP)
   - Circumcision Policy Statement
     Policy Statement regarding giving a child procedural analgesia (EMLA cream) before performing a circumcision procedure. Website: http://pediatrics.aappublications.org/content/130/3/585.short.
Palliative Care for Children
This statement presents an integrated model for providing palliative care for children living with a life-threatening or terminal condition.
Website: http://pediatrics.aappublications.org/content/106/2/351.full?sid=edb8fd1a-d136-4a3a-b639-7e7ddd2c1d2e

Prevention and Management of Pain in the Neonate: An Update
The objectives of this statement are to increase awareness that neonates experience pain; provide a physiological basis for neonatal pain and stress assessment and management by health care professionals; make recommendations for reduced exposure of the neonate to noxious stimuli and to minimize associated adverse outcomes; and recommend effective and safe interventions that relieve pain and stress.
Website: http://pediatrics.aappublications.org/content/118/5/2231.full?sid=8e3673c9-d572-4a43-ad5e-db6e87c4d48b.

- Guidelines for Care of Children in the Emergency Department  Website: http://www.acep.org/practres.aspx?id=29134

3. American Society of Pain Management Nurses (ASPMN)
Male Infant Circumcision Pain Management
The ASPMN opposes the participation of nurses and other healthcare professionals in the performance of male neonatal circumcision without an anesthetic to treat the pain inherent in the procedure.

V. Special Populations
D. Cultural Considerations in Palliative Care
Section Description: This section offers resources related to cultural issues in pain and palliative care and guidelines for cultural competency.

City of Hope Publications


Recommended Publications


3. Cultural Diversity in Health and Illness, 8th Edition

4. Transcultural Concepts in Nursing Care


36. Pain and Its Transformations: The Interface of Biology and Culture


**Educational Materials/Curriculum**

1. Cancer Fact Sheets - Intercultural Cancer Council
   - The Cancer Fact Sheets were created because medically underserved populations, such as racial and ethnic minorities, experience disproportionately greater suffering and compromised health from cancer. Website: http://www.iccnetwork.org/cancerfacts/
2. Fast Facts and Concepts – Palliative Care Network of Wisconsin (PCNOW)
- African Americans and End-of-Life Care #204
- Asking about Cultural Beliefs in Palliative Care #216
- Cultural Aspects of Pain Management, 2nd Ed. #078
- Improving Communication When Hearing Loss is Present #241

3. Pain Care Fast Facts: 5-Minute Clinical Inservice - UW Health, University of Wisconsin Hospital & Clinics, Madison, WI

Guidelines/Clinical Pathways
   - This guide serves as a resource for those wanting to undertake quality improvement initiatives to improve culturally and linguistically appropriate service and to reduce disparities in care for multicultural patients.

2. Cultural Competence in Cancer Care, A Healthcare Professional’s Passport – Intercultural Cancer Council
   - This pocket guide is intended to be a reference along a cultural journey, which health care professionals can explore when providing cancer care.
   Website: http://iccnetwork.org/pocketguide/index.html.

3. Selected Patient Information Resources in Asian Languages (SPIRAL)
   - SPIRAL is a joint initiative of the South Cove Community Health Center and Tufts University Hirsh Health Sciences Library. SPIRAL aims to increase access to Asian-language health information for consumers and health care providers.
   Website: http://spiral.tufts.edu/brochures.shtml.

Other Organizational Links
Cancer Health Disparities http://www.cancer.gov/health-disparities
Cross Cultural Health Care Program http://www.xculture.org
Cultural Diversity in Healthcare http://gagalanti.com/
Diversity Rx http://DiversityRx.org
Ethnogeriatrics https://geriatrics.stanford.edu/
Ethnomed (Ethnic Medicine Information) http://www.ethnomed.org
Intercultural Cancer Council http://www.iccnetwork.org
Intercultural Communication Institute http://www.intercultural.org
Multicultural Health Clearinghouse http://www.mckinley.uiuc.edu/multiculturalhealth/
National Center for Cultural Competence http://nccc.georgetown.edu/
National Coalition of Ethnic Minority Nurse Associations http://www.ncemna.org/
V. Special Populations
   E. Sickle Cell Disease

This section includes physician and patient resource guides in pain management and palliative care in sickle cell disease as well as clinical pathways for treatment. Videos and guidelines for treatment are also available.

Recommended Publications


**Educational Materials/Curriculum**
1. The Sickle Cell Information Center - Georgia Comprehensive Sickle Cell Center, Atlanta, GA
   Website: http://scinfo.org/.

**Guidelines/Clinical Pathways**
1. The Management of Sickle Cell Disease - National Institute of Health

2. Sickle Cell Pain Relief Record - St. Francis Hospital & Medical Center, Hartford, CT
   Website: http://www.medicalhomeinfo.org/downloads/pdfs/Sickle_Cell_Pain_Relief_Record-CT.pdf.

3. Sickle Cell Disease: Critical Elements of Care - The Center for Children with Special Health Needs Children's Hospital and Regional Medical Center, Seattle, WA
   Website: http://cshcn.org/sites/default/files/webfm/file/CriticalElementsOfCare-SickleCell.pdf

**Other Organizational Links**
American Sickle Cell Anemia Association
http://www.ascaa.org/

Sickle Cell Anemia - MedLine Plus

Sickle Cell Disease - EMedicineHealth

Sickle Cell Disease - KidsHealth
http://kidshealth.org/parent/medical/heart/sickle_cell_anemia.html

Sickle Cell Disease - National Organization for Rare Disorders

Sickle Cell Disease and Your Baby - March of Dimes

Sickle Cell Disease Association of America, Inc.
http://www.sicklecelldisease.org/

SickleCellKids.org
http://www.sicklecellkids.org/

Sickle Cell Society
http://sicklecellsociety.org/

**Position Statements/Standards**
1. American Academy of Pediatrics Position Statements
   - Health Supervision for Children with Sickle Cell Disease
     Timely and appropriate treatment of SCD is critical, because life-threatening complications develop rapidly. It is essential that every child with SCD receive comprehensive care that is coordinated through a medical home with appropriate expertise. Website: http://pediatrics.aappublications.org/content/109/3/526.full.html.
V. Special Populations
F. HIV/AIDS

Section Description: This section includes books and pamphlet order forms along with information on professional organizations focused on AIDS care.

City of Hope Publications

Recommended Publications

2. HIV Essentials 2014, 7th Edition

3. MMHIV: Medical Management of HIV Infection, 16th Edition
   A Guide to Primary Care of People with HIV/AIDS
   A Pocket Guide to Adult HIV/AIDS Treatment

4. 100 Questions and Answers About HIV and AIDS, 2nd Edition


   Website: http://www.jbpub.com/Catalog/9780763754594/Authors/.


**Educational Materials/Curriculum**

1. Fast Facts and Concepts – Palliative Care Network of Wisconsin (PCNOW)
   - Cannabinoids in the Treatment of Symptoms in Cancer and AIDS #093
   - Prognosis in HIV and AIDS #213
   - Prognosis in HIV Associated Malignancies #214
**Guidelines/Clinical Pathways**

1. AIDS Education & Training Centers National Resource Center
   - Guides for HIV/AIDS Clinical Care
   - Clinicians Reference Tools
   - 12 Considerations for Providing Timely HIV/AIDS Care
   Website: [http://aidsetc.org/resources](http://aidsetc.org/resources)

2. AIDS/HIV Guidelines & Recommendations - Center for Disease Control and National Prevention & Information Network


**Other Organizational Links**

- AIDS Project Los Angeles: [http://www.apla.org](http://www.apla.org)
- amFAR AIDS Research: [http://www.amfar.org/](http://www.amfar.org/)
- AVERTing HIV and AIDS: [http://www.avert.org/hiv_usa.htm](http://www.avert.org/hiv_usa.htm)
- HIV/AIDS Program - Indian Health Services: [http://www.ihs.gov/hivaid/index.cfm](http://www.ihs.gov/hivaid/index.cfm)
Position Statements/Standards
1. American Nurses Association
   - Bloodborne and Airborne Diseases

2. Association of Nurses in AIDS Care (ANAC)
   - Positions Statements on HIV/AIDS
   Website: http://www.nursesinaidscare.org/i4a/pages/index.cfm?pageid=3300.

3. The International Council of Nurses
   - HIV Infection and AIDS

V. Special Populations
G. Chronic Non-Malignant Pain & Headache
   Section Description: This section offers resources related to Fibromyalgia, chronic pain and headaches.

Recommended Publications
1. The Migraine Brain: Imaging Structure and Function
   Website: http://www.amazon.com/.

2. The Cleveland Clinic Manual of Headache Therapy
   Website: http://www.amazon.com/.

   Website: http://www.amazon.com/.


5. Comprehensive Review of Headache Medicine

6. Headache Simplified

7. The Headache Cure

   Website: http://www.jbpub.com/catalog/9780763746407/.

9. What Your Doctor May Not Tell You About Fibromyalgia: The Revolutionary Treatment that Can Reverse the Disease
   Website: http://fibromyalgiatreatment.com/books&vids.htm.

10. Fibromyalgia - Up Close & Personal
11. **Taking Charge of Fibromyalgia: Everything You Need to Know to Manage Fibromyalgia, 5th Edition**

12. **Living Well with Migraine Disease and Headaches: What Your Doctor Doesn’t Tell You...that You Need to Know**
   Website: http://www.harpercollins.com/books/9780060766856/Living_Well_with_Migraine_Disease_and_Headaches/index.aspx.


14. **The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners**
   Website: http://www.amazon.com/Fibromyalgia-Syndrome-Definition-Practitioners-Musculoskeletal/dp/0789025744.

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**Educational Materials/Curriculum**

1. **Headache 2013 – Robbins Headache Clinic**
   - A comprehensive guide to headache treatment, including advanced approaches for when nothing has helped
   Website: http://www.amazon.com/.


3. **Health and Nutrition Facts for You - UW Health, University of Wisconsin Hospital & Clinics, Madison, WI**
   - Migraine Headaches
   Website: http://www.uwhealth.org/health/topic/special/migraine-headaches/hw116874.html

4. **Overview of Pediatric Migraine – Medscape Reference**

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**Guidelines/Clinical Pathways**

1. **Fibromyalgia Treatment Guidelines - Livestrong Foundation**

2. **Guidelines for All Healthcare Professionals in the Diagnosis and Management of Migraine, Tension-Type, Cluster and Medication-Overuse Headaches - British Association for the Study of Headache**

3. **Migraine Headache - American Academy of Neurology**
   Website: https://www.aan.com/Guidelines/Home/GetGuidelineContent/120.

4. **Practice Parameter: Evidence-based Guidelines for Migraine Headache – American Academy of Neurology**
   Website: http://www.neurology.org/cgi/content/full/55/6/754.

5. **Complex Regional Pain Syndrome: Treatment Guidelines - Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)**
   These guidelines have been written for a professional audience.

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**Other Organizational Links**

- American Chronic Pain Association http://www.theacpa.org/
Cluster Headaches.com
Chronic Non-Malignant Pain

Fibromyalgia, Chronic Fatigue, Central Sensitivity Syndrome
Fibromyalgia Support Group
Fibromyalgia Treatment Center
Fibromyalgia Network
For Grace: Empowering Women in Pain
Headache - Kids Health
Headache Symptom & Signs Index
Help for Headaches
International Headache Society
Headache Symptom & Signs Index
Help for Headaches
International Headache Society
International Myopain Society
M.A.G.N.U.M. Awareness Group
Managing Back Pain

MigraineInformation.org
Migraine Research Foundation
National Fibromyalgia Association
National Fibromyalgia Partnership, Inc.
National Fibromyalgia Research Association
National Headache Foundation
National Institute of Neurological Disorders: Headache Pain.com
Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)
Robbins Headache Clinic
Spine-Health
World Institute of Pain

http://www.clusterheadaches.com/newvisitors.html
http://dewarlorx.com/fibromyalgia.htm
http://www.mdjunction.com/fibromyalgia
http://fibromyalgiatreatment.com/
http://www.fmnetnews.com/
http://www.forgrace.org/women/in/pain_home/
http://www.kidshealth.org/kid/ill_injure/sick/headache.html
http://www.medicinenet.com/headache/symptoms.htm
http://www.headache-help.org/
http://www.ihs-headache.org/
http://www.medicinenet.com/headache/symptoms.htm
http://www.headache-help.org/
http://www.ihs-headache.org/
http://www.myopain.org/
http://www.migraines.org/
http://www.rd.com/health/conditions/chronic-back-pain-breakthroughs/2/
http://www.migraineinformation.org/
http://www.migraineresearchfoundation.org/
http://www.fmaware.org/
http://www.fmpartnership.org/
http://www.nfра.net/
http://www.headaches.org
http://www.pain.com/
http://www.rsdso/index2.html
http://www.headachedrugs.com/
http://spine-health.com/
http://www.worldinstituteofpain.org/
VI. Education

A. Professional Competencies and Educational Programs

Section Description: This section includes materials from previous Pain Resource Nurse (PRN) programs at the City of Hope and similar programs including agendas, objectives, tests, and syllabi. Additional resources include self-paced learning modules, pain management competency packets and curriculum, treatment and training guidelines, and case conference packets. These resources are available in various forms such as interactive CD, videotapes, and bound copies.

For measurement tools on Knowledge and Attitudes Survey Regarding Pain refer to Section IX. Research Instruments/Resources.

City of Hope Publications


Recommended Publications

1. Pain Assessment and Pharmacologic Management


Education Materials/Curriculum

1. Advanced Certification for Palliative Care Program - The Joint Commission
   - The Advanced Certification Program for Palliative Care is designed to recognize hospital inpatient programs that demonstrate exceptional patient and family-centered care in order to optimize the quality of life for patients with serious illness. Palliative care involves addressing physical, emotional, social and spiritual needs and facilitating patient autonomy, access to information and choice.
   - Website: [http://www.jointcommission.org/certification/palliative_care.aspx](http://www.jointcommission.org/certification/palliative_care.aspx)

2. Competency Guidelines for Cancer Pain in Nursing Education and Practice - Wisconsin Cancer Pain Initiative
   - Criteria used as basic competency in pain management for nurses. Useful for student evaluation or to establish clinical competency of nurses. Website: [http://trc.wisc.edu/WCPI_RN.pdf](http://trc.wisc.edu/WCPI_RN.pdf).
3. Creating Organizational Change Through the Pain Resource Nurse Program - Joint Commission Journal on Quality and Patient Safety
   - Establishing a PRN program entails conquering a number of management challenges and is an effective strategy in creating organizational change to improve the state of pain control. This research article is available through Ingentaconnect at http://www.ingentaconnect.com/content/jcaho/jcjqs/2006/00000032/00000001/art00004.

4. Developing Patient/Client Health Information - Calgary Health Region, Canada
   - This online manual was created to serve as a reference for busy healthcare providers in developing attractive, informative and easy to read materials to enhance patient learning.

5. End-of-Life Nursing Education Consortium (ELNEC) - American Association of Colleges of Nursing (AACN)
   - A comprehensive national education program to improve end-of-life care by nurses.
   - Website: http://www.aacn.nche.edu/ELNEC/.

6. Fact Sheets - International Association for the Study of Pain (IASP), Seattle, WA
   - Available in Spanish, French, Portuguese, Russian, Arabic, and Chinese.
   - Barriers to Cancer Pain Treatment
   - Epidemiology of Cancer Pain
   - Psychological Aspects of Cancer Pain
   - Psychological Interventions for Cancer Pain
   - Treatment-Related Pain

7. Guidelines for Pain Case Conferences & Guidelines for a Pain Conference for an Individual Patient - University of Wisconsin Hospital & Clinics, Madison, WI

8. Master of Science in Pain Research, Education and Policy - Tufts University
   - An interdisciplinary postgraduate education that sets the standard for pain education.
   - For more information: Website: www.tufts.edu/med/prep

9. National Association of Social Workers (NASW) Online Courses
   - Understanding End-of-Life Care: The Social Worker’s Role
   - Understanding Cancer: The Social Worker’s Role
   - Website: http://www.naswwebed.org/.

10. National Comprehensive Cancer Network (NCCN) Interactive CME
    - Continuing education programs via webcast and podcast.
    - Website: http://nccn.org/interactive/.

11. Nurses Self Paced Learning Module on Pain Management - Dominican Santa Cruz Hospital, Santa Cruz, CA
    - Learning module directed at nurses in the area of pain management.
    - Website: http://prc.coh.org/pdf/Nurses_Self_Paced_Dominican.pdf.

12. Pain Management Certification for Nurses - American Nurses Credentialing Center (ANCC), Baltimore, MD
    - ANCC collaborated with the American Society for Pain Management Nursing (ASPMN) for the first nurse-focused pain management certification available in the United States.
    - Website: http://www.nursecredentialing.org/Certification/NurseSpecialties/PainManagement.html.

13. Pain Management Nursing Certification Preparation Course - American Society for Pain Management Nursing (ASPMN)
    - ASPMN has a variety of materials available for sale to assist you prepare to take the pain management nursing exam.
    - Website: http://www.aspmn.org/documents/ASPMN%20APRN%20Recognition%202014%20Application.pdf.
    - Certification Prep Course
14. Pain Management Competency Packet
   - To assist preceptors to provide feedback to new nurses on ability to assess and manage pain. These tools define the competencies for clinical nurses in hospitals with a structured pain program.
   - Pain Management Competency - Developed by Nursing Research & Education at the City of Hope, Duarte, CA
     Website: http://prc.coh.org/pdf/COH_Competency.pdf.
   - Pain Management Competency - Patient Care Team, University of Wisconsin Hospital & Clinics, Madison, WI.
     Website: http://prc.coh.org/pdf/UW_Competency.pdf.

15. Pain Management: An Interactive CD for Clinical Staff Development - Abbott Northwestern Hospital, Minneapolis, MN
   - A comprehensive pain management training tool based on evidence-based procedures and JACHO guidelines with 6-7.2 hours of CEU credits are available for nurses, physicians and pharmacists.
     Website: http://www.amazon.com/gp/product/0834219034/ref=sr_1_1/?ie=UTF8

16. Pain Management Resources Packet - Margo McCaffery, RN, MS, FAAN
   - Pain Management: Assessment & Overview of Analgesics (CD) - Margo McCaffery, RN, MS, FAAN & Chris Pasero, MS, RN.
     Website: http://linkinghub.elsevier.com/retrieve/pii/S0885392401003839
   - Contemporary Issues in Pain Management (Video) - This video series addresses the problems nurses encounter in daily practice. Videos include Pain in Infants and Children, Pain in the Elderly and the Physiology and Pharmacologic Management of Pain. Email: Margopain@aol.com.
   - Pain Management and Pharmacologic Management (Book) - Margo McCaffery, RN, MS, FAAN & Chris Pasero, MS, RN.
     Website: http://www.amazon.com/.

17. Pain Management Self Learning Module - Kaiser Permanente, Los Angeles, CA
   - A self-learning module based on current standards of care in pain management.

18. Pain Research Forum
   - An interactive web community dedicated to finding treatments for untreatable pain conditions and help researchers by improving information sharing, by fostering new collaborations among researchers, and by raising interest in pain research among a wider community of scientists and clinicians.
     Website: http://www.painresearchforum.org/

19. Pain Resource Nurse (PRN) Training Program - City of Hope, Duarte, CA
   - Agenda and objectives developed for a Pain Resource Nurse Training Program
     Website: http://prc.coh.org/2014%20Obj-Agenda.pdf

   - Implementation tool-kit designed to assist clinicians/educators in hospital settings to coordinate and implement a PRN Program as a means of improving the quality of pain management.
     Website: http://trc.wisc.edu/items.asp?itemID=114.

   - Privilege: Pain Resource Nurse - guidelines developed for job evaluation and performance criteria to be utilized for annual review of the Pain Resource Nurse position.
     Website: http://prc.coh.org/pdf/Privilege_UW.pdf
   - Pain Resource Nurse Role: Description and Responsibilities - Purpose and Policy governing description and responsibilities of the Pain Resource Nurse role.
     Website: http://prc.coh.org/pdf/PRN%20Role.pdf.
   - Pre-test - Pain Resource Nurse Training Program - this 47 question post-test is developed for the Pain Resource Nurse Training Program.
     Website: http://prc.coh.org/pdf/PRN_Pre-Test.pdf.

22. Palliative Care/Pain Management Training Programs
   - Preceptorships, fellowships and pain training programs for nurses, physicians and others.
     Website: http://prc.coh.org/pdf/Preceptorships.pdf.
23. Program in Palliative Care Education and Practice
   - Palliative care courses offered at Harvard University for medical and nursing educators.
     Website: http://www.hms.harvard.edu/pallcare/index.htm.

24. The Future of Nursing: Leading Change, Advancing Health – Institute of Medicine
   - This IOM report is a thorough examination of the nursing workforce. Their recommendations focus on the critical intersection between the health needs of diverse, changing patient populations across the lifespan and the actions of the nursing workforce.

25. The Pain Community
   - To build and strengthen an active, energized and diverse community of people affected by pain by providing a foundation of support where education, wellness information and advocacy are promoted.
     Website: http://paincommunity.org/

Guidelines/Clinical Pathways
1. Core Curriculum for Pain Management Nursing – American Society for Pain Management Nursing
   A comprehensive guide to effective pain management in the healthcare setting and a review of course material for passing the pain management certification. Website: http://www.amazon.com.

Other Organizational Links
Advancing Expert Care: HPNA, HPNF, HPCC http://advancingexpertcare.org/
American Association of Colleges of Nursing http://www.aacn.nche.edu/
American Medical Association http://www.ama-assn.org/
American Society of Law, Medicine & Ethics http://www.aslme.org/
American Society of Pain Management Nurses http://www.aspman.org/
National League for Nursing http://www.nln.org
Oncology Nursing Society Continuing Education https://www.ons.org/education
Online Nurse Practitioner Programs http://onlinenursepractitionerprograms.com/governmental-resources/

Position Statements/Standards
1. Hospice and Palliative Nurses Association
   - Pain Management.
     Website: http://prc.coh.org/HPNA-PM.pdf.

2. State of California Board of Registered Nursing
   - The Nurses Role in Pain Management.
     Website: https://medical.wesrch.com/User_images/Pdf/MS1_1225761426.pdf.

VI. Education
B. Patient and Family Education
Section Description: This section includes educational kits and books, instructional guides and videos and health information sheets on various procedures appropriate for lay community

City of Hope Publications
doi: 10.1097/njh.00000000000000165


**Recommended Publications**


3. Everything Nobody Tells You About Cancer Treatment and Your Sex Life from A to Z


5. Family Carers in Palliative Care: A Guide for Health and Social Care Professionals

6. The Chronic Pain Solution: Your Personal Path to Clinical Relief

**Educational Materials**

1. A Helping Handbook: When a Loved One is Critically Ill - Stephanie Waxman
   - This 48 page Helping Handbook is a safe place to put private thoughts, to be inspired by poetry, to be reminded that we are not the first ones to encounter conflicting feelings at a time of illness. Website: [http://www.stephaniewaxman.com/01_writer/01_downloads/SW_HHandBook.pdf](http://www.stephaniewaxman.com/01_writer/01_downloads/SW_HHandBook.pdf).

2. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs - The National Academies Press
   - Psychosocial health care addresses the emotional challenges that can accompany a serious illness as well as the life challenges that can prevent good healthcare and patient’s ability to take care of themselves. Read the book online, free. Website: [http://www.nap.edu/catalog.php?record_id=11993](http://www.nap.edu/catalog.php?record_id=11993).
3. **Cancer Pain Education for Patients and the Public (CPEPP)**
   - City of Hope investigators (Betty Ferrell, Marcia Grant, and Gloria Juarez) conducted an education project funded by the National Cancer Institute to address the multiple opportunities for cancer pain education and to provide resources for successful implementation. The project materials include outlines, Power Point presentations, handouts and a comprehensive bibliography for each module. An article summarizing this project was published in the *Journal of Pain and Symptom Management*, 2002, 23(3), 7-8, which provides further detail regarding the training program. Website: [http://prc.coh.org/Pt-familyEd.asp](http://prc.coh.org/Pt-familyEd.asp) under Educational Materials.
   - **Module I:** Pain Management for Individual Patient Education
   - **Module II - Cultural Considerations in Patient and Public Education**
   - **Module III - Pain Education provided through group settings**
   - **Module IV - Public Education for Pain Management**
   - **Module V - Telephone Education**
   - **Module VI - The JCAHO Imperative; Improved Pain Management**
   - **Module VII - Professional Education as a Prerequisite to Patient Education; Involving Colleagues in Pain Education**
   - **Module VIII - Overcoming Institutional Barriers to Pain Education**

4. **Cancer Pain: Your Guide to Relief - HealthMark Multimedia**
   - HealthMark Multimedia is a health-related, interactive solution for patients and healthcare organizations. It is used by patients in making treatment and self-care decisions, health care professionals for education purposes, and parents and children to learn about prevention and staying healthy.

5. **Coping with Cancer: Supportive and Palliative Care - National Cancer Institute**
   - About Children with Cancer
   - Financial, Insurance, and Legal Information
   - Finding Healthcare Services
   - For Caregivers, Family, and Friends
   - Managing Emotional Effects
   - Managing Physical Effects
   - Supportive and Palliative Care Clinical Trials
   - Survivorship - Living With and Beyond Cancer

6. **Easing Cancer Pain - Michigan State University**
   - An interactive CD program designed to empower people with cancer who suffer from pain. It provides a wealth of resources to help them understand their pain and seek effective treatment.
   - Website: [http://commtechlab.msu.edu/sites/cancerpain/index.html](http://commtechlab.msu.edu/sites/cancerpain/index.html).

7. **End-of-Life: Helping with Comfort and Care - U.S. National Institutes of Health, National Institute on Aging**
   - This booklet provides an overview of issues commonly facing people caring for someone nearing the end-of-life.

8. **Fact Sheets on Cancer Pain - International Association for the Study of Pain (IASP), Seattle, WA**
   - Available in Spanish, French, Portuguese, Russian, Arabic, and Chinese.
   - Assessment of Cancer Pain
   - Barriers to Cancer Pain Treatment
   - Cancer Pain Treatment
   - Partners and Caregivers of Cancer Patients Having Pain
9. **Financial Issues and Cancer - American Cancer Society**
   - Advanced Illness: Financial Guidance for Cancer Survivors and Their Families
   - Coping Financially with the Loss of a Loved One: Financial Guidance for Families
   - Find Support and Treatment
     Website: [http://www.cancer.org/treatment/index](http://www.cancer.org/treatment/index)
   - Health Insurance and Financial Assistance for the Cancer Patient

10. **Guide to Controlling Cancer Pain - American Cancer Society**
    - Learn about a variety of methods for pain control and discover how to achieve the optimal balance between pain relief and potential side effects of pain medication. This resource can help people with cancer partner with their health care teams to create effective pain-relief plans tailored to their unique situations.

11. **Health and Nutrition Facts for You - UW Health, University of Wisconsin Hospital & Clinics, Madison, WI**
    More than 60 topics are available under the pain section
    - Constipation from Opioids (Narcotics)
      Website: [http://www.uwhealth.org/healthfacts/gi/4843.html](http://www.uwhealth.org/healthfacts/gi/4843.html)
    - Continuous Subcutaneous Lidocaine for Pain Management
      Website: [http://www.uwhealth.org/healthfacts/pain/5314.html](http://www.uwhealth.org/healthfacts/pain/5314.html)
    - Coping with Your Chronic Pain
      Website: [http://www.uwhealth.org/healthfacts/pain/5298.html](http://www.uwhealth.org/healthfacts/pain/5298.html)
    - Fibromyalgia
      Website: [http://www.uwhealth.org/healthfacts/pain/5641.html](http://www.uwhealth.org/healthfacts/pain/5641.html)
    - How to Relieve Pain without Medicine
      Website: [http://www.uwhealth.org/healthfacts/pain/4448.html](http://www.uwhealth.org/healthfacts/pain/4448.html)
    - Intravenous Patient Controlled Analgesia
      Website: [http://www.uwhealth.org/healthfacts/pain/4273.html](http://www.uwhealth.org/healthfacts/pain/4273.html)
    - Pain Management
      Website: [http://www.uwhealth.org/health/topic/special/pain-management/aba6263.html](http://www.uwhealth.org/health/topic/special/pain-management/aba6263.html)
    Website: [http://www.uwhealth.org/healthfacts/pain/](http://www.uwhealth.org/healthfacts/pain/).

12. **Leukemia & Lymphoma Society Resource Center**
    - The latest information for patients, caregivers and healthcare professionals.
    Website: [http://www.lls.org/#/resourcecenter/](http://www.lls.org/#/resourcecenter/).

13. **Mesothelioma**
    - [Lean on Me - Cancer Through a Carer’s Eyes](http://www.asbestos.com/book/)
    - [100 Questions & Answers About Mesothelioma](http://www.asbestos.com/book/)
    - [Mesothelioma Center Blog](http://www.asbestos.com/blog/)

14. **Pain Control After Surgery - Cleveland Clinic Health Information Center**
    - Types of pain control treatments including Patient-Controlled Epidural Analgesia, Patient-Controlled Intravenous Analgesia, NSAIDS, and narcotics.
    Website: [http://my.clevelandclinic.org/health/treatments_and_procedures/hic_Pain_Control_after_Surgery](http://my.clevelandclinic.org/health/treatments_and_procedures/hic_Pain_Control_after_Surgery).

15. **Pain - National Cancer Institute**
    - Important facts about cancer pain, treatment that will help you learn about pain control for people with cancer, including how to work with your doctors, nurses, and pharmacists to find the best method to control your pain.

16. **Pain Multimedia Library - StopPain.org**
    - Visit the Pain Multimedia Library for the latest information and treatment options for common pain syndromes. These Flash presentations include CRPs, Low Back Pain, Migraine Headache, Shingles, and Sickle Cell Pain. Available in Spanish and Russian.
    Website: [http://www.stoppain.org/pain_medicine/content/chronicpain/library.asp](http://www.stoppain.org/pain_medicine/content/chronicpain/library.asp).
17. Passport to Comfort: Reducing Barriers to Pain & Fatigue Management - City of Hope, Duarte, CA
   - This model addresses patient, professional and system barriers to the relief of pain and fatigue and is based on established guidelines developed by the National Comprehensive Cancer Network (NCCN). An NCI supported program. Most available in English and Spanish. Website: http://prc.coh.org/Pt-familyEd.asp #18
   - Passport to Comfort – Pain Management & Fatigue Management
   - Key Teaching Points: Pain Assessment & Pain Management
   - Key Teaching Points: Fatigue Assessment
   - Key Teaching Points: Fatigue Management
   - Tip Sheet – Energy Conservation and Exercise
   - Tip Sheet – Strategies to Help Promote Improved Sleep/Wake Patterns
   - Tip Sheet – Nutrition to Manage Fatigue
   - Tip Sheet – Recommendations for Treating Constipation
   - Tip Sheet – Coping with Emotional and Social Impact of Pain and Fatigue
   - Constipation Card
   - Emotional Card
   - Dyspnea (Difficult Breathing)
   - Fatigue Card with Scale
   - Nausea and Vomiting Card
   - Nutritional Card
   - Pain Card
   - Patient Knowledge Assessment Tool – Fatigue
   - Patient Knowledge Assessment Tool – Pain
   - Patient Spiritual Care Card
   - Sleep Card
   - Spirituality Card
   - Available Resources at City of Hope
   - NCCN Guideline for Supportive Care

   - This latest edition brings together information on pharmaceutical and non-pharmaceutical patient assistance programs (PAPs) and reimbursement resources. Website: http://www.nxtbook.com/nxtbooks/accc/2013patientassistance/

19. Patient Bill of Rights – American Cancer Society
   - A summary of the Consumer Bill of Rights and Responsibilities that was adopted by the US Advisory Commission on Consumer Protection and Quality in the Health Care Industry in 1998. Website: http://www.cancer.org/docroot/mit/content/mit_3_2_patients_bill_of_rights.asp

20. Patient Education
   - Poetry of Pain - The poems explore the frustration, fear, anger, depression, acknowledgement and hope that Linda Martinson experienced as a person dealing with chronic pain. Website: http://www.amazon.com/Poetry-Pain-Linda-Louise-Martinson/dp/0964897822
   - Pain: You Can Get Help - National Institute of Health - The booklet is written to increase patient awareness of the importance of treating pain. Website: http://www.nia.nih.gov/health/publication/pain
   - Guide to Controlling Cancer Pain - American Cancer Society
     Website: http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/pain/pain-diary/pain-control-toc
   - Relieving Cancer Pain - Fred Hutchinson Cancer Research Center includes a video of cancer patients and clinicians discussing problems and solutions for managing cancer pain and a book which lists barriers to pain relief, things to tell your doctor and a treatment plan for recording medication information. Website: http://www.fhcrc.org/science/clinical/biobehavioral/patient_materials.html

21. Patient Education Plan - Kaiser Permanente, Los Angeles, CA
   - Developed by the Medical Care Program - Southern California region. A checklist used for patient teaching and chart documentation. Includes key content for pain education. Website: http://prc.coh.org/html/pt_ed_plan.asp
22. **Patient Medication Information - Fox Chase Cancer Center, Philadelphia, PA**
   - Patient handouts regarding eleven medications including: Dilaudid tablets, Fentanyl patch, MS Contin, Morphine concentrate, Morphine Sulfate tablets or capsules, Oxycodone plus Acetaminophen, Oxycontin, Choline Magnesium Trisalicylate, Ibuprofen, Desipramine, and Nortriptyline.

23. **Patient Support and Treatment - American Cancer Society**
   - Helps guide, support and inform patients through every step of their journey.

   - Available free to patients and treatment facilities.
   - Website: [http://patientresource.net/](http://patientresource.net/).

25. **R.A. Bloch Cancer Foundation & Block Cancer Hotline**
   - There are over 300 up to date cancer support organizations listed supporting specific types of cancer, organizations offering financial aid, blogs, a cancer checklist, patient matching services, meditation, transportation and more.
   - Website: [http://blochcancer.org/about/free-books/](http://blochcancer.org/about/free-books/).

   - The online booklet details nutrition and cancer guidelines, including nutrition during treatment and suggestions for eating to provide maximum immunity.

   - A 70 page resource guide that provides the patient or caregiver with help as they face the challenges encountered by those who suffer from pain.

28. **The Resource Center of the Alliance of State Pain Initiatives Patient Education**

29. **Treatment Guidelines for Patients™ by Cancer Site – National Comprehensive Cancer Network (NCCN)**
   - An educational tool for patients and oncology professionals. Guidelines include breast cancer, chronic myelogenous leukemia, melanoma, malignant pleural mesothelioma, multiple myeloma, non-small cell lung cancer, ovarian cancer and prostate cancer.

30. **Understanding and Managing Pain: Information for Patients - The British Pain Society, London, UK**
   - This online booklet explores how to form a partnership between the patient and the health professionals working with them and how to get the best pain relief out of this partnership.
   - Website: [http://www.britishpainsociety.org/pub_patient.htm#understand](http://www.britishpainsociety.org/pub_patient.htm#understand).

**Guidelines/Clinical Pathways**

1. **Treatment Guidelines - American Cancer Society (ACS)**
   - Coping with Physical & Emotional Changes Website: [http://www.cancer.org/docroot/MBC/MBC_0.asp](http://www.cancer.org/docroot/MBC/MBC_0.asp)
   - Prevention & Early Detection of Cancer Website: [http://www.cancer.org/docroot/PED/ped_0.asp](http://www.cancer.org/docroot/PED/ped_0.asp).

**Other Organizational Links**

- American Cancer Society [http://www.cancer.org](http://www.cancer.org)
- Cancer and Careers [http://www.cancerandcareers.org](http://www.cancerandcareers.org)
- Cancer Network [http://www.cancernetwork.com/](http://www.cancernetwork.com/)
VII. Quality Improvement

This section includes medical review tools, strategic plans, performance and quality improvement packets, a manual for building an institutional commitment to pain management, and sample materials for quality improvement committee.

City of Hope Publications


Recommended Publications

1. Wall and Melzack’s Textbook of Pain, 6th Edition


Educational Materials/Curriculum

1. Action Plan - Long Term Care - Medical College of Wisconsin, Milwaukee, WI
   - This action plan is a format for an institution to implement a strategic plan in establishing a pain management program.

Guidelines/Clinical Pathways

   - Downloadable publications that advance balanced approaches to pain management policy, consumer protection and professional development. Website: http://www.rwjf.org/pr/product.jsp?id=21059.

2. Joint Commission Perspectives - Joint Commission Resources, Chicago, IL
   - Joint Commission Perspectives is your primary source for changes to standards, accreditation requirements, and JCAHO initiatives, including the new accreditation process.
   - Website: http://www.jcrinc.com/The-Joint-Commission-Perspectives/.
3. Medical Record Audit Form - University of Wisconsin Hospital & Clinics, Madison, WI
   - Comprehensive audit tool to review documentation of pain assessment, analgesic prescribing and administration practices. Website: http://prc.coh.org/pdf/Medical%20Record%20Audit%20Form.pdf.

4. Pain Care Packet - The Chambersburg Hospital, Chambersburg, PA
   - Includes a 4 page packet containing a 9 item Pain Questionnaire for use after discharge, a 7 item Pain Service Outcome Survey and an 11 item outline of “Rights of the Patient and Responsibility of the Physician.” Website: http://prc.coh.org/pdf/pain_questionnaire_chambersburg.pdf.

5. Pain Management Program/Strategic Plan - Dominican Santa Cruz Hospital, Santa Cruz, CA
   - The Strategic Plan includes a 16-page packet describing a pain management program and strategic plan. A vision statement, basic assumptions, targets, goals, and strategies for implementation are outlined. Website: http://prc.coh.org/pdf/dominican_pain_mgmt_program.pdf.

6. Patient-Centered Care Improvement Guide - Picker Institute, Boston, MA
   - This guide is filled with best practices and practical implementation tools thanks to the generosity of hospitals across the United States whose commitment to advancing patient-centered care. Website: http://planetree.org/wp-content/uploads/2012/01/Patient-Centered-Care-Improvement-Guide-10-28-09-Final.pdf.

7. Patient Questionnaire on Pain Management - Willamette Falls Hospital, Oregon City, OR
   - A simple questionnaire used to assess patient satisfaction with pain after hospitalization. The tool is formatted for easy use as a mailed survey. Website: http://prc.coh.org/pdf/pt_questionnaire_willamette.pdf.

   - Care of Patient Experiencing Cancer Related Pain
   - Chart Audit Tool
   - Commitment to Cancer Pain Management Statement
   - MS Drip Protocol
   - Pain Assessment Flowsheet
   - Palliative Care Protocol
   - Patient Outcome Questionnaire
   - Patient Rating Guide
   Website: http://prc.coh.org/pdf/QA_st_lukes.pdf.

9. The Resource Center of the Alliance of State Pain Initiatives (ASPI)
   - Building an Institutional Commitment to Pain Management
   - Handbook of Cancer Pain Management
   - Nursing Competency Guidelines
   - Pain Resource Nurse Program Curriculum & Planning Guide
   - The Post-Operative Pain (POP) Management Project Lecture Series CD
   Website: http://trc.wisc.edu/items.asp?itemID=11
   Website: http://trc.wisc.edu/items.asp?itemID=12
   Website: http://trc.wisc.edu/WCPI_RN.pdf
   Website: http://trc.wisc.edu/items.asp?itemID=114
   Website: http://trc.wisc.edu/items.asp?itemID=105

Other Organizational Links
- Agency for Healthcare Research and Quality http://www.ahrq.gov
- American Health Quality Association http://www.ahqa.org/
- Center to Advance Palliative Care http://www.capc.org
- EPERC (End-of-Life/Palliative Education Resource Center) http://www.mcw.edu/EPERC/FastFactsandConcepts
- Institute for Healthcare Improvement http://www.ihi.org
- National Committee for Quality Assurance (NCQA) http://www.ncqa.org/
- The Commonwealth Fund http://www.commonwealthfund.org/
- The Joint Commission http://www.jointcommission.org/
VII. Quality Improvement

A. Cost Effectiveness

Section Description: This section includes several City of Hope publications related to cost issues in pain management. For more information see Section V. A. Family Caregiving

City of Hope Publications


Recommended Publications


Guidelines/Clinical Pathways

1. A Guide to Building a Hospital-Based Palliative Care Program - Center to Advance Palliative Care
   Website: https://shop.capc.org/?product=001

Other Organizations Links

- Center to Advance Palliative Care
  Website: http://www.capcmssm.org/
- Health Economics Information Resources:
  - A Self Study Course
    Website: http://www.nlm.nih.gov/nichsr/edu/healthecon/00_he_intro.html
  - Health Economics Resource Center
    Website: http://www.herc.research.va.gov/resources/faq_a01.asp

VIII. Ethical and Legal Issues

Section Description: This section includes materials and resources related to ethical, legal and regulatory issues in pain management, decision-making and the relief of suffering.

City of Hope Publications


Recommended Publications


   - Website: http://www.theamericanennurse.org/index.php/2011/06/01/the-practice-of-ethics/

   - DOI: 10.3912/OJIN.Vol17No01EthCol01.
   Website: http://www.amazon.com

5. Clinical Ethics: A practical Approach to Ethical Decisions in Clinical Medicine, 7th Edition
   Website: http://www.amazon.com

6. Ethical Issues in Chronic Pain Management
   Website: http://www.amazon.com

7. Moral Dilemmas in Community Health Care: Cases and Commentaries
   Website: http://www.amazon.com

8. Code of Ethics for Nurses with Interpretive Statements
   Website: http://www.amazon.com/


10. Suffering
    Website: http://www.jbpub.com/catalog/086720723X/.

**Educational Materials/Curriculum**

1. In the Face of Pain
   - Ethics and Pain Fact Sheet

**Guidelines/Clinical Pathways**


   - This 42 page document provides guidelines that can be used by governments and health professionals to assess the national opioids control policies and their administration of any country to determine if they contain the provisions, procedures and cooperation that are necessary to ensure the availability of opioid analgesics. Available in 22 languages. Website: http://whqlibdoc.who.int/hq/2000/who_edm_qsm_2000.4.pdf

   - Downloadable publications that advance balanced approaches to pain management policy, consumer protection and professional development. Website: http://www.rwjf.org/pr/product.jsp?id=21059.

   Website: https://www.healthlawyers.org/hrsources/Pl/Pages/AGuidetoLegalIssuesinLife-LimitingConditions.aspx.

6. Model Policy for the Use of Opioid Analgesics in the Treatment of Chronic Pain - Federation of State Medical Boards USA
**Other Organizations Links**

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<tr>
<th>Organization</th>
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<tr>
<td>American Society for Bioethics and Humanities</td>
<td><a href="http://www.asbh.org">http://www.asbh.org</a></td>
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<td>American Society of Law, Medicine &amp; Ethics (ASLME)</td>
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<td>American Society of Pain Management Nurses (ASPMN)</td>
<td><a href="http://www.aspmn.org">http://www.aspmn.org</a></td>
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<tr>
<td>American Society on Aging: Legal and Ethical Issues</td>
<td><a href="http://www.asaging.org/blog/content-source/101">http://www.asaging.org/blog/content-source/101</a></td>
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<td>BWH Office of Clinical Ethics</td>
<td><a href="http://www.brighamandwomens.org/Patients_Visitors/pcs-ethics/">http://www.brighamandwomens.org/Patients_Visitors/pcs-ethics/</a></td>
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<td>Caring Community - Wellness Through Life’s End</td>
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<td>Center for Ethics in Health Care</td>
<td><a href="http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/">http://www.ohsu.edu/xd/education/continuing-education/center-for-ethics/</a></td>
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<td>Center for Practice Bioethics</td>
<td><a href="http://www.practicalbioethics.org/">http://www.practicalbioethics.org/</a></td>
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<td>Center for Bioethics</td>
<td><a href="http://www.ahc.umn.edu/bioethics/">http://www.ahc.umn.edu/bioethics/</a></td>
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<td>Code of Ethics for Nurses</td>
<td><a href="http://www.nursingworld.org/codeofethics">http://www.nursingworld.org/codeofethics</a></td>
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<tr>
<td>Emerging Solutions in Pain</td>
<td><a href="http://www.emergingsolutionsinpain.com/">http://www.emergingsolutionsinpain.com/</a></td>
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<td>Ethical Issues - American Nurses Association</td>
<td><a href="http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources">http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources</a></td>
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<td>Pain &amp; Policy Studies Group</td>
<td><a href="http://www.painpolicy.wisc.edu/">http://www.painpolicy.wisc.edu/</a></td>
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<td>The Center for Ethics and Human Rights</td>
<td><a href="http://www.nursingworld.org/ethics/">http://www.nursingworld.org/ethics/</a></td>
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<td>The Hastings Center</td>
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<td>The Legal Side of Pain</td>
<td><a href="http://legalsideofpain.com/index.cfm">http://legalsideofpain.com/index.cfm</a></td>
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**Key References**

1. American Society of Law, Medicine & Ethics  
   - A community of colleagues across three disciplines exploring the major health issues to protect public health; reduce racial, ethnic, and economic health disparities; promote patient safely and quality of care; and facilitate dialogue on emerging biomedical science and research. Website: [http://www.aslme.org/](http://www.aslme.org/).

**Position Statements/Standards**  
(see Section III. Palliative Care)

1. Ethics and Human Rights – American Nurses Association  
   Website: [http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements](http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Ethics-Position-Statements)

2. Promoting Pain Relief and Preventing Abuse of Pain Medications: A Critical Balancing Act  
   - A joint statement, published by 21 health organizations and the Drug Enforcement Administration  
   The roles of both health professionals and law enforcement personnel in maintaining the balances between patient care and diversion prevention are critical. Website: [http://www.deadiversion.usdoj.gov/pubs/advisories/painrelief.pdf](http://www.deadiversion.usdoj.gov/pubs/advisories/painrelief.pdf).
IX. Research Instruments/Resources

Section Description: This section includes numerous clinical and research tools addressing quality of life, pain, psychosocial assessment, medical staff knowledge and attitudes, brief pain surveys, palliative care and needs assessments from various sources are included in this section.

1. Advanced Practice Nurse (APN) Toolkit
   - The APN toolkit website contains a compendium of tools used in APN related research. The measurement instruments listed on this website have been organized according to the Participatory, Evidence-based, Patient-focused Process, for guiding the development, implementation, and evaluation of Advanced practice nursing (PEPPA) framework. Website: http://apntoolkit.mcmaster.ca/

2. Brief Pain Inventory
   - The BPI is a brief, simple, and easy to use tool for the assessment of pain in both clinical and research settings. The BPI uses simple numeric rating scales from 0 to 10 that are easy to understand and easy to translate into other languages. It is a well validated instrument to measure pain intensity, functionality and the impact of pain on one’s life in the past 24 hours and within the past week. It was developed by Charles Cleeland, PhD and is available through the Pain Research Group at MD Anderson Cancer Center. Website: http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory-users-guide.html

3. Brief Pain Surveys
   - This is a collection of 6 brief surveys: Pain Assessment/Behavior Survey; Pain/Gender Survey; Brief Cancer Pain Information Survey; Pain Addiction Survey; Brief Pharmacology Survey; Test Questions. These short surveys developed by Margo McCaffery and Betty Ferrell are intended for practical use in situations such as staff education where limited time and resources are available for data collection or analysis. Website: http://prc.coh.org/Brief%20Pain%20Surveys-11.pdf

4. Clinical Decision Making Tool - City of Hope, Duarte, CA
   - This 14-item survey assesses nurses’ clinical decision making regarding pain management. Website: http://prc.coh.org/pdf/clinical_decision_making.pdf

5. Controlling Pain Vignettes - City of Hope, Duarte, CA
   - Vignettes for use with health care professionals, published in a series in the journal Nursing, provide case vignettes related to patient characteristics (i.e. age, behavior) and pain control. Options are presented along with the “right choice” and its rationale. Useful as a brief survey to assess staff knowledge and decisions regarding pain. Website: http://prc.coh.org/pdf/controlling_pain.pdf

6. Edmonton Assessment Tools - Regional Palliative Care Program in Edmonton Alberta, CAN
   - Online tools to measure discomfort and symptom assessment of dying patients. Website: http://www.palliative.org/newpc/professionals/tools/elas.html

7. End-of-Life Professional Caregiver Survey - Yale School of Nursing
   - This is an excellent tool for use to assess staff knowledge about palliative care. Website: http://nursing.yale.edu/node/1681/done?sid=1838

8. FACIT Questionnaires
   - Functional Assessment of Chronic Illness Therapy, (FACIT), manages questionnaires that measure health-related quality of life for people with chronic illnesses. The first questionnaire, The Functional Assessment of Cancer Therapy-General (FACT-G), was developed and validated over 10 years ago, and has been used in hundreds of studies worldwide. Since then over 40 questionnaires have been developed and translated some of them into over 45 different languages. They have also developed and translated instruments for fatigue, treatment satisfaction, spiritual well-being, HIV disease, multiple sclerosis, and other chronic conditions. Website: http://www.facit.org/FACITOrg/Questionnaires

9. Family Pain Questionnaire - City of Hope, Duarte, CA
   - The Family Pain Questionnaire (FPQ) is a sixteen-item ordinal scale that measures the knowledge and experience of a family caregiver in managing chronic cancer pain. This tool can be used in clinical practice as well as research. Website: http://prc.coh.org/pdf/FPQTOOL.pdf
10. SF Health Surveys
   - The surveys are designed for use in clinical practice and research, health policy evaluations, and general population surveys. The SF-36 includes one multi-item scale that assesses eight health concepts. It has been used extensively in QOL research in studying adjustment to various chronic illnesses and it has been translated into over 80 languages. Website: http://www.qualitymetric.com/WhatWeDo/GenericHealthSurveys/tabid/184/Default.aspx.

11. Instruments Used in End of Life Care Education, City of Hope, Duarte, CA
   - A collection of instruments currently in use by City of Hope investigators to assess staff knowledge and needs to improve end of life care. Curriculum Survey for Nursing Schools; Clinical Nurse Survey; Home Care/Hospice Agencies; Home Care Nurses and HHAs; Knowledge Assessment for Nurses; Knowledge Assessment for HHA’s; Chart Audit Tool; and a Case Analysis Form. Website: http://www.qualitymetric.com/WhatWeDo/GenericHealthSurveys/tabid/184/Default.aspx.

12. Knowledge and Attitudes Survey Regarding Pain - City of Hope, Duarte, CA (see Item “24” below for pediatric version).
   - An instrument to measure knowledge and attitudes regarding pain in health care professionals. Used extensively by clinical settings for several years, this tool provides descriptive data regarding areas of needed pain education. Website: http://www.qualitymetric.com/WhatWeDo/GenericHealthSurveys/tabid/184/Default.aspx.

13. M.D. Anderson Symptom Inventory (MDASI) – MD Anderson Cancer Center, TX

14. McGill Pain Questionnaire
   - The McGill Quality of Life Instrument (MQOL) is a 20-item scale specifically developed to measure quality of life at the end of life. The MQOL was designed to measure quality of life of people at all stages of a life-threatening illness. The MQOL assesses general domains applicable to all patients, incorporates the existential domain, balances physical and non-physical aspects of quality of life, and includes both positive and negative influences on quality of life. Website: http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/mdanderson-symptom-inventory.html.

15. McGill Short-Form Pain Questionnaire
   - The McGill Short Form Pain Questionnaire is a patient-reported instrument that employs 16 items plus a single-item global scale, each with a 2-day time frame. There are five domains that include: physical well-being, physical symptoms, psychological, existential, and support. The instrument was designed to be general in nature in order to maintain brevity and to assure applicability to all patients. It has been used in various terminally ill patients. Website: http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/mdanderson-symptom-inventory.html.

16. Medical Algorithms Project - Institute for Algorithmic Medicine
   - More than 12,500 algorithms, organized into 45 chapters, are available as spreadsheets which can be opened in your browser. Website: http://www.medal.org/visitor/login.aspx. (Login required)

17. Medical Staff Knowledge & Attitudes Pain Survey - Dartmouth-Hitchcock Medical Center, Lebanon, NH

18. Memorial Symptom Assessment Scale (MSAS)
   - The MSAS is a 32-item verbal rating scale that measures psychological and physical symptoms with regard to their presence, frequency, severity, and degree of distress associated with them. The MSAS has been shown to be reliable and valid. Additionally, the MSAS assesses both physical and emotional symptoms. Website: http://www.npcrc.org/files/news/memorial_symptom_assessment_scale.pdf.

19. National Palliative Care Research Center (NPCRC)
   - The NPCRC is committed to stimulating, developing, and funding research directed at improving care for seriously ill patients and their families. Website: http://www.npcrc.org/.
20. Needs at the End-of-Life Screening Tool (NEST) - Buehler Center on Aging
   - NEST is a comprehensive assessment and outcome measures instrument.

21. Pain Audit Tools - City of Hope, Duarte, CA
   - These tools have been used extensively in pain/QA efforts. Includes pain chart audit instrument, a version for surgical pain, and a patient interview tool. (Also see related articles under Pain Assessment Tools).
   Website: http://prc.coh.org/pdf/pain_audit_tools.pdf.

22. Patient Pain Questionnaire - City of Hope, Duarte, CA
   - The Patient Pain Questionnaire (PPQ) is a sixteen-item ordinal scale that measures the knowledge and experience of a patient in managing chronic cancer pain. This tool can be useful in clinical practice as well as for research.

23. Patient-Reported Outcome and Quality of Life Instruments Database (PROQOLID)
   - ProQolid describes more than 470 Patient-Reported Outcome instruments in a structured format and is now available in two levels at www.proqolid.org. The first level is free of charge and contains basic useful information of these instruments. The second level, which provides significantly more information about the instruments, also includes review copies of over 500 original instruments, 170 user manuals and 1010 translations, most in PDF format. It is restricted to annual subscribers. ProQolid is updated regularly in close collaboration with the instruments' authors with 40 new instruments added in 2008.

24. Pediatric Nurses’ Knowledge and Attitudes Survey Regarding Pain – Children’s Medical Center of Dallas, TX
   - Instrument to access pediatric nurses’ knowledge and attitudes regarding pain in children.
   Website: http://prc.coh.org/pdf/ped_KA_survey.pdf.

25. Pediatric Nurses’ Knowledge and Attitudes Survey© – Manworren and Shriners Hospitals for Children
   - Modified Pediatric Nurses Knowledge and Attitudes Survey (PNKAS) regarding pain in burns, orthopedics and spinal cord injuries. The answer key is also included.

26. Promoting Excellence in End of Life Care
   - This website includes validated tools for clinical assessment and research in palliative care.
   Website: http://www.promotingexcellence.org/.

27. Psychosocial Pain Assessment Form - City of Hope, Duarte, CA
   - Developed by Shirley Otis-Green, MSW, LCSW. This 8-page assessment and guided interview form measures the impact of pain on five domains; economics, social support, activities of daily living, emotional problems, and coping behaviors as perceived by the interviewer, patient and significant other.
   Website: http://prc.coh.org/pdf/Psychosocial%20Pain%20Assessment%20Form.pdf.

28. Quality of Life Instruments - City of Hope, Duarte, CA
   - Bone Marrow Transplant Survivors- is an 84-item tool specific for use in BMT.
   - Breast Cancer Patient Version – is a 46-item tool specific for use in Breast Cancer
   - Ovarian Cancer Patient Version – is a 45-item tool specific for use in Ovarian Cancer. Includes Spanish version.
   - Patient/Cancer Survivor Version – is a 41-item ordinal scale that measures quality of life through physical, psychological, social, and spiritual domains. This tool has been used extensively in pain and cancer survivorship research. Also includes Spanish version of the instrument.
   - Quality of Life Family Version – is a 37-item instrument that measures QOL of a family member caring for a patient with cancer. Also includes Spanish version of instrument.
   - Quality of Life Ostomy Version – is a 43-item tool specific for use in Patients with an Ostomy
   - Staff Survey on Ostomy Care - a 32-item tool specific for staff
Quality Care at the End of Life Survey - This survey was designed based on the National Consensus Project for Quality Palliative Care Guidelines and was developed and used at the City of Hope as a tool for assessing quality care. Users are invited to adapt and use it in their own institutions to assess the quality of care provided and to measure the institution's performance in comparison with national guidelines.

- Thyroid Version - is a 34-item tool specific for use in Thyroid Cancer.
  Website: http://prc.coh.org/res_inst.asp. (# 29)

29. RN Needs Assessment: Pain Management - University of Wisconsin Hospitals & Clinics, Madison, WI
- This two-page survey assists in planning continuing education programs in pain management for nurses.
  Website: http://prc.coh.org/html/rn_needs.htm.

30. Rehabilitation Professionals’ Knowledge and Attitudes Survey Regarding Pain – Boston School of Occupational Therapy, Boston, MA
- This instrument was developed as an inter-disciplinary tool to assess knowledge and attitudes regarding pain in rehabilitation professionals. This tool was developed using the OT/PT IASP Pain Curriculum in conjunction with 6 clinical experts.

31. Survivorship Needs Assessment Tools
Survivor Care Summary/Plan:
- Cancer Treatment Plan and Summary - American Society of Clinical Oncology (ASCO)
  Website: http://pda.asco.org/patient/Survivorship/ASCO+Cancer+Treatment+Summaries  Generic template
- Journey Forward Care Plan Builder Website: www.journeyforward.org
- Livestrong Care Plan-Furnished by Penn Medicines Oncolink Website: http://www.oncolink.com/oncolife/
- Breast Cancer Survivorship Care Plan - NCI Community Cancer Centers Program (NCCC)
  Website: http://ncccp.cancer.gov/NCCCP-ASCO-Breast-Cancer-Survivorship-Care-Plan.pdf

Survivorship Needs Assessments:
- Cancer Survivors Survey of Needs - Mayo Clinic Cancer Center
  Website: http://prc.coh.org/Survivorship/P-Mayo%20PCCC.pdf
- Survivor Needs Assessment (English) - St. Luke’s Hospital and Health Network
- Survivor Needs Assessment (Spanish) - St. Luke’s Hospital and Health Network
  Website: http://prc.coh.org/Survivorship/StL%20Span.pdf
- Survivor Assessment Tool (Patient) - University of Tennessee Medical Center Cancer Institute
  Website: http://prc.coh.org/Survivorship/SAT-PT.pdf
- Survivor Assessment Tool (Physician) - University of Tennessee Medical Center Cancer Institute
  Website: http://prc.coh.org/Survivorship/SAT-MD.pdf.
- Pearlman-Mayo Survey of Needs – Pearlman Cancer Center
  Website: http://prc.coh.org/res_inst.asp

32. Toolkit of Instruments to Measure End of Life Care (TIME)
- This is an extensive website, funded by the Robert Wood Johnson Foundation, and developed and maintained by Joan Teno, MD, MS at Brown University. It includes an Executive Summary reporting the status and need of Instruments in end of life care along with listings, links, and access to various instruments measuring various aspects of EOL care. Slide presentations, new instruments and old draft instruments are also available on the website. Instrument sections are divided as follows: Quality of Life, Pain and Other Symptoms, Emotional and Cognitive Symptoms, Functional Status, Survival Time and Aggressive Care, Advance Care Planning, Continuity of Care, Spirituality, Grief and Bereavement, Caregiver Well-being, and Patient Centered Reports and Rankings (e.g. satisfaction) with Quality of Care. Website: http://www.chcr.brown.edu/pccoc/toolkit.htm.

33. WHO (Five) Well-Being Index – Psychiatric Research Unit, WHO Collaborating Centre for Mental Health, Frederiksborg General Hospital, Denmark  (In 28 languages )
Website: http://www.who-5.org/.
X. Other Resources

Video Listing
1. Palliative Care Video Resource List
   Website: http://prc.coh.org/Video%20List%202012.asp

Journals/Newsletters
3. American Journal of Hospice & Palliative Medicine – a peer reviewed research journal published bi-monthly. The focus is on hospice and palliative care news and research. Website: http://ajh.sagepub.com/
4. Bridges: Connecting Cancer Survivors – Memorial Sloan-Kettering’s newsletter for survivors written by survivors. Website: http://www.mskcc.org/mskcc/html/86252.cfm?Email_PageName=December+2008+Lately@mskcc.org&Email_OID=newsletter-toc-439714
5. CancerWise – an online newsletter published monthly by The University of Texas M. D. Anderson Cancer Center. Each issue includes a cancer survivor’s story, related Q&A with M.D. Anderson experts, the latest reports on cancer treatment and research and tips for cancer survivorship and prevention. Website: http://www.cancerwise.org/
6. ChiPPS Pediatric & Palliative Care Newsletter – a quarterly newsletter from the Children’s Project on Palliative/Hospice Services (ChiPPS) and the National Hospice and Palliative Care Organization Website: http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409
7. ELNEC Connections – The End-of-Life Nursing Education Consortium is a quarterly newsletter to showcase efforts in end-of-life nursing education and practice. Website: http://www.aacn.nche.edu/elnec/publications/elnec-connections
8. European Journal of Palliative Care – official journal of the European Association for Palliative Care. Published six times a year by Hayward Medical Communications. Website: http://www.ejpc.eu.com/ejpchome.asp?FR=1
10. Innovations in End-of-Life Care – an international, online journal featuring peer-reviewed promising practices in end-of-life care. Website: http://www2.edc.org/lastacts/
13. Journal of Cancer Survivorship – a quarterly peer reviewed journal which presents papers relevant to improving the understanding, prevention, and management of the multiple areas related to cancer survivorship that can affect quality of care, longevity and quality of life of cancer survivors. Website: http://www.springer.com/public+health/journal/11764

15. **Journal of the National Comprehensive Cancer Network (JNCCN)** – JNCCN is dedicated to improving the quality of cancer care locally, nationally, and internationally while enhancing the collaboration between academic medicine and the community physician. Website: [http://www.nccn.org/JNCCN/default.asp](http://www.nccn.org/JNCCN/default.asp).


21. **Memorial Sloan-Kettering Cancer Center** monthly e-newsletter. Content includes a variety of topics related to cancer care including literature abstracts of current research studies, brief clinical articles, position postings and a calendar of conferences. Website: [http://www.mskcc.org/cancer-care/counseling-support/e-mail-newsletter](http://www.mskcc.org/cancer-care/counseling-support/e-mail-newsletter).

22. **NHPCO Newsline** – National Hospice and Palliative Care Organization (NHPCO) sponsored monthly newsletter for members. It details NHPCO activities and provides a calendar of events along with updates on legislative issues that may impact hospice care. Website: [http://www.nhpc.org/i4a/pages/index.cfm?pageid=3327](http://www.nhpc.org/i4a/pages/index.cfm?pageid=3327).


26. **Pain Pathways** – World Institute of Pain online quarterly magazine designed to address the needs and interests of people living with chronic, acute and cancer pain. Website: [http://www.painpathways.org/](http://www.painpathways.org/).

27. **Palliative Medicine Journal** – international interdisciplinary journal dedicated to improving knowledge and clinical practice in the palliative care of patients with far advanced disease. Website: [http://pmj.sagepub.com/](http://pmj.sagepub.com/).

28. **Palliative & Supportive Care** – an international journal of palliative medicine that focuses on the psychiatric, psychosocial, spiritual, existential, ethical, and philosophical aspects of palliative care. Website: [http://journals.cambridge.org/action/displayJournal?jid=PAX](http://journals.cambridge.org/action/displayJournal?jid=PAX).

29. **Progress in Palliative Care** – multidisciplinary journal that provides information on all aspects of palliative care. Website: [http://maney.co.uk/index.php/journals/ppc/](http://maney.co.uk/index.php/journals/ppc/).

31. **Supportive Care in Cancer** - provides members of the Multinational Association of Supportive Care in Cancer (MASCC) the most recent scientific and social information on aspects of supportive care for cancer patients at all stages of the disease. Website: [http://www.mascc.org/mc/page.do?sitePagId=86996&orgId=mascc](http://www.mascc.org/mc/page.do?sitePagId=86996&orgId=mascc).

### Media Resources

1. American Society of Clinical Oncology (ASCO)
   - ASCO Podcasts and Virtual Meetings
     Website: [http://www.asco.org/ASCOv2/MultiMedia/Virtual+Meeting](http://www.asco.org/ASCOv2/MultiMedia/Virtual+Meeting).

2. Beth Israel Medical Center, Department of Pain Medicine & Palliative Care: StopPain.org
   - Topics in Pain Management: A Slide Compendium
     Website: [http://www.stoppain.org/for_professionals/compendium/](http://www.stoppain.org/for_professionals/compendium/).

3. Cancer Pain Education for Patients and the Public (CPEPP) Training Program Slides
   - A program conducted by City of Hope Investigators (Betty Ferrell, Marcia Grant, and Gloria Juarez) funded by the National Cancer Institute. This project was designed to address the multiple opportunities for cancer pain education and to provide resources for successful implementation. The project materials on this site include outlines, PowerPoint presentations, handouts and a comprehensive bibliography for each module. Website: [http://prc.coh.org/other_resources.asp](http://prc.coh.org/other_resources.asp), Educational Materials, #3.

4. Interfaith Care for the Ill – Mobile Application

5. International Psycho-Oncology Society


11. Palliative Care: A Lifeline to Quality of Life Website: [http://www.youtube.com/watch?v=qXh7TW3lyP4](http://www.youtube.com/watch?v=qXh7TW3lyP4).

X. Other Resources

A. Related Organizations and Websites

Section Description: This section includes various professional and patient organizations focused on pain management or end-of-life care. Website links are provided.

A

- AARP – http://www.aarp.org
- Academy of Integrative Health & Medicine – http://aihm.org/
- Administration on Aging – http://www.aoa.gov/
- Advancing Excellence in America’s Nursing Homes – http://www.nhqualitycampaign.org/
- Advancing Expert Care: HPNA, HPFN, HPCC – http://advancingexpertcare.org/
- Aging with Dignity – http://www.agingwithdignity.org
- AIDS Answers – http://aids.answers.com/
- AIDS.org – http://www.aids.org/
- AIDSMEDS – http://www.aidsmeds.com/
- AIDS Project Los Angeles – http://www.apla.org
- A Lion in the House – http://www.lioninthehouse.com/
- Alzheimer’s Association – http://www.alz.org
- Alzheimer’s Disease Education and Referral Center – http://www.nia.nih.gov/alzheimers
- American Academy of Medical Acupuncture – http://www.medicalacupuncture.org/
- American Association for Long Term Care Nursing – http://ltcnursing.org/
- American Association of Colleges of Nursing – http://www.aacn.nche.edu/
- American Association of Critical-Care Nurses – http://www.aacn.org/
- American Association of Pastoral Counselors – http://www.aapc.org/
- American Cancer Society – http://www.cancer.org (also in Asian and Pacific Languages and Español)
- American Childhood Cancer Foundation – http://www.acco.org/
- American Chronic Pain Association – http://www.theacpa.org
American College of Physicians Ethics, Professionalism and Human Rights Committee: Information Resources for Physicians

- Supporting Family Caregivers -
- American College of Rheumatology - http://www.rheumatology.org/
- American Hospice Foundation - http://www.americanhospice.org
- American Hospital Association - http://www.aha.org
- American Massage Therapy Association - http://www.amtamassage.org
- American Nurses Credentialing Center - http://www.nursecredentialing.org/
- American Psychosocial Oncology Society (APOS) - http://www.apos-society.org/
- American Sickle Cell Anemia Association - http://www.ascaa.org/
- American Society on Aging (ASA) - http://www.asaging.org/
- American Society of Anesthesiologists - http://www.asahq.org
- American Society for Bioethics and Humanities - http://www.asbh.org/
- American Society for Pain Management Nursing (ASPMN) - http://www.aspmn.org
- American Society of Clinical Oncology (ASCO) - http://www.asco.org
- American Society of Law, Medicine & Ethics (ASLME) - http://www.aslme.org
- Americans for Better Care of the Dying (ABCD) - http://www.abcd-caring.org
- amfAR the Foundation for AIDS Research - http://www.amfar.org/
- Andrew Weil, MD - http://www.drweil.com/
- Annals of Surgical Oncology - http://www.annalssurgicaloncology.org/
- Arizona Center for Integrative Medicine - http://integrativemedicine.arizona.edu/
- Arthritis Foundation - http://www.arthritis.org
- Association for Applied and Therapeutic Humor - http://www.aath.org/
- Association of Cancer Online Resources (ACOR) - http://www.acor.org
- Association of Clinical Pastoral Education - http://www.acpe.edu
- Association of Death Education and Counseling (ADEC) - http://www.adec.org
- Association of Nurses in AIDS Care (ANAC) - http://www.nursesinaidscare.org/
- Association of Oncology Social Work (AOSW) - http://www.aosw.org
- Association of Pediatric Hematology/Oncology Nurses (APHON) - http://www.aphon.org
- Association of Professional Chaplains - http://professionalchaplains.org/

B

- Bandaides & Blackboards - http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/
- Before I Die: Medical Care and Personal Choices - http://www.thirteen.org/bid/
- Be The Match: Bone Marrow Donor - http://www.marrow.org/
- Between a Rock and a Hard Place: Clinical Ethics in Action -

C

- C-Change: Collaborating to Conquer Cancer - http://c-changetogether.org/
- CARF: Commission on Accreditation of Rehabilitation Facilities - http://www.carf.org/
- Canadian Association of Psychosocial Oncology - http://www.capo.ca/
Complementary & Alternative Medicine -

Complementary Medicine/Alternative Medicine News -
http://www.medicalnewstoday.com/categories/complementary_medicine

Complementary and Integrative Medicine Program - http://mayoresearch.mayo.edu/cimp/

Corporate Angel Network, Inc. (CAN) – http://www.corpangelnetwork.org

COS Multidisciplinary Education in Oncology - http://cos.ca/

Crisis, Grief, & Healing - http://www.webhealing.com


Cross Cultural Health Care Program - http://xculture.org

CureSearch Children's Cancer - http://www.curesearch.org

Cure - http://curetoday.com/

Cure SMA (Spinal Muscular Atrophy) – http://www.fsma.org/


Dia de la Mujer Latina - http://diadelamujerlatina.org/

Diversity - Association of American Medical Colleges – http://www.aamc.org/diversity/

Diversity Rx - http://www.diversityrx.org/

Duke Cancer Institute – http://www.cancer.duke.edu/

Dying Well – http://www.dyingwell.org

Education in Palliative and End-of-Life Care (EPEC) – http://www.epec.net/

Elizabeth Glaser Pediatric AIDS Foundation – http://www.pedaids.org/

Elizabeth Kübler Ross Foundation – http://www.ekrfoundation.org/

Emerging Solutions in Pain – http://www.emergingsolutionsinpain.com/

End-of-Life - AARP – http://www.aarp.org/families/end_life/


End-of-Life Nursing Education Consortium (ELNEC) – http://www.aacn.nche.edu/elnec

End-of-Life/Palliative Education Resource Center (EPERC) – http://www.mcw.edu/EPERC/EPERC/FastFactsandConcepts

Ethnogeriatrics – https://geriatrics.stanford.edu/

Ethnomed (Integrating Cultural Information into Clinical Practice) – http://www.ethnomed.org/

European Association of Palliative Care – http://www.eapcnet.org/


Family Caregiver Alliance – http://www.caregiver.org

Family Caregiver Support Group – http://www.caregiversupportnetwork.org/default.asp?id=1


Fibromyalgia Information Foundation – http://www.myalgia.com/

Fibromyalgia Network – http://www.fmnetnews.com


Fibromyalgia Treatment Center – http://fibromyalgiatreatment.com/


Frankly Speaking About Cancer – http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Frankly-Speaking-About-Cancer

Full Circle of Care – http://www.fullcirclecare.org/


Gerontological Society of America - http://www.geron.org/

Get Palliative Care – http://www.getpalliativecare.org
- Griefnet - http://www.griefnet.org
- Growth House, Inc. - http://www.growthhouse.org

H
- Harvard Medical School Center for Palliative Care - http://www.hms.harvard.edu/pallcare/
- HealthCare Chaplaincy Network - http://www.healthcarechaplaincy.org/
- AllRefer.com: Health - http://health.allrefer.com/
- Hospice - http://www.hospicenet.org/
- Hospice For Patients and Families - http://www.hospicenet.org/
- Hospice Foundation of America - http://hospicefoundation.org/
- Hospice Home Page - http://www.scu.edu/Hospice/
- Hospice Patients Alliance - http://www.hospicepatients.org/

I
- In the Face of Pain - http://inthefaceofpain.com/
- Initiative for Pediatric Palliative Care - http://www.ippcweb.org/
- Institute for Healthcare Improvement - http://www.ihi.org
- Institute of Medicine - http://www.iom.edu
- Integrative Medicine - http://www.mdanderson.org/departments/cimer/
- Intercultural Cancer Council - http://iccnetwork.org/
- Intercultural Communication Institute - http://www.intercultural.org/
- International Association for Hospice and Palliative Care - http://www.hospicecare.com/
- International Association of Physicians in AIDS Care (IAPAC) - http://www.iapac.org/
- International Association for the Study of Pain (IASP) - http://www.iasp-pain.org
- International Children's Palliative Care Network - http://www.icpcn.org/
- International Myopain Society (IMS) - http://www.myopain.org/
- International Palliative Care Family Carer Research Collaboration - http://www.centreforpallcare.org/index.php/research/ipfccrc/
- International Society for Quality of Life Research (ISOQOL) - http://www.isoqol.org/

J
- Joint Centre for Bioethics - http://www.jointcentreforbioethics.ca/

K
- Kids Against Cancer - http://www.kidsagainstcancer.org
- KidsHealth - http://www.kidshealth.org/

L
- LIVESTRONG - http://www.livestrong.org
Liam’s Foundation for Pediatric Palliative Care – http://www.liamsfoundation.org/
Listen with Your Heart -
http://www.cancer.org/treatment/understandingyourdiagnosis/talkingaboutcancer/listenwithyourheart
Long Term Care Planning Network - http://www.ltclanningnetwork.com/
Loving Touch Infant Massage – http://www.lovingtouch.com/
Low Cost Prescription Drugs: Patient Assistant Programs -
http://www.thelivingweb.net/lowcost_prescription_drugs.html

Make A Wish Foundation - http://www.wish.org
Medal Medical Algorithms – http://www.medical.org/
Memorial Sloan Kettering Cancer Care - http://www.mskcc.org
Mesothelioma & Asbestos Awareness Center – http://www.maaacenter.org/
Mesothelioma Cancer Alliance – http://www.mesothelioma.com/
Mesothelioma Treatment - http://www.asbestos.com/treatment/
Mom Always: Help for Mothers Facing Terminal Diagnosis - http://www.momalways.org/
Multicultural Health Clearinghouse - http://www.mckinley.uiuc.edu/multiculturalhealth/
Multicultural Tool Kit - http://www2.ons.org/ClinicalResources/SpecialPopulations/Transcultural/Toolkit
Multinational Association of Supportive Care in Cancer – http://mascc.org/

National Alliance for Caregiving – http://www.caregiving.org/
National Alliance for Hispanic Health - http://www.hispanichhealth.org/
National Association for Home Care & Hospice - http://www.nahc.org/
National Brain Tumor Society - http://www.braintumor.org/
National Cancer Comprehensive Network – http://www.nccn.org/
National Center for Cultural Competence – http://ncc.georgetown.edu/
National Center for Health Statistics - http://www.cdc.gov/nchs/
National Coalition for Cancer Survivorship – http://www.canceradvocacy.org/
National Comprehensive Cancer Network (NCCN) - http://www.nccn.org/
National Consensus Project for Quality Palliative Care - http://www.nationalconsensusproject.org/
National Fibromyalgia Association - http://www.fmaware.org/
National Fibromyalgia Research Association - http://www.nfra.net/
National Headache Foundation – http://www.headaches.org/
National Hospice and Palliative Care Organization – http://www.nhpc.org
National League for Nursing – http://www.nln.org/
National Organization for Rare Disorders – http://www.rarediseases.org
National Palliative Care Research Center – http://www.npcrc.org/
National Patient Travel Center – http://www.patienttravel.org/
National Pediatric and Family HIV Resource Center – http://www.thebody.com/content/art5977.html
National Prevention Information Network (NPIN) – http://www.cdcnpin.org/
National Prison Hospice Association – http://www.npha.org
National Shingles Foundation. – http://www.vzvfoundation.org/
National Vulvodynia Association – http://www.nva.org
Navigating Cancer and Blood Disorders – http://www.navigatingcancer.com/
Neuropathy Association – http://www.neuropathy.org
New York State Partnership for Long-Term Care – http://www.nyspltc.org/
NIH Senior Health: Complementary Health Approaches - http://nihseniorhealth.gov/complementaryhealthapproaches/whatarecomplementaryhealthapproaches/01.html
Not Dead Yet - http://notdeadyetnewscommentary.blogspot.com/
Nursing World – http://nursingworld.org/
Office of Minority Health – http://minorityhealth.hhs.gov/
On Our Own Terms: Moyers on Dying in America – http://www.pbs.org/wnet/onourownterms
OncoLink – http://www.oncolink.com/
Oncology Nursing Society – http://www.ons.org
Organ Procurement and Transplantation Network – http://optn.transplant.hrsa.gov/
Osher Center for Integrative Medicine – http://www.usher.ucsf.edu/
Oxford Pain Internet Site – http://www.medicine.ox.ac.uk/bandolier/booth/painpag/
Pain & Chemical Dependency - http://www.stoppain.org/pcd/default.asp
Pain Connection – http://www.painconnection.org
Pain Community – http://paincommunity.org
PainEDU – https://www.painedu.org/
Palliative Care - http://www.growthhouse.org/palliat.html
Palliative Care Communication Institute – http://pccinstitute.com/
Palliative Care Network – http://palliativecarenetwork.com/
Palliative Care Network Community - http://www.pcn-e.com/community/
Pancreatic Cancer Action Network – http://www.pancan.org/
Partners Against Pain – http://www.partnersagainstpain.com
Pathways, Education & Consultation in End-of-Life Care - http://www.pathwayseol.com/
Patient Advocate Foundation – http://patientadvocate.org/
Patient Education Institute – http://www.patient-education.com
Pediatric Art Therapy for Children with Cancer - http://www.tracyskids.org/
Planet Cancer - http://myplanet.planetcancer.org/
Post Pals: Brightening the Lives of Children - http://www.postpals.co.uk/
Program for Multicultural Health - http://www.med.umich.edu/multicultural/
Promoting Excellence in End-of-Life Care – http://www.promotingexcellence.org
Promoting Excellence in End-of-Life Care (Pediatric) – http://www.mywhatever.com/cifwriter/content/41/pe177.html
Prostate Net - http://prostate-online.org/

Quality of Life with Cancer Supportive Care – http://www.cancersupportivecare.com/qol.html#TOC

R.A. Bloch Cancer Foundation and Hotline – http://blochcancer.org/
RSDSA: Supporting the CPRS Community – http://www.rsdso.org/
Resources and Links for Patients and Families – www.aosw.org/AOSW/AOSWMain/People-Affected-by-Cancer/resources-and-links.aspx
Respecting Choices: Advanced Care Planning – http://www.respectingchoices.org/
Rheumatoid Arthritis - http://www.healthline.com/health/rheumatoid-arthritis
Robbins Headache Clinic - http://www.headachedrugs.com/
Rosalynn Carter Institute for Caregiving – http://www.rosalynncarter.org/
SAMfund for Young Adult Survivors of Cancer) – http://www.thesamfund.org/
Sickle Cell Disease - For Kids & Teens - http://kidshealth.org/kid/health_problems/blood/sickle_cell.html
Sickle Cell Disease Association of America – http://www.sicklecelldisease.org
Sickle Cell Information Center – http://www.scinfo.org/
Simonton Cancer Center – http://www.simontoncenter.com
Social Work Hospice and Palliative Care Network – http://www.swhpn.org/
Society of Surgical Oncology – http://www.surgonc.org/
StopPain.org – http://www.stoppain.org/
Strengthening the Spirit – http://www.cancercare.org/publications/56-strengthening_the_spirit
Suncoast Hospice – http://www.thehospice.org
Supportive Care Coalition – http://www.supportivecarecoalition.org/
Susan G. Komen for the Cure – http://ww5.komen.org/

The Center for Health & Healing – http://www.healthandhealingny.org/highlights.asp
The Importance of Spirituality in Cancer Care – http://www.integrativeoncology-essentials.com/2012/08/spirituality-and-cancer/
The Joint Commission – http://www.jointcommission.org/
The TMJ Association - http://www.tmj.org
Think Cultural Health - https://www.thinkculturalhealth.hhs.gov/
Today’s Caregiver – http://www.caregiver.com/
Transcultural Nursing - http://www.culturediversity.org/
Transcultural Nursing Society - http://www.tcns.org/
U

- Union for International Cancer Control - http://uicc.org/
- United Hospital Fund - http://www.uhfnyc.org

V

- Vulvar Pain Foundation - http://www.vulvarpainfoundation.org

W

- WebMD - Health - http://my.webmd.com/
- Well Spouse Association - http://www.wellspouse.org/
- Women's Cancer Network - http://www.wcn.org
- World Institute of Pain - http://worldinstituteofpain.org

Y

- Young Survival Coalition - http://www.youngsurvival.org