

## City of Hope Pain & Palliative Care Resource Center

Resources for Pain, Palliative Care, Quality of Life and Cancer Survivorship



### 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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## TABLE OF CONTENTS

<i>I.</i>	<i>Quality of Life and Cancer Survivorship.....</i>	<i>3</i>
	<i>A. Lung Cancer.....</i>	<i>11</i>
	<i>B. Ovarian.....</i>	<i>12</i>
	<i>C. Breast.....</i>	<i>12</i>
<i>II.</i>	<i>Spirituality.....</i>	<i>12</i>
<i>III.</i>	<i>Palliative Care.....</i>	<i>18</i>
	<i>A. Palliative Surgery.....</i>	<i>31</i>
	<i>B. Communication.....</i>	<i>33</i>
<i>IV.</i>	<i>Pain and Symptom Management</i>	
	<i>A. Pain Assessment Tools.....</i>	<i>35</i>
	<i>B. Pharmacology/Policies and Procedures.....</i>	<i>37</i>
	<i>C. Complementary, Alternative and Integrative Approaches .....</i>	<i>42</i>
<i>V.</i>	<i>Special Populations</i>	
	<i>A. Family Caregiving.....</i>	<i>47</i>
	<i>B. Pain Management, Palliative, and Long-Term Care in the Elderly.....</i>	<i>57</i>
	<i>C. Pediatrics.....</i>	<i>61</i>
	<i>D. Cultural Considerations in Palliative Care.....</i>	<i>70</i>
	<i>E. Sickle Cell Disease.....</i>	<i>74</i>
	<i>F. HIV/AIDS.....</i>	<i>77</i>
	<i>G. Chronic Non-Malignant Pain &amp; Headache .....</i>	<i>80</i>
<i>VI.</i>	<i>Education</i>	
	<i>A. Professional Competencies and Educational Programs.....</i>	<i>83</i>
	<i>B. Patient and Family Education.....</i>	<i>87</i>
<i>VII.</i>	<i>Quality Improvement.....</i>	<i>92</i>
	<i>A. Cost Effectiveness.....</i>	<i>94</i>
<i>VIII.</i>	<i>Ethical and Legal Issues.....</i>	<i>94</i>
<i>IX.</i>	<i>Research Instruments/Resources.....</i>	<i>97</i>
<i>X.</i>	<i>Other Resources.....</i>	<i>101</i>
	<i>A. Related Organizations and Websites .....</i>	<i>104</i>

# 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

1. Sun, V., Kim, J., Kim, J.Y., Raz, D.J., Merchant, S., Chao, J., Chung, V., Jimenez, T., Wittenberg, E., Grant, M. & Ferrell, B. (2015). Dietary alterations and restrictions following surgery for upper gastrointestinal cancers: key components of a health-related quality of life intervention. *European Journal of Oncology Nursing*, DOI: 10.1016/j.ejon.2015.01.008
2. Sun, V., Grant, M., McMullen, M., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., & Krouse, R. S. (2014). From diagnosis through survivorship: Health-care experiences of colorectal cancer survivors with ostomies. *Support Care Cancer*, 22(6), 1563-1570. DOI: 10.1007/s00520-014-2118-2.
3. Sun, V., Grant, M., McMullen, C. K., Altschuler, A., Mohler, M. J., Hornbrook, M. C., Herrinton, L. J., Baldwin, C. M., & Krouse, R. S. (2013). Surviving colorectal cancer: long-term, persistent ostomy-specific concerns and adaptations. *Journal of Wound, Ostomy & Continence Nursing*, 40(1), 61-72. DOI: 10.1097/WON.0b013e3182750143.
4. Sun, V., Cooke, L., Chung, V., Uman, G., Smith, T.J. & Ferrell, B. (2014). Feasibility of a palliative care intervention for cancer patients in phase I clinical trials. *Journal of Palliative Medicine*, 17(12): 1365-1368.
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8. Grant, M., Economou, D., Ferrell, B. R., & Uman, G. (2012). Educating health care professionals to provide institutional changes in cancer survivorship care. *Journal of Cancer Education*, Published online 24 January 2012.
9. Grant, M., Cooke, L., Williams, A. C., Bhatia, S., Popplewell, L., Uman, G., & Forman, S. (2012). Functional status and health-related quality of life among allogeneic transplant patients at hospital discharge: A comparison of sociodemographic, disease and treatment characteristics. *Supportive Care in Cancer*, 20(11), 2697-2704. DOI: 10.1007/s00520-012-1389-8.
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11. Sun, V., Borneman, T., Koczywas, M., Cristea, M., Piper, B., Uman, G., & Ferrell, B. R. (2012). Quality of life and barriers to symptom management in colon cancer. *European Journal of Oncology Nursing*, 16(3), 276-280. DOI:10.1016/j.ejon.2011.06.011.
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16. Gemmill, R., Kravits, K., Ortiz, M., Anderson, C., Lai, L., & Grant, M. (2011). What do surgical oncology staff nurses know about colorectal cancer ostomy care? *The Journal of Continuing Education in Nursing*, 42(2), 81-89. DOI: 10.3928/00220124-20101101-04.
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20. Grant, M., Economou, D., & Ferrell, B. (2010). Oncology nurse participation in survivorship care. *Clinical Journal of Oncology Nursing*, 14(6) 709-715. DOI: 10.1188/10.CJON.709-715.
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65. Carter, A., Robison, L. L., Francisco, L., Smith, D., Grant, M., Baker, K. S., et al. (2006). Prevalence of conception and pregnancy outcomes after hematopoietic cell transplantation: report from the Bone Marrow Transplant Survivor Study. *Bone Marrow Transplant, 37*(11), 1023-1029. DOI: 10.1038/sj.bmt.1705364.
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68. Ferrell, B. R., Cullinane, C. A., Ervin, K., Melancon, C., Uman, G. C., & Juarez, G. (2005). Perspectives on the impact of ovarian cancer: Women's views of quality of life. *Oncology Nursing Forum, 32* (6), 1143-1149. DOI: 10.1188/05.ONF.1143-1149.
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71. Ferrell, B. R., Smith, S., Cullinane, C., & Melancon, C. (2003). Psychological wellbeing and quality of life in ovarian cancer survivors. *Cancer, 98*(5), 1061-1071.

### **Recommended Publications**

1. Childhood Cancer Survivors: A Practical Guide to Your Future, 3<sup>rd</sup> Edition (2012).  
 - Keen, N, Hobbie, W., Ruccione, K. (2006). CA: Sebastopol: O'Reilly Media. ISBN# 978-0-596-52851-5.  
 Website: <http://www.amazon.com/Childhood-Cancer-Survivors-Practical-Future/dp/145711867X>.
2. Schlairet, M., Heddon, M. A., Griffis, M. (2010). Piloting a needs assessment to guide development of a survivorship program for a community cancer center. *Oncology Nursing Forum, 37*(4), 501-508. DOI: 10.1188/10.ONF.501-508.

3. Koensgen, D., Oskay-Oezcelik, G., Katsares, I., Walle, U., Klapp, C., Mustea, A., et al. (2010). Development of the Berline Symptom Checklist Ovary (BSCL-O) for the measurement of quality of life of patients with primary and recurrent ovarian cancer: Results of a phase I and II study. *Supportive Cancer Care, 18*(8), 931-942. DOI 10.1007/s00520-009-0733-0.
4. Syrjala, K. L., Yi, J. C., Artherholt, S. B., Stover, A. C., & Abrams, J. R. (2010). Measuring musculoskeletal symptoms in cancer survivors who receive hematopoietic cell transplantation. *Journal of Cancer Survivorship, 4*, 225-235. DOI: 10.1007/s11764-010-0126-x.
5. Menses, K. & Benz, R. (2010). Quality of life in cancer survivorship: 20 years later. *Seminars in Oncology Nursing, 26*(1), 36-46. DOI:10.1016/j.soncn.2009.11.006.
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15. **Work and Cancer Survivors**  
- Feuerstein, M. (2010). NY: Springer Science & Business. ISBN: 978-1441981554. Website: <http://www.amazon.com>.
16. Boehm, D. U., Lebrecht, A., Eckhardt, T., Albrick, S., Schmidt, M., Siggelkow, W., et al. (2009). Quality of life and adjuvant tamoxifen treatment in breast cancer patients. *European Journal of Cancer Care, 18*(5), 500-506. DOI: 10.1111/j.1365-2354.2008.01015.x.
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20. Zebrack, B. (2009). Developing a new instrument to assess the impact of cancer in young adult survivors of childhood cancer. *Journal of Cancer Survivorship, 3*, 1932-2259.
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24. Miller, K. D. & Triano, L. R. (2008). Medical issues in cancer survivors: A review. *Cancer Journal, 14*(6), 375-387. DOI: 10.1097/PPO.0b013e3181818ee3dc.
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27. 100 Questions & Answers About Life After Cancer: A Survivor's Guide
  - Tolbert, P. & Damaskos, P. (2008). MA: Jones and Bartlett Publishers. ISBN: 978-0763750695. Website: <http://www.jbpub.com/catalog/9780763750695/>.
28. Sharp, L. K., Kinahan, K. E., Didwania, A., & Stolley, M. (2007). Quality of life in adult survivors of childhood cancer. *Journal of Pediatric Oncology Nursing, 24*(4), 220-226. DOI: 10.1177/1043454207303885.
29. Sevy, R., & Riley, M. (2007). Partnering with cancer survivors. *Oncology Issues (Sept/Oct)*, 42-45.
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31. Handbook of Cancer Survivorship
  - Feuerstein, M. (2007). NY: Springer Science & Business. ISBN: 0387345612. Website: <http://www.springer.com/public+health/book/978-0-387-34561-1>.
32. Cancer Survivorship - Today and Tomorrow
  - Ganz, P. A. (2007). NY: Springer Science & Business. ISBN: 387343490. Website: <http://www.springer.com/medicine/oncology/book/978-0-387-34349-5>.
33. Implementing Cancer Survivorship Care Planning
  - A National Coalition for Cancer Survivorship and Institute of Medicine National Cancer Policy Forum Workshop, The Lance Armstrong Foundation, The Nation Cancer Institute, Hewitt, M. & Ganz, P. A. (2007). DC: The National Academies Press. ISBN: 309095956. Website: [http://www.nap.edu/catalog.php?record\\_id=11739](http://www.nap.edu/catalog.php?record_id=11739).
34. A Guide to Survivorship for Women with Ovarian Cancer
  - Montz, F. J, Bristow, R. E., & Anastasia, P. J. (2007). MD: John Hopkins University Press. ISBN: 0801880912. Website: <http://www.amazon.com/Survivorship-Ovarian-Cancer-Hopkins-Health/dp/product-description/0801880912>.
35. Everyone's Guide to Cancer Survivorship: A Road Map for Better Health
  - Gautier, H. & Rosenbaum, E. H. (2007). NJ: Andrews McMeel Publishing. ISBN: 0740768700. Website: <http://www.andrewsmcmeel.com/products/?isbn=0740768700>.

36. The Cancer Survivor's Guide – The Essential Handbook to Life after Cancer
  - Feuerstein, M. & Findley, P. (2006). NY: Marlowe & Company. ISBN: 569243328.  
Website: [http://www.perseusbooks.com/perseus/book\\_detail.jsp?isbn=1569243328](http://www.perseusbooks.com/perseus/book_detail.jsp?isbn=1569243328).
37. From Cancer Patient to Cancer Survivor: Lost in Transition
  - Hewitt, M., Greenfield, S., & Stoval, E. (2005). DC: The National Academies Press. ISBN: 309095956.  
Website: [http://books.nap.edu/catalog.php?record\\_id=11468#toc](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
  - Includes sections on Fatigue, Pain, Complications/Side Effects, Nutritional Concerns, Emotional Concerns, Treatment Related Issues, Clinical Trials, Information for Caregivers and Loved Ones, and Survivorship and End of Life Issues. Website: <http://www.cancer.gov/cancertopics/coping>.
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, care givers, 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://blohcancer.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](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](http://www.cdc.gov/cancer/survivorship/what_cdc_is_doing/action_plan.htm).

## **Other Organizational Links**

A Lion in the House	<a href="http://www.lioninthehouse.com/">http://www.lioninthehouse.com/</a>
American Cancer Society	<a href="http://www.cancer.org">http://www.cancer.org</a>
CancerCare	<a href="http://www.cancercare.org">http://www.cancercare.org</a>
Cancer Support Community	<a href="http://www.cancersupportcommunity.org/">http://www.cancersupportcommunity.org/</a>
Cancer Survivor Toolbox	<a href="http://www.canceradvocacy.org/toolbox/">http://www.canceradvocacy.org/toolbox/</a>
CureToday	<a href="http://www.curetoday.com">http://www.curetoday.com</a>
Institute of Medicine	<a href="http://www.iom.edu">http://www.iom.edu</a>
International Society for Quality of Life Research	<a href="http://www.isoqol.org/">http://www.isoqol.org/</a>
Leukemia & Lymphoma Society	<a href="http://www.leukemia-lymphoma.org/hm_lls">http://www.leukemia-lymphoma.org/hm_lls</a>
Livestrong Foundation	<a href="http://www.livestrong.org/cancersupport/">http://www.livestrong.org/cancersupport/</a>
Memorial Sloan-Kettering Cancer Care	<a href="http://www.mskcc.org/mskcc/html/58022.cfm">http://www.mskcc.org/mskcc/html/58022.cfm</a>
National Cancer Institute: Cancer Survivorship Research	<a href="http://dccps.nci.nih.gov/ocs/">http://dccps.nci.nih.gov/ocs/</a>
National Coalition for Cancer Survivorship	<a href="http://www.canceradvocacy.org">http://www.canceradvocacy.org</a>
Oncology Nursing Society: The Cancer Journey	<a href="http://www.thecancerjourney.org/survivor">http://www.thecancerjourney.org/survivor</a>
Planet Cancer	<a href="http://myplanet.planetcancer.org/">http://myplanet.planetcancer.org/</a>
Quality of Life with Cancer Supportive Care	<a href="http://www.cancersupportivecare.com/qol.html#TOC">http://www.cancersupportivecare.com/qol.html#TOC</a>
SAMfund (Young Adult Survivors of Cancer)	<a href="http://www.thesamfund.org">http://www.thesamfund.org</a>
Survivorship Center: Living Beyond Cancer	<a href="http://www.mskcc.org/mskcc/html/58022.cfm">http://www.mskcc.org/mskcc/html/58022.cfm</a>
UCLA Cancer Center Survivorship	<a href="http://www.cancer.ucla.edu/Index.aspx?page=6">http://www.cancer.ucla.edu/Index.aspx?page=6</a>
Young Survival Coalition	<a href="http://www.youngsurvival.org">http://www.youngsurvival.org</a>

## **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**

1. Koczywas, M., Williams, A.C, Cristea, M. Reckamp, K., Grannis, F., Tiep, B., Uman, G., Ferrell, B. (2013). Longitudinal changes in function, symptom burden, and quality of life in patients with early lung cancer. *Annals of Surgical Oncology*, 20(6) 1788-1797. DOI: 10.1245/s10434-012-2741-4
2. Grant, M., Sun, V., Fujinami, R., Sidhu, R., Otis-Green, S., Juarez, G., Klein, L., & Ferrell, B. (2013). Family caregiver burden, skills preparedness, and quality of life in non-small cell lung cancer. *Oncology Nursing forum*, 40(4), 337-346. DOI: 10.1188/13.ONF.337-346.
3. Koczywas M, Cristea M, Thomas J, McCarty C, Borneman T, Del Ferraro C, Sun V, Uman G, Ferrell B. (2013). Interdisciplinary palliative care intervention in metastatic non-small-cell lung cancer. *Clinical Lung Cancer*. 14(6), 736-744. DOI:10.1016/j.clc.2013.06.008.

## 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

1. Otis-Green, S., Wakabayashi, M.T., Morgan, R., Hakim, A., Ferrell, B., Sun, V., Yang, E. & Grant, M. (2013). Palliative care opportunities for women with advanced ovarian cancer associated with intraperitoneal chemotherapy. *Journal of Palliative Medicine*, 16(1), 44-53. DOI: 10.1089/jpm.2012.0174.
2. Sun, V., Otis-Green, S., Morgan, R., Wakabayashi, M., Hakim, A., Callado, M. E., Yang, E., Ferrell, B. & Grant, M. (2013). Toxicities, complications, and clinical encounters during intraperitoneal chemotherapy in 17 women with ovarian cancer. *European Journal of Oncology Nursing*, 17(3), 375-380. DOI:10.1016/j.ejon.2012.10.005
3. Matzo, M., Graham, C., Troup, C. L., & Ferrell, B. (2014). Development of a patient education resource for women with gynecologic cancers: Cancer treatment and sexual health. *Clinical Journal of Oncology Nursing*, 18(3), 343-348.

## 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

1. Juarez, G., Hurria, A., Uman, G. & Ferrell, B. R. (2103). Impact of a bilingual education intervention on the quality of life of Latina breast cancer survivors. *Oncology Nursing Society*, 40(1), E50-E60. DOI: 10.1188/13.ONF.E50-E60.

## 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

1. Skalla, K., Ferrell, B. (2015) Challenges in assessing spiritual distress in survivors of cancer. *Clinical Journal of Oncology Nursing*, 19(1): 99-104. DOI: 10.1188/15.CJON.99-104
2. Wittenberg, E., Ferrell, B., Goldsmith, J., & Buller, H. (2015). Provider Difficulties With Spiritual and Forgiveness Communication at the End of Life. *American Journal of Hospice and Palliative Medicine*, 1-6. DOI:10.1177/1049909115591811
3. Ellington, L., Reblin, M., Ferrell, B., Puchalski, C., Otis-Green, S., Handzo, G., Doyon, K. & Clayton, M. F. (2014). The religion of 'I don't know': Naturalistic observation of spiritual conversations occurring during cancer home hospice nurse visits. *Omega: Journal of Death and Dying*, In Press
4. Ferrell, B., Otis-Green, S., Baird, P., & Garcia, A., (2014). Nurses' responses to requests for forgiveness at the end of life. *Journal of Pain and Symptom Management*, 46(2), 631-641. DOI: 10.1016/j.painsymman.2013.05.009
5. Puchalski, C. Ferrell, B., Otis-Green, S., Handzo, G. (2014) Overview of spirituality in palliative care. UpToDate.
6. Bulkley, J., McMullen, C. K., Hornbrook, M. C., Grant, M., Altschuler, A, Wendel, C. S. & Krouse, R. S. (2013). Spiritual well-being in long-term colorectal cancer survivors with ostomies. *Psycho-Oncology*, 22(11), 2513-2521. DOI: 10.1002/pon.3318.

7. Ferrell, B., Otis-Green, S., and Economou, D. (2013). Spirituality in cancer care at the end of life. *The Cancer Journal: The Journal of Principles and Practice of Oncology*, 19(5), 431-437. DOI: 10.1097/PPO.0b013e3182a5baa5.
8. Borneman, T., Bluman, O., Klein, L., Thomas, J., Ferrell, B. (2013) Spiritual care for Jewish patients facing a life threatening illness. *Journal of Palliative Care*, 29(1) 58-62
9. Ferrell, B. R., & Munevar, C. (2012). Domain of spiritual care. *Progress in Palliative Care*, 20(2), 66-71. DOI: 10.1179/1743291X12Y.0000000013.
10. Ferrell, B., & Baird, P. (2012). Deriving meaning and faith in caregiving. *Seminars in Oncology Nursing*, 28(4), 256-261. DOI: 10.1016/j.soncn.2012.09.008.
11. Otis-Green, S., Ferrell, B. R., Borneman, T., Puchalski, C., Uman, G., & Garcia, A. (2012). Integrating spiritual care within palliative care: An overview of nine demonstration projects. *Journal of Palliative Medicine*, 15(2), 154-163. DOI: 10.1089/jpm.2011.0211. .
12. Borneman, T., Ferrell, B. R., & Puchalski, C. M. (2010). Evaluation of the FICA tool for spiritual assessment. *Journal of Pain and Symptom Management*, 40(20), 163-173. DOI: 10.1016/j.jpainsymman.2009.12.019.
13. Wong, F. L., Fransisco, L., Togawa, K., Bosworth, A., Golzales, M., Hanby, C., Sabado, M., Grant, M., Forman, S. J., & Bhatia, S., (2010). Long-term recovery after hematopoietic cell transplantation: Predictors of quality-of-life concerns. *Blood*, 115(12), 2508-2519. DOI: 10.1182/blood-2009-06-225631.
14. Puchalski, C., Ferrell, B. R., Virani, R., Otis-Green, S., Baird, P., Bull, J. et al., (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *Journal of Palliative Medicine*, 12(10), 885-904. DOI: 10.1089=jpm.2009.0142.
15. Baldwin, C. M., Grant, M., Wendel, C. Rawl, S., Schmidt, C. M., Ko, C., & Krouse, R. S. (2008). Influence of intestinal stomal on spiritual quality of life of U.S. veterans. *Journal of Holistic Nursing*, 26(3), 185-194. DOI: 10.1177/0898010108315185.
16. Crane-Okada, R. (2007). A compass for the cancer journey: Scientific, spiritual, and practical directives. *Oncology Nursing Forum*, 34(5), 945-954. DOI: 10.1188/07.ONF.945-955.
17. Ferrell, B. R. (2007). Meeting spiritual needs: What is an oncologist to do? *Journal of Clinical Oncology*, 25(5), 467-468. DOI: 10.1200/JCO.2006.09.3724.
18. Otis-Green, S. (2006). Spiritual palliative care. *Journal of Palliative Medicine*, 9, 1477-1478.
19. Ferrell, B. R., Smith, S. L., Juarez, G., & Melancon, C. H. (2003). Meaning of illness and spirituality in ovarian cancer survivors. *Oncology Nursing Forum*, 30(2), 249-257. DOI: 10.1188/03.ONF.249-257.
20. Otis-Green, S., Sherman, R., Perez, M., & Baird, P. (2002). An integrated psychosocial spiritual model for cancer pain management. *Cancer Practice*, Special Issue: Issues in cancer pain management: Models of success, 10(Supp. s1), 58-65. DOI: 10.1046/j.1523-5394.10.s.1.13.x.

### **Recommended Publications**

1. Spirituality in Healthcare
  - Cobb, M. R., Puchalski, C. M., & Rumbold, B. R. (2012). NY: Oxford University Press. ISBN: 978-0199571390. Website: <http://www.amazon.com/dp/0199571392>.
2. Principles and Practice of Palliative Care and Supportive Oncology, 4<sup>th</sup> Edition, esp. Section II: #54 Spirituality
  - Berger, A. M., Shuster Jr., J. L., Von Roenn, J. H. (2012). MA: Lippincott Williams & Wilkins. ISBN: 978-1451121278. Website: <http://www.amazon.com/dp/0199571392>.
3. Selman, L., Siegert, R., Harding, R., Harding, R., Gysels, M., Speck, P., & Higginson, I. J. (2011). A psychometric evaluation of measures of spirituality validated in culturally diverse palliative care populations. *Journal of Pain and Symptom Management*, 42(4), 604-622. DOI: 10.1016/j.jpainsymman.2011.01.015.

4. Oxford American Handbook of Hospice and Palliative Medicine, esp. Chapter 21: Spiritual Issues in Palliative Care
  - Bruera, E. & Yennarajalingam, S. (Eds). (2011). NY: Oxford University Press. ISBN: 978-0195380156.  
Website: <http://www.amazon.com>
5. Making Health Care Whole: Integrating Spirituality into Patient Care
  - Puchalski, C. M., & Ferrell, B. R. (2010). PA: Templeton Press. ISBN: 978-1599473505.  
Website: [http://www.templetonpress.org/book.asp?book\\_id=148](http://www.templetonpress.org/book.asp?book_id=148).
6. Oxford Textbook of Palliative Nursing, esp. Section III. Psychosocial Support
  - Ferrell, B. R., Coyle, N., & Paice, J., (2015). NY: Oxford University Press. ISBN: 9780199332342  
Website:  
<http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199332342>.
7. Alcorn, S. R., Balboni, M. J., Prigerson, H. G., Reynolds, A., Phelps, A. C., Wright, A. A., et al., (2010). If God wanted me yesterday, I wouldn't be here today: Religious and spiritual themes in patients' experiences of advanced cancer. *Journal of Palliative Medicine*, 13(5), 581-588. DOI: 10.1089/jpm.2009.0343.
8. Patterson, M. (2010). Prayer shawls: A blessing in every stitch. *Health Progress*, 91(3), 49-51.  
Website: [www.chausa.org/workarea/DownloadAsset.aspx?id=2147485267](http://www.chausa.org/workarea/DownloadAsset.aspx?id=2147485267).
9. Abu-Ras, W., & Laird, L. (2010). How Muslim and non-Muslim chaplains serve Muslim patients? Does the interfaith chaplaincy model have room for Muslims' experiences? *Journal of Religious Health*, 50(1), 46-61.  
DOI 10.1007/s10943-010-9357-4.
10. Salman, K., & Zoucha, R. (2010). Considering faith within culture when caring for the terminally ill Muslim patient and family. *Journal of Hospice and Palliative Nursing*, 12(3), 156-163. DOI: 10.1097/NJH.0b013e3181e24a52.
11. Albers, G., Echteld, M. A., de Vet, H. C. W., Onwuteaka, Philipsen, B. D., van der Linden, M. H. M., & Deliens, L. (2010). Content and spiritual items of quality-of-life instruments appropriate for use in palliative care: A review. *Journal of Pain and Symptom Management*, 40(2), 290-300. DOI: 10.1016/j.jpainsymman.2009.12.012.
12. Psychology, Religion, and Spirituality
  - Nelson, J. M. (2009). NY: Springer. ISBN: 978-0-387-87572-9 (Print) 978-0-387-87573-6 (E-book).  
DOI: 10.1007/978-0-387-87573-6. Website: <http://www.springer.com/psychology/book/978-0-387-87572-9>.
13. The Medical Manual for Religio-Cultural Competence: Caring for Religiously Diverse Populations
  - Tanenbaum. (2009). Tanenbaum Center for Interreligious Understanding. ASIN: B0033T7O8Q.  
Website: <http://www.amazon.com/The-Medical-Manual-Religio-Cultural-Competence/dp/B0033T7O8Q>.
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### **Educational Materials/Curriculum**

1. Completing a Life: A Resource for Taking Charge, Finding Comfort, Reaching Closure
  - 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/>.
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/>.
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>.
4. Fast Facts and Concepts - Palliative Care Network of Wisconsin (PCNOW)
 

For a complete listing of Fast Facts and Concepts see <http://www.mypcnow.org/#!fast-facts/c6xb>

  - Taking a Spiritual History #19
  - Music Therapy #108
  - Physicians and Prayer Requests #120
5. Interfaith Care for the Ill - Mobile Application
  - This app is for healthcare professionals looking for the right words of spiritual comfort in difficult circumstances relating to death or illness. It offers overviews of central beliefs, traditional prayers, and descriptions of common practices relating to illness and end-of-life care for Buddhism, Christianity, Hinduism, Islam, and Judaism. Available at iTunes <http://itunes.apple.com/us/app/interfaith-care-for-the-ill/id421099962?mt=8>.



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
  - Spiritual & religious care competencies assessment tools for specialists in palliative care. Website: <http://www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/spritual-religious-care-competencies.pdf>.
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	<a href="http://www.holisticmedicine.org/">http://www.holisticmedicine.org/</a>
American Holistic Nurses Association	<a href="http://www.ahna.org/">http://www.ahna.org/</a>
Association of Professional Chaplains	<a href="http://www.professionalchaplains.org/index.aspx?id=127">http://www.professionalchaplains.org/index.aspx?id=127</a>
Canadian Society for Spirituality & Social Work	<a href="http://w3.stu.ca/stu/sites/spirituality/index.html">http://w3.stu.ca/stu/sites/spirituality/index.html</a>
Can't Believe I Have Cancer	<a href="http://cantbelieveihavecancer.org/">http://cantbelieveihavecancer.org/</a>
Chaplains on Hand -Providing Spiritual Comfort	<a href="http://Chaplainsonhand.org">Chaplainsonhand.org</a>
Finding Comfort in Spirituality	<a href="http://www.nccn.org/patients/resources/life_with_cancer/spirituality.aspx">http://www.nccn.org/patients/resources/life_with_cancer/spirituality.aspx</a>
HealthCare Chaplaincy Network - Helps people faced with distress of illness and suffering to find comfort and meaning	<a href="http://www.healthcarechaplaincy.org/">http://www.healthcarechaplaincy.org/</a>
National Center for Complementary & Alternative Medicine	<a href="http://nccam.nih.gov">http://nccam.nih.gov</a>
Strengthening the Spirit	<a href="http://www.cancercare.org/publications/56-strengthening-the-spirit">http://www.cancercare.org/publications/56-strengthening-the-spirit</a>
Tanenbaum Center for Interreligious Understanding	<a href="https://www.tanenbaum.org/">https://www.tanenbaum.org/</a>
The Importance of Spirituality in Cancer Care	<a href="http://www.integrativeoncology-essentials.com/2012/08/spirituality-and-cancer/">http://www.integrativeoncology-essentials.com/2012/08/spirituality-and-cancer/</a>

### **Position Statements/Standards**

1. American Holistic Nurses Association (AHNA) Position Statements  
Website: <http://www.ahna.org/Resources/Publications/PositionStatements/tabid/1926/Default.aspx#P1>.
2. Hospice and Palliative Nurses Association (HPNA) Position Statements
  - Spiritual Care Website: <http://www.hpna.org/DisplayPage.aspx?Title1=Position%20Statements>.

3. National Comprehensive Cancer Network. (NCCN)  
 You must log in to access these documents. Registration is free:  
[http://www.nccn.org/professionals/physician\\_gls/f\\_guidelines.asp](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp)
  - Palliative Care: [http://www.nccn.org/professionals/physician\\_gls/PDF/palliative.pdf](http://www.nccn.org/professionals/physician_gls/PDF/palliative.pdf)
  - Distress Management: [http://www.nccn.org/professionals/physician\\_gls/PDF/distress.pdf](http://www.nccn.org/professionals/physician_gls/PDF/distress.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

1. Virani, R., Malloy, P., Dahlin, C., & Coyne, P. (2014). Creating a fabric for palliative care in safety net hospitals: End-of-Life Nursing Education Consortium for Public Hospitals. *Journal of Hospice & Palliative Nursing*, 16(5), 312-319. DOI: 10.1097/NJH.000000000000074.
2. Del Ferraro, D., Ferrell, B., Van Zyl, K., Freeman, B., & Klein, L. (2014). Improving palliative cancer care. *Journal of the Advanced Practitioner in Oncology*, 5(5), 331-338.
3. Borneman, T., Irish, T., Sidhu, R., Koczywas, M., & Cristea, M. (2014). Death awareness, feelings of uncertainty, and hope in advanced lung cancer patients: Can they coexist. *International Journal of Palliative Nursing*, 20(6), 271-277.
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5. Malloy, P., Paice, J., Coyle, N., Coyne, P., Smith, T., & Ferrell, B. (2014). Promoting palliative care worldwide through international nursing education. *Journal of Transcultural Nursing*, 25 (4), 410-417. DOI: 10.1177/10436596/4523993.
6. Ferrell, B., R., Smith, T. J., Levit, L., & Balogh, E. (2104). Improving the quality of cancer care: Implications for palliative care. *Journal of Palliative Medicine*, 17(4), 393-399. DOI: 10.1089/jpm.2013.0536
7. Otis-Green, S., Sidhu, R. K., Del Ferraro, C., & Ferrell, B. (2014). Integrating social work into palliative care for lung cancer patients and families: A multidimensional approach. *Journal of Psychosocial Oncology*, 32(4), 431-446. DOI: 10.1080/07347332.2014.917140.
8. Freeman, B. (2013). CARES: An acronym organized tool for the care of the dying. *Journal of Hospice & Palliative Nursing*, 15(3), 147-153. DOI: 10.1097/NJH.0b013e318287c782.
9. Otis-Green, S., Yang, E., & Lynne, L. (2013). ACE Project - Advocating for clinical excellence: Creating change in the delivery of palliative care. *Omega*, 67(1-2), 5-19.
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11. Otis-Green, S. (2013). Editorial: Changing the change agents through palliative care education for psycho-oncology professionals. *Omega*, 67(1-2), 1-4.
12. Cooke, L., Grant, M., Gemmill, R. (2012). Discharge needs of allogeneic transplantation recipients. *Clinical Journal of Oncology Nursing*, 16(4), E142-E149. DOI: 10.1188/12.CJON.E142-E149.
13. Williams, A. C., Grant, M., Tiep, B., & Hayter, J. (2012). Dyspnea management in early-stage lung cancer. *Journal of Hospice & Palliative Nursing*, 14(5), 332-340. DOI: 10.1097/NJH.0b013e318258043a.

14. Del Ferraro, C., Grant, M., Koczywas, M., & Dorr-Uyemura, L. A. (2012). Management of anorexia-cachexia in late-stage lung cancer patients. *Journal of Hospice & Palliative Nursing, 14*(6), 397-402. DOI: 10.1097/NJH.0b013e31825f3470.
15. Smith, T., Temin, S., Alesi, E., Abernethy, A., Balboni, T., Basch, E., Ferrell, B. R., Loscalzo, M., Meier, D., Paice, J., Peppercorn, J., Somerfield, M., Stovall, E., & Von Roenn, J. (2012). American Society of Clinical Oncology Provisional Clinical Opinion: The integration of palliative care into standard oncology care. *Journal of Clinical Oncology, 30*(8), 880-887. DOI: 10.1200/JCO.2011.38.5161.
16. Borneman, T., Piper, B., Koczywas, M., Munevar, C., Sun, V., Uman, G., & Ferrell, B. R. (2012). A qualitative analysis of cancer-related fatigue in cancer-related fatigue in ambulatory oncology. *Clinical Journal of Oncology Nursing, 16*(1), E26-E32. DOI: 10.1188/12.CJON.E26-E32.
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### **Recommended Publications**

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Website: <http://www.amazon.com/Principles-Practice-Palliative-Supportive-Oncology/dp/145112127X>.
2. Tarascon Palliative Medicine Pocketbook
  - Moses, B. (2013). MA: Tarascon Publishing. ISBN: 1449634214.  
Website: <http://www.amazon.com>.
3. Death and Dying: Life and Living, 7<sup>th</sup> Edition
  - Corr, C. A., Nabe, C. M., & Corr, D. M. (2012). CA: Wadsworth Publishing Company. ISBN: 13: 9780495506461.  
Website: <http://www.amazon.com>.
4. Grief and Loss: Theories and Skills for Helping Professionals, 2<sup>nd</sup> Edition
  - Walsh, K. (2012). MA: Pearson Publishers. ISBN: 9780205827091.  
Website: <http://www.pearsonhighered.com/educator/product/Grief-and-Loss-Theories-and-Skills-for-the-Helping-Professions-2E/9780205827091.page>.
5. Handbook of Health Social Work, 2<sup>nd</sup> Edition
  - Gehlert, S. & Browne, T. (2011). NY: John Wiley & Sons. ISBN: 0471714313.  
Website: <http://www.amazon.com>.
6. Conversations in Palliative Care: Questions and Answers with the Experts, 3rd Edition
  - Panke, J.T., & Coyne, P. (2011). PA: Hospice and Palliative Nurses Association.  
Website: <http://www.amazon.com>.
7. Living With Dying: A Handbook of End-of-Life Care for Practitioners
  - Berzoff, J., & Silverman, P. (2010). NY: Columbia University Press. ISBN: 0231127944.  
Website: <http://www.amazon.com/Living-With-Dying-End-Life-ebook/dp/B006OR93LO>
8. Making Health Care Whole: Integrating Spirituality into Patient Care
  - Puchalski, C. M., & Ferrell, B. R. (2010). PA: Templeton Press. ISBN: 9781599473505.  
Website: [http://www.templetonpress.org/book.asp?book\\_id=148](http://www.templetonpress.org/book.asp?book_id=148).
9. Reflections of a Loving Partner: Caregiving at the End of Life
  - Martin, C. A. (2010). FL: Quality of Life Publishing Co. ISBN: 978-0-9816219-3-7  
Website: <http://www.candrewmartin.com/>.
10. Palliative Care: Transforming the Care of Serious Illness
  - Meier, D. E., Isaacs, S. L., & Hughes, R. (Eds.) (2010). CA: Jossey-Bass. ISBN: 978-0-470-52717-7  
Website: <http://www.josseybass.com/WileyCDA/WileyTitle/productCd-047052717X.html>.
11. Dickens, D. S. (2010). Comparing pediatric deaths with and without hospice support. *Pediatric Blood Cancer*, 54, 746-750. DOI: 10.1002/pbc.22413.
12. The Last Dance: Encountering Death and Dying, 9<sup>th</sup> Edition
  - DeSpelder, L. A., & Strickland A. L. (2010). McGraw-Hill, ISBN: 978-0073405469.  
Website: [http://highered.mcgraw-hill.com/sites/0073532010/information\\_center\\_view0/new\\_to\\_this\\_edition.html](http://highered.mcgraw-hill.com/sites/0073532010/information_center_view0/new_to_this_edition.html).
13. Swallowed by a Snake: The Gift of the Masculine Side of Healing, 2<sup>nd</sup> Edition
  - Golden, T. R. (2010). Golden Healing Publishing LLC. ISBN: 978-0965464918.  
Website: <http://www.amazon.com/>.

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
  - Website: <http://store.hospicefoundation.org/home.php?cat=2>.
15. Dorman, S., Jolley, C., Abernethy, A., Durrow, D., Johnson, M., Farquhar, M., et al. (2009). Researching breathlessness in palliative care: Consensus statement of the National Cancer Research Institute Palliative Care Breathlessness Subgroup. *Palliative Medicine*, 23, 213-227. DOI: 10.1177/0269216309102520.
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18. Palliative Care Nursing: Quality Care to the End-of-Life, 3<sup>rd</sup> Edition
  - Matzo, M., & Sherman, D. (2009). NY: Springer Publishing Company. ISBN: 9780826157911. Order online at [http://www.springerpub.com/prod.aspx?prod\\_id=57911](http://www.springerpub.com/prod.aspx?prod_id=57911).
19. Counseling Individuals with Life-Threatening Illness
  - Doka, K. J. (2009). NY: Springer Publishing Company. ISBN: 978-0826115416  
Website: <http://www.springerpub.com/product/9780826115416>.
20. The End of Life Advisor
  - Dolan, S. R., & Vizzard, A. R. (2009). Kaplan Publishing. ISBN: 978-1-4277-9839-8  
Website: <http://www.kaptest.com/bookstore/Law/Show-All/9781427798398;jsessionid=FE80984F4B5853445EB3AC68B70C89AE?cid=343949>.
21. Pain Management: The Resource Guide for Home Health & Hospice Nurses
  - Long, C. O., & Morgan, B. M. (2008). MD: Hopkins Medical Products, Inc. ISBN: 978-1601464606.  
Website: <http://www.amazon.com/Pain-Management-Resource-Health-Hospice/dp/1601464606>.
22. Communication as Comfort: Multiple Voices in Palliative Care
  - Ragan, S. L., Wittenberg-Lyles, E. M., Goldsmith, J., & Sanchez-Reilly, S. (2008). NY: Routledge, Taylor & Francis Group. ISBN: 0805858083. Website: <http://www.routledge.com/books/details/9780805858099/>
23. Handbook of Bereavement Research and Practice: Advances in Theory and Intervention
  - Stroebe, M. S., Hansson, R. O., Schut, H., & Stroebe, W. (2008). American Psychological Association. ISBN: 978-1-4338-0351-2 Website: <http://www.apa.org/pubs/books/4318045.aspx>.
24. Harper, J., Hinds, P. S., Baker, J. N., Hicks, J., Spunt, S. L., & Razzouk, B. I. (2007). Creating a palliative and end-of-life program in a cure-oriented pediatric setting: The zig-zag method. *Journal of Pediatric Oncology Nursing*, 24(5), 246-254. DOI: 10.1177/1043454207303882.
25. Hospice and Palliative Nursing: Scope and Standards of Practice, 4<sup>th</sup> Edition
  - Hospice and Palliative Nurses Association. (2007). MD: American Nurses Association. ISBN: 1558102078.  
Website: <http://www.geronurseonline.org/Homepages/HomeLeftMiddle/HospiceandPalliativeNursing.html>.
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28. Pain Management: The Resource Guide for Home Health & Hospice Nurses
  - Long, C. O. & Morgan, B. M. (2008). MD: HcPro, Inc. ISBN: 1601464606.  
Website: <http://www.amazon.com/Pain-Management-Resource-Health-Hospice/dp/1601464606>.
29. Living Through Loss: Interventions Across the Life Span
  - Hooyman, N. R. (2008). NY: Columbia University Press. ISBN: 023112470  
Website: <http://www.amazon.com/Living-Through-Loss-Interventions-Foundations/dp/0231122470>.
30. A National Framework and Preferred Practices for Palliative and Hospice Care Quality
  - Corrigan, J. M. (2006). DC: National Quality Forum. ISBN: 1933875062.  
Website: <http://www.rwjf.org/content/dam/farm/reports/reports/2006/rwjf13081>.
31. A Grace Disguised: How the Soul Grows Through Loss, Expanded Edition
  - Sittser, J. (2005). MI: Zondervan Publishing House. ISBN: 9780310258957  
Website: <http://zondervan.com/9780310258957>.
32. Ambiguous Loss: Learning to Live with Unresolved Grief
  - Boss, P. (2000). MA: Harvard University Press. ISBN: 978-0674003811  
Website: <http://www.amazon.com>.
33. Healing after Loss: Daily Meditations for Working Through Grief
  - Hickman, M. W. (1994). NY: Avon Books. ISBN: 978-0380773381. Christian slant but excellent reviews.  
Website: <http://www.amazon.com/>.
34. **Oxford University Press Books**
  - Oxford Textbook of Palliative Social Work
    - Altilio, T. & Otis-Green, S. (2011). New York, NY: Oxford University Press.  
Website: <http://www.amazon.com/Oxford-Textbook-Palliative-Social-Work/dp/0199739110>
  - Oxford Textbook of Palliative Nursing
    - Ferrell, B. R., Coyle, N., & Paice, J., (2015). NY: Oxford University Press. ISBN: 9780199332342  
Website:  
<http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199332342>.
  - Oxford Textbook of Palliative Medicine, 4<sup>th</sup> Edition
    - Hanks, G., Cherny, N. I., Christakis, N. A., Fallon, M., Kaasa, S., & Portenoy, R. K. (2009). NY: Oxford University Press. ISBN: 0198570295. Website: <http://www.amazon.com/>.
  - The Nature of Suffering and the Goals of Nursing
    - Ferrell, B. R., & Coyle, N. (2008). NY: Oxford University Press. ISBN: 0195333128.  
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.
  - 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 **C**omfort, **A**irway, **R**estlessness, **E**motional support, and **S**elf care to organize the most common needs and education requirements to support the dying patient and their family.  
Website: <http://prc.coh.org/CARES.pdf> and <http://prc.coh.org/CARES%202.pdf>.
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.  
Website: <http://blog.nutritioncare.org/between-a-rock-and-a-hard-place-clinical-ethics-in-action/>.
6. Completing a Life: A Resource for Taking Charge, Finding Comfort, Reaching Closure
  - 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. Hospice and Palliative Nurses Association publication. Website: [http://www.hpna.org/Publications\\_APNCC.aspx](http://www.hpna.org/Publications_APNCC.aspx).
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>.
9. End-of-Life Nursing Education Consortium (ELNEC) Project: Advancing Higher Education in Nursing
  - 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](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  
Website: <http://www.apa.org/pi/aids/programs/eol/end-of-life-diversity.aspx>.
  - End-of-Life Care  
Website: <http://www.apa.org/pi/aids/programs/eol/end-of-life-factsheet.aspx>.
13. Fact Sheets - International Association for the Study of Pain (IASP), Seattle, WA  
Available in Spanish, French, Portuguese, Russian, Arabic, and Chinese.
  - 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&ContentID=7198>.
14. Fast Facts and Concepts - Palliative Care Network Of Wisconsin (PCNOW)  
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; Case Analysis Form. Website: [http://prc.coh.org/pdf/EOL\\_instruments.pdf](http://prc.coh.org/pdf/EOL_instruments.pdf).
16. Palliative Care Quiz for Nursing
  - Ross, M. M., McDonald, B., & Mc Guinness, J. (1996). The palliative care quiz for nursing (PCQN): the development 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. *Journal of Pain and Symptom Management*, 39(5), 914-923. DOI:10.1016/j.jpainsymman.2010.01.009.
  - Hospice and Palliative Nurses Association Position Statement on Palliative Sedation.  
Website: <http://www.hpna.org/PicView.aspx?ID=707>
  - Position Statement on Palliative Sedation - American Academy of Hospice and Palliative Medicine.  
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, 2<sup>nd</sup> 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](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](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	<a href="http://advancingexpertcare.org/">http://advancingexpertcare.org/</a>
American Academy of Hospice and Palliative Medicine	<a href="http://www.aahpm.org">http://www.aahpm.org</a>
American Hospice Foundation	<a href="http://www.americanhospice.org/">http://www.americanhospice.org/</a>
American Journal of Nursing	<a href="http://www.AJNonline.com">http://www.AJNonline.com</a>
American Society for Pain Management Nursing	<a href="http://www.aspmn.org">http://www.aspmn.org</a>
Americans for Better Care of the Dying (ABCD)	<a href="http://www.abcd-caring.org/">http://www.abcd-caring.org/</a>
Association of Death Education and Counseling (ADEC)	<a href="http://www.adec.org">http://www.adec.org</a>

Before I Die: Medical Care and Personal Choices	<a href="http://www.thirteen.org/bid/">http://www.thirteen.org/bid/</a>
Bereavement Support Group	<a href="http://www.mdjunction.com/bereavement">http://www.mdjunction.com/bereavement</a>
Care Search: Palliative Care Knowledge Network	<a href="http://www.caresearch.com.au/caresearch/Default.aspx">http://www.caresearch.com.au/caresearch/Default.aspx</a>
Center for Healthcare Decisions	<a href="http://www.chcd.org/index.html">http://www.chcd.org/index.html</a>
Center for Hospice Care	<a href="http://www.centerforhospice.org/">http://www.centerforhospice.org/</a>
Center to Advance Palliative Care (CAPC)	<a href="http://www.capc.org/">http://www.capc.org/</a>
Coalition for Compassionate Care of California	<a href="http://finalchoices.org">http://finalchoices.org</a>
Compassion and Choices	<a href="http://www.compassionandchoices.org/">http://www.compassionandchoices.org/</a>
CURE	<a href="http://www.curetoday.com">http://www.curetoday.com</a>
Dying Well	<a href="http://www.dyingwell.org">http://www.dyingwell.org</a>
EPEC (Education in Palliative and End-of-Life Care)	<a href="http://www.epec.net/">http://www.epec.net/</a>
End-of-Life: Exploring Death in America	<a href="http://www.npr.org/programs/death/971106.death.html">http://www.npr.org/programs/death/971106.death.html</a>
End-of-Life Nursing Education Consortium (ELNEC)	<a href="http://www.aacn.nche.edu/elneec/">http://www.aacn.nche.edu/elneec/</a>
EPERC (End-of-Life/Palliative Education Resource Center)	<a href="http://www.eperc.mcw.edu/EPERC">http://www.eperc.mcw.edu/EPERC</a>
European Association for Palliative Care	<a href="http://www.eapcnet.org/">http://www.eapcnet.org/</a>
Get Palliative Care	<a href="http://www.getpalliativecare.org">http://www.getpalliativecare.org</a>
Griefnet.org	<a href="http://www.griefnet.org/">http://www.griefnet.org/</a>
Growth House	<a href="http://www.growthhouse.org/">http://www.growthhouse.org/</a>
Harvard Medical School Center for Palliative Care	<a href="http://www.hms.harvard.edu/cdi/pallcare/">http://www.hms.harvard.edu/cdi/pallcare/</a>
Hospice Foundation of America	<a href="http://www.hospicefoundation.org/">http://www.hospicefoundation.org/</a>
Hospice Home Page	<a href="http://www.scu.edu/Hospice/">http://www.scu.edu/Hospice/</a>
Hospice For Patients and Families	<a href="http://www.hospicenet.org/">http://www.hospicenet.org/</a>
Hospice Patients Alliance	<a href="http://www.hospicepatients.org/">http://www.hospicepatients.org/</a>
Inter-Institutional Collaborating Network On End of Life Care	<a href="http://growthhouse.org/iicn.html">http://growthhouse.org/iicn.html</a>
Mom Always: Help for Mothers Facing Terminal Diagnosis	<a href="http://www.momalways.org/">http://www.momalways.org/</a>
National Hospice and Palliative Care Organization	<a href="http://www.nhpco.org/">http://www.nhpco.org/</a>
National Palliative Care Research Center	<a href="http://www.npcrc.org/">http://www.npcrc.org/</a>
National Prison Hospice Association	<a href="http://www.npha.org/">http://www.npha.org/</a>
On Our Own Terms: Moyers on Dying	<a href="http://www.pbs.org/wnet/onourown/terms/">http://www.pbs.org/wnet/onourown/terms/</a>
Palliative Care Network	<a href="http://palliativecarenetwork.com/">http://palliativecarenetwork.com/</a>
Pallipedia: Online Palliative Care Dictionary	<a href="http://pallipedia.org/">http://pallipedia.org/</a>
Pathways, Education & Consultation in End of Life Care	<a href="http://www.pathwayseol.com/">http://www.pathwayseol.com/</a>
Promoting Excellence in End-of-Life Care	<a href="http://www.promotingexcellence.org/">http://www.promotingexcellence.org/</a>
Stop Pain	<a href="http://www.stoppain.org/">http://www.stoppain.org/</a>
Suncoast Hospice	<a href="http://www.thehospice.org">http://www.thehospice.org</a>
Supportive Care Coalition	<a href="http://www.supportivecarecoalition.org/">http://www.supportivecarecoalition.org/</a>

## **Position Statements/Standards**

1. A Position Statement from American Nursing Leaders
  - Advanced Practice Nurses Role In Palliative Care Position Statement  
Website: <http://www.dyingwell.org/downloads/apnpos.pdf>.
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
  - Foregoing Nutrition and Hydration
  - Nursing Care and Do-Not-Resuscitate Decisions
  - Privacy and Confidentiality  
Website: <http://nursingworld.org/MainMenuCategories/HealthcareandPolicyIssues/ANAPositionStatements.aspx>.
4. American Society of Pain Management Nurses (ASPMN) Position Statements
  - Pain Management at the End-of-Life  
Website: [http://www.aspmn.org/documents/PainManagementattheEndofLife\\_August2013.pdf](http://www.aspmn.org/documents/PainManagementattheEndofLife_August2013.pdf).
  - The Use of "As Needed" Range Orders for Opioid Analgesics in the Management of Pain  
Website: <http://www.aspmn.org/documents/RangeOrderPublished2014.pdf>.
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  
Website: <http://www.hpna.org/DisplayPage.aspx?Title1=Position%20Statements>.
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**

1. Sun, V., Krouse, R. S. (2014). Palliative surgery: Incidence and outcomes. *Seminars Oncology Nursing*; 30, 234-241. DOI: 10.1016/j.soncn.2014.08.005 .
2. Collins, L. K., Goodwin, J. A., Spencer, H. J., Guevara, C., Ferrell, B., McSweeney, J., & Badgwell, B. D. (2013). Patient reasoning in palliative surgical oncology. *Journal of surgical oncology*, 107(4), 372-375. DOI:10.1002/jso.23215
3. Ferrell, B. R., Koczywas, M., Grannis, F., & Harrington, A., (2011). Palliative care in lung cancer. *Surgical Clinics of North America*, 91(2), 403-417. DOI: 10.1016/j.suc.2010.12.003.
4. Juarez, G., Ferrell, B. R., Uman, G., Podnos, Y., & Wagman, L. D. (2008). Distress and quality of life concerns of family caregivers of patients undergoing palliative surgery. *Cancer Nursing* 31(1), 2-10. DOI: 10.1097/01.NCC.0000305682.13766.c2.
5. Smith, D. D., & McCahill, L. E. (2008). Predicting life expectancy and symptom relief following surgery for advanced malignancy. *Annals of Surgical Oncology*, 15(12), 3335-3341. DOI: 10.1245/s10434-008-0162-1.
6. Podnos, Y. D., & Wagman, L. D. (2007). The surgeon and palliative care. *Annals of Surgical Oncology*, 14(4), 1257-1263. DOI: 10.1245/s10434-006-9222-6.
7. Wagman, L. D. (2007). Progress in palliative surgery—is it a subspecialty? *Journal of Surgical Oncology*, 96(6), 449-450. DOI: 10.1002/jso.20825.
8. Podnos, T. D., Juarez, G., Pameijer, C., Uman, G. C., Ferrell, B. R., & Wagman, L. D. (2007). Surgical palliation of advanced gastrointestinal tumors. *Journal of Palliative Medicine*. 10(4), 871-876. DOI: 10.1089/jpm.2006.0174.
9. Podnos, Y. D., Juarez, G., Pameijer, C., Choi, K., Ferrell, B. R., Wagman, L. (2007). Impact of surgical palliation on quality of life in patients with advanced malignancy: Results of the decisions and outcomes in palliative surgery (DOPS) trial. *Annals of Surgical Oncology*, 14(2), 922-928. DOI: 10.1245/s10434-006-9238-y.
10. Cullinane, C. A., Paz, I. B., Smith, D., Carter, N., & Grannis, F. W. (2004). Prognostic factors in the surgical management of pericardial effusion in patients with malignancy. *Chest*, 125(4), 1328-1334. DOI: 10.1378/chest.125.4.1328.
11. Wagman, L. D. Palliative surgical oncology. (2004). *Surgical Oncology Clinics N Am*, 13(3), XIII-XIV. DOI: 10.1016/j.soc.2004.04.002.
12. Borneman, T., Chu, D., Wagman, L., Ferrell, B. R., Juarez, G., McCahill, L., & Uman. G. (2003). Concerns of family caregivers of patients with cancer facing palliative surgery for advanced malignancies. *Oncology Nursing Forum*, 30(6), 997-1005.
13. Cullinane, C., Borneman, T., Smith, D., Chu, D., Ferrell, B. R., & Wagman, L. (2003). The surgical treatment of cancer: A comparison of resource utilization following procedures performed with a curative and palliative intent. *Cancer*, 98(10), 2266-2273. DOI: 10.1002/cncr.11777.
14. McCahill, L. E., Smith, D., Borneman, T., Juarez, G., Cullinane, C., Chu, D., Ferrell, B. R., & Wagman, L. (2003). A prospective evaluation of palliative outcomes for surgery of advanced malignancies. *Annals of Surgical Oncology*, 10(6), 654-663.
15. Cullinane, C. A., Chu, D., & Mamelak, A. N. (2002). Current surgical options in the control of cancer pain. *Cancer Practice*, 10(Suppl. 1), S21-S26. DOI: 10.1046/j.1523-5394.10.s.1.7.x.
16. Krouse, R.S., McCahill, L.E., Easson, A. M., & Dunn, G.P. (2002). When the sun can set on an unoperated bowel obstruction: Management of malignant bowel obstruction. *Journal of the American College of Surgeons*, 195(1), 117-128.
17. McCahill, L. E., & Ferrell, B. R. (2002). Palliative surgery for cancer pain. *Western Journal of Medicine*, 176, 107-110.

18. McCahill, L. E., Krouse, R., Chu, D., Juarez, G., Uman, G., Ferrell, B. R., & Wagman, L. (2002). Indications and use of palliative surgery-results of society of surgical oncological survey. *Annals of Surgical Oncology*, 9(1), 104-112.

### **Recommended Publications**

1. The M.D. Anderson Surgical Oncology Handbook, 5<sup>th</sup> Edition  
- Feig, B. W., & Ching, D. C. (2011). MA: Lippincott Williams & Wilkins. ISBN #: 1608312844.  
Website: <http://www.amazon.com>
2. Sartori, E., Chiudinelli, F., Pasinetti, B., Sostegni, B., & Maggino, T. (2010). Possible role of palliative surgery for bowel obstruction in advanced ovarian cancer patients. *European Journal of Gynaecological Oncology*, 37(1), 31-36.
3. Guimaraes, G. C., Baiocchi, G., Ferreira, F. O., Kumagai, L. Y., Fallopa, C. C., Aguiar, S., et al. (2010). Palliative pelvic exenteration for patients with gynecological malignancies. *Archives of Gynecology & Obstetrics*, online article. DOI: 10.1007/s00404-010-1544-8.
4. Fujibayashi, S., Neo, M., Miyaki, K., Nakayama, T., Nakamura, T. (2010). The value of palliative surgery for metastatic spinal disease: Satisfaction of patients and their families. *The Spine Journal*, 10, 42-49. DOI: 10.1016/j.spinee.2009.06.016.
5. Suarez, J., Jimenez, J., Vera, R., Tarifa, A., Balen, E., Arrazubi, V., et al. (2010). Stent or surgery for incurable obstructive colorectal cancer: An individualized decision. *International Journal for Colorectal Disease*, 25, 91-96. DOI: 10.1007/s00384-009-0814-z.
6. Gullick, J. G., & Stainton, M. C. (2009). Taking a chance: The experience of lung volume reduction procedures for chronic obstructive pulmonary disease. *Chronic Illness*, 5, 293-304. DOI: 10.1177/1742395309349547.
7. Kucukmetin, A., Naik, R., Bryand, A., & Dickinson, H. O. (2009). Palliative surgery versus medical management for bowel obstruction in ovarian cancer (Protocol). *The Cochrane Library, Issue 2*. DOI: 10.1002/14651858.CD007792.pub2.
8. Badgwell, B. D., Smith, K., Liu, P., Bruera, E., Curley, S. A., & Cormier, J. N. (2009). Indicators of surgery and survival in oncology inpatients requiring surgical evaluation for palliation. *Support Care in Cancer*, 17, 727-734. DOI: 10.1007/s00520-008-0554-6.
9. Scott, E. N., Garcea, G., Doucas, H., Steward, W. P. Dennison, A. R., & Berry, D. P. (2009). Surgical bypass vs. endoscopic stenting for pancreatic ductal adenocarcinoma. *HPB*, 11(2), 118-124. DOI: 10.1111/j.1477-2574.2008.00015.x\.
10. Augustine, M. M., & Pawlik, T. M. (2009). Palliation of advanced gastrointestinal malignancies using minimally invasive strategies. *Progress in Palliative Care*, 17(5), 250-260. DOI: 10.1179/0969926609X12455871937260.
11. Hoshi, M., Takami, M., Ieguchi, M., & Takaoka, K. (2009). Gefitinib is effective for pathological fracture of metastatic non-small cell lung cancer. *European Journal of Orthopaedic Surgery & Traumatologie*, 19, 181-185. DOI: 10.1007/s00590-008-0406-6.
12. Krouse, R. S. (2009). Future directions of palliative surgery. *Progress in Palliative Care*, 17(5), 261-265. DOI: 10.1179/0969926609X12455871937341.
13. Mazel, C., Balabaud, L., Bennis, S. Hansen, S. (2009). Cervical and thoracic spine tumor management: Surgical indications, techniques, and outcomes. *Orthopedic Clinics of North America*, 40, 75-92. DOI:10.1016/j.ocl.2008.09.008.
14. Dunn, G. P. (2009). Principles and core competencies of surgical palliative care: An overview. *Otolaryngologic Clinics of North America*, 42, 1-13. DOI:10.1016/j.otc.2008.09.003.
15. Bibliography - Palliative surgery. (2009). *Progress in Palliative Care*, 17(5), 266-296. DOI: 10.1179/0969926609X12455871937468.
16. Young-Spint, M., Guner, Y. S., Meyers, F. J., Schneider, P., Khatri, V. P. (2009). Radical palliative surgery: New limits to pursue. *Pediatric Surgery International*, 25, 917-921. DOI: 10.1007/s00383-009-2471-2.



17. Bafford, A. C., Burstein, H. J., Barkley, C. R., Smith, B. L., Lipsitz, S., Inglehard, J. D., et al. (2009). Breast surgery in stage IV breast cancer: Impact of staging and patient selection on overall survival. *Breast Cancer Research & Treatment*, *115*, 7-12. DOI: 10.1007/s10549-008-0101-7.
18. Surgical Palliative Care: A Resident's Guide
  - Dunn, G. P., Martensen, R., & Weissman, D. (2009). American College of Surgeons and the Cunniff-Dixon Foundation. Website: <http://www.facs.org/palliativecare/surgicalpalliativecareresidents.pdf>.
19. Terzis, J. K., & Kokkalis, Z. T. (2008). Outcomes of secondary shoulder reconstruction in obstetrical brachial plexus palsy. *Plastic and Reconstructive Surgery*, *122*(6), 1812-1822. DOI: 10.1097/PRS.0b013e31818cc1fc.
20. Lin, S-Z., Tong, H-F., You, T., Yu, Y-J., Wu, W-J., Chen, C., et al. (2008). Palliative gastrectomy and chemotherapy for stage IV gastric cancer. *Journal of Cancer Research & Clinical Oncology*, *134*, 187-192. DOI: 10.1007/s00432-007-0268-z.
21. Guarracino, F., Gemignani, R., Pratesi, G., Melfi, F., & Ambrosino, N. (2008). Awake palliative thoracic surgery in a high-risk patient: One-lung, non-invasive ventilation combined with epidural blockade. *Anaesthesia*, *63*, 761-763. DOI:10.1111/j.1365-2044.2008.05443.x.
22. Witzigmann, H., Lang, H., & Lauer, H. (2008). Guidelines for palliative surgery of cholangiocarcinoma. *HPB*, *10*, 154-160. DOI: 10.1080/13651820801992567.
23. Surgical Palliative Care (Supportive Care)
  - Dunn, G. & Johnson, A. (Eds.) (2004). NY: Oxford University Press. ISBN #: 0198510004. Website: <http://www.amazon.com>

### **Other Organizational Links**

American Society of Clinical Oncology	<a href="http://www.asco.org/">http://www.asco.org/</a>
Annals of Surgical Oncology	<a href="http://www.annsurgoncol.org/Roster_and_board.html">http://www.annsurgoncol.org/Roster_and_board.html</a>
Association of Oncology Social Workers	<a href="http://www.aosw.org/">http://www.aosw.org/</a>
Canadian Association of Psychosocial Oncology	<a href="http://www.capo.ca/">http://www.capo.ca/</a>
COS Multidisciplinary Education in Oncology	<a href="http://www.cos.ca">http://www.cos.ca</a>
Oncology Nursing Society	<a href="http://www.ons.org/">http://www.ons.org/</a>
Palliative Care	<a href="http://www.nlm.nih.gov/medlineplus/palliativecare.html">http://www.nlm.nih.gov/medlineplus/palliativecare.html</a>
Palliative Care in Cancer	<a href="http://www.cancer.gov/cancertopics/factsheet/Support/palliative-care">http://www.cancer.gov/cancertopics/factsheet/Support/palliative-care</a>
Palliative Care Quality Network	<a href="http://www.pcqn.org/">http://www.pcqn.org/</a>
Society of Surgical Oncology	<a href="http://www.surgonc.org/">http://www.surgonc.org/</a>

## **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**

1. Goldsmith, J., Wittenberg-Lyles, E., Frisby B, Small Platt, C. (2014). The entry-level physical therapist: A case for COMFORT communication training. *Health Communication*. Aug 1-9. DOI: 10.1080/10410236.2014.898014.
2. Wittenberg-Lyles, E., Goldsmith, J., Ferrell, B., & Burchett, M. (2014). Assessment of an interprofessional online curriculum for palliative care communication training. *Journal of Palliative Medicine*, *17*(x) 1-7. DOI: 10.1089/jpm.2013.0270.
3. Wittenberg-Lyles, E., Goldsmith, J., & Ferrell, B. (2013). Oncology nurse communication barriers to patient-centered care. *Clinical Journal of Oncology Nursing*, *17*(2), 152-158. DOI: 10.1188/13.CJON.152-158.

4. Goldsmith, J., Ferrell, B., Wittenberg-Lyles, E., & Ragan, S. (2013). Palliative care communication in oncology nursing. *Clinical Journal of Oncology Nursing, 17*(2), 163-167. DOI: 10.1188/13.CJON.163-167.
5. Wittenberg-Lyles, E., Goldsmith, J., Richardson, B., Hallett, J., & Clark, R. (2013). The practical nurse: A case for COMFORT curriculum training. *American Journal of Hospice and Palliative Care, 30*(2), 162-166. PMID: 22584148. DOI: 10.1177/1049909112446848.
6. Goldsmith, J., & Wittenberg-Lyles, E. (2013). COMFORT: Evaluating a new communication curriculum with nurse leaders. *Journal of Professional Nursing, 29*, 388-394. DOI:10.1016/j.profnurs.2012.05.017.
7. Wittenberg-Lyles, E., Goldsmith, J., Ferrell, B., Parker Oliver, D., & Pfeifle, A. (2012). COMFORT-IPE: Communication training for Interprofessional Patient-Centered Care. *MedEd Portal Publications Online*.
8. Wittenberg-Lyles E, Goldsmith J, Oliver D, Demiris, & G, Rankin A,. (2012). Targeting communication interventions to decrease caregiver burden. *Seminars in Oncology Nursing, 28*(4), 262-270.
9. Wittenberg-Lyles, E., Demiris, G., Ferrell B. R. & Shaunfield, S. (2012). Volunteers as facilitators of communication about pain: A feasibility study. *Research on Aging, 34*(2), 246-253. DOI: 10.1177/0164027511426879.
10. Mazanec, P., Daly, B., Ferrell, B. R., Prince-Paul, M. (2011). Lack of communication and control: Experiences of distance caregivers of parents with advanced cancer. *Oncology Nursing Forum, 38*(3), 307-313. DOI: 10.1188/11.ONF.307-313.
11. Wittenberg-Lyles, E., Oliver, D. P., Demiris, G., & Baldwin, P. (2010). The ACTIVE intervention in hospice interdisciplinary team meetings: Exploring family caregiver and hospice team communication. *Journal of Computer-Mediated Communication, 15*, 465-481. DOI: 10.1111/j.1083-6101.2010.01502.x.
12. Malloy, P., Virani, R., Kelly, K., & Munevar, C. (2010). Beyond bad news: Communication skills of nurses in palliative care. *Journal of Hospice and Palliative Nursing, 12*(3), 166-174. DOI: 10.1097/NJH.0b013e3181d99fee.
13. Villagran, M., Goldsmith, J., Wittenberg-Lyles, E., & Baldwin, P. (2010). Creating COMFORT: A communication-based model for breaking bad news. *Communication Education, 59*(3), 220-234. DOI: 10.1080/0363452100362403.
14. Wittenberg-Lyles, E., Goldsmith, J., & Ragan, S. (2010). The COMFORT initiative: Palliative nursing and the centrality of communication. *Journal of Hospice & Palliative Nursing, 12*(5), 293-297. DOI: 10.1097/NJH.0b013e3181ebb45e.
15. Matzo, M., Sherman, D., Sheehan, D., Ferrell, B. R., & Penn, B. (2003). Communication skills for end-of-life nursing care: Teaching strategies from the ELNEC curriculum. *Nursing Education Perspectives, 24*(4), 176-183.

### **Recommended Publications**

1. Communication in Palliative Nursing
  - Wittenberg-Lyles, E., Goldsmith, J., Ferrell, B., & Ragan, S. (2012). New York, NY: Oxford University Press. ISBN: 978-0199796823. Website: <http://www.amazon.com>
2. New Challenges in Communication with Cancer Patients
  - Surbone, A., Zwitter, M., Rajer, M., & Stiefel, R. (Eds). (2012). NY: Springer. ISBN: 978-1461433682. Website: <http://www.amazon.com/dp/0199571392>.
3. Penn, C., Watermeyer, J. & Evans, M. (2011). Why don't patients take their drugs? The role of communication, context and culture in patient adherence and the work of the pharmacist in HIV/AIDS. *Patient Education and Counseling, 83*, 310-318. DOI:10.1016/j.pec.2011.02.018
4. Dying with Comfort: Family Illness Narratives and Early Palliative Care
  - Wittenberg-Lyles, E. & Goldsmith, J. (2010). NY: Hampton Press. ISBN: 978-1572739857. Website: <http://www.amazon.com>.
5. Coorenbos, A. Z., Lindhorst, T., Schim, S. M., van Schaik, E., Demiris, G., Wechen, H. A., & Curtis, J. R. (2010). Development of a web-based educational intervention to improve cross-cultural communication among hospice providers. *Journal of Social Work in End-of-Life & Palliative Care, 6*, 236-255. DOI: 10.1080/15524256.2010.529022

6. Song, M-K., Donovan, H. S., Piraino, B. M., Choi, J., Bernardini, J., Verosky, D., & Ward, S. E. (2010). Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. *Applied Nursing Research, 23*, 65-72. DOI:10.1016/j.apnr.2008.05. 002.
7. Bowman, K. F., Rose, J. H., Radziewicz, R. M., O'Toole, E. E., & Berila, R. A (2009). Family caregiver engagement in a coping and communication support intervention tailored for advanced cancer patients and families. *Cancer Nursing, 32*(1), 73-81. DOI: 10.1097/01.NCC.0000343367.98623.83.
8. Zhukovsky, D. S., Herzog, C. E., Kaur, G., Palmer, J. L., & Bruera, E. (2009). The impact of palliative care consultation on symptom assessment, communication needs, and palliative interventions in pediatric patients with cancer. *Journal of Palliative Medicine, 12*(4), 343-349. DOI: 10.1089=jpm.2008.0152.
9. Communication as Comfort: Multiple Voices in Palliative Care
  - Ragan, S. L, & Wittenberg-Lyles, E. (2008). NY: Routledge. ISBN: 978-0805858082. Website: [http:// www.amazon.com](http://www.amazon.com).

### **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>
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>.
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>

### **Other Organizational Links**

- |   |   |
|---|---|
| Communicating with Patients             | <a href="http://www.aha.org/advocacy-issues/communicatingpts">http://www.aha.org/advocacy-issues/communicatingpts</a>   |
| Palliative Care Communication Institute | <a href="http://www.pccinstitute.com/">http://www.pccinstitute.com/</a>   |
| - Also on Facebook                      | <a href="https://www.facebook.com/pccinstitute?ref=aymt_homepage_panel">https://www.facebook.com/pccinstitute?ref=aymt_homepage_panel</a>   |
| - Also on Twitter @pallcarecomm         | <a href="https://twitter.com/search?q=palliative%20care%20communication%20institute&amp;src=typd">https://twitter.com/search?q=palliative%20care%20communication%20institute&amp;src=typd</a> |

## 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
  - Pasero, C. & McCaffery, M. (2010). MO: St Louis, Elsevier Mosby. ISBN: 978-0-323-05696-0.
  - Section II: Assessment, particularly Chapter 3: Assessment Tools. Forms, checklists, tips, and strategies for assessing acute and chronic pain, nociceptive and neuropathic pain, pain in adults, children, infants, cognitively impaired persons, and persons who cannot self-report. Many tools for a variety of populations in English and several other languages. Fifteen pages of references at the end of the section. Website:  
[http://www.us.elsevierhealth.com/product.jsp?sid=EHS\\_US\\_BS-SPE-424&isbn=9780323056960&lid=EHS\\_US\\_BS-DIS-4&iid=null](http://www.us.elsevierhealth.com/product.jsp?sid=EHS_US_BS-SPE-424&isbn=9780323056960&lid=EHS_US_BS-DIS-4&iid=null).
2. Herr, K., Bursch, H., Ersek, M., Miller, L. L., Swafford, K. (2010). Use of pain-behavioral assessment tools in the nursing home: Expert consensus recommendations for practice. *Journal of Gerontological Nursing, 36*(3), 18-29.  
DOI: 10.3928/00989134-20100108-04.

#### Pain Assessment Tools

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://www.coh.org/patient-family-community-education/Documents/symptom-management/Communication %20Cards.final.10.06doc.pdf](http://www.coh.org/patient-family-community-education/Documents/symptom-management/Communication%20Cards.final.10.06doc.pdf) .
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, 2<sup>nd</sup> ed., #78
  - Pediatric Pain Assessment Scales, #117
  - Pain Assessment in the Cognitively Impaired #126
  - Pseudoaddiction, 2<sup>nd</sup> ed., #69
  - Establishing Pain Relief Goals Website: <http://prc.coh.org/pdf/Goals-FF%205-10.pdf>.
  - 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>.
  - What is Neuropathic Pain? Website: <http://prc.coh.org/pdf/NeuroPain11.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](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](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](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](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.  
Website: <http://prc.coh.org/pdf/Psychosocial%20Pain%20Assessment%20Form.pdf>.
  - Psychosocial Pain Assessment Forms in Spanish (for adults and children/adolescents):  
Adults: <http://prc.coh.org/pdf/Forma%20%20Adultos%20PS.pdf>.  
Children/Adolescents: <http://prc.coh.org/pdf/Formulario%20Ninos.pdf>.
9. State of the Art Review of Tools for Assessment of Pain in Nonverbal Older Adults
  - 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.)
  - Assessment of Discomfort in Dementia (ADD) Protocol, (Kovach, C.R., 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**

1. Paice, J. A., & Ferrell, B. R. (2011). The management of cancer pain. *CA: A Cancer Journal for Clinicians*, 61(3), 157-182. DOI: 10.3322/caac.20112.
2. Borneman, T., Koczywas, M., Sun, V. C., Piper, B. F., Uman, G., & Ferrell, B. (2010). Reducing patient barriers to pain and fatigue management. *Journal of Pain and Symptom Management*, 39(3), 486-501. DOI: 10.1016/j.jpainsymman.2009.08.007.
3. Borneman, T., & Ferrell, B. R. (2010). Maximizing cancer pain management. *Coping with Cancer*, 24(1), 15-15.

4. Sun, V., Borneman, T., Piper, B., Koczywas, M., & Ferrell, B. (2008). Barriers to pain assessment and management in cancer survivorship. *Journal of Cancer Survivorship, 2*(1), 65-71. DOI: 10.1007/s11764-008-0047-0.
5. Otis-Green, S., Lucas, S., Spolum, M., Ferrell, B., & Grant, M. (2008). Promoting excellence in pain management and palliative care for social workers. *Journal of Social Work in End-of-Life & Palliative Care, 4*(2), 120-134. DOI: 10.1080/15524250802353942.
6. Ferrell, B., Levy, M. H., & Paice, J. (2008). Managing pain from advanced cancer in the palliative care setting. *Clinical Journal of Oncology Nursing, 12*(4), 575-581. DOI: 10.1188/08.CJON.575-581.

### **Recommended Publications**

1. Pain Assessment and Pharmacologic Management
  - Pasero, C., & McCaffery, M. (2010). MO: Elsevier Mosby. ISBN: 978-0-323-05696-0.
  - Sections III (Nonopioid Analgesics), IV (Opioid Analgesics), and V (Adjuvant Analgesics). Website: <http://www.amazon.com>.
2. Oxford Textbook of Palliative Medicine, 4<sup>th</sup> Edition
  - Hanks, G., Cherny, N. I., Christakis, N. A., Fallon, M., Kaasa, S., & Portenoy, R. K. (Eds.) (2010). NY: Oxford University Press. ISBN: 978-0-19-857029-5.
  - Section 10.1 The Management of Pain, pages 587-800. Website: <http://www.amazon.com>.
3. van Wilgen, C. P., & Keizer, D. (2010). The sensitization model to explain how chronic pain exists without tissue damage. *Pain Management Nursing, 1*-6. published online, <http://www.sciencedirect.com/science/article/pii/S1524904210000329> DOI: 10.1016/j.pmn.2010.03.001.
4. Miaskowski, C. (2010). Outcome measures to evaluate the effectiveness of pain management in older adults with cancer. *Oncology Nursing Forum, 37*(5), 27-32. DOI: 10.1188/10.ONF.S1.27-32.
5. Marceau, L. D., Link, C. L., Smith, L. D. (2010). In-clinic use of electronic pain diaries: Barriers of implementation among pain physicians. *Journal of Pain and Symptom Management, 40*(3), 391-404. DOI:10.1016/j.jpainsymman.2009.12.021.
6. Brant, J. M. (2010). Practical approaches to pharmacologic management of pain in older adults with cancer. *Oncology Nursing Forum, Supplement to 37*(5), 17-26. DOI: 10.1188/10.ONF.S1.17-26.
7. von Gunten, C. F., Bruera, E., Pirrello, R. D., & Portenoy, R. K. (2010). New opioids: Expensive distractions or important additions to practice? *Journal of Palliative Medicine, 13*(5), 505-511. DOI: 10.1089/jpm.2010.9815.
8. Lentz, J., McMillan, S. C. (2010). The impact of opioid-induced constipation on patients near the end of life. *Journal of Hospice and Palliative Nursing, 12*(1), 29-38. DOI: 10.1097/NJH.0b013e3181cde1d2.
9. Lovell, M. R., Forder, P. M., Stockler, M. R., Butow, P., Briganti, E. M., Chye, R., et al. (2010). A randomized controlled trial of a standardized educational intervention for patients with cancer pain. *Journal of Pain and Symptom Management, 40*(1), 49-59. DOI:10.1016/j.jpainsymman.2009.12.013.
10. Demystifying Opioid Conversion Calculations: A Guide to Effective Dosing
  - McPherson, M. L. (2009). Bethesda, MD: American Society of Health System-Pharmacists. ISBN: 978-1585281985. Website: <http://www.ashp.org/bookstore/ClinicalReferences/ProductDetails/tabid/199/Default.aspx?ProductId=4216>.

### **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](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. Website: <http://prc.coh.org/pdf/Home%20Health%20Care%20Case%20Studies.pdf>.

2. Fast Facts and Concepts – Palliative Care Network of Wisconsin (PCNOW)

Website: <http://www.mypcnow.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 Bertebral 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
- Coping with Pain
- Establishing Pain Relief Goals
- Intravenous Lidocaine for Perioperative Pain

Website: <http://prc.coh.org/pdf/TopLid11.pdf>

Website: <http://prc.coh.org/pdf/Coping-FF%205-10.pdf>

Website: <http://prc.coh.org/pdf/Goals-FF%205-10.pdf>

Website: <http://prc.coh.org/FF%20LidolVPer12-10.pdf>

- 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-09.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/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/FF/TransFen11.pdf>
- Transitional Analgesia Website: <http://prc.coh.org/pdf/TranAna11.pdf>
- Transverses Abdominis Plane (TAP) Block Website: <http://prc.coh.org/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
  - For full explanation, sample agreements, and newer terminology regarding the use of opioid agreements see Appendix B. Pasero, C. & McCaffery, M. (2010). *Pain Assessment and Pharmacologic Management*. MO: St Louis, Elsevier Mosby. ISBN: 978-0-323-05696-0  
Website: <http://www.elsevier.com/wps/find/bookdescription.advertisers/722199/description#description>.
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>
  - Quick Reference Guide for Symptom Management Pain Card  
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.  
Website: <http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/prc2013.pdf>.
2. Palliative Care and Pain Management - Memorial Sloan-Kettering Cancer Center, New York, NY  
Website: <http://www.mskcc.org/mskcc/html/96732.cfm>.
3. Care of the Patient Receiving Conscious Sedation - Canadian Society of Gastroenterology Nurses & Associates  
Website: <http://csgna.com/en/guidelines/sedation.html>.
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://cchealth.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)
  - Website: <http://www.amazon.com/Core-Curriculum-Pain-Management-Nursing/dp/0721690890>.



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](http://www.jpain.org/article/S1526-5900(08)00831-6/abstract)
  - Opioids for Chronic Noncancer Pain: Prediction and Identification of Aberrant Drug-Related Behaviors: A Review of the Evidence for an American Pain Society and American Academy of Pain Medicine Clinical Practice Guideline  
Website: [http://www.jpain.org/article/S1526-5900\(08\)00832-8/abstract](http://www.jpain.org/article/S1526-5900(08)00832-8/abstract)
  - Research Gaps on Use of Opioids for Chronic Noncancer Pain: Findings From a Review of the Evidence for an American Pain Society and American Academy of Pain Medicine Clinical Practice Guideline  
Website: [http://www.jpain.org/article/S1526-5900\(08\)00830-4/abstract](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](https://medical.wesrch.com/User_images/Pdf/MS1_1225761426.pdf)
9. Pain Management Resource Manual - Virginia Commonwealth University, Richmond, VA
  - 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.  
Website: <http://www.paineducation.vcu.edu/documents/PainManual.pdf>.
10. Principles of Analgesic Use in the Treatment of Acute Pain and Cancer Pain, 6<sup>th</sup> Edition – American Pain Society
  - 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), 2<sup>nd</sup> Edition
  - Download guidelines from Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)  
Website: [http://www.rsds.org/3/clinical\\_guidelines/index.html](http://www.rsds.org/3/clinical_guidelines/index.html).
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.  
Website: <http://www.ashp.org/DocLibrary/BestPractices/TGSedatives.aspx>.
  - Guidelines and levels of care for pediatric intensive care units  
Website: <http://www.learnicu.org/Docs/Guidelines/PediatricIntensiveCare.pdf>.
15. Symptom Management Algorithms: A Handbook for Palliative Care, 3<sup>rd</sup> Edition  
Website: [http://www.hpna.org/Item\\_Details.aspx?ItemNo=1-888411-07-4](http://www.hpna.org/Item_Details.aspx?ItemNo=1-888411-07-4).

## **Other Organizational Links**

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

## **Key References**

1. A Physician's Guide to Pain and Symptom Management in Cancer Patients, 3<sup>rd</sup> Edition
  - Abraham, J. L. (2014). MD: Johns Hopkins University Press. ISBN: 9781421414034. An excellent resource that should be used to prevent and treat suffering as health care professionals accompany the patient and family through the experience of living with cancer. Website: <https://jhupbooks.press.jhu.edu/content/physicians-guide-pain-and-symptom-management-cancer-patients-0>.
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  
Website: <http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1518&navItemNumber=648>.

## **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**

1. Kravits, K. (2015). Hypnosis for the Management of Anticipatory Nausea and Vomiting. *Journal of the Advanced Practitioner in Oncology*, 6(3), 225-229. DOI: 10.6004/jadpro.2015.6.3.4
2. Burhenn, P., Olausson, J., Villegas, G., & Kravits, K. (2014). Evidence-based practice: Guided imagery for pain control. *Clinical Journal of Oncology Nursing*, 18(5), 501-502.
3. Kravits, K. (2013). Hypnosis: Adjunct therapy for cancer pain management. *Journal of the Advanced Practitioner in Oncology*, 4(2), 83-88.

4. Montgomery, G., Schnur, J.B., & Kravits, K. (2013). Hypnosis for cancer care: Over 200 years young. *CA: A Cancer Journal for Clinicians*, 63(1), 31-44. DOI: 10.3322/caac.21165.
5. Miller, M. & Kravits, K. (2013). Nurses' use of art in hospice settings. *Journal of Hospice and Palliative Nursing*, 15(1), 5-10. DOI: 10.1097/NJH.0b013e31827ce345.
6. Lew, M. W., Kravits, K., Garberoglio, C., & Williams, A. C. (2011). Use of preoperative hypnosis to reduce postoperative pain and anesthesia-related side effects. *International Journal of Clinical and Experimental Hypnosis*, 59(4), 406-423. DOI: 10.1080/00207144.2011.594737.
7. Kravits, K., McAllister-Black, R., Grant, M., & Kirk, C. (2010). Self-care strategies for nurses: A psycho-educational intervention for stress reduction and the prevention of burnout. *Applied Nursing Research*, 23, 130-138. DOI:10.1016/j.apnr.2008.08.002.
8. Rojas-Cooley, T., & Grant, M. (2006). Complementary and alternative medicine: Oncology nurses' experiences, educational interests, and resources. *Oncology Nursing Forum*, 33(3), 581-588.
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10. Kravits, K. (2013). Overview of evidence-based non-pharmacological therapies used in cancer palliative care. In *Evidence-Based Non-Pharmacological Therapies Used in Cancer Palliative Care*. Ed. Cho. W. NY: Springer Publishing. ISBN: 978-9400758322. Website: <http://www.amazon.com/>.

### **Recommended Publications**

1. Tracy, S. M. (2010). Piloting tailored teaching on nonpharmacologic enhancements for postoperative pain management in older adults. *Pain Management Nursing*, 1(3), 148-158. DOI:10.1016/j.pmn.2009.06.002.
2. Chen, Y. L., & Francis, A. J. P. (2010). Relaxation and imagery for chronic, nonmalignant pain: Effects on pain symptoms, quality of life and mental health. *Pain Management Nursing*, 1(3), 159-168. DOI:10.1016/j.pmn.2009.05.005.
3. Hollis, A. S. H. (2010). Acupuncture as a treatment modality for the management of cancer pain: The state of the science. *Oncology Nursing Forum*, 37(5), E344-E348. DOI: 10.1188/10.ONF.E344-E348.
4. Dean-Clower, E., Doherty-Gilman, A. M., Keshaviah, A., Baker, F., Kaw, C., Lu, W., et al. (2010). Acupuncture as palliative therapy for physical symptoms and quality of life for advanced cancer patients. *Integrative Cancer Therapies*, 9(2), 158-167. DOI: 10.1177/1534735409360666.
5. Black, C. D., Herring, M. P., Hurley, D. J., & O'Connor, P. J. (2010). Ginger (*zingiber officinale*) reduces muscle pain caused by eccentric exercise. *The Journal of Pain*, 11(9), 894-903. DOI: 10.1016/j.jpain.2009.12.013.
6. Galbraith, S., Fagan, P., Dip, G., Perkins, P., Lynch, A., & Booth, S. (2010). Does the use of a handheld fan improve chronic dyspnea? A randomized controlled, crossover trial. *Journal of Pain and Symptom Management*, 39(5), 831-838. DOI: 10.1016/j.jpainsymman.2009.09.024.
7. Sprod, L. K. Palesh, O. G., Janelins, M. C., Pippone, L. J., Heckler, C. E., Adams, M. J., et al. (2010). Exercise, sleep quality, and mediators of sleep in breast and prostate cancer patients receiving radiation therapy. *Community Oncology*, 7(10), 463-471.
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11. King, K. (2010). A review of the effects of guided imagery on cancer patients with pain. *Complementary Health Practice Review*, 15(2), 98-107. DOI: 10.1177/1533210110388113.

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14. Integrative Health: A Holistic Approach for Health Professionals
  - Koopsen, C., & Young, C. (2009). NM: Jones & Bartlett Publishers. ISBN: 9780763757618. Website: <http://www.jbpub.com/catalog/9780763757618/>.
15. Nahin, R. L., Barnes, P. M., Stussman, B. J., & Bloom, B. (2009). Costs of complementary and alternative medicine (CAM) and frequency of visits to CAM practitioners: United States, 2007. *National Health Statistics Reports, 18*.
16. Integrative Oncology
  - Abrams, D. & Weil, A. (2009). NY: Oxford University Press. ISBN: 978-0195309447 Website: <http://www.oup.com/us/catalog/general/subject/Medicine/Oncology/?view=usa&ci=9780195309447>.
17. The Mindfulness Solution to Pain: Step-by-Step Techniques for Chronic Pain Management
  - Gardner-Nix, J., & Costin-Hall, L. (2009). CA: New Harbinger Publications. ISBN: 1572245815. Website: <http://www.newharbinger.com/productdetails.cfm?PC=715>.
18. Damos, D., Austerlitz, C., Allison, R. R., Pova, H., & Sibata, C. (2009). Nutrition and orthomolecular supplementation in lung cancer patients. *Integrative Cancer Therapies, 8*, 398-408. DOI: 10.1177/1534735409344333.
19. Greeson, J. M. (2009). Mindfulness research update: 2008. *Complementary Health Practice Review, 14*(1), 10-18. DOI: 10.1177/1533210108329862.
20. Battaglini, C. L., Hackney, A. C., Garcia, R., Groff, D., Evans, E., & Shea, T. (2009). The effects of an exercise program in leukemia patients. *Integrative Cancer Therapies, 8*(2), 130-138. DOI: 10.1177/1534735409334266.
21. Integrative Pain Medicine: The Science and Practice of Complementary and Alternative Medicine in Pain Management
  - Audett, J.F., & Bailey, A. (2008). NY: Humana Press. ISBN: 1588297861. Website: <http://www.springer.com/humana+press/book/978-1-58829-786-0?detailsPage=toc>.
22. Oxford Handbook of Complementary Medicine.
  - Ernst, E., Pittler, M. H., Wider, B., & Broddy, K. (2008). NY: Oxford University Press. ISBN: 978-0199206773 Website: <http://www.oup.com/us/catalog/general/subject/Medicine/PrimaryCare/?view=usa&ci=9780199206773>.
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28. Enhancing Cancer Care: Complementary Therapy and Support
  - Barraclough, J (Ed.). (2007). NY: Oxford University Press. ISBN: 978-0199297559
  - Website: <http://www.amazon.com/Enhancing-Cancer-Care-Complementary-Therapy/dp/019929755X>.
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33. Psychosocial Nursing Care Along the Cancer Continuum, 2<sup>nd</sup> Edition
  - Carroll-Johnson, R. M., Gorman, L. M., & Bush, N.J. (2006). PA: Oncology Nursing Society
  - 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, 3<sup>rd</sup> Edition
  - Webb, S. (2005). MA: Lippincott, Williams & Wilkins. ISBN: 158255417.
  - Website: <http://www.lww.com/product/?978-1-58255-417-4>.
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48. Women and Pain: Why It Hurts and What You Can Do
  - Young, M. & Baar, K. (2002). NY: Hyperion. ISBN: 078688679.
  - Especially Chapter 14: Foods That Heal, Chapter 15: Manual Muscle Strategies, Chapter 16: Natures Remedies, Chapter 17: Exercise for Relief and Prevention, Chapter 18: Mind-Body Therapies, Chapter 19: Acupuncture and Reflexology
  - Website: <http://karenbaar.com/work3.htm>.
49. Choices in Healing: Integrating the Best of Conventional Complementary Approaches to Cancer
  - Lerner, M. (1996). MA: The MIT Press. ISBN: 0262621045.
  - Website: <http://mitpress.mit.edu/catalog/item/default.asp?tid=3852&ttype=2>.

### **Educational Materials/Curriculum**

1. Academy for Guided Imagery
  - Interactive guided imagery self paced audio/video/DVD study course
  - Website: <http://www.academyforguidedimagery.com/>.
2. Coping Skills for Bone Marrow Transplantation and Relaxation and Imagery
  - This handbook identifies and explains coping skills for Bone Marrow Transplantation, including relaxation and imagery. The accompanying CD focuses on relaxation and imagery with a theme of increasing comfort during treatment. Website: <http://www.fhcrc.org/en/labs/clinical/projects/biobehavioral-sciences/patient-materials.html>.
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.
  - Website: <http://www.jblearning.com/catalog/9781284035834/>
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 has a listing of Dr. Siegel's articles and books and a blog post where he answers patients questions.
  - Website: <http://berniesiegelmd.com/>.
5. Fast Facts and Concepts -Palliative Care Network of Wisconsin (PCNOW)
 

For a complete listing of Fast Facts and Concepts see <http://www.mypcnow.org/#!fast-facts/c6xb>.

  - 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>

## **Other Organizational Links**

Academic Consortium for Complementary & Alternative Health Care	<a href="http://www.accahc.org/">http://www.accahc.org/</a>
Academy of Integrative Health & Medicine	<a href="http://aihm.org/">http://aihm.org/</a>
American Academy of Medical Acupuncture	<a href="http://www.medicalacupuncture.org/">http://www.medicalacupuncture.org/</a>
American Art Therapy Association	<a href="http://www.arttherapy.org/">http://www.arttherapy.org/</a>
American Holistic Nurses Association	<a href="http://www.ahna.org/">http://www.ahna.org/</a>
American Music Therapy Association	<a href="http://www.musictherapy.org">http://www.musictherapy.org</a>
Andrew Weil, MD: What is Integrative Medicine	<a href="http://www.drweil.com/drw/u/ART02054/Andrew-Weil-Integrative-Medicine.html">http://www.drweil.com/drw/u/ART02054/Andrew-Weil-Integrative-Medicine.html</a>
Arizona Center for Integrative Medicine	<a href="http://integrativemedicine.arizona.edu/">http://integrativemedicine.arizona.edu/</a>
Association for Applied and Therapeutic Humor	<a href="http://www.aath.org/">http://www.aath.org/</a>
Complementary and Alternative Medicine - American Cancer Society:	<a href="http://www.cancer.org/Treatment/TreatmentsandSideEffects/ComplementaryandAlternativeMedicine/index">http://www.cancer.org/Treatment/TreatmentsandSideEffects/ComplementaryandAlternativeMedicine/index</a>
Complementary and Alternative Medicine - Merck Manual:	<a href="http://www.merckmanuals.com/professional/sec22/ch330/ch330a.html">http://www.merckmanuals.com/professional/sec22/ch330/ch330a.html</a>
Healing Beyond Borders	<a href="http://www.healingtouchinternational.org/">http://www.healingtouchinternational.org/</a>
National Cancer Institute: Complementary and Alternative Medicine	<a href="http://www.cancer.gov/cancertopics/cam">http://www.cancer.gov/cancertopics/cam</a>
National Center for Complementary & Alternative Medicine	<a href="http://nccam.nih.gov">http://nccam.nih.gov</a>
NIH Senior Health Complementary Health Approaches	<a href="http://nihseniorhealth.gov/cam/toc.html">http://nihseniorhealth.gov/cam/toc.html</a>
Office of Cancer Complementary & Alternative Medicine	<a href="http://www.cancer.gov/cam/">http://www.cancer.gov/cam/</a>
Simonton Cancer Center	<a href="http://www.simontoncenter.com">http://www.simontoncenter.com</a>
The Center for Health & Healing	<a href="http://www.healthandhealingny.org/">http://www.healthandhealingny.org/</a>

## **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%20%20Alternative%20List.pdf>.
  - Music as Medicine Bibliography  
Website: [http://prc.coh.org/pdf/music\\_as\\_medicine\\_bib.pdf](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  
Website: <http://www.rn.ca.gov/pdfs/regulations/npr-b-28.pdf>.

3. Hospice and Palliative Nurses Associates (HPNA)
  - Complementary Therapies in Palliative Care Nursing Practice  
Website: <http://www.hpna.org/DisplayPage.aspx?Title1=Position%20Statements>

## 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

1. Sun, V., Grant, M., Koczywas, M., Freeman, B., Zachariah, F., Fujinami, R., Del Ferraro, C., Uman, G. & Ferrell, B. (2015). Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. *Cancer*. DOI: 10.1002/cncr.29567
2. Juarez, G., Branin, J., Rosales, M. (2014). The cancer caregiving experience of caregivers of Mexican Ancestry. *Hispanic Health Care International*, 12(3), 120-129. DOI: 10.1891/1540-4153.12.3.120.
3. Fujinami, R., Sun, V., Zachariah, F., Uman, G., Grant, M., & Ferrell, B. (2014). Family caregivers' distress levels related to quality of life, burden, and preparedness. *Psycho-Oncology*, Published online May 2014. DOI: 10.1002/pon.3562.
4. Hanson, J., Ferrell, B., & Grant, M. (2013). Website and Resources for Cancer Family Caregivers. *J Adv Pract Oncol* 4(4), 269-272.
5. Grant, M., Sun, V., Fujinami, R., Sidhu, R., Otis-Green, S., Juarez, G., Klein, L., & Ferrell, B. (2013). Family caregiver burden, skills preparedness, and quality of life in non-small cell lung cancer. *Oncology Nursing forum*, 40(4), 337-346. DOI: 10.1188/13.ONF.337-346.
6. Ferrell, B. R., Hanson, J., & Grant, M. G. (2012). An overview and evaluation of the oncology family caregiver project: improving quality of life and quality of care for oncology family caregivers. *Psycho-Oncology*, published online. DOI: 10.1002/pon.3198.
7. Fujinami, R., Otis-Green, S., Klein, L., Sidhu, R., and Ferrell, B. (2012). Quality of life of family caregivers and challenges faced in caring for patients with lung cancer. *Clinical Journal of Oncology Nursing*, 16(6), 615; E210-220:
8. Given, B., & Grant, M. (2012). Studies of caregivers of older patients needed. *Journal of Geriatric Oncology*, 3(4), 295-298. DOI: 10.1016/j.jgo.2012.07.007.
9. Grant, M., & Ferrell, B. R. (2012). Oncology family caregivers: Introduction. *Seminars in Oncology Nursing*, 28(4), 203-204. DOI: 10.1016/j.soncn.2012.09.001.
10. Grant, M., & Ferrell, B. R. (2012). Nursing Role Implications for Family Caregiving. *Seminars in Oncology Nursing*, 28(4), 279-282. DOI: 10.1016/j.soncn.2012.09.011.
11. Otis-Green, S., Juarez, G. (2012). Enhancing the social well-being of family caregivers. *Semin Oncol Nurs*, 28(4), 246-255. DOI: 10.1016/j.soncn.2012.09.007.
12. Wittenberg-Lyles, E., Demiris, G., Oliver, D. P., & Burt, S. (2011). Reciprocal suffering: Caregiver concerns during hospice care. *Journal of Pain and Symptom Management*, 41(2), 383-393. DOI: 10.1016/j.jpainsymman.2010.04.026.
13. Ferrell, B. R., Grant, M., Koczywas, M., Hurria, A., Loscalzo, M., Juarez, G., Otis-Green, S., Uman, G., & Borneman, T. (2011). Family caregiver QOL and self-care concerns in lung cancer. *CHEST Journal*, 140(4\_MeetingAbstracts), 1051A-1051A. DOI: 10.1378/chest.1114776.



14. Bevans, M., Castro, K., Prince, P., Shelburne, N., Prachenko, O., Loscalzo, M., et al. (2010). An individualized dyadic problem-solving education intervention for patients and family caregivers during allogeneic hematopoietic stem cell transplantation. *Cancer Nursing, 33*(2), e24-e32. DOI: 10.1097/NCC.0b013e3181be5e6d.
15. Cooke, L., Gemmill, R., Kravits, K., & Grant, M. (2009). Psychological issues of stem cell transplant. *Seminars in Oncology Nursing, 25*(2), 139-150. DOI: 10.1016/j.soncn.2009.03.008.
16. Juarez, G., Ferrell, B. R., Uman, G., Podnos, Y., & Wagman, L. D. (2008). Distress and quality of life concerns of family caregivers of patients undergoing palliative surgery. *Cancer Nursing, 31*(1), 2-10. DOI: 10.1097/01.NCC.0000305682.13766.c2.
17. Muñoz, C., Juarez, G., Muñoz, M. L., Portnow, J., Fineman, I., Badie, B., et al. (2008). The quality of life of patients with malignant gliomas and their caregivers. *Social Work in Health Care, 47*(4), 455-478. DOI: 10.1080/00981380802232396.
18. Morris, M. E., Grant, M., & Lynch, J. C. (2007). Patient-reported family distress among long-term cancer survivors. *Cancer Nursing, 30*(1), 1-8.
19. Borneman, T., Chu, D., Wagman, L., Ferrell, B. R., Juarez, G., McCahill, L., & Uman, G. (2003). Concerns of family caregivers of patients with cancer facing palliative surgery for advanced malignancies. *Oncology Nursing Forum, 30*(6), 997-1005.
20. Borneman, T., Stahl, C., Ferrell, B. R., Smith D. (2002). The concept of hope in family caregivers of cancer patients at home. *Journal of Hospice and Palliative Nursing, 4*(1), 21-33.
21. Ferrell, B. R., Ervin, K., Smith, S., Marek, T., Melancon, C. (2002). Family perspectives of ovarian cancer. *Cancer Practice, 10*(6), 269-276.
22. Ferrell, B. R. (2001). Pain observed: The experience of pain from the family caregiver's perspective. *Clinics in Geriatric Medicine, 17*(3), 595-609.

### **Recommended Publications**

1. Cure's 2014 Cancer Guide  
Website: <http://www.curetoday.com/publications/cure/2014/cancer-guide2014/Before-Treatment-Making-Sense-of-Cancer-Therapies>.
2. Principles and Practice of Palliative Care and Supportive Oncology, 4<sup>th</sup> Edition, esp. Part C #52 Caregiving in the Home  
- Berger, A. M., Shuster Jr., J. L., Von Roenn, J. H. (2012). MA: Lippincott Williams & Wilkins.  
ISBN: 978-1451121278.  
Website: <http://www.amazon.com/Principles-Practice-Palliative-Supportive-Oncology/dp/145112127X>.
3. What You Need to Know as a Cancer Caregiver  
- American Cancer Society. (2012). American Cancer Society.  
Website: <http://www.cancer.org/acs/groups/cid/documents/webcontent/acspc-027595-pdf.pdf>.
4. Given, B., Given, C., & Sherwood, P.. (2012). The challenge of quality cancer care for family caregivers. *Seminars in Oncology Nursing, 28*(4), 205-212.
5. Glajchen M. (2012). Physical well-being of oncology caregivers: An important quality-of-life domain. *Seminars in Oncology Nursing, 28*(4), 226-235.
6. Jayani, R, Hurria, Arti. (2012). Caregivers of older adults with cancer. *Seminars in Oncology Nursing, 28*(4), 221-225.
7. Jones, B. (2012). The challenge of quality care for family caregivers in pediatric cancer care. *Seminars in Oncology Nursing, 28*(4), 213-220.
8. Mazanec, P. (2012). Distance caregiving a parent with cancer. *Seminars in Oncology Nursing, 28*(4), 271-278.
9. Northouse, L, Katapodi, M, Schafenacker, A, Weiss, D. (2012). The impact of caregiving on the psychological well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing, 28*(4), 236-245.

10. Oxford Textbook of Palliative Social Work
  - Altilio, T. & Otis-Green, S. (2011) NY: Oxford University Press. ISBN: 978-0199739110.
  - 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

Website:  
<http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199739110>.
11. Help Wanted: Caregiver
  - Pinchot, L. J. (2011). PA: Oncology Nursing Society. ISBN: 978-1890504977
  - Website: <http://esource.ons.org/ProductDetails.aspx?SKU=INPU0606>.
12. American Cancer Society Complete Guide to Family Caregiving: The Essential Guide to Cancer Caregiving at Home, 2<sup>nd</sup> Ed.
  - Bucher, J. A., Houts, P. S., & Ades, T. (Eds). (2011). Atlanta, GA: American Cancer Society. ISBN: 978-0944235003.
  - Website: <http://www.amazon.com/American-Cancer-Society-Complete-Caregiving/dp/094423500X>.
13. Handbook for Mortals, 2<sup>nd</sup> Edition
  - Lynn, J. & Harrold, J. (2011). NY: Oxford University Press. ISBN: 0195116623.
  - Website: <http://www.oup.com/us/catalog/general/subject/Psychology/Health/?view=usa&ci=9780195146011>
14. A Caregiver's Guide to the Dying Process
  - Hospice Foundation of America. (2011).
  - Website: [http://hospicefoundation.org/hfa/media/Files/Hospice\\_TheDyingProcess\\_Docutech-READERSPREADS.pdf](http://hospicefoundation.org/hfa/media/Files/Hospice_TheDyingProcess_Docutech-READERSPREADS.pdf)
15. Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., Mood, D. W. (2010). Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians*, 60(5), 317-339. DOI: 10.3322/caac.20081.
16. Burns, C. M., LeBlanc, T. W., Abernethy, A., & Currow, D. (2010). Young caregivers in the end-of-life setting: A population-based profile of an emerging group. *Journal of Palliative Medicine*, 13(10), 1225-1235. DOI: 10.1089/jpm.2010.0004.
17. Blum, K., & Sherman, D. W. (2010). Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing*, 26(4), 243-258. DOI: 10.1016/j.soncn.2010.08.005.
18. Francis, L. E., Worthington, J., Kypriotakis, G., Rose, J. H. (2010). Relationship quality and burden among caregivers for late-stage cancer patients. *Support Care Cancer*, 18, 1429-1436. DOI: 10.1007/s00520-009-0765-5.
19. Northfield, S., & Nebauer, M. (2010). The caregiving journey for family members or relatives with cancer: How do they cope? *Clinical Journal of Oncology Nursing*, 14(5), 567-577. DOI: 10.1188/10.CJON.567-577.
20. Foster, T. L., Lafond, D. A., Reggio, C., & Hinds, P. S. (2010). Pediatric palliative care in childhood cancer nursing: From diagnosis to cure or end of life. *Seminars in Oncology Nursing*, 26(4), 205-221. DOI: 10.1016/j.soncn.2010.08.003.
21. Oliver, D. P., Demiris, G., Wittenberg-Lyles, E., Porock, D., Collier, J., & Arthur, A. (2010). Caregiver participation in hospice interdisciplinary team meetings via videophone technology: A pilot study to improve pain management. *American Journal of Hospice and Palliative Medicine*, 27(7), 465-473. DOI: 10.1177/1049909110362402.
22. Reflections of a Loving Partner: Caregiving at the End of Life
  - Martin, C. A. (2010). Naples, FL: Quality of Life Publishing Co. ISBN: 978-0981621937
  - Website: <http://www.amazon.com/Reflections-Loving-Partner-Caregiving-Life/dp/0981621937>.
23. Dying with Comfort: Family Illness Narratives and Early Palliative Care
  - Wittenberg-Lyles, E., Goldsmith, J., Ragan, S. L., & Sanchez-Reilly, S. (2010). NJ: Hampton Press. ISBN: 1572739843.
  - Website: [http://www.hamptonpress.com/Merchant2/merchant.mvc?Screen=PROD&Product\\_Code=978-1-57273-985-7](http://www.hamptonpress.com/Merchant2/merchant.mvc?Screen=PROD&Product_Code=978-1-57273-985-7).

24. The Survivorship Net: A Parable for the Family, Friends, and Caregivers of People with Cancer
  - Owens, J. Cass, B. (2010). GA: American Cancer Society. ISBN: 978-1604430189.  
Website: <http://www.amazon.com/Survivorship-Net-Parable-Friends-Caregivers/dp/1604430184>.
25. Passages in Caregiving: Turning Chaos into Confidence
  - Sheehy, G. (2010). NY: HarperCollins Publishers. ISBN: 978-0061661204.  
Website: <http://www.amazon.com>
26. Oxford Textbook of Palliative Nursing
  - Ferrell, B. R., Coyle, N., & Paice, J., (2015). NY: Oxford University Press. ISBN: 9780199332342.  
Section I: Principles of Patient and Family Assessment  
Section III: Supporting Families in Palliative Care  
Website:  
<http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199332342>.
27. The Caregiver's Path to Compassionate Decision Making: Making Choices for Those Who Can't
  - Kind, V. (2010). TX: Greenleaf Book Group. ISBN: 978-1608320417.  
Website: <http://www.amazon.com/Caregivers-Path-Compassionate-Decision-Making/dp/1608320413>.
28. Cancer Journey: A Caregiver's View From the Passenger Seat
  - Siegfried, C. Z. (2010). WA: Pleasant Word. ISBN: 978-1414115498  
Website: <http://www.caregivercancerjourney.com/>.
29. Harden, J., Falahee, M., Bickes, J., Schafenacker, A., Walker, J., Mood, D., & Northouse, L. (2009). Factors associated with prostate cancer patients' and their spouses' satisfaction with a family-based intervention. *Cancer Nursing*, 32(6), 482-492. DOI: 10.1097/NCC.0b013e3181b311e9.
30. Hinds, P. S., Oakes, L. L., Hicks, J., Powell, B., Srivastava, D. K., Spunt, S. L., et al. (2009). "Trying to be a good parent" as defined by interviews with parents who made phase I, terminal care, and resuscitation decisions for their children. *Journal of Clinical Oncology*, 27(35), 5979-5985. DOI: 10.1200/JCO.2008.20.0204.
31. Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009). Content validity and satisfaction with a stroke caregiver intervention program. *Journal of Nursing Scholarship*, 41(4), 368-375. DOI: 10.1111/j.1547-5069.2009.01282.x.
32. Bradley, S. E., Sherwood, P. R., Kuo, J., Dammerer, C. M., Gettig, E. A., Ren, D., et al. (2009). Perceptions of economic hardship and emotional health in a pilot sample of family caregivers. *Journal of Neurooncology*, 93(3), 333-342. DOI: 10.1007/s11060-008-9778-z.
33. Family Carers in Palliative Care: A Guide for Health and Social Care Professionals
  - Hudson, P. & Payne, S. (2009). NY: Oxford University Press. ISBN: 0199216908.  
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/>.
35. Harden, J., Northouse, L., Cimprich, B., Pohl, J. M., Liang, J., & Kershaw, T. (2008). The influence of developmental life stage on quality of life in survivors of prostate cancer and their partners. *Journal of Cancer Survivorship*, 2(2), 84-94. DOI: 10.1007/s11764-008-0048-z.
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37. Honea, N. J., Brintnall, R., Given, B., Sherwood, P., Colao, D. B., Somers, S. C., & Northouse, L. L. (2008). Putting evidence into practice: Nursing assessment and interventions to reduce family caregiver strain and burden. *Clinical Journal of Oncology Nursing, 12*(3), 507-516. DOI: 10.1188/08.CJON.507-516.
38. Supporting Family Caregivers
  - American Journal of Nursing. (2008). 108(9-Suppl). Entire issue devoted to family caregiver issues. Website: <http://journals.lww.com/ajnonline/toc/2008/09001>.
39. Cancer Caregiving A-to-Z: An At-Home Guide for Patients and Families
  - American Cancer Society (2008). GA: American Cancer Society. ISBN: 978-0944235928. Website: <http://www.amazon.com/Cancer-Caregiving-Z-Patients-Families/dp/0944235921>.
40. Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework
  - Centers for Disease Control & Prevention. (2008). GA: Self published. Website: <http://www.cdc.gov/aging/caregiving/assuring.htm>.
41. Kwak, J., Salmon, J. R., Acquaviva, K. D., Brandt, K., & Egan, K. A. (2007). Benefits of training family caregivers on experiences of closure during end-of-life care. *Journal of Pain and Symptom Management, 33*(4), 434-445. DOI: 10.1016/j.jpainsymman.2006.11.006.
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43. Northouse, L. L., Mood, D. W., Schafenacker, A., Montie, J. E., Sandler, H. M., Forman, J. D., et al. (2007). Randomized clinical trial of a family intervention for prostate cancer patients and their spouses. *CANCER, 110*(12), 2809-2818. DOI: 10.1002/cncr.23114.
44. A Family Caregiver Speaks Up: It Doesn't Have to Be This Hard
  - Mintz, S. G. (2007). VA: Capital Books, Inc. ISBN: 978-1933102467. Website: <http://www.amazon.com/Family-Caregiver-Speaks-Up-Capital/dp/1933102462>.
45. Sherwood, P. R., Given, B. A., Given C. W., Schiffman, R. F., Murman, D. L., Lovely, M., et al. (2006). Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Research in Nursing & Health, 29*, 105-120. DOI: 10.1002/nur.20116.
46. Schumacher, K. L., Beidler, S. M., Beeber, A. S., Gambino, P. (2006). A transactional model of cancer family caregiving skill. *Advances in Nursing Science, 29*(3), 271-286.
47. Kim, Y., Loscalzo, M. J., Wellisch, D. K., & Spillers, R. L. (2006). Gender differences in caregiving stress among caregivers of cancer survivors. *Psycho-Oncology, 15*, 1086-1092. DOI: 10.1002/pon.1049.
48. Lewis, F. M. (2006). The effects of cancer survivorship on families and caregivers. *American Journal of Nursing, 106*(3-Suppl), 20-21, 23-25.
49. Given, B. & Sherwood, P. R. (2006). Family care for the older person with cancer. *Seminars in Oncology Nursing, 22*(1), 43-50. DOI: 10.1016/j.soncn.2005.10.006.
50. Given, B., Given, C. W., Sirorskii, A., Jeon, S., Sherwood, P., & Rahbar, M. (2006). The impact of providing symptom management assistance on caregiver reaction: Results of a randomized trial. *Journal of Pain and Symptom Management, 32*(5), 433-443. DOI:10.1016/j.jpainsymman.2006.05.019.
51. The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent
  - Jacobs, B. J. (2006). NY: The Guilford Press. ISBN: 978-1572307292. Website: [http://www.guilford.com/cgi-bin/cartscript.cgi?page=pr/jacobs.htm&dir=pp/gg&cart\\_id=997317.27682](http://www.guilford.com/cgi-bin/cartscript.cgi?page=pr/jacobs.htm&dir=pp/gg&cart_id=997317.27682).
52. Northouse, L. L. (2005). Helping families of patients with cancer. *Oncology Nursing Forum, 32*(4), 743-750. DOI: 10.1188/05.ONF.743-750.

53. Glajchen, M., Kornblith, A., Homel, P., Fraidin, L, Mauskop, A., & Portenoy, R. K. (2005). Development of a brief assessment scale for caregivers of the medically ill. *Journal of Pain and Symptom Management, 29*(3), 245-254. DOI: 10.1016/j.jpainsymman.2004.06.017.
54. Sherwood, P. R., Given, C. W., Given, B. A., von Eye, A. (2005). Caregiver burden and depressive symptoms: Analysis of common outcomes in caregivers of elderly patients. *Journal of Aging and Health, 17*(2), 125-147. DOI: 10.1177/0898264304274179.
55. Salmon, J. R., Kwak, J., Acquaviva, K. D., Egan, K. A., Brandt, K. (2005). Validation of the caregiving at life's end questionnaire. *American Journal of Hospice & Palliative Medicine, 22*(3), 188-194. DOI: 10.1177/104990910502200307.
56. When the Focus Is on Care
  - Foley, K. M., Back, A., Bruera, E., Coyle, N., Loscalzo, M. J., Shuster, J. L., Teschendorf, B., & von Roenn, J. H. (Eds.) (2004). GA: American Cancer Society ISBN: 978-0944235539. Website: <http://www.amazon.com>.
57. Breast Cancer Husband How to Help Your Wife (and Yourself) Through Diagnosis, Treatment, and Beyond Silver, M. (2004). PA: Rodale Inc. ISBN: 978-1579548339. Website: <http://www.amazon.com>
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59. Glajchen, M. (2004). The emerging role and needs of family caregivers in cancer care. *Journal of Supportive Oncology, 2*(2), 145-155. .
60. Williams, R., Hinds, P. S., Ke, W., & Hu, X. J. (2004). A comparison of calorie and protein intake in hospitalized pediatric oncology patients dining with a caregiver versus patients dining alone: A randomized, prospective clinical trial. *Journal of Pediatric Oncology Nursing, 21*(4), 223-232. DOI: 10.1177/1043454204265861.
61. Haley, W. E. (2003). Family caregivers of elderly patients with cancer: Understanding and minimizing the burdens of care. *Supportive Oncology, 12*( Supp.), 25-29.
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
  - McLeod, B. W. (2000). NY: John Wiley & Sons, Inc. ISBN: 978-0471392170. Website: <http://www.amazon.com>.
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### **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 Website: [http://www.rosalynncarter.org/UserFiles/File/RCI\\_Position\\_Paper100310\\_Final.pdf](http://www.rosalynncarter.org/UserFiles/File/RCI_Position_Paper100310_Final.pdf).

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)  
For a complete listing of Fast Facts and Concepts see <http://www.mypcnw.org/#!fast-facts/c6xb>.
  - 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, 2<sup>nd</sup> 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, 2<sup>nd</sup> 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, 2<sup>nd</sup> 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.helpforcancer caregivers.org/>.
7. Home Alone: Family Caregivers Providing Complex Chronic Care
  - Reinhard, S., Levine, C., & Samis, S. (2012). AARP and United Hospital Fund.  
Website: <http://www.uhfnyc.org/publications/880853>.
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](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
  - National Association of Social Workers  
Website: <http://www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf>.

### **Other Organizational Links**

Aging Parents and Elder Care	<a href="http://www.aging-parents-and-elder-care.com/">http://www.aging-parents-and-elder-care.com/</a>
AARP: Caregiving Resource Center	<a href="http://www.aarp.org/relationships/caregiving-resource-center/">http://www.aarp.org/relationships/caregiving-resource-center/</a>
AARP: Valuing the Invaluable: The Economic Value of Family Caregiving	<a href="http://www.aarp.org/relationships/caregiving/info-11-2008/i13_caregiving.html">http://www.aarp.org/relationships/caregiving/info-11-2008/i13_caregiving.html</a>

American Cancer Society (ACS): Caring for the Patient with Cancer at Home	<a href="http://www.cancer.org">http://www.cancer.org</a> <a href="http://www.cancer.org/acs/groups/cid/documents/webcontent/002818-pdf.pdf">http://www.cancer.org/acs/groups/cid/documents/webcontent/002818-pdf.pdf</a>
Listen with Your Heart	<a href="http://www.cancer.org/Treatment/UnderstandingYourDiagnosis/TalkingaboutCancer/ListenwithYourHeart/index">http://www.cancer.org/Treatment/UnderstandingYourDiagnosis/TalkingaboutCancer/ListenwithYourHeart/index</a>
American Chronic Pain Association	<a href="http://theacpa.org/">http://theacpa.org/</a>
American College of Physicians Ethics, Professionalism and Human Rights Committee: Information Resources for Physicians Supporting Family Caregivers	<a href="http://www.acponline.org/running_practice/ethics/issues/policy/caregivers_appendix.pdf">http://www.acponline.org/running_practice/ethics/issues/policy/caregivers_appendix.pdf</a>
Assisted Living Directory	<a href="http://www.assisted-living-directory.com/">http://www.assisted-living-directory.com/</a>
Be the Match: Bone Marrow Donor	<a href="http://www.marrow.org/">http://www.marrow.org/</a>
CANCER <i>Care</i> Caregiving	<a href="http://www.cancercare.org/">http://www.cancercare.org/</a> <a href="http://www.cancercare.org/tagged/caregiving">http://www.cancercare.org/tagged/caregiving</a>
Cancer Hope Network	<a href="http://www.cancerhopenetwork.org/">http://www.cancerhopenetwork.org/</a>
Cancer.Net: Caregiver Support	<a href="http://www.cancer.net/coping/caregiving">http://www.cancer.net/coping/caregiving</a>
Cancer Support Community Frankly Speaking About Cancer	<a href="http://www.cancersupportcommunity.org/">http://www.cancersupportcommunity.org/</a> <a href="http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Frankly-Speaking-About-Cancer">http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Frankly-Speaking-About-Cancer</a>
Caregiver Action Network	<a href="http://caregiveraction.org/">http://caregiveraction.org/</a>
Caregiving.com	<a href="http://www.caregiving.com">http://www.caregiving.com</a>
Caregiver Resource Center	<a href="http://www.aarp.org/home-family/caregiving/">http://www.aarp.org/home-family/caregiving/</a>
Caring.com	<a href="http://www.caring.com/">http://www.caring.com/</a>
Families Facing Cancer: Emotional & Practical Support	<a href="http://familiesfacingcancer.org/">http://familiesfacingcancer.org/</a>
Family Caregiver Alliance	<a href="http://www.caregiver.org/caregiver/jsp/home.jsp">http://www.caregiver.org/caregiver/jsp/home.jsp</a>
Family Caregiver Support Network	<a href="http://www.caregiversupportnetwork.org/default.asp?id=1">http://www.caregiversupportnetwork.org/default.asp?id=1</a>
Full Circle of Care	<a href="http://www.fullcirclecare.org/">http://www.fullcirclecare.org/</a>
International Palliative Care Family Carer Research Collaboration	<a href="http://www.centreforpallcare.org/index.php/research/ipcfrc/">http://www.centreforpallcare.org/index.php/research/ipcfrc/</a>
Joe's House: A Lodging Guide for Cancer Patients	<a href="http://www.joeshouse.org/">http://www.joeshouse.org/</a>
Leukemia & Lymphoma Society: Long-Distance Caregiving Caregivers' Guide for Bone Marrow/Stem Cell Transplant: Practical Perspective	<a href="http://www.lls.org/diseaseinformation/forcaregivers/longdistancecaregiving/">http://www.lls.org/diseaseinformation/forcaregivers/longdistancecaregiving/</a> <a href="http://www.lls.org/resourcecenter/suggestedreading/adultpatientcaregivers/caregiving/caregiversguideforbonemarrow">http://www.lls.org/resourcecenter/suggestedreading/adultpatientcaregivers/caregiving/caregiversguideforbonemarrow</a>
Lotsa Helping Hands	<a href="http://www.lotsahelpinghands.com/">http://www.lotsahelpinghands.com/</a>
National Alliance for Caregiving	<a href="http://www.caregiving.org/">http://www.caregiving.org/</a>
National Cancer Institute:	
· Caring for the Caregiver booklet	<a href="http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver.pdf">http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver.pdf</a>
· Coping with Cancer: For Caregivers, Family, Friends	<a href="http://www.cancer.gov/cancertopics/coping/familyfriends">http://www.cancer.gov/cancertopics/coping/familyfriends</a>
· Deep Water: Making Sense of a Cancer Diagnosis (YouTube)	<a href="http://www.cancer.gov/cancertopics/coping/life-after-treatment">http://www.cancer.gov/cancertopics/coping/life-after-treatment</a>
· Facing Forward: Life After Cancer Treatment	<a href="http://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq">http://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq</a>
· Family Caregivers in Cancer: Roles & Challenges	

· Factors to Consider in Caregiver Assessment	<a href="http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/HealthProfessional/page6">http://www.cancer.gov/cancertopics/pdq/supportivecare/caregivers/HealthProfessional/page6</a>
· When Someone You Love Has Advanced Cancer	<a href="http://www.cancer.gov/cancertopics/coping/when-someone-you-love-has-advanced-cancer">http://www.cancer.gov/cancertopics/coping/when-someone-you-love-has-advanced-cancer</a>
· When Someone You Love Has Completed Cancer Treatment	<a href="http://www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment.pdf">http://www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment.pdf</a>
· When Someone You Love Is Being Treated for Cancer	<a href="http://www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated">http://www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated</a>
· Caring for the Caregiver	<a href="http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver">http://www.cancer.gov/cancertopics/coping/caring-for-the-caregiver</a>
National Comprehensive Cancer Network (NCCN) Patient and Caregiver Resources	<a href="http://www.nccn.com/">http://www.nccn.com/</a> <a href="http://www.nccn.org/patients/resources/default.aspx">http://www.nccn.org/patients/resources/default.aspx</a>
Navigating Cancer and Blood Disorders	<a href="http://www.navigatingcancer.com/">http://www.navigatingcancer.com/</a>
Patient Resource Net Patient Resource Cancer Guide	<a href="http://www.patientresource.net">http://www.patientresource.net</a> <a href="http://www.patientresource.net/Cancer_Guides.aspx">http://www.patientresource.net/Cancer_Guides.aspx</a>
Resources and Links for Patients and Families	<a href="http://www.aosw.org/AOSW/AOSWMain/People-Affected-by-Cancer/resources-and-links.aspx">www.aosw.org/AOSW/AOSWMain/People-Affected-by-Cancer/resources-and-links.aspx</a>
Rosalynn Carter Institute for Caregiving	<a href="http://www.rosalynncarter.org/">http://www.rosalynncarter.org/</a>
Today's Caregiver	<a href="http://www.caregiver.com">http://www.caregiver.com</a>
Well Spouse Association	<a href="http://www.wellspouse.org/">http://www.wellspouse.org/</a>

## **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](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  
Website: <http://www.mdanderson.org/patient-and-cancer-information/care-centers-and-clinics/childrens-cancer-hospital/family-centered-care/index.html>.  
- Patient and Caregiver Support Line  
Website: <http://www.mdanderson.org/patient-and-cancer-information/guide-to-md-anderson/patient-and-family-support/anderson-network/cancer-support-programs/request-support.html>  
- Patient and Family Support  
Website: <http://www.mdanderson.org/patient-and-cancer-information/guide-to-md-anderson/patient-and-family-support/index.html>



4. Memorial Sloan-Kettering Cancer Center – New York, New York  
 Website: <http://www.mskcc.org/mskcc/html/44.cfm>
  - Counseling & Support for Caregivers & Families  
 Website: <http://www.mskcc.org/cancer-care/counseling-support/caregivers-families>
  - A Guide for Caregivers  
 Website: [http://www.mskcc.org/patient\\_education/\\_assets/downloads-english/353.pdf](http://www.mskcc.org/patient_education/_assets/downloads-english/353.pdf)
  
5. Norris Cotton Cancer Center – Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire  
 Website: <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/>
  - Patient and Caregiver Support Groups  
 Website: <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/>
  - Role of Caregivers  
 Website: <https://www.roswellpark.org/media/audio/role-caregivers-s-sharcot>
  - BMT Orientation and Caregiver Program  
 Website: <http://www.roswellpark.org/specialized-services/bmt/patient-information/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  
 Website: [http://www.hopkinsmedicine.org/kimmel\\_cancer\\_center/patient\\_information/videos/caregivers.html](http://www.hopkinsmedicine.org/kimmel_cancer_center/patient_information/videos/caregivers.html)
  
9. University of Michigan Comprehensive Cancer Center – Ann Arbor, Michigan  
 Website: <http://mcancer.org/>
  - Thrive: Focusing on the Caregiver  
 Website: <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>
  - Caregivers benefit from cancer support programs  
 Website: [http://www.cancer.med.umich.edu/news/hm\\_cancerdistress.shtml](http://www.cancer.med.umich.edu/news/hm_cancerdistress.shtml)
  
10. UW Carbone Cancer Center – University of Wisconsin, Madison, Wisconsin  
 Website: <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.osher.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/cancercaresymptoms/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

1. Dale, W., Mohile, S., Eldadah, B., Trimble, E., Schilsky, R., Cohen, H., Muss, H., Schmader, K., Ferrell, B. R., Extermann, M., Nayfield, S., & Hurria, A. (2012). Biological, clinical, and psychosocial correlates at the Interface of Cancer and Aging Research. *The Journal of the National Cancer Institute, 104*(8), 581-589. DOI: 10.1093/jnci/djs145.
2. Kelly, K., Thrane, S., Virani, R., Malloy, P., & Ferrell, B. R. (2011). Expanding palliative care nursing education in California: The ELNEC geriatric project. *International Journal of Palliative Nursing, 17*(4), 188-194.
3. Borneman, T., Koczywas, M., Sun, V., Piper, B.F., Uman, G., Ferrell, B.R. (2010). Reducing patient barriers to pain and fatigue management. *Journal of Pain and Symptom Management, 39*(3), 486-501. DOI:10.1016/j.jpainsymman.2009.08.007.
4. Kelly, K., Ersek, M., Virani, R., Malloy, P., & Ferrell, B. R. (2008). End-of-life nursing education consortium geriatric training program improving palliative care in community geriatric care settings. *Journal of Gerontological Nursing, 34*(5), 28-35.

#### Recommended Publications

1. Geriatric Palliative Care
  - Goldhirsch, S., & Chai, E., Meier, D, & Jane Morris. (2014). NY: Oxford University Press. ISBN: 019538931X.  
Website: <http://www.Amazon.com>
2. Jablonski, A. M., DuPen, A. R., & Ersek, M (2011). The use of algorithms in assessing and managing persistent pain in older adults, *American Journal of Nursing, 111*(3), 34-43. DOI: 10.1097/10.1097/01.NAJ.0000395239.60981.2f.
3. Herr, K., Coyne, P. J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. *Pain Management Nursing, 12*(4), 230-250. DOI: 10.1016/j.pmn,2011.10.002.
4. Strohbuecker, B., Eisenmann, Y., Galushko, M., Montage, T., & Voltz, R. (2011). Palliative care needs of chronically ill nursing home residents in Germany: Focusing on living, not dying. *International Journal of Palliative Nursing, 17*(1), 27-34.
5. Evidence-Based Geriatric Nursing Protocols for Best Practice, 4<sup>th</sup> Edition
  - Boltz, M., Capezuti, E. Fulmer, T., Zwicker, D., & O'Meara, A. (2011). NY: Springer Publishing Company. ISBN: 0826171281. Website: <http://www.amazon.com>.

6. McCleane, G. (2010). Pain management in older people. *Reviews in Clinical Gerontology, 20*, 183-192. DOI: 10.1017/S0959259810000146.
7. Ersek, M., Herr, K., Neradilek, M. B., Buck, H. G., & Black, B. (2010). Comparing the psychometric properties of the Checklist of Nonverbal Pain Behaviors (CNPI) and the Pain Assessment of Advanced Dementia (PAIN-AD) instruments. *Pain Medicine, 11*(3), 395-404. DOI: 10.1111/j.1526-4637.2009.00787.x.
8. Herr, K., Bursch, H., Ersek, M., Miller, L. L., & Swafford, K. (2010). Use of pain-behavioral assessment tools in the nursing home: Expert consensus recommendations for practice. *Journal of Gerontological Nursing, 36*(3), 18-29. DOI: 10.3928/00989134-20100108-04.
9. Coker, E., Papaioannou, A., Kaasalainen, S., Dolovich, L., Turpie, I., & Taniguchi, A. (2010). Nurses' perceived barriers to optimal pain management in older adults on acute medical units. *Applied Nursing Research, 23*, 139-146. DOI: 10.1016/j.apnr.2008.07.003.
10. Kaye, A. D., Baluch, A., & Scott, J. T. (2010). Pain management in the elderly population: A review. *The Ochsner Journal, 10*(3), 179-187.
11. Arnstein, P. (2010). Balancing analgesic efficacy with safety concerns in the older patient. *Pain Management Nursing, 11*(2, Suppl 1), S11-S22. DOI:10.1016/j.pmn.2010.03.003.
12. Herr, K. (2010). Pain in the older adult: An imperative across all health care settings. *Pain Management Nursing, 11*(2), S1-S10. DOI: 10.1016/j.pmn.2010.03.005.
13. Bruckenthal, P. (2010). Integrating nonpharmacologic and alternative strategies into a comprehensive management approach for older adults with pain. *Pain Management Nursing, 11*(2), S23-S31. DOI: 10.1016/j.pmn.2010.03.004
14. Wood, B. M., Nicholas, M. K., Blyth, F., Asghari, A., & Gibson, S. (2010). Assessing pain in older people with persistent pain: The NRS is valued but only provides part of the picture. *The Journal of Pain, 11*(12), 1259-1266. DOI: 10.1016/j.jpain.2010.02.025.
15. Takai, Y., Yamamoto-Mitani, N., Okamoto, Y., Koyama, K., & Honda, A. (2010). Literature review of pain prevalence among older residents of nursing homes. *Pain Management Nursing, 11*(4), 209-223. DOI: 10.1016/j.pmn.2010.08.006.
16. Gianni, W., Ceci, M., Bustacchini, S., Corsonello, A., Abbatecola, A. M., Brancati, A. M., et al. (2009). Opioids for the treatment of chronic non-cancer pain in older people. *Drugs & Aging, 26* (Suppl 1), 63-73. DOI: 10.2165/11534670-000000000-00000.
17. McKendrick, M. W., Ogan, P., & Care, C. C. (2009). A 9-year follow-up of post herpetic neuralgia and predisposing factors in elderly patients following herpes zoster. *The British Infection Society, 59*, 416-421. DOI:10.1016/j.jinf.2009.09.008
18. American Geriatrics Society Panel on the Pharmacological Management of Persistent Pain in Older Persons (2009). Pharmacological management of persistent pain in older persons. *Journal of American Geriatrics Society, 57*, 1331-1346. DOI: 10.1111/j.1532-5415.2009.02376.x. Website: [http://www.americangeriatrics.org/files/documents/2009\\_Guideline.pdf](http://www.americangeriatrics.org/files/documents/2009_Guideline.pdf).
19. Pain Management for Older Adults, A Self Help Guide  
- Hadjistavropoulos, T., & Hadjistavropoulos, H. D. (2008). WA: IASP Press. ISBN: 931092701.  
Website: [http://ebooks.iasp-pain.org/pain\\_management\\_for\\_older\\_adults/](http://ebooks.iasp-pain.org/pain_management_for_older_adults/).
20. D'Arcy, Y. (2008). Pain in the older adult. *The Nurse Practitioner, 33*(3), 18-24. DOI: 10.1097/01.NPR.0000312997.00834.ce.
21. Blyth, F. M., Rochat, S., Cumming, R. G., Creasey, H., Handelsman, D. J. Le Couteur, D. G., et al. (2008). Pain, frailty and comorbidity on older men: The CHAMP study. *Pain, 140*, 224-230. DOI:10.1016/j.pain.2008.08.011.
22. Cann, P. (2008). Pain in older adults should not be seen as part of ageing. *British Journal of Community Nursing, 13*(12), 574-576.

23. Pain in Older People
  - Crome, P., Lally, F., & Main, C. J. (2008). Oxford University Press. ISBN: 0199212619.  
Website: <http://www.amazon.com/>.
24. Pain Management for Older Adults, A Self Help Guide
  - Hadjistavropoulos, T., & Hadjistavropoulos, H. D. (2008). WA: IASP Press. ISBN: 931092701  
Website: <http://www.amazon.com/PAIN-MANAGEMENT-FOR-OLDER-ADULTS/dp/0931092701>

### **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/>.
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%209-09.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.  
Website: <http://www.amda.com/tools/cpg/chronicpain.cfm>.
2. The Management of Persistent Pain in Older Persons
  - Clinical Practice Guidelines from the American Geriatrics Society.  
Download guidelines at [http://www.americangeriatrics.org/products/positionpapers/persistent\\_pain\\_guide.shtml](http://www.americangeriatrics.org/products/positionpapers/persistent_pain_guide.shtml).
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>
  - Overview, Criteria for Evaluation, Comparison Grid, Comparison of Tool Items with AGS 2002 Persistent Pain Guidelines, Review References
  - Abbey Pain Scale (Abbey) (Abbey J, et al.)
  - Assessment of Discomfort in Dementia (ADD) Protocol, (Kovach, C.R., 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)	<a href="http://www.aarp.org">http://www.aarp.org</a>
Administration on Aging	<a href="http://www.aoa.gov/">http://www.aoa.gov/</a>
Advancing Excellence in America's Nursing Homes	<a href="http://www.nhqualitycampaign.org/">http://www.nhqualitycampaign.org/</a>
AgingCare.com: Connecting caregivers	<a href="http://www.agingcare.com/">http://www.agingcare.com/</a>
Aging with Dignity	<a href="http://www.agingwithdignity.org">http://www.agingwithdignity.org</a>
Aging Parents and Elder Care	<a href="http://www.aging-parents-and-elder-care.com/">http://www.aging-parents-and-elder-care.com/</a>
Alzheimer's Association	<a href="http://www.alz.org/">http://www.alz.org/</a>
Alzheimer's Disease Education & Referral (ADEAR)	<a href="http://www.nia.nih.gov/alzheimers">http://www.nia.nih.gov/alzheimers</a>
American Assisted Living Nurses Association	<a href="http://www.alnursing.org/">http://www.alnursing.org/</a>
American Association for Long Term Care Nursing	<a href="http://ltcnursing.org/">http://ltcnursing.org/</a>
American Chronic Pain Association	<a href="http://www.theacpa.org/">http://www.theacpa.org/</a>
American Geriatrics Society	<a href="http://www.americangeriatrics.org">http://www.americangeriatrics.org</a>
American Society on Aging	<a href="http://www.asaging.org">http://www.asaging.org</a>
Care Force: Excellence in Care Management	<a href="http://www.careforce.com/">http://www.careforce.com/</a>
Caregiver Action Network	<a href="http://www.caregiveraction.org/">http://www.caregiveraction.org/</a>
Caregiving.com	<a href="http://caregiving.com/">http://caregiving.com/</a>
Caring.com	<a href="http://www.caring.com/">http://www.caring.com/</a>
Clinical Geriatrics	<a href="http://www.clinicalgeriatrics.com">http://www.clinicalgeriatrics.com</a>
Geriatric Pain	<a href="http://www.geriatricpain.org/Pages/home.aspx">http://www.geriatricpain.org/Pages/home.aspx</a>
GerIPal: A Geriatrics and Palliative Care Blog	<a href="http://www.geripal.org/">http://www.geripal.org/</a>
Gerontological Advanced Practice Nurses Association	<a href="https://www.gapna.org/">https://www.gapna.org/</a>
Gerontological Society of America	<a href="http://www.geron.org/">http://www.geron.org/</a>
In the Face of Pain	<a href="http://inthefaceofpain.com/">http://inthefaceofpain.com/</a>
Long Term Care Planning Network	<a href="http://www.ltclplanningnetwork.com/">http://www.ltclplanningnetwork.com/</a>
MISS Foundation: A Community for Grieving Families	<a href="http://www.missfoundation.org/index.html">http://www.missfoundation.org/index.html</a>
National Association Directors of Nursing Administration in Long Term Care	<a href="http://nadona.org/">http://nadona.org/</a>
National Gerontological Nursing Association	<a href="http://www.ngna.org/">http://www.ngna.org/</a>
National Institute on Aging	<a href="http://www.nih.gov/nia/">http://www.nih.gov/nia/</a>
Nurses Improving Care for Healthsystem Elders	<a href="http://nicheprogram.org/">http://nicheprogram.org/</a>
Organ Procurement and Transplantation Network	<a href="http://optn.transplant.hrsa.gov/">http://optn.transplant.hrsa.gov/</a>
Palliative Care for Seniors, Care Givers and Families	<a href="http://www.hydrotherapybathing.com/resources/palliative-care-for-seniors/">http://www.hydrotherapybathing.com/resources/palliative-care-for-seniors/</a>
Rheumatoid Arthritis (RA) Learning Center	<a href="http://healthtools.aarp.org/learning-center/rheumatoid-arthritis">http://healthtools.aarp.org/learning-center/rheumatoid-arthritis</a>
SeniorNet	<a href="http://www.seniornet.org">http://www.seniornet.org</a>
StopPain.org	<a href="http://www.stoppain.org/">http://www.stoppain.org/</a>

## 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**

1. Cooke, L., Chung, C., & Grant, M. (2011). Psychosocial care for adolescent and young adult hematopoietic cell transplant patients. *Journal of Psychosocial Oncology, 29*(4), 394-414. DOI: 10.1080/07347332.2011.582636.
2. Patel, S. K., Mullins, W., Turk, A., Dekel, N., Kinjo, C., & Sato, J. K. (2010). Distress screening, rater agreement, and services in pediatric oncology. *Psycho-Oncology*, Epub. DOI: 10.1002/pon.
3. Landier, W., & Tse, A. M. (2010). Use of complementary and alternative medical interventions for the management of procedure-related pain, anxiety, and distress in pediatric oncology: An integrative review. *Journal of Pediatric Nursing, 25*(6), 566-579. DOI:10.1016/j.pedn.2010.01.009.
4. Casillas, J., Kahn, K. L., Doose, M., Landier, W., Bhatia, S., Hernandez, J., & Zeltzer, L. K. (2010). Transitioning childhood cancer survivors to adult-centered healthcare: Insights from parents, adolescent, and young adult survivors. *Psycho-Oncology, 19*, 982-990. DOI: 10.1002/pon.1650.
5. Harrington Jacobs, H., Ferrell, B. R., Virani, R., & Malloy, P. (2009). Appraisal of the pediatric end-of-life nursing education consortium training program. *Journal of Pediatric Nursing, 24*(3), 216-221. DOI: 10.1016/j.pedn.2008.03.001.
6. Landier, W., & Bhatia, S. (2008). Cancer survivorship: A pediatric perspective. *The Oncologist, 13*, 1181-1192. DOI: 10.1634/theoncologist.2008-0104.

#### **Recommended Publications**

1. Life & Loss: A Guide to Help Grieving Children, 3<sup>rd</sup> Edition
  - Goldman, L. (2013). NY: Routledge. ISBN: 978-0415630801.  
Website: [http://www.amazon.com/Life-Loss-Guide-Grieving-Children/dp/0415630800/ref=dp\\_ob\\_title\\_bk](http://www.amazon.com/Life-Loss-Guide-Grieving-Children/dp/0415630800/ref=dp_ob_title_bk).
2. Wong's Essentials of Pediatric Nursing, 9<sup>th</sup> Edition
  - Wilson, D., & Hockenberry, M. M. (2012). PA: Mosby. ISBN: 978-0323083430.  
Website: <http://www.amazon.com>.
3. Palliative and End of Life Care for Children and Young People: Home, Hospice, Hospital
  - Grinyer, A. (2012). NJ: Wiley-Blackwell ISBN: 978-0470656143.  
Website: <http://www.amazon.com>.
4. Lindley, L. C. (2011). Healthcare reform and concurrent curative care for terminally ill children: A policy analysis. *Journal of Hospice and Palliative Nursing, 13*(3), 81-88. DOI: 10.1097/NJH.0b013e318202e308.
5. Cantrell, M. A. (2011). A narrative review summarizing the state of the evidence on the health-related quality of life among childhood cancer survivors. *Journal of Pediatric Oncology Nursing, 28*(2), 75-82. DOI: 10.1177/1043454210377901.
6. Fitchett, G., Lyndes, K. A., Cadge, W., Berlinger, N., Flanagan, E., & Misasi, J. (2011). The role of professional chaplains on pediatric palliative care teams: Perspectives from physicians and chaplains. *Journal of Palliative Medicine, 14*(6), 704-707. DOI: 10.1089/jpm.2010.0523.
7. Anghelescu, D. L., Oaks, L. L., & Hankins, G. M. (2011). Treatment of pain in children after limb-sparing surgery: An institution's 26-year experience. *Pain Management Nursing, 12*(2), 82-94. DOI:10.1016/j.pmn.2010.02.002.

8. Puckey, M., & Bush, A. (2011). "Passage to paradise" ethics and end-of-life decisions in children. *Paediatric Respiratory Reviews*, 12, 139-143. DOI:10.1016/j.prrv.2010.10.003.
9. Rogers, S. K., Gomez, C. F., Carpenter, P., Farley, J., Holson, D., Markowitz, M., et al. (2011). Quality of life for children with life-limiting and life-threatening illnesses: Description and evaluation of a regional, collaborative model for pediatric palliative care. *American Journal of Hospice & Palliative Medicine*, 28(3), 161-170. DOI: 10.1177/1049909110380594.
10. Simpson, E. C. & Penrose, C. V. (2011). Compassionate extubation in children at hospice and home. *International Journal of Palliative Nursing*, 17(4), 164-169.
11. Griffiths, M., Schweitzer, R., & Yates, P. (2011). Childhood experiences of cancer: An interpretative phenomenological analysis approach. *Journal of Pediatric Oncology Nursing*, 28(2), 83-92. DOI: 10.1177/1043454210377902.
12. Johnston, C. C., Fernandes, A. M., & Campbell-Yeo, M. (2011). Pain in neonates is different. *Pain*, 152, S65-S73. DOI: 10.1016/j.pain.2010.10.008.
13. Conte, T. M. (2011). Pediatric oncology nurse and grief education: A telephone survey. *Journal of Pediatric Oncology Nursing*, 28(2), 93-99. DOI: 10.1177/1043454210377900.
14. Marcello, K. R., Stefano, J. L., Lampron, K., Barrington, K. J., Mackley, A. B., & Janvier, A. (2011). The influence of family characteristics on perinatal decision making. *Pediatrics*, 127, e934-e939. DOI: 10.1542/peds.2009-3010.
15. Yeh, C. H., Wai, J. P. M., Lin U., & Chiang, Y. (2011). A pilot study to examine the feasibility and effects of a home-based aerobic program on reducing fatigue in children with acute lymphoblastic leukemia. *Cancer Nursing*, 34(1), 3-12, DOI:10.1097/NCC.0b013e3181e4553c.
16. O'Shea, E. R., Wallace, M., Griffin, M. Q., & Fitzpatrick, J. J. (2011). The effect of an educational session on pediatric nurses' perspectives toward providing spiritual care. *Journal of Pediatric Nursing*, 26, 34-43. DOI:10.1016/j.pedn.2009.07.009.
17. Pousset, G., Bilsen, J., Cohen, J., Mortier, F., & Deliens, L. (2011). Continuous deep sedation at the end of life of children in Flanders, Belgium. *Journal of Pain and Symptom Management*, 41(2)449-455. DOI: 10.1016/j.jpainsymman.2010.04.025.
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20. Textbook of Interdisciplinary Pediatric Palliative Care
  - Wolfe, J., Hinds, P. S., & Sourkes, B. M. (2011). Philadelphia, PA: Elsevier. ISBN: 978-1-4377-0262-0. Website: [http://www.elsevier.com/wps/find/bookdescription.cws\\_home/723289/description#description](http://www.elsevier.com/wps/find/bookdescription.cws_home/723289/description#description)
21. A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief
  - Kuebelbeck, A. & Davis, D. L. (2011). MD: The Johns Hopkins University Press. ISBN: 978-0801897627. Website: <http://www.amazon.com>.
22. Foster, T. L., Lafond, D. A., Reggio, C., & Hinds, P. S. (2010). Pediatric palliative care in childhood cancer nursing: From diagnosis to cure or end of life. *Seminars in Oncology Nursing*, 26(4), 205-221. DOI: 10.1016/j.soncn.2010.08.003.
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40. National Association of Neonatal Nurses (NANN) Board of Directors (2010). Palliative care for newborns and infants: Position statement #3051. *Advances in Neonatal Care, 10*(6), 287-293.
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57. Oxford Textbook of Palliative Nursing
  - Ferrell, B. R., Coyle, N., & Paice, J., (2015). NY: Oxford University Press. ISBN: 9780199332342
  - Website:  
<http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199332342>.

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

Chapter 59: Palliative Care in the Neonatal Intensive Care Unit  
Chapter 60: Grief and Bereavement in Pediatric Palliative Care  
Chapter 61: Pediatric Pain: Knowing the Child Before You

58. Children With Cancer: A Comprehensive Reference Guide for Parents  
- Bracken, J. M. (2010). NY: Oxford University Press. ISBN: 978-0195147391  
Website: <http://www.oup.com/us/catalog/general/subject/Medicine/Oncology/?view=usa&ci=9780195147391>.
59. Essentials of Pediatric Hematology/Oncology Nursing: A Core Curriculum, 3<sup>rd</sup> Edition  
- Kline, N. E., Hobbie, W. L., Hooke, M. D., Rodgers, C. & O'Brien Shea, J. (2010). ISBN: 978-0966619331.  
Website: <http://www.amazon.com/>.
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- Hennessy, J. (2009). IL: Association of Pediatric Hematology/Oncology Nurses (APHON).  
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 - Price, J., & McNeilly, P. (2009). UK: Palgrave MacMillan. ISBN #: 0230200028.  
 Website: <http://www.palgrave.com/products/title.aspx?PID=283933>.
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85. Epstein, E. G. (2008). End-of-life experiences of nurses and physicians in the newborn intensive care unit. *Journal of Perinatology, 28*, 771-778.
86. Welch, S. B. (2008). Can the death of a child be good? *Journal of Pediatric Nursing, 23*(2), 120-125. DOI:10.1016/j.pedn.2007.08.015.
87. Hospice Care For Children, 3rd Edition  
 - Armstrong-Dailey, A., & Zarbock, S. (2008). NY: Oxford University Press. ISBN #: 0195340701.  
 Website:  
<http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780195340709>.
88. Empty Arms: Coping After Miscarriage, Stillbirth and Infant Death  
 - Ilse, S. (2008). MN: Wintergreen Press. ISBN: 978-0960945665. Website: <http://www.amazon.com/>.
89. Living with Grief: Children and Adolescents  
 - Doka, K. (2008). DC: Hospice Foundation of America. ISBN #: 978-1-893349-09-4  
 Website: <http://www.amazon.com>

## **Educational Materials/Curriculum**

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>
2. Children's Cancer Pain Can Be Relieved, A Guide for Parents and Families - The Resource Center  
- A 12-page booklet in Q&A format. Website: <http://trc.wisc.edu/items.asp?itemID=15>.
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>
4. Essentials of Pediatric Oncology Nursing: A Core Curriculum, 3<sup>rd</sup> 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>.
5. Fast Facts and Concepts - Center to Advance Palliative Care (CAPC)  
For a complete listing of Fast Facts and Concepts see <http://www.mypcnow.org/#!fast-facts/c6xb>.  
- 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>.
7. A Lion in the House - LION  
- Educational DVD modules based on *A Lion in the House* documentary film at <http://www.lioninthehouse.com/>. The real-life intimate case studies serve as conversational starters to assist health care professionals and students to sensitively explore issues of childhood and young adult cancer. The seven modules include: Nurse-Patient-Family Relationships, Pediatric End-of-Life Case Studies, Siblings Stories, Disparities, Spirituality and Childhood Cancer, Childhood Cancer and School Issues, and Childhood Cancer Survivorship Stories.  
Website: <http://www.lioninthehouse.com/index.htm>.
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/>.
9. Health Facts for You - UW Health, University of Wisconsin Hospital & Clinics, Madison, WI  
-Pediatrics, Parenting  
Website: <http://www.uwhealth.org/healthfacts/parenting/>  
-EMLA Cream (for needle sticks)  
Website: <http://www.uwhealth.org/healthfacts/pain/5706.html>  
-Intranasal Analgesia Prior to Insertion of Nasogastric Tube  
Website: <http://prc.coh.org/FF%20Intranasal-A3-11.pdf>.

- 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](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/pediatricparenting/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.  
Website: <http://www.amazon.ca/Pediatric-Symptom-Management-Algorithms-Palliative/dp/1888411155>.

### **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
  - Behavior assessment scale for use in non-verbal children or others unable to provide reports of pain. Reliability and validity information provided at <http://wps.prenhall.com/wps/media/objects/3103/3178396/tools/flacc.pdf>.
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.anestesiarianimazione.com/2004/06c.asp>.
4. Pediatric Clinical Practice Guidelines & Policies Book/CD Set, 13<sup>th</sup> Edition - American Academy of Pediatrics
  - A compendium of evidence based research for pediatric practice.  
Website: <http://www.amazon.com>.
5. Pediatric Nurses' Knowledge and Attitudes Survey Regarding Pain - © Manworren
  - Instrument to assess 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  
Website: [http://prc.coh.org/pdf/ped\\_KA\\_survey.pdf](http://prc.coh.org/pdf/ped_KA_survey.pdf). Answer key: [http://prc.coh.org/pdf/ped\\_KA\\_key.pdf](http://prc.coh.org/pdf/ped_KA_key.pdf).
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.  
Website: <http://prc.coh.org/pdf/PNKAS-2002.pdf>. Answer key website: <http://prc.coh.org/pdf/PNKAS-AK2002.pdf>.
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>.

9. Wong-Baker Faces Pain Rating Scale – Donna Wong & Connie Baker  
 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	<a href="http://www.aap.org">http://www.aap.org</a>
Association of Pediatric Hematology/Oncology Nurses	<a href="http://www.aphon.org">http://www.aphon.org</a>
Association of Pediatric Oncology Social Workers	<a href="http://www.aposw.org">http://www.aposw.org</a>
Bandaides and Blackboards	<a href="http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/">http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/</a>
Child/Adolescent Health	<a href="http://www.ahrq.gov/child/">http://www.ahrq.gov/child/</a>
Children’s Hospice International	<a href="http://www.chionline.org">http://www.chionline.org</a>
Compassion Books for Children	<a href="http://www.compassionbooks.com/categories/For-Children/">http://www.compassionbooks.com/categories/For-Children/</a>
Compassionate Friends: Supporting Family After a Child Dies	<a href="http://www.compassionatefriends.org">http://www.compassionatefriends.org</a>
CureSearch for Children’s Cancer	<a href="http://www.curesearch.org/">http://www.curesearch.org/</a>
Cure SMA (Spinal Muscular Atrophy)	<a href="http://www.curesma.org/sma/about-sma/">http://www.curesma.org/sma/about-sma/</a>
End-of-Life Care for Children with Terminal Illness	<a href="http://kidshealth.org/parent/system/ill/bfs_hospice_care.html">http://kidshealth.org/parent/system/ill/bfs_hospice_care.html</a>
End of Life Nursing Education Consortium (ELNEC)	<a href="http://www.aacn.nche.edu/ELNEC/">http://www.aacn.nche.edu/ELNEC/</a>
Griefnet.org	<a href="http://www.griefnet.org/support/sg2.html">http://www.griefnet.org/support/sg2.html</a>
Initiative for Pediatric Palliative Care.	<a href="http://www.ippcweb.org/">http://www.ippcweb.org/</a>
International Children’s Palliative Care Network	<a href="http://www.icpcn.org.uk">http://www.icpcn.org.uk</a>
Kidsaid - 2 Kids, 4 Kids, By Kids	<a href="http://kidsaid.com/">http://kidsaid.com/</a>
Liam’s Foundation for Pediatric Palliative Care	<a href="http://liamsfoundation.org/foundation.html">http://liamsfoundation.org/foundation.html</a>
Loving Touch (Infant Massage)	<a href="http://www.lovingtouch.com/">http://www.lovingtouch.com/</a>
Make a Wish Foundation	<a href="http://www.wish.org">http://www.wish.org</a>
National Children’s Cancer Society	<a href="http://www.thenccs.org/aboutNCCS">http://www.thenccs.org/aboutNCCS</a>
National Hospice and Palliative Care Organization Pediatric Hospice	<a href="http://www.nhpco.org">http://www.nhpco.org</a> <a href="http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409">http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409</a>
Organ Procurement and Transplantation Network	<a href="http://optn.transplant.hrsa.gov/">http://optn.transplant.hrsa.gov/</a>
Pediatric Art Therapy for Children with Cancer	<a href="http://www.tracyskids.org/">http://www.tracyskids.org/</a>
Post Pals	<a href="http://www.postpals.co.uk/">http://www.postpals.co.uk/</a>
SHARE, Pregnancy and Infant Loss Support, Inc.	<a href="http://www.nationalshareoffice.com">http://www.nationalshareoffice.com</a>
What is Pediatric Palliative Care	<a href="http://getpalliativecare.org/whatis/pediatric/">http://getpalliativecare.org/whatis/pediatric/</a>

### **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>.
2. American College of Emergency Physicians (ACEP) Policy Statements
    - Guidelines for Care of Children in the Emergency Department Website: <http://www.acep.org/practres.aspx?id=29134>
    - Sedation in the Emergency Department  
Website: [http://www.acep.org/Clinical---Practice-Management/Sedation-in-the-Emergency-Department/?\\_\\_taxonom\\_yid=471113](http://www.acep.org/Clinical---Practice-Management/Sedation-in-the-Emergency-Department/?__taxonom_yid=471113).
  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.  
Website: <http://www.aspmn.org/documents/Circumcision.pdf>.

## 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

1. Juarez, G., Mayorga, L., Hurria, A., & Ferrell, B. R. (2013). Survivorship education for Latina breast cancer survivors: Empowering survivors through education. *Psicooncologia*, 10(1), 57-68. DOI: 10.5209/rev\_PSIC.2013.v10.41947.
2. Campesino, M., Koithan, M., Ruiz E., Glover, J., Juarez, G., Choi, M., et al. (2012). Surgical treatment differences among Latina and African American breast cancer survivors. *Oncology Nursing Forum*, 39(4), E324-E331. DOI: 10.1188/12.ONF.E324-E331.
3. Thrane, S. (2010). Hindu end of life: Death, dying, suffering, and karma. *Journal of Hospice & Palliative Nursing*, 12(6), 337-342. DOI: 10.1097/NJH.0b013e3181f2ff11.

#### Recommended Publications

1. Culture Care Diversity & Universality: A Worldwide Nursing Theory, 3<sup>rd</sup> Edition
  - Leininger, M. M. & McFarland, M. (2014). MA: Jones & Bartlett Publishers. ISBN: 978-1284026627.  
Website: <http://www.amazon.com/Leiningers-Culture-Care-Diversity-Universality/dp/1284026620>
2. Transcultural Health Care: A Culturally Competent Approach, 4th Edition
  - Purnell, L. D., & Paulanka, B. J. (2012). PA: F. A. Davis Company. ISBN #: 0803637055.  
Website: <http://www.amazon.com>.
3. Cultural Diversity in Health and Illness, 8th Edition
  - Spector, R. E. (2012). NJ: Prentice Hall. ISBN: 0135035899.  
Website: <http://www.amazon.com/Cultural-Diversity-Health-Illness-Edition/dp/0132840065>.
4. Transcultural Concepts in Nursing Care
  - Andrews, M. M. & Boyle, J. S. (2011). MA: Lippincott Williams & Wilkins. ISBN: 0781790379.  
Website: <http://www.amazon.com>.

5. Wilson, L. D. (2011). Cultural competency: Beyond the vital signs. Delivering holistic care to African Americans. *Nursing Clinics of North America*, 46, 219-232. DOI:10.1016/j.cnur.2011.02.007
6. McCormick, A. J. (2011). Self-determination, the right to die, and culture: A literature review. *Social Work*, 56(2), 119-128.
7. Tung, W-C. (2011). Hospice care in Chinese culture: A challenge to home care professionals. *Home Health Care Management & Practice*, 23(1), 67-68. DOI: 10.1177/1084822310383000.
8. Boehmer, U., Miao, X., & Orzonoff, A. (2011). Cancer survivorship and sexual orientation. *Cancer*, 117(16), 3796-3804. DOI: 10.1002/cncr.25950.
9. Robinsin, K. M. & Monsivais, J. J. (2011). Acculturation, depression, and function in individuals seeking pain management in a predominately Hispanic southwestern border community. *Nursing Clinics of North America*, 46, 193-199. DOI:10.1016/j.cnur.2011.02.009.
10. Shaw, S. J. & Armin, J. (2011). The ethical self-fashioning of physicians and health care systems in culturally appropriate health care. *Culture, Medicine, and Psychiatry*, 35, 236-261. DOI 10.1007/s11013-011-9215-1.
11. Bullock, K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, 7, 83-98. DOI: 10.1080/15524256.2011.548048.
12. Robinson, K. M. & Monsivais, J. J. (2011). Malingerer? No evidence in a predominantly Hispanic workers' compensation population with chronic pain. *Pain Management Nursing*, 12(1), 33-40. DOI:10.1016/j.pmn.2009.08.002.
13. Knochel, K. A., Quam, J. K., & Croghan, C. F. (2011). Are old lesbian and gay people well served? Understanding the perceptions, preparation, and experiences of aging services providers. *Journal of Applied Gerontology*, 30(3), 370-389. DOI: 10.1177/0733464810369809.
14. Davies, B., Larson, J., Contro, N. & Cabrera, A. P. (2011). Perceptions of discrimination among Mexican American families of seriously ill children. *Journal of Palliative Medicine*, 14(1), 71-76. DOI: 10.1089/jpm.2010.0315.
15. Coorenbos, A. Z., Lindhorst, T., Schim, S. M., van Schaik, E., Demiriz, G., Wechen, H. A., & Curtis, J. R. (2010). Development of a web-based educational intervention to improve cross-cultural communication among hospice providers. *Journal of Social Work in End-of-Life & Palliative Care*, 6, 236-255. DOI: 10.1080/15524256.2010.529022
16. Berkman, C. S. & Ko, E. (2010). What and when Korean American older adults want to know about serious illness. *Journal of Psychosocial Oncology*, 28, 244-259. DOI: 10.1080/07347331003689029.
17. Loiki, J., Gillick, M., Mayer, S., Prager, K., Simon, J. R., Steinberg, A., et al. (2010). The critical role of religion: Caring for the dying patient from an Orthodox Jewish perspective. *Journal of Palliative Medicine*, 13(10), 1267-1271. DOI: 10.1089/jpm.2010.0088.
18. Schim, S. M., Doorenbos, A. Z. (2010). A three-dimensional model of cultural congruence: Framework for intervention. *Journal of Social Work for End-of-Life & Palliative Care*, 6, 256-270. DOI: 10.1080/15524256.2010.529023.
19. Mazanec, P. M., Daly, B. J., & Townsend, A. (2010). Hospice utilization and end-of-life care decision making of African Americans. *American Journal of Hospice & Palliative Medicine*, 27(8), 560-566. DOI: 10.1177/1049909110372087.
20. Kehl, K. A., & Gartner, C. M. (2010). Can you hear me now? The experience of a deaf family member surrounding the death of loved ones. *Palliative Medicine*, 24(1), 88-93. DOI: 10.1177/0269216309348180.
21. Stein, G. L. Beckerman, N. L., & Sherman, P. A. (2010). Lesbian and gay elders and long-term care: Identifying the unique psychosocial perspectives and challenges. *Journal of Gerontological Social Work*, 53, 421-435. DOI: 10.1080/01634372.2010.496478.
22. Anngela-Cole, L., Ka'Opua, L., Busch, M. (2010). Issues confronting social workers in the provision of palliative care services in the Pacific Basin (Hawai'i and the U. S. affiliated Pacific Island Nations and territories). *Journal of Social Work in End-of-Life & Palliative Care*, 6, 150-163. DOI: 10.1080/15524256.2010.529015.



23. Davies, B., Contro, N., Larson, J., & Widger, K. (2010). Culturally-sensitive information sharing in pediatric palliative care. *Pediatrics*, 125(4), e859-e865. DOI: 10.1542/peds.2009-0722.
24. Crump, S. K., Schaffer, M. A., & Schulte, E. (2010). Critical care nurses' perceptions of obstacles, supports, and knowledge needed in providing quality end-of-life care. *Dimensions of Critical Care Nursing*, 29(6), 297-306. DOI: 10.1097/DCC.0b013e3181f0c43c.
25. Song, M-K., Donovan, H. S., Piraino, B. M., Choi, J., Bernardini, J., Verosky, D., & Ward, S. E. (2010). Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. *Applied Nursing Research*, 23, 65-72. DOI:10.1016/j.apnr.2008.05.002.
26. Kagawa-Singer, M. Dadia, A. V., Yu, M. D., & Surbone, A. (2010). Cancer, culture, and health disparities: Time to chart a new course? *CA: A Cancer Journal for Clinicians*, 60, 12-39. DOI: 10.3322/caac.20051.
27. DeSanto-Madeya, S., Nilsson, M., Loggers, E. T., Paulk, E., Stieglitz, H., Kupersztoch, Y. M. & Prigerson, H. G. (2009). Associations between United States acculturation and the end-of-life experience of caregivers of patients with advanced cancer. *Journal of Palliative Medicine*, 12(12), 1143-1149. DOI: 10.1089/jpm.2009.0063
28. Mitchell, B. L. & Mitchell, L. C. (2009). Review of the literature on cultural competence and end-of-life treatment decisions: The role of the hospitalist. *Journal of the National Medical Association*, 101(9), 920-926.
29. Johnstone, M-J. & Kanitsaki, O. (2009). Ethics and advance care planning in a culturally diverse society. *Journal of Transcultural Nursing*, 20(4), 405-416. DOI: 10.1177/1043659609340803.
30. Davies, B. & Larson, J. (2009). Conducting a qualitative culture study of pediatric palliative care. *Qualitative Health Research*, 19(1), 5-16. DOI: 10.1177/1049732308327346.
31. Mackinnon, C. J. (2009). Applying feminist, multicultural, and social justice theory to diverse women who function as caregivers in end-of-life and palliative home care. *Palliative and Supportive Care*, 7, 501-512. DOI: 10.1017/S1478951509990514.
32. Guide to Culturally Competent Health Care, 2nd Edition
  - Purnell, L. D. (2009). PA: F. A. Davis Company. ISBN: 0803620640.
  - Website: <http://www.amazon.com>.
33. Beyond Politics: A Social and Cultural History of Federal Healthcare Conscience Protections
  - American Society of Law, Medicine & Ethics (2009).
  - Website: <http://www.aslme.org/index.php/beyond-politics-a-social-and-cultural-history-of-federal-healthcare-conscience-protections.html>.
34. Brown, J. P. & Tracy, J. K. (2008). Lesbians and cancer: An overlooked health disparity. *Cancer Causes Control*, 19, 1009-1020. DOI 10.1007/s10552-008-9176-z.
35. Davidson, J. E., Boyer, M. L., Casey, D., Matzel, S. C., Walden, D. (2008). Gap analysis of cultural and religious needs of hospitalized patients. *Critical Care Nursing Quarterly*, 31(2), 119-126.
36. Pain and Its Transformations: The Interface of Biology and Culture
  - Coakley, S. & Kaufman Shelemay, K. (2008). MA: Harvard University Press. ISBN: 0674024567.
  - Website: <http://www.amazon.com>.
37. Caring for Patients from Different Cultures
  - Galanti, G. (2008). PA: University of Pennsylvania Press. ISBN: 0812220315.
  - Website: <http://www.amazon.com>.

### **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)  
For a complete listing of Fast Facts and Concepts see <http://www.mypcnw.org/#!fast-facts/c6xb>.
  - African Americans and End-of-Life Care #204
  - Asking about Cultural Beliefs in Palliative Care #216
  - Cultural Aspects of Pain Management, 2<sup>nd</sup> 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
  - Cultural Aspects of Pain Management Website: <http://prc.coh.org/pdf/CAPM.pdf>.

### **Guidelines/Clinical Pathways**

1. Multicultural Health Care: A Quality Improvement Guide – National Committee for Quality Assurance
  - 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.  
Website: <http://www.ncqa.org/tabid/676/Default.aspx>.
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	<a href="http://www.cancer.gov/health-disparities">http://www.cancer.gov/health-disparities</a>
Cross Cultural Health Care Program	<a href="http://www.xculture.org">http://www.xculture.org</a>
Cultural Diversity in Healthcare	<a href="http://gagalanti.com/">http://gagalanti.com/</a>
Diversity Rx	<a href="http://DiversityRx.org">http://DiversityRx.org</a>
Ethnogeriatrics	<a href="https://geriatrics.stanford.edu/">https://geriatrics.stanford.edu/</a>
Ethnomed (Ethnic Medicine Information)	<a href="http://www.ethnomed.org">http://www.ethnomed.org</a>
Intercultural Cancer Council	<a href="http://www.iccnetwork.org">http://www.iccnetwork.org</a>
Intercultural Communication Institute	<a href="http://www.intercultural.org">http://www.intercultural.org</a>
Minority Nurse: What Color is Your Pain?	<a href="http://www.minoritynurse.com/nurse-led-interventions/what-color-your-pain">http://www.minoritynurse.com/nurse-led-interventions/what-color-your-pain</a>
Multicultural Health Care and Cultural Competence	<a href="https://network-health.org/Providers/Programs-and-Services/Multicultural-health-care-and-cultural-competence.aspx">https://network-health.org/Providers/Programs-and-Services/Multicultural-health-care-and-cultural-competence.aspx</a>
Multicultural Health Clearinghouse	<a href="http://www.mckinley.uiuc.edu/multiculturalhealth/">http://www.mckinley.uiuc.edu/multiculturalhealth/</a>
National Center for Cultural Competence	<a href="http://nccc.georgetown.edu/">http://nccc.georgetown.edu/</a>
National Institute on Minority Health/Health Disparities	<a href="http://www.nimhd.nih.gov/">http://www.nimhd.nih.gov/</a>
National Coalition of Ethnic Minority Nurse Associations	<a href="http://www.ncemna.org/">http://www.ncemna.org/</a>
Office of Minority Health Resource Center	<a href="http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&amp;lvlid=3">http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&amp;lvlid=3</a>
Provider’s Guide to Quality & Culture	<a href="http://erc.msh.org/mainpage.cfm?file=1.0.htm&amp;module=provider&amp;-language=English">http://erc.msh.org/mainpage.cfm?file=1.0.htm&amp;module=provider&amp;-language=English</a>

Think Cultural Health	<a href="https://www.thinkculturalhealth.hhs.gov/">https://www.thinkculturalhealth.hhs.gov/</a>
Transcultural C.A.R.E. Associates	<a href="http://www.transculturalcare.net/">http://www.transculturalcare.net/</a>
Transcultural Nursing	<a href="http://www.culturediversity.org/">http://www.culturediversity.org/</a>
Transcultural Nursing Society	<a href="http://www.tcns.org/">http://www.tcns.org/</a>

## 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**

1. Darbarai, D. S., Ballas, S. K., & Clauw, D. J. (2014). Thinking beyond sickling to better understand pain in sickle cell disease. *European Journal of Haematology*, 93(2), 89-95. DOI: 10.1111/ejh.12340.
2. Darbari, D. S., Neely, M., van den Anker, J., & Rana, S. (2011). Increased clearance of morphine in sickle cell disease: Implications for pain management. *The Journal of Pain*, 12(5), 531-538. DOI:10.1016/j.jpain.2010.10.012.
3. Fisher, L. (2011). Perioperative care of the patient with sickle cell disease. *AORN Journal*, 93(1), 150-159. DOI: 10.1016/j.aorn.2010.08.019.
4. Reagan, M. M., DeBaun, M. R., & Frei-Jones, M. (2011). Multi-modal intervention for the inpatient management of sickle cell pain significantly decreases the rate of acute chest syndrome. *Pediatric Blood Cancer*, 56, 262-266. DOI 10.1002/pbc.22808.
5. Brandow, A. M., Weisman, S. J., & Panepinto, J. A. (2011). The impact of a multidisciplinary pain management model on sickle cell disease pain hospitalizations. *Pediatric Blood Cancer*, 56, 789-793. DOI 10.1002/pbc.22874.
6. Ameringer, S. & Smith, W. R. (2011). Emerging biobehavioral factors of fatigue in sickle cell disease. *Journal of Nursing Scholarship*, 43(1), 22-29. DOI: 10.1111/j.1547-5069.2010.01376.x.
7. Hope and Destiny: A Patient's and Parent's Guide to Sickle Cell Anemia and Sickle Cell Trait, 3<sup>rd</sup> Edition  
- Platt, Jr., A. F., Eckman, J., & Hsu, L. (2011). IN: Hilton Publishing. ISBN: 9780984144709.  
Website: <http://www.amazon.com/Hope-Destiny-Patient-Parents-Disease/dp/0984144706>.
8. Navaid, M. & Melvin, T. (2010). A palliative care approach in treating patients with sickle cell disease using exchange transfusion. *American Journal of Hospice & Palliative Medicine*, 27(3), 215-218. DOI: 10.1177/1049909109356966.
9. Wright, J. & Ahmedzai, S. H. (2010). The management of painful crisis in sickle cell disease. *Current Opinion in Supportive and Palliative Care*, 4, 97-106. DOI: 10.1097/SPC.0b013e328339429a.
10. Ballas, S. K., Bauserman, R. L., McCarthy, W. F., Castro, O. L. Smith, W. R. & Waclawiw, M. A. (2010). Hydroxyurea and acute painful crises in sickle cell anemia: Effects on hospital length of stay and opioid utilization during hospitalization, outpatient acute care contacts, and at home. *Journal of Pain and Symptom Management*, 40(6), 870-882. DOI:10.1016/j.jpainsymman.2010.03.020.
11. Edwards, L. Y. & Edwards, C. L. (2010). Psychosocial treatments in pain management of sickle cell disease. *Journal of the National Medical Association*, 102(11), 1084-1094.
12. Wilkie, D. J., Johnson, B., Mack, A. K., Labotka, R., & Molokie, R. E. (2010). Sickle cell disease: An opportunity for palliative care across the life span. *Nursing Clinics of North America*, 45, 375-397. DOI:10.1016/j.cnur.2010.03.003.
13. Hyacinth, H. I, Gee, B. E., & Hibbert, J. M. (2010). The role of nutrition in sickle cell disease. *Nutrition and Metabolic Insights*, 3, 56-67. DOI: 10.4137/NMI.S5048. .

14. Zempsky, W. T., Loisel, K. A., McKay, K., Lee, B. H., Hagstrom, J. N., & Schechter, N. L. (2010). Do children with sickle cell disease receive disparate care for pain in the emergency department? *The Journal of Emergency Medicine*, *39*(5), 691-695. DOI:10.1016/j.jemermed.2009.06.003.
15. Mousa, S. A., Al Momen, A., Al Sayegh, F., Al Jaouni, S., Nasrullah, Z., Al Saeed, H., et al. (2010). Management of painful vaso-occlusive crisis of sickle-cell anemia: Consensus opinion. *Clinical and Applied Thrombosis/Hemostasis*, *16*(4), 365-376. DOI: 10.1177/1076029609352661.
16. Dampier, C., Lieff, S., LeBeau, P. Rhee, S., McMurray, M., Rogers, Z., et al. (2010). Health-related quality of life in children with sickle cell disease: A report from the Comprehensive Sickle Cell Centers Clinical Trial Consortium. *Pediatric Blood Cancer*, *55*, 485-494. DOI 10.1002/pbc.22497.
17. Odesina, V., Bellini, S., Leger, R., Bona, R., Delaney, C., Andemariam, B., et al. (2010). Evidence-based sickle cell pain management in the emergency department, *Advanced Emergency Nursing Journal*, *32*(2), 102-111. DOI: 10.1097/TME.0b013e3181da588c.
18. Solomon, L. R. (2010). Pain management in adults with sickle cell disease in a medical center emergency department. *Journal of the National Medical Association*, *102*(1), 1025-1032.
19. Taylor, L. E. V., Stotts, N. A., Humphreys, J., Treadwell, M. J., & Miaskowski, C. (2010). A review of the literature on the multiple dimensions of chronic pain in adults with sickle cell disease. *Journal of Pain and Symptom Management*, *40*(3), 416-435. DOI:10.1016/j.jpainsymman.2009.12.027.
20. Wilkie, D. J., Molokie, R., Boyd-Seal, D., Suarez, M. L., Kim, Y. O., Zong, S., et al. (2010). Patient-reported outcomes: Descriptors of nociceptive and neuropathic pain and barriers to effective pain management in adult outpatients with sickle cell disease. *Journal of the National Medical Association*, *102*(1), 18-27.
21. Sickle Cell Anemia: A Mother's Perspective What Every Parent Should Know  
- Lipscome, M & Chamberlin, M. (2010). CreateSpace. ISBN: 978-1456450670  
Website: <https://wwwcreatespace.com/3509281>.
22. 21st Century Ultimate Medical Guide to Sickle Cell Anemia - Authoritative Clinical Information for Physicians and Patients (Two CD Set)  
- US Government. (2009). FL: Progressive Management. ISBN: 978-1422023105.  
Website: <http://www.amazon.com>
23. Miscola, P. Sorrentino, F., Scaramucci, L., de Fabritiis, P., Cianciulli, P. (2009). Pain syndromes in sickle cell disease: An update. *Pain Medicine*, *10*(3), 470-480. DOI:10.1111/j.1526-4637.2009.00601.x.
24. Cotton, S., Grosseohme, D., Rosenthan, S. L., McGrady, M. E., Roberts, Y. H., Hines, J., et al. (2009). Religious/spiritual coping in adolescents with sickle cell disease: A pilot study. *Journal of Pediatric Hematology Oncology*, *31*(5), 313-318. DOI:10.1097/MPH.0b013e31819e40e3.
25. Howard, J., Thomas, V. J., & Rawle, H. M. (2009). Pain management and quality of life in sickle cell disease. *Expert Reviews Pharmacoeconomics Outcomes, Research*, *9*(4), 347-352. DOI:10.1586/ERP.09.32.
26. McClellan, C. B., Schatz, J. C., Puffer, E., Sanchez, C. E., Stancil, M. T., & Roberts, C. W. (2009). Use of handheld wireless technology for a home-based sickle cell pain management protocol. *Journal of Pediatric Psychology*, *34*(5), 564-573. DOI:10.1093/jpepsy/jsn121.
27. O'Connell-Edwards, C. F., Edwards, C. L., Pearce, M., Wachholtz, A. B., Wood, M., Muhammad, M., et al. (2009). Religious coping and pain associated with sickle cell disease: Exploration of a non-linear model. *Journal of African American Studies*, *13*, 1-13. DOI 10.1007/s12111-008-9063-4.
28. Field, J. J., Knight-Perry, J. E., & DeBaun, M. R. (2009). Acute pain in children and adults with sickle cell disease: Management in the absence of evidence-based guidelines. *Current Opinion in Hematology*, *16*, 173-178. DOI:10.1097/MOH.0b013e328329e167
29. Mann-Jiles, V. & Morris, D. L. (2009). Quality of life of adult patients with sickle cell disease. *Journal of the American Academy of Nurse Practitioners*, *21*, 349-349. DOI:10.1111/j.1745-7599.2009.00416.x.

30. Benjamin, L. (2008). Pain management in sickle cell disease: Palliative care begins at birth? *Hematology/the Education Program of the American Society of Hematology*, 466-474.
31. Barakat, L. P., Patterson, C. A., Daniel, L. C., & Dampier, C. (2008). Quality of life among adolescents with sickle cell disease: Mediation of pain by internalizing symptoms and parenting distress. *Health and Quality of Life Outcomes*, 2008, 6(60) 1-9. Accessed at: <http://www.hqlo.com/content/6/1/60>.

### **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  
Website: [http://www.nhlbi.nih.gov/health/prof/blood/sickle/sc\\_mngt.pdf](http://www.nhlbi.nih.gov/health/prof/blood/sickle/sc_mngt.pdf).
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](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	<a href="http://www.ascaa.org/">http://www.ascaa.org/</a>
Sickle Cell Anemia - MedLine Plus	<a href="http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html">http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html</a>
Sickle Cell Disease - EMedicineHealth	<a href="http://www.emedicinehealth.com/sickle_cell_crisis/article_em.htm">http://www.emedicinehealth.com/sickle_cell_crisis/article_em.htm</a>
Sickle Cell Disease - KidsHealth	<a href="http://kidshealth.org/parent/medical/heart/sickle_cell_anemia.html">http://kidshealth.org/parent/medical/heart/sickle_cell_anemia.html</a>
Sickle Cell Disease -National Organization for Rare Disorders	<a href="http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/25/viewAbstract">http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/25/viewAbstract</a>
Sickle Cell Disease and Your Baby - March of Dimes	<a href="http://www.marchofdimes.org/baby/sickle-cell-disease-and-your-baby.aspx">http://www.marchofdimes.org/baby/sickle-cell-disease-and-your-baby.aspx</a>
Sickle Cell Disease Association of America, Inc.	<a href="http://www.sicklecelldisease.org/">http://www.sicklecelldisease.org/</a>
SickleCellKids.org	<a href="http://www.sicklecelkids.org/">http://www.sicklecelkids.org/</a>
Sickle Cell Society	<a href="http://sicklecellsociety.org/">http://sicklecellsociety.org/</a>

### **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**

1. Malloy, P., Paice, J., Ferrell, B. R., Ali, Z., Munyoro, E., Coyne, P., & Smith, T. (2011). Advancing palliative care in Kenya. *Cancer Nursing, 34*(1), E10-E13. DOI: 10.1097/NCC.0b013e3181ea73dd.

#### **Recommended Publications**

1. The Sanford Guide to HIV/AIDS Therapy 2014, 22<sup>nd</sup> Edition
  - Saag, M. S., Chambers, H. F., Eliopoulos, G. M., Gilbert, D. N., & Moellering, R. C. (2011). VA: Antimicrobial Therapy, Inc. ISBN: 978-1930808638. Website: <http://www.sanfordguide.com/>.
2. HIV Essentials 2014, 7<sup>th</sup> Edition
  - Sax, P. E., Cohen, C. J., & Kuritzkes, D. R. (2014). MA: Jones & Bartlett Publishers. ISBN: 0763777099. Website: <http://www.amazon.com>.
3. MMHIV: Medical Management of HIV Infection, 16th Edition
  - Bartlett, J. G., Gallant, J. E., & Pham, P.A. (2012). MD: Knowledge Source Solutions. ISBN: 978-0983711100. Website: <http://www.amazon.com>.

A Guide to Primary Care of People with HIV/AIDS

  - Bartlett, J. G., Cheever, L. W., Johnson, M. P., & Paauw, D. S. (2012). U.S. Department of Health & Human Services. Website: <http://www.amazon.com>.

A Pocket Guide to Adult HIV/AIDS Treatment

  - Bartlett, J. G. (2012). U. S. Department of Health & Human Services. Website: <http://www.amazon.com>.
4. 100 Questions and Answers About HIV and AIDS, 2<sup>nd</sup> Edition
  - Gallan, J. (2012). NM: Jones and Bartlett Publishers. ISBN: 0763750425. Website: <http://www.amazon.com>.
5. Fausto, J. A., & Selwyn, P. A. (2011). Palliative care in the management of advanced HIV/AIDS. *Primary Care Clinics in Office Practice, 38*, 311-326. DOI:10.1016/j.pop.2011.03.010.
6. Lyon, M. E. Garvie, P. A., Kao, E., Briggs, L., He, J., Malow, R., et al. (2011). Spirituality in HIV-infected adolescents and their families: FAMily CEntered (FACE) advance care planning and medication adherence. *Journal of Adolescent Health, 48*, 633-636. DOI:10.1016/j.jadohealth.2010.09.006.
7. Ruiz, M. & Cefalu, C. (2011). Palliative care program for Human Immunodeficiency Virus-infected patients: Rebuilding of an academic urban program. *American Journal of Hospice & Palliative Medicine, 28*(1), 16-21. DOI: 10.1177/1049909110371468.
8. Chu, C. & Selwyn, P. A. (2011). An epidemic in evolution: The need for new models of HIV care in the chronic disease era. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*. DOI:10.1007/s11524-011-9552-y
9. Penn, C., Watermeyer, J. & Evans, M. (2011). Why don't patients take their drugs? The role of communication, context and culture in patient adherence and the work of the pharmacist in HIV/AIDS. *Patient Education and Counseling, 83*, 310-318. DOI:10.1016/j.pec.2011.02.018
10. Krug, R., Karus, D., Selwyn, P. A., & Raveis, V. H. (2010). Late-stage HIV/AIDS patients' and their familial caregivers' agreement on the palliative care outcome scale. *Journal of Pain and Symptom Management, 39*(1), 23-32. DOI:10.1016/j.jpainsymman.2009.05.010.
11. Breitbart, W., Rosenfeld, B., Gibson, C., Kramer, M., Li, Y., Tomarken, A., et al. (2010). Impact of treatment for depression on desire for hastened death in patients with advanced AIDS. *Psychosomatics, 51*(2), 98-105.

12. Hillier S. L., Louw Q., Morris L., Uwimana J., & Statham S. (2010). Massage therapy for people with HIV/AIDS. *Cochrane Database of Systematic Reviews* 2010, Issue 1. DOI:10.1002/14651858.CD007502.pub2.
13. DeMarco, R. F. (2010). Palliative care and African American women living with HIV. *Journal of Nursing Education, 49*(8), 462-465. DOI: 10.3928/01484834-20100430-08.
14. ANAC's Core Curriculum for HIV/AIDS in Nursing, 3<sup>rd</sup> Edition
  - Association of Nurses in AIDS Care. (2010). MA: Jones & Bartlett Publishers. ISBN: 0763754595. Website: <http://www.jbpub.com/Catalog/9780763754594/Authors/>.
15. Handbook of HIV and Social Work: Principles, Practice, and Populations
  - Poindexter, C. C. (2010). NJ: John Wiley & Sons, Inc. ISBN: 978-0470260937 Website: <http://www.wiley.com/WileyCDA/WileyTitle/productCd-0470260939.html>.
16. Hayajneh, F. A., Al-Hussami, M. (2009). Predictors of quality of life among women living with Human Immunodeficiency Virus/AIDS. *Journal of Hospice and Palliative Nursing, 17*(5), 255-261.
17. Richter, L., Chandan, U., & Roachat, T. (2009). Improving hospital care for young children in the context of HIV/AIDS and poverty. *Journal of Child Health Care, 13*(3), 198-211. DOI: 10.1177/1367493509336680.
18. Simpkins, E. P., Silberry, G. K. & Hutton, N. (2009). Thinking about HIV infection. *Pediatrics in Review, 30*, 337-349. DOI: JO.I542/pir.30-9-337.
19. Kell, M. W. & Walley, J. D. (2009). Palliative care for HIV in the era of antiretroviral therapy availability: Perspectives of nurses in Lesotho. *BMC Palliative Care, 8*(11). DOI: 10.1186/1472-684X-8-11.
20. Harding, R., Brits, H., & Penfold, S. (2009). Paediatric antiretroviral therapy outcomes under HIV hospice care in South Africa. *International Journal of Palliative Nursing, 15*(3), 142-145.
21. The Workgroup on Palliative and End-of-Life Care in HIV/AIDS Workgroup (2009). Integrating palliative care into the continuum of HIV care: An agenda for change. Website: [http://www.promotingexcellence.org/hiv/downloads/hiv\\_report.pdf](http://www.promotingexcellence.org/hiv/downloads/hiv_report.pdf).
22. The Person with HIV/AIDS: Nursing Perspectives, 4<sup>th</sup> Ed.
  - Durham, J. D. & Lashley, F. R. (2009). NY: Springer Publishing Company. ISBN: 978-0826121370 Website: <http://www.amazon.com>.
23. Lyon, M. E., Williams, P. L., Woods, E. R., Hutton, N., Butler, A. M., Sibinga, E., et al. (2008). Do-not-resuscitate orders and/or hospice care, psychological health, and quality of life among children/adolescents with Acquired Immune Deficiency Syndrome. *Journal of Palliative Medicine, 11*(3), 459-469. DOI: 10.1089/jpm.2007.0148.
24. Hughes, A., Davies, B., & Gudmundsdottir, M. (2008). "Can you give me respect?" Experiences of the urban poor on a dedicated AIDS nursing home unit. *Journal of the Association of Nurses in AIDS Care, 19*(5), 342-356. DOI:10.1016/j.jana.2008.04.008.
25. Morgan, B. D. & Kochan, K. A. (2008). I'll always want more: Complex issues in HIV palliative care. *Journal of Hospice and Palliative Nursing, 10*(5), 265-271.
26. Allen, D. & Marshall, E. S. (2008). Children with HIV/AIDS: A vulnerable population with unique needs for palliative care. *Journal of Hospice and Palliative Nursing, 10*(6), 359-367.

### **Educational Materials/Curriculum**

1. Fast Facts and Concepts – Palliative Care Network of Wisconsin (PCNOW)  
For a complete listing of Fast Facts and Concepts see <http://www.mypcnow.org/#!/fast-facts/c6xb>.
  - 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 CareWebsite: <http://aidsetc.org/resources>
2. AIDS/HIV Guidelines & Recommendations - Center for Disease Control and National Prevention & Information Network  
Website: <http://www.cdcnpin.org/scripts/hiv/cdc.asp>.
3. Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector - World Health Organization  
Website: <http://www.who.int/hiv/pub/2010progressreport/en/index.html>.
4. Resource Guide for Providing Palliative Care Services through the Ryan White CARE Act - U. S. Department of Health & Human Services.  
Website: <http://www.hab.hrsa.gov/>.

## **Other Organizational Links**

AIDS.org	<a href="http://www.aids.org/">http://www.aids.org/</a>
AIDS Answers.com	<a href="http://aids.answers.com/">http://aids.answers.com/</a>
AIDS Healthcare Foundation	<a href="http://www.aidshealth.org/">http://www.aidshealth.org/</a>
Aids Info	<a href="http://www.aidsinfo.nih.gov/">http://www.aidsinfo.nih.gov/</a>
AIDS ~ Official Journal of the International AIDS Society	<a href="http://www.aidsonline.com/">http://www.aidsonline.com/</a>
AIDS Meds	<a href="http://www.aidsmeds.com/">http://www.aidsmeds.com/</a>
AIDS Project Los Angeles	<a href="http://www.apla.org">http://www.apla.org</a>
amFAR AIDS Research	<a href="http://www.amfar.org/">http://www.amfar.org/</a>
Association of Nurses in AIDS Care (ANAC)	<a href="http://www.nursesinaidscare.org/">http://www.nursesinaidscare.org/</a>
AVERTing HIV and AIDS	<a href="http://www.avert.org/hiv_usa.htm">http://www.avert.org/hiv_usa.htm</a>
Elizabeth Glaser Pediatric AIDS Foundation	<a href="http://www.pedaids.org/">http://www.pedaids.org/</a>
GMHC Fight Aids. Love Life	<a href="http://www.gmhc.org/">http://www.gmhc.org/</a>
HIV/AIDS	<a href="http://www.publichealth.org/resources/hiv-aids/">http://www.publichealth.org/resources/hiv-aids/</a>
HIV/AIDS Clinical Care	<a href="http://aids-clinical-care.jwatch.org/">http://aids-clinical-care.jwatch.org/</a>
HIV/AIDS Program ~ Indian Health Services	<a href="http://www.ihs.gov/hivaids/index.cfm">http://www.ihs.gov/hivaids/index.cfm</a>
HIV Clinical Resource	<a href="http://www.hivguidelines.org/">http://www.hivguidelines.org/</a>
HRSA HIV/AIDS Program	<a href="http://hab.hrsa.gov/">http://hab.hrsa.gov/</a>
International Association of Providers of AIDS Care (IAPAC)	<a href="http://www.iapac.org/">http://www.iapac.org/</a>
Pediatric HIV/AIDS Care, Inc.	<a href="http://www.k12academics.com/national-directories/volunteer-program/pediatric-aidshiv-care-inc">http://www.k12academics.com/national-directories/volunteer-program/pediatric-aidshiv-care-inc</a>
The Body: The Complete AIDS/HIV Resource	<a href="http://www.thebody.com/">http://www.thebody.com/</a>
U.S. National HIV/AIDS Hotlines & Resources	<a href="http://www.thebody.com/index/hotlines/national.html">http://www.thebody.com/index/hotlines/national.html</a>
Women, Children, and HIV	<a href="http://www.womenchildrenhiv.org/">http://www.womenchildrenhiv.org/</a>



## **Position Statements/Standards**

1. American Nurses Association
  - Bloodborne and Airborne DiseasesWebsite: <http://nursingworld.org/MainMenuCategories/HealthcareandPolicyIssues/ANAPositionStatements/blood.aspx>.
2. Association of Nurses in AIDS Care (ANAC)
  - Positions Statements on HIV/AIDSWebsite: <http://www.nursesinaidscare.org/i4a/pages/index.cfm?pageid=3300>.
3. The International Council of Nurses
  - HIV Infection and AIDSWebsite: [http://www.icn.ch/images/stories/documents/publications/position\\_statements/A07\\_HIV-AIDS.pdf](http://www.icn.ch/images/stories/documents/publications/position_statements/A07_HIV-AIDS.pdf).

## **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
  - Borsook, D., May, A., Goadsby, P. J., & Hargreaves, R. (2012). NY: Oxford University Press. ISBN: 978-0199754564.Website: <http://www.amazon.com/>.
2. The Cleveland Clinic Manual of Headache Therapy
  - Tepper, S. J., & Tepper, D. E. (2011). NY: Springer. ISBN: 978-1461401780.Website: <http://www.amazon.com/>.
3. The Migraine Brain: Your Breakthrough Guide to Fewer Headaches, Better Health
  - Berstein, C., & McArdle, E. (2009). NY: Free Press. ISBN: 141654769. Website: <http://www.amazon.com/>.
4. The Relaxation & Stress Reduction Workbook, 6<sup>th</sup> Edition
  - Davis, M., McKay, M., & Eshelman, E. R. (2008). CA: New Harbinger Publications. ISBN: 1572242140.Website: <http://www.amazon.com/Relaxation-Reduction-Workbook-Harbinger-Self-Help/dp/1572245492>.
5. Comprehensive Review of Headache Medicine
  - Levin, M. (2008). NY: Oxford University Press. ISBN: 0195366735.Website: <http://www.oup.com/us/catalog/general/subject/Medicine/Neurology/?view=usa&ci=9780195366730>.
6. Headache Simplified
  - Marcus, D. A. (2008). UK: TFM Publishing. ISBN: 1903378672. Website: <http://www.amazon.com>.
7. The Headache Cure
  - Kandel, J. & Sudderth, D. (2005). NY: McGraw-Hill. ISBN: 0071457364.Website: <http://www.amazon.com>.
8. Fibromyalgia: The Complete Guide From Medical Experts and Patients
  - Ostalecki, S. (2007). NM: Jones and Bartlett Publishers. ISBN: 0763746401.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
  - St. Amand, R. P. & Craig Marek, C. (2006). NY: Wellness Central. ISBN: 0446694444Website: <http://fibromyalgiatreatment.com/books&vids.htm>.
10. Fibromyalgia - Up Close & Personal
  - Pellegrino, M. J. (2005). OH: Anadem Publishing. ISBN: 1890018503.Website: <http://www.amazon.com/Fibromyalgia-Personal-Mark-J-Pellegrino/dp/1890018503>.

11. Taking Charge of Fibromyalgia: Everything You Need to Know to Manage Fibromyalgia, 5<sup>th</sup> Edition
  - Kelly, J. W., & Devonshire, R. (2005). MN: Fibromyalgia Educational Systems, Inc. ISBN: 0966577418.  
Website: <http://www.amazon.com>.
12. Living Well with Migraine Disease and Headaches: What Your Doctor Doesn't Tell You...that You Need to Know
  - Robert, T. (2005). NY: Harper Collins. ISBN: 0060766856.  
Website: [http://www.harpercollins.com/books/9780060766856/Living\\_Well\\_with\\_Migraine\\_Disease\\_and\\_Headaches/index.aspx](http://www.harpercollins.com/books/9780060766856/Living_Well_with_Migraine_Disease_and_Headaches/index.aspx).
13. Advanced Therapy of Headache, 2<sup>nd</sup> Edition
  - Purdy, R. A., Rapoport, A., Sheftell, F., & Tepper, S. (2004). PA: BC Decker. ISBN: 1550092529.  
Website: <http://www.amazon.com/Advanced-Therapy-Headache-Allan-Purdy/dp/1550092529>.
14. The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners
  - Russell, I. J. (2004). NY: The Haworth Press, Inc. ISBN: 9870789025746.  
Website: <http://www.amazon.com/Fibromyalgia-Syndrome-Definition-Practitioners-Musculoskeletal/dp/0789025744>.

### **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/>.
2. Headache: The Journal of Head and Face Pain - American Headache Society  
Website: <http://www.wiley.com/bw/journal.asp?ref=0017-8748&site=1>.
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>  
Health and Nutrition Facts for You website: <http://www.uwhealth.org/healthfacts/>
4. Overview of Pediatric Migraine - Medscape Reference  
Website: <http://emedicine.medscape.com/article/1179268-overview>.

### **Guidelines/Clinical Pathways**

1. Fibromyalgia Treatment Guidelines - Livestrong Foundation  
Website: <http://www.livestrong.com/article/23193-fibromyalgia-treatment-guidelines/>.
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  
Website: [http://www.bash.org.uk/wp-content/uploads/2012/07/10102-BASH-Guidelines-update-2\\_v5-1-indd.pdf](http://www.bash.org.uk/wp-content/uploads/2012/07/10102-BASH-Guidelines-update-2_v5-1-indd.pdf).
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.  
Website: [http://www.rds.org/3/clinical\\_guidelines/index.html](http://www.rds.org/3/clinical_guidelines/index.html).

### **Other Organizational Links**

American Academy of Pain Management	<a href="http://www.aapainmanage.org/">http://www.aapainmanage.org/</a>
American Chronic Pain Association	<a href="http://www.theacpa.org/">http://www.theacpa.org/</a>
American Headache Society	<a href="http://www.achenet.org">http://www.achenet.org</a>

Cluster Headaches.com	<a href="http://www.clusterheadaches.com/newvisitors.html">http://www.clusterheadaches.com/newvisitors.html</a>
Chronic Non-Malignant Pain	<a href="http://www.clevelandclinicmeded.com/medicalpubs/disease-management/psychiatry-psychology/chronic-nonmalignant-pain/">http://www.clevelandclinicmeded.com/medicalpubs/disease-management/psychiatry-psychology/chronic-nonmalignant-pain/</a>
Fibromyalgia, Chronic Fatigue, Central Sensitivity Syndrome	<a href="http://dewarlorx.com/fibromyalgia.htm">http://dewarlorx.com/fibromyalgia.htm</a>
Fibromyalgia Support Group	<a href="http://www.mdjunction.com/fibromyalgia">http://www.mdjunction.com/fibromyalgia</a>
Fibromyalgia Treatment Center	<a href="http://fibromyalgiatreatment.com/">http://fibromyalgiatreatment.com/</a>
Fibromyalgia Network	<a href="http://www.fmnetnews.com/">http://www.fmnetnews.com/</a>
For Grace: Empowering Women in Pain	<a href="http://www.forgrace.org/women/in/pain_home/">http://www.forgrace.org/women/in/pain_home/</a>
Headache ~ Kids Health	<a href="http://www.kidshealth.org/kid/ill_injure/sick/headache.html">http://www.kidshealth.org/kid/ill_injure/sick/headache.html</a>
Headache Symptom & Signs Index	<a href="http://www.medicinenet.com/headache/symptoms.htm">http://www.medicinenet.com/headache/symptoms.htm</a>
Help for Headaches	<a href="http://www.headache-help.org/">http://www.headache-help.org/</a>
International Headache Society	<a href="http://www.ihs-headache.org/">http://www.ihs-headache.org/</a>
Headache Symptom & Signs Index	<a href="http://www.medicinenet.com/headache/symptoms.htm">http://www.medicinenet.com/headache/symptoms.htm</a>
Help for Headaches	<a href="http://www.headache-help.org/">http://www.headache-help.org/</a>
International Headache Society	<a href="http://www.ihs-headache.org/">http://www.ihs-headache.org/</a>
International Myopain Society	<a href="http://www.myopain.org/">http://www.myopain.org/</a>
M.A.G.N.U.M. Awareness Group	<a href="http://www.migraines.org/">http://www.migraines.org/</a>
Managing Back Pain	<a href="http://www.rd.com/health/conditions/chronic-back-pain-breakthroughs/2/">http://www.rd.com/health/conditions/chronic-back-pain-breakthroughs/2/</a>
MigraineInformation.org	<a href="http://www.migraineinformation.org/">http://www.migraineinformation.org/</a>
Migraine Research Foundation	<a href="http://www.migraineresearchfoundation.org/">http://www.migraineresearchfoundation.org/</a>
National Fibromyalgia Association	<a href="http://www.fmaware.org/">http://www.fmaware.org/</a>
National Fibromyalgia Partnership, Inc.	<a href="http://www.fmpartnership.org/">http://www.fmpartnership.org/</a>
National Fibromyalgia Research Association	<a href="http://www.nfra.net/">http://www.nfra.net/</a>
National Headache Foundation	<a href="http://www.headaches.org">http://www.headaches.org</a>
National Institute of Neurological Disorders: Headache	<a href="http://www.ninds.nih.gov/disorders/headache/headache.html/">http://www.ninds.nih.gov/disorders/headache/headache.html/</a>
Pain.com	<a href="http://www.pain.com/">http://www.pain.com/</a>
Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)	<a href="http://www.rsds.org/index2.html">http://www.rsds.org/index2.html</a>
Robbins Headache Clinic	<a href="http://www.headachedrugs.com/">http://www.headachedrugs.com/</a>
Spine-Health	<a href="http://spine-health.com/">http://spine-health.com/</a>
World Institute of Pain	<a href="http://www.worldinstituteofpain.org/">http://www.worldinstituteofpain.org/</a>

## 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**

1. Grant, M., Ferrell, B., Hanson, J. Sun, V., & Uman, G. (2012). The enduring need for the Pain Resource Nurse (PRN) training program. *Journal of Cancer Education, 26*(4), 598-603. DOI: 10.1007/s13187-011-0268-1.
2. Cohen, M., Ferrell, B. R., Vrabell, M., Visovsky, C., Schaefer, B. (2010). What does it mean to be an oncology nurse? Reexamining the life cycle. *Oncology Nursing Forum, 37*(5), 561-570. DOI: 10.1188/10.ONF.561-570.
3. Ferrell, B. R., Virani, R., Malloy, P., & Kelly, K. (2010). The preparation of oncology nurses in palliative care. *Seminars in Oncology Nursing, 26*(4), 259-265. DOI: 10.1016/j.soncn.2010.08.001.
4. Otis-Green, S., Ferrell, B., Spolum, M., Uman, G., Mullan, P., Baird, P., Grant, M. (2009). An overview of the ACE project ~ Advocating for clinical excellence: Transdisciplinary palliative care education. *Journal of Cancer Education, 24*(2), 120-126. DOI: 10.1080/08858190902854616.
5. Piper, B. F., Borneman, T., Chih-Yi Sun, V., Koczywas, M., Uman, G., Ferrell, B. R., & James, R. L. (2008). Cancer-related fatigue: Role of oncology nurses in translating national comprehensive cancer network assessment guidelines into practice. *Clinical Journal of Oncology Nursing, 12*(5), 37-47. DOI: 10.1188/08.CJON.S2.37-47.
6. Ferrell, B., Paice, J., & Koczywas, M. (2008). New standards and implications for improving the quality of supportive oncology practice. *Journal of Clinical Oncology, 26*(23), 3824-3831. DOI: 10.1200/JCO.2007.15.7552.
7. Otis-Green, S., Lucas, S., Spolum, M., Ferrell, B. R., & Grant, M. (2008). Promoting excellence in pain management and palliative care for social workers. *Journal of Social Work in End-of-Life and Palliative Care, 4*(2), 120-134. DOI: 10.1080/15524250802353942.

#### **Recommended Publications**

1. Pain Assessment and Pharmacologic Management
  - Pasero, C., & McCaffery, M. (2010). PA: Elsevier. ISBN #: 0323056962.  
Website: <http://www.amazon.com>.
2. Cancer Nursing: Principles and Practice, 7th Edition
  - Yarbrow, C. H., Gobel, B. H., & Wujcik, D. (2010). NM: Jones and Bartlett Publishers. ISBN: 0763763578.  
Website: <http://www.jbpub.com/catalog/9780763763572/>.
3. Pain: Clinical Manual, 2<sup>nd</sup> Edition
  - McCaffery, M., & Pasero, C. (1999). PA: Elsevier. ISBN: 081515609X.  
Website: [http://www.amazon.com/dp/081515609X/?tag=mh0b-20&hvadid=3524563779&ref=pd\\_sl\\_4fqb0d0mf1\\_b](http://www.amazon.com/dp/081515609X/?tag=mh0b-20&hvadid=3524563779&ref=pd_sl_4fqb0d0mf1_b).

#### **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/jcjq/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.  
Website: <http://www.ability4life.com/wp-content/uploads/CalgaryMedWords05.pdf>.
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  
Website: <http://www.iasp-pain.org/Advocacy/Content.aspx?ItemNumber=1106>.
7. Guidelines for Pain Case Conferences & Guidelines for a Pain Conference for an Individual Patient - University of Wisconsin Hospital & Clinics, Madison, WI  
Website: [http://prc.coh.org/pdf/UW\\_Guidelines\\_for\\_Pain\\_Case\\_Conferences.pdf](http://prc.coh.org/pdf/UW_Guidelines_for_Pain_Case_Conferences.pdf).
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](http://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](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  
Website: [https://live.blueskybroadcast.com/bsb/client/CL\\_DEFAULT.asp?Client=217472&PCAT=1556&CAT=1556](https://live.blueskybroadcast.com/bsb/client/CL_DEFAULT.asp?Client=217472&PCAT=1556&CAT=1556).

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](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](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/sr=8-1/qid=1143822735/ref=sr\\_1\\_1/104-2649966-8483958?\\_encoding=UTF8](http://www.amazon.com/gp/product/0834219034/sr=8-1/qid=1143822735/ref=sr_1_1/104-2649966-8483958?_encoding=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](mailto:Margopain@aol.com).
  - Pain: Clinical Manual, 2<sup>nd</sup> Edition (Book) - Website: <http://www3.us.elsevierhealth.com/PAIN/preface.html>.
  - 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.  
Website: [http://prc.coh.org/pdf/Self\\_Learning\\_Kaiser.pdf](http://prc.coh.org/pdf/Self_Learning_Kaiser.pdf).
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>
20. Pain Resource Nurse (PRN) Program Curriculum & Planning Guide - The Resource Center, Madison, WI
  - 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>.
21. Pain Resource Nurse Training Program Packet - University of Wisconsin Hospital & Clinics, Madison, WI
  - 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](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/UW%20PRN%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/UW\\_PRN\\_Pre-Test.pdf](http://prc.coh.org/pdf/UW_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.  
Website: <http://www.thefutureofnursing.org/IOM-Report>.
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	<a href="http://advancingexpertcare.org/">http://advancingexpertcare.org/</a>
American Association of Colleges of Nursing	<a href="http://www.aacn.nche.edu/">http://www.aacn.nche.edu/</a>
American Medical Association	<a href="http://www.ama-assn.org/">http://www.ama-assn.org/</a>
American Society of Law, Medicine & Ethics	<a href="http://www.aslme.org/">http://www.aslme.org/</a>
American Society of Pain Management Nurses	<a href="http://www.aspmn.org/">http://www.aspmn.org/</a>
National League for Nursing	<a href="http://www.nln.org">http://www.nln.org</a>
Oncology Nursing Society Continuing Education	<a href="https://www.ons.org/education">https://www.ons.org/education</a>
Online Nurse Practitioner Programs	<a href="http://onlinenursepractitionerprograms.com/governmental-resources/">http://onlinenursepractitionerprograms.com/governmental-resources/</a>

### **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](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**

1. Borneman, T., Sun, V., Williams, A.C., Fujinami, R., Del Ferraro, C., Burhenn, P., Irish, T., Zachariah, F., van Zyl, C., Buga, S. (2015). Support for Patients and Family Caregivers in Lung Cancer: Educational Components of an Interdisciplinary Palliative Care Intervention. *Journal of Hospice & Palliative Nursing*, 17(4), 309-318.  
doi: 10.1097/njh.0000000000000165

2. Borneman, T., Koczywas, M., Sun, V., Piper, B., Smith-Idell, C., Laroya, B., Uman, G., & Ferrell, B. R. (2011). Effectiveness of a clinical intervention to eliminate barriers to pain and fatigue management in oncology. *Journal of Palliative Medicine*, 14(2), 197-205. DOI: 10.1089/jpm.2010.0268.
3. Evans, C., Chiou, C., Fitzgerald, K., Evans, W., Ferrell, B. R., Dale, W., Fried, I., Gandra, S., Denee-Sommers, B., & Patrick, D. (2011). Development of a new patient-reported outcome measure in sarcopenia. *Journal of American Medical Directors Association*, 12, 226-233. DOI: 10.1016/j.jamda.2010.09.010.
4. Borneman, T., Koczywas, M., Chih-Yi Sun, V., Piper, B. F., Uman, G., & Ferrell, B. R. (2010). Reducing patient barriers to pain and fatigue management. *Journal of Pain and Symptom Management*, 39(3), 486-501. DOI: 10.1016/j.jpainsymman.2009.08.007.
5. O'Mara, A., Germain, D., Ferrell, B. R., & Borneman, T. (2008). Challenges to and lessons learned from conducting palliative care research. *Journal of Pain and Symptom Management*, 37(3), 387-394. DOI: 10.1016/j.jpainsymman.2008.03.014.
6. Piper, B., Borneman, T., Sun, V., Koczywas, M., Uman, G., Ferrell, B. R., & James, R. (2008). Assessment of cancer-related fatigue (CRF): Role of oncology nurses in translating assessment guidelines into practice. *Clinical Journal of Oncology Nursing*, 12(5 Suppl), 37-47. DOI: 10.1188/08.CJON.S2.37-47.
7. Muñoz, C., Juarez, G., Muñoz, M. L., Portnow, J., Fineman, I., Badie, B., Mamelak, A., & Ferrell, B. R. (2008). The quality of life of patients with malignant gliomas and their caregivers. *Social Work in Health Care*, 47(4), 455-478. DOI: 10.1080/00981380802232396.

### **Recommended Publications**

1. Butcher, L. (2013). New social media site for cancer patients. *Oncology Times*, 35(18), 12. DOI: 10.1097/01.COT.0000435398.65946.0b.
2. Handbook of Health Social Work, 2<sup>nd</sup> Edition
  - Gehlert, S. & Arthur Browne, T. (2011). NJ: John Wiley and Sons. ISBN: 9780470643655. Website: <http://www.wiley.com/WileyCDA/WileyTitle/productCd-047064365X.html>.
3. Everything Nobody Tells You About Cancer Treatment and Your Sex Life from A to Z
  - University of Oklahoma College of Nursing. (2011). Website: <http://prc.coh.org/A-Z%20Booklet%209-14.pdf>.
4. Merck Manual Home Health Handbook, Third Edition
  - Porter, R. (2009). PA: Merck Publishing. ISBN: 978-0911910308. Website: <http://www.amazon.com>.
5. Family Carers in Palliative Care: A Guide for Health and Social Care Professionals
  - Hudson, P. & Payne, S. (2009). NY: Oxford University Press. ISBN: 0199216908. Website: <http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine/?view=usa&ci=9780199216908>
6. The Chronic Pain Solution: Your Personal Path to Clinical Relief
  - Dilliard, J. N., & Hirschman, L. A. (2008). CAN: Random House. ASIN: B001NJUOEO. Website: <http://www.amazon.com>. Kindle Edition

### **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/O1\\_writer/O1\\_downloads/SW\\_HHandBook.pdf](http://www.stephaniewaxman.com/O1_writer/O1_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> 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. Website: <http://sbir-cancercontrol.cancer.gov/sbir/viewProduct.do?prodId=894257>.
  
5. **Coping with Cancer: Supportive and Palliative Care- National Cancer Institute**
  - About Children with Cancer  
Website: <http://www.cancer.gov/cancertopics/coping/children-with-cancer>
  - Financial, Insurance, and Legal Information  
Website: <http://www.cancer.gov/cancertopics/coping/financial-legal>
  - Finding Healthcare Services  
Website: <http://www.cancer.gov/cancertopics/coping/healthservices>
  - For Caregivers, Family, and Friends  
Website: <http://www.cancer.gov/cancertopics/coping/familyfriends>
  - Managing Emotional Effects  
Website: <http://www.cancer.gov/cancertopics/coping/emotionaleffects>
  - Managing Physical Effects  
Website: <http://www.cancer.gov/cancertopics/coping/physicaleffects>
  - Supportive and Palliative Care Clinical Trials  
Website: <http://www.cancer.gov/about-cancer/treatment/clinical-trials>
  - Survivorship - Living With and Beyond Cancer  
Website: <http://www.cancer.gov/cancertopics/coping/survivorship>
  
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>.
  
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. Website: <http://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care>
  
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  
Website: <http://www.iasp-pain.org/>.

9. Financial Issues and Cancer - American Cancer Society
  - Advanced Illness: Financial Guidance for Cancer Survivors and Their Families  
Website: <http://www.cancer.org/acs/groups/content/@editorial/documents/document/acsq-020184.pdf>
  - Coping Financially with the Loss of a Loved One: Financial Guidance for Families -  
Website:  
<http://www.cancer.org/acs/groups/content/@editorial/documents/document/copingfinanciallywiththelossof.pdf>
  - Find Support and Treatment  
Website: <http://www.cancer.org/treatment/index>
  - Health Insurance and Financial Assistance for the Cancer Patient  
Website: <http://www.cancer.org/acs/groups/cid/documents/webcontent/002562-pdf.pdf>.
  
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.  
Website: <http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/pain/paindiary/index>.
  
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) <http://www.uwhealth.org/healthfacts/gi/4843.html>
  - Continuous Subcutaneous Lidocaine for Pain Management <http://www.uwhealth.org/healthfacts/pain/5314.html>
  - Coping with Your Chronic pain <http://www.uwhealth.org/healthfacts/pain/5298.html>
  - Fibromyalgia <http://www.uwhealth.org/healthfacts/pain/5641.html>
  - How to Relieve Pain without Medicine <http://www.uwhealth.org/healthfacts/pain/4448.html>
  - Intravenous Patient Controlled Analgesia <http://www.uwhealth.org/healthfacts/pain/4273.html>
  - Pain Management <http://www.uwhealth.org/health/topic/special/pain-management/aba6263.html>

Website: <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/>.
  
13. Mesothelioma
  - Lean on Me - Cancer Through a Carer's Eyes Website: <http://www.asbestos.com/book/>
  - 100 Questions & Answers About Mesothelioma Website: <http://www.asbestos.com/book/>
  - Mesothelioma Center Blog Website: <http://www.asbestos.com/blog/>  
Website: <http://www.asbestos.com/mesothelioma/>.
  
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.  
Website: <http://www.cancer.gov/about-cancer/treatment/side-effects/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
  
18. Patient Assistance and Reimbursement Guide – The Association of Community Cancer Centers
  - 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](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/paindiary/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.fhcr.org/science/clinical/biobehavioral/patient\\_materials.html](http://www.fhcr.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](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.  
Website: [http://prc.coh.org/html/pt\\_med\\_info.asp](http://prc.coh.org/html/pt_med_info.asp).
23. Patient Support and Treatment - American Cancer Society
  - Helps guide, support and inform patients through every step of their journey.  
Website: <http://www.cancer.org/treatment/index>.
24. Patient Resource Cancer Guide to Treatment-Related Side Effects - Patient Resource LLC
  - Available free to patients and treatment facilities.  
Website: <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/>.
26. The Cancer Nutrition Handbook - Cancer Nutrition Center
  - The online booklet details nutrition and cancer guidelines, including nutrition during treatment and suggestions for eating to provide maximum immunity. Website: <http://www.cancernutrition.com/handbook.htm>.
27. The Handbook for People with Pain, 4<sup>th</sup> Edition - In the Face of Pain
  - 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.  
Website: [http://www.inthefaceofpain.com/content/uploads/2011/07/PainHandbookEng\\_4th\\_edition.pdf](http://www.inthefaceofpain.com/content/uploads/2011/07/PainHandbookEng_4th_edition.pdf).
28. The Resource Center of the Alliance of State Pain Initiatives Patient Education
  - Cancer Pain Can Be Relieved, 2<sup>nd</sup> Edition - Website: <http://trc.wisc.edu/items.asp?itemID=14>
  - Children's Cancer Pain Can Be Relieved - Website: <http://trc.wisc.edu/items.asp?itemID=15>
  - Eight Facts Everyone Should Know About Cancer Pain - Website: <http://trc.wisc.edu/items.asp?itemID=16>.
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. Website: <http://www.nccn.org/patients/guidelines/cancers.aspx>.
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)
  - Advanced Cancer Website: [http://www.cancer.org/docroot/CRI/CRI\\_2x.asp?sitearea=&dt=79](http://www.cancer.org/docroot/CRI/CRI_2x.asp?sitearea=&dt=79)
  - 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	<a href="http://www.cancer.org">http://www.cancer.org</a>
Cancer and Careers	<a href="http://www.cancerandcareers.org">http://www.cancerandcareers.org</a>
Cancer Connect	<a href="http://www.cancerconsultants.com/">http://www.cancerconsultants.com/</a>
Cancer Network	<a href="http://www.cancernetwork.com/">http://www.cancernetwork.com/</a>
Cancer Support Community	<a href="http://www.thewellnesscommunity.org/">http://www.thewellnesscommunity.org/</a>

DrugWatch.com	<a href="http://www.drugwatch.com/">http://www.drugwatch.com/</a>
Foundation for Women's Cancer	<a href="http://www.wcn.org/">http://www.wcn.org/</a>
Fran's Place ~ Center for Cancer Counseling	<a href="http://centerforcancercounseling.org/aboutus.htm">http://centerforcancercounseling.org/aboutus.htm</a>
Mesothelioma & Asbestos Awareness Center	<a href="http://www.asbestos.com/mesothelioma/">http://www.asbestos.com/mesothelioma/</a>
National Cancer Institute	<a href="http://www.cancer.gov/">http://www.cancer.gov/</a>
Pain Community News	<a href="http://paincommunity.org">http://paincommunity.org</a>
Patient Advocate Foundation	<a href="http://patientadvocate.org/">http://patientadvocate.org/</a>
Patient Education Institute	<a href="http://www.patient-education.com">http://www.patient-education.com</a>
Spine Health	<a href="http://spine-health.com/">http://spine-health.com/</a>
Selected Patient Information Resources in Asian Languages (SPIRAL)	<a href="http://spiral.tufts.edu/">http://spiral.tufts.edu/</a>

### **Position Statements/Standards**

1. Hospice and Palliative Nurses Associates (HPNA) Position Statement
  - Spiritual Care  
Website: <http://www.hpna.org/DisplayPage.aspx?Title1=Position%20Statements>.

## **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**

1. Balogh, E., Ganz, P., Murphy, s., Nass, S., Ferrell, B. R., & Stovall, E. (2011). Patient-centered cancer treatment planning: Improving the quality of oncology care. A National Coalition for Cancer Survivorship and Institute of Medicine workshop. *The Oncologist*, 16 1800-1805.

### **Recommended Publications**

1. Wall and Melzack's Textbook of Pain, 6th Edition
  - McMahon, S. & Koltzenburg, M. (2013). PA: Saunders/Elsevier. ISBN: 978-0702040597.  
Website: <http://www.amazon.com>.
2. The Healthcare Quality Book: Vision, Strategy, and Tools, 2<sup>nd</sup> Edition
  - Ransom, E. R., Joshi, M. S., Nash, D. B., & Ransom, S. B. (2008). IL: Health Administration Press. ISBN: 1567933017.  
Website: <http://www.ache.org/pubs/redesign/productcatalog.cfm?pc=WWW1-2116>.

### **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.  
Website: <http://prc.coh.org/pdf/ActionPlan.pdf>.

### **Guidelines/Clinical Pathways**

1. Addressing State Policy Issues in End-of-Life Care – Robert Wood Johnson Foundation
  - 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](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](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](http://prc.coh.org/pdf/pt_questionnaire_willamette.pdf).
8. Quality Assurance Packet - Saint Luke's Shawnee Mission Health System, Shawnee Mission, KS
  - 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](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 <http://trc.wisc.edu/items.asp?itemID=11>
  - Handbook of Cancer Pain Management <http://trc.wisc.edu/items.asp?itemID=12>
  - Nursing Competency Guidelines [http://trc.wisc.edu/WCPI\\_RN.pdf](http://trc.wisc.edu/WCPI_RN.pdf)
  - Pain Resource Nurse Program Curriculum & Planning Guide <http://trc.wisc.edu/items.asp?itemID=114>
  - The Post-Operative Pain (POP) Management Project Lecture Series CD <http://trc.wisc.edu/items.asp?itemID=105>

### **Other Organizational Links**

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

## 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

1. Ferrell, B. R. (2000). The cost of comfort: Economics of pain management in oncology. *Oncology Economics*, 1(9), 56-61.

#### Recommended Publications

1. Lyman, G. H. (2007). Economics of cancer care. *Journal of Oncology Practice*, 3(3), 113-114. DOI: 10.1200/JOP.0731501.

#### 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

<http://www.capcmssm.org/>

Health Economics Information Resources:

[http://www.nlm.nih.gov/nichsr/edu/healthecon/00\\_he\\_intro.html](http://www.nlm.nih.gov/nichsr/edu/healthecon/00_he_intro.html)

-A Self Study Course

Health Economics Resource Center

[http://www.herc.research.va.gov/resources/faq\\_a01.asp](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

1. Laneader, A., Angelos, P., Ferrell, B. R., Kolker, A., Miner, T., Padilla, G., Swaney, J., Krouse, R., & Casarett, D. (2007). Ethical issues in research to improve the management of malignant bowel obstruction: challenges and recommendations. *Journal of Pain and Symptom Management*, 34(Supl 1), S20-S27. DOI: 10.1016/j.jpainsymman.2007.04.007.
2. Ferrell, B. R. (2007). Beyond politics - the patient in pain. *Center for Practical Bioethics*, 3(3), 10-15.
3. Ferrell, B. R. (2006). Understanding the moral distress of nurses witnessing medically futile care. *Oncology Nursing Forum*, 33(5), 922-930. DOI: 10.1188/06.ONF.922-930.
4. Ferrell, B. R. (2005). Ethical perspectives on pain and suffering. *Pain Management Nursing*, 6(3), 83-90. DOI: 10.1016/j.pmn.2005.06.001.
5. Sullivan, M., & Ferrell, B. R. (2005). Ethical challenges in the management of chronic nonmalignant pain: Negotiating through the cloud of doubt. *The Journal of Pain*, 6(1), 2-9. DOI: 10.1016/j.jpain.2004.10.006.

#### Recommended Publications

1. Health Care Ethics: Critical Issues for the 21st Century, 2nd Edition  
- Morrison, E. E. & Furlong, B. (2013). NM: Jones and Bartlett Publishers. ISBN #: 978-1449665357.  
Website: <http://www.amazon.com/Health-Care-Ethics-Critical-Century/dp/1449665357>.
2. The American Nurse. (2011). The practice of ethics. MD: The American Nurse Association.  
Website: <http://www.theamericannurse.org/index.php/2011/06/01/the-practice-of-ethics/>
3. Bernhofer, E. (2011). Ethics and pain management in hospitalized patients. *Online Journal of Issues in Nursing*, 17(1). DOI: 10.3912/OJIN.Vol17No01EthCol01.

4. Guide to Code of Ethics for Nurses: Interpretation and Application.
  - Fowler, D. M. (2010). MD: American Nursing Association, Nursebooks.org. ISBN: 978-1558102583  
Website: <http://www.amazon.com>
5. Clinical Ethics: A practical Approach to Ethical Decisions in Clinical Medicine, 7<sup>th</sup> Edition
  - Jonsen, A., Siegler, M. & Winslade, W. (2010). NY: McGraw-Hill. ISBN: 13: 978-0071634144.  
Website: <http://www.amazon.com>
6. Ethical Issues in Chronic Pain Management
  - Schatman, M. E. (2007). NY: Informa Healthcare. ISBN: 0849392683.  
Website: <http://www.amazon.com>
7. Moral Dilemmas in Community Health Care: Cases and Commentaries
  - White, B. & Zimbelman, J. (2005). NY: Pearson Longman. ISBN: 0321133552.  
Website: <http://www.amazon.com>.
8. Code of Ethics for Nurses with Interpretive Statements
  - American Nurses Association. (2001). ISBN-13: 978-1558101760.  
Website: <http://www.amazon.com/>.
9. Palliative Care Ethics: A Companion for All Specialties, 2<sup>nd</sup> Edition
  - Randall, F., & Downie, R. S. (1999). NY: Oxford University Press. ISBN: 0192630687.  
Website: <http://www.oup.com/us/catalog/general/subject/Medicine/PalliativeMedicine>.
10. Suffering
  - Ferrell, B. R. (1996). NM: Jones and Bartlett Publishers. ISBN: 086720723.  
Website: <http://www.jbpub.com/catalog/086720723X/>.

### **Educational Materials/Curriculum**

1. In the Face of Pain
  - Ethics and Pain Fact Sheet  
Website: [http://www.inthefaceofpain.com/content/uploads/2011/12/factsheet\\_Ethics.pdf](http://www.inthefaceofpain.com/content/uploads/2011/12/factsheet_Ethics.pdf).

### **Guidelines/Clinical Pathways**

1. Achieving Balance in State Pain Policy: A Guide to Evaluation – Pain & Policy Studies Group, University of WI  
Website: <http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/prc2013.pdf>  
Achieving Balance in State & Federal Pain Policy: A Guide to Evaluation – Pain & Policy Studies Group, University of WI  
Website: <http://www.painpolicy.wisc.edu/sites/www.painpolicy.wisc.edu/files/evalguide2013.pdf>
2. Achieving Balance in National Opioids Control Policy: Guidelines for Assessment -World Health Organization
  - 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](http://whqlibdoc.who.int/hq/2000/who_edm_qsm_2000.4.pdf)
3. Addressing State Policy Issues in End of Life Care - Robert Wood Johnson Foundation
  - 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>.
4. Guide to Legal Issues in Life-Limiting Conditions - American Health Lawyers Association, Washington, DC  
Website: <https://www.healthlawyers.org/hlresources/PI/Pages/AGuidetoLegalIssuesinLife-LimitingConditions.aspx>.
5. Model Policy for the Use of Opioid Analgesics in the Treatment of Chronic Pain - Federation of State Medical Boards USA  
Website: <http://www.pcass-o.org/sites/default/files/FSMB%20Pain%20Policy%20%28July%202013%29.pdf>.



## **Other Organizations Links**

American Society for Bioethics and Humanities	<a href="http://www.asbh.org">http://www.asbh.org</a>
American Society of Law, Medicine & Ethics (ASLME)	<a href="http://www.aslme.org">http://www.aslme.org</a>
American Society of Pain Management Nurses (ASPMN)	<a href="http://www.aspmn.org/">http://www.aspmn.org/</a>
American Society on Aging: Legal and Ethical Issues	<a href="http://www.asaging.org/blog/content-source/101">http://www.asaging.org/blog/content-source/101</a>
BWH Office of Clinical Ethics	<a href="http://www.brighamandwomens.org/Patients_Visitors/pceethics/">http://www.brighamandwomens.org/Patients_Visitors/pceethics/</a>
Caring Community ~ Wellness Through Life's End	<a href="http://caringcommunity.org/">http://caringcommunity.org/</a>
Center for Ethics in Health Care	<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>
Center for Practice Bioethics	<a href="http://www.practicalbioethics.org/">http://www.practicalbioethics.org/</a>
Center for Bioethics	<a href="http://www.ahc.umn.edu/bioethics/">http://www.ahc.umn.edu/bioethics/</a>
Clinical Ethics in Action	<a href="http://blog.nutritioncare.org/between-a-rock-and-a-hard-place-clinical-ethics-in-action/">http://blog.nutritioncare.org/between-a-rock-and-a-hard-place-clinical-ethics-in-action/</a>
Code of Ethics for Nurses	<a href="http://www.nursingworld.org/codeofethics">http://www.nursingworld.org/codeofethics</a>
Emerging Solutions in Pain	<a href="http://www.emergingsolutionsinpain.com/">http://www.emergingsolutionsinpain.com/</a>
Ethical and Legal Issues: Aging in the Know	<a href="http://www.helpingyoucare.com/5751/ethical-and-legal-issues-aging-in-the-know">http://www.helpingyoucare.com/5751/ethical-and-legal-issues-aging-in-the-know</a>
Ethical Issues - American Nurses Association	<a href="http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources">http://www.nursingworld.org/MainMenuCategories/EthicsStandards/Resources</a>
Pain & Policy Studies Group	<a href="http://www.painpolicy.wisc.edu/">http://www.painpolicy.wisc.edu/</a>
The Center for Ethics and Human Rights	<a href="http://www.nursingworld.org/ethics/">http://www.nursingworld.org/ethics/</a>
The Hastings Center	<a href="http://www.thehastingscenter.org/">http://www.thehastingscenter.org/</a>
The Legal Side of Pain	<a href="http://legalsideofpain.com/index.cfm">http://legalsideofpain.com/index.cfm</a>

## **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 safety and quality of care; and facilitate dialogue on emerging biomedical science and research. Website: <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>
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>.

## 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](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](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/esas.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://prc.coh.org/pdf/Instruments.pdf>.
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://prc.coh.org/Knowledge%20%20&%20Attitude%20Survey%207-14.pdf>
13. M.D. Anderson Symptom Inventory (MDASI) - MD Anderson Cancer Center, TX
  - The MDASI is used for patients with symptoms due to cancer and cancer treatment to assess the severity of multiple symptoms and the impact of symptoms on daily functioning. Website: <http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/mdanderson-symptom-inventory.html>.
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://prc.coh.org/pdf/McGill%20Pain%20Questionnaire.pdf>.
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://prc.coh.org/pdf/McGill%20Short-Form%20Pain%20Questionnaire.pdf>.
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
  - A 46 item instrument used to assess medical staff regarding knowledge and attitudes regarding pain. Website: <http://prc.coh.org/html/medka.htm>.
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](http://www.npcrc.org/files/news/memorial_symptom_assessment_scale.pdf). MSAS-SF (Short form). Website: [http://www.npcrc.org/files/news/memorial\\_symptom\\_assessment\\_scale\\_short.pdf](http://www.npcrc.org/files/news/memorial_symptom_assessment_scale_short.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/>.

  - Measurement and Evaluation Tools - Pain and Symptom Management Website: <http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx>

20. Needs at the End-of-Life Screening Tool (NEST) - Buehler Center on Aging
  - NEST is a comprehensive assessment and outcome measures instrument.  
Website: [http://www.npcrc.org/files/news/needs\\_end\\_of\\_life\\_screening\\_NEST.pdf](http://www.npcrc.org/files/news/needs_end_of_life_screening_NEST.pdf)
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](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.  
Website: [http://prc.coh.org/pdf/pt\\_pain.pdf](http://prc.coh.org/pdf/pt_pain.pdf).
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](http://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 assess pediatric nurses' knowledge and attitudes regarding pain in children.  
Answer key: <http://prc.coh.org/pdf/PNKAS-AK2002.pdf>.  
Website: [http://prc.coh.org/pdf/ped\\_KA\\_survey.pdf](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.  
Website: <http://prc.coh.org/pdf/PNKAS-2002.pdf>. Answer key: <http://prc.coh.org/pdf/PNKAS-AK2002.pdf>.
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>.
  - Psychosocial Pain Assessment Forms in Spanish (for adults and children/adolescents):  
Spanish - Adults: <http://prc.coh.org/pdf/Forma%20%20Adultos%20PS.pdf>.  
Spanish - Children/Adolescents: <http://prc.coh.org/pdf/Formulario%20Ninos.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](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](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.  
Website: [http://prc.coh.org/html/rehab\\_professionals.htm](http://prc.coh.org/html/rehab_professionals.htm).
31. Survivorship Needs Assessment Tools  
Survivorship 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](http://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  
Website: <http://prc.coh.org/Survivorship/St%20Luke%20Eng.pdf>
  - Survivor Needs Assessment (Spanish) - St. Luke’s Hospital and Health Network  
Website: <http://prc.coh.org/Survivorship/StLuke%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](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/pcoc/toolkit.htm>.
33. WHO (Five) Well-Being Index – Psychiatric Research Unit, WHO Collaborating Centre for Mental Health, Frederiksberg 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**

1. **American Chronic Pain Association Chronicle** - a patient-oriented quarterly newsletter. It includes letters, essays, articles, and book reviews written by people with chronic pain or their families. Periodically, healthcare professionals have inclusions. Website: <http://www.theacpa.org/60/Chronicle.aspx>.
2. **American Geriatrics Society Newsletter** - dedicated to improving the health, independence and quality of life of all older people. Website: <http://www.americangeriatrics.org/files/documents/newsletters/2012q4/index.html>
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](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/elnecc/publications/elnecc-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/ejpc/home.asp?FR=1>.
9. **Health Progress: Journal of the Catholic Health Association of the United States** - Official journal of the Catholic Health Association of the United States, published six times a year on topics of importance to Catholic health care. Website: <http://www.chausa.org/home/>.
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/>.
11. **Journal for Interdisciplinary Research on Religion and Science** - an international forum for interdisciplinary research on philosophy, religion, and science. An e-journal published twice a year. Website: <http://www.jirrs.org/>.
12. **Journal for the Scientific Study of Religion** -- is a multi-disciplinary journal that publishes articles, research notes, and book reviews on the social scientific study of religion. Substantive areas include both micro-level analysis of religious organizations, institutions, and social change. Website: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1468-5906](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1468-5906).
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>.

14. **Journal of Hospice and Palliative Nursing** –a bi-monthly peer-reviewed journal for nurses in hospice and palliative care settings. Website: [http://www.nursingcenter.com/library/journalissue.asp?Journal\\_ID=260877&Issue\\_ID=576277](http://www.nursingcenter.com/library/journalissue.asp?Journal_ID=260877&Issue_ID=576277).
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>.
16. **Journal of Pain & Palliative Care Pharmacotherapy** – advances in acute, chronic, and end-of-life pain and symptom control.  
Website: <http://informahealthcare.com/loi/ppc>.
17. **Journal of Pain and Symptom Management** – monthly journal that publishes original articles and other clinical papers.  
Website: <http://www.elsevier.com/locate/jpainsymman>.
18. **Journal of Palliative Medicine** – the journal covers the team approach to palliative medicine, pain and symptom management, palliative-care education, legal, ethical, and reimbursement issues, and more.  
Website: [http://www.liebertpub.com/publication.aspx?pub\\_id=41](http://www.liebertpub.com/publication.aspx?pub_id=41).
19. **Journal of Psychosocial Nursing and Mental Health Services** – covers current news in psychosocial nursing, updates on psychopharmacology, geopsychiatry, and mental health nursing. Website: <http://www.healio.com/psychiatry/journals/jpn/>.
20. **Journal of Religion and Health** – explores contemporary modes of religious and spiritual thought with particular emphasis on their relevance to current medical and psychological research. Publishes original peer-reviewed articles that deal with mental and psychical health in relation to religion and spirituality of all kinds.  
Website: <http://www.springer.com/public+health/journal/10943>.
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>.
22. **NHPCO Newslines** – 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>.
23. **PAIN** – official publication of the International Association for the Study of Pain (IASP).  
Website: <http://www.iasp-pain.org/PublicationsNews/PAIN.aspx?navItemNumber=570>.
24. **Pain: Clinical Updates** – International Association for the Study of Pain (IASP) - provides periodic supplements devoted to specific pain conditions and related research.  
Website: <http://www.iasp-pain.org/PublicationsNews/PainClinicalUpdates.aspx?navItemNumber=571>.
25. **Pain Medicine** – official journal of the American Academy of Pain Medicine. Published 4 times a year by Blackwell Science, Inc. Website: [http://www.painmed.org/Library/Pain\\_Medicine\\_Journal.aspx](http://www.painmed.org/Library/Pain_Medicine_Journal.aspx).
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/>.
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/>.
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>.
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/>.

30. **Psycho-Oncology** - quarterly journal concerned with the psychological, behavioral, and ethical aspects of cancer.  
Website: <http://www.wiley.com/WileyCDA/WileyTitle/productCd-PON.html>.
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?sitePagelId=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>.
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
  - For healthcare professionals looking for the right words of spiritual comfort in difficult circumstances relating to death or illness. This app offers overviews of central beliefs, traditional prayers, and descriptions of common practices relating to illness and end-of-life care for Buddhism, Christianity, Hinduism, Islam, and Judaism.  
Available at iTunes <http://itunes.apple.com/us/app/interfaith-care-for-the-ill/id421099962?mt=8>.
5. International Psycho-Oncology Society
  - Multilingual Core Curriculum Lectures in Psycho-Oncology(English, French, German, Hungarian, Spanish, & Italian)  
Website: <http://ipos-society.org/publications/multilingual-core-curriculum-in-psycho-oncology/>.
6. American Academy of Hospice and Palliative Medicine (AAHPM) Blog  
Website: <http://www.aahpm.org/apps/blog/>
7. GeriPal: A Geriatric & Palliative Care Blog  
Website: <http://www.geripal.org/>
8. Get Palliative Blog  
Website: <http://getpalliativecare.org/blog/>
9. Pain Care Blog  
Website: <http://www.paincareblog.com/>.
10. Pain Care MD  
Website: <http://www.paincaremd.com/paincare-blog/>
11. Palliative Care: A Lifeline to Quality of Life  
Website: <http://www.youtube.com/watch?v=qXh7TW3lyP4>
12. Palliative Care Success Blog  
Website: <http://palliativemedicine.blogspot.com/>.



13. Pallimed: A Hospice & Palliative Medicine Blog  
Website: <http://www.pallimed.org/>.
14. Smart Patients (an online community for cancer patients)  
Website: <https://www.smartpatients.com/>
15. Stronger Together - Cancer Digital Magazine - FREE resources for ALL people touched by cancer
16. The Health Care Blog  
Website: <http://thehealthcareblog.com/>.
17. The Integrator Blog (Integrative Medicine)  
Website: [http://theintegratorblog.com/index.php?option=com\\_content&task=view&id=868&Itemid=189](http://theintegratorblog.com/index.php?option=com_content&task=view&id=868&Itemid=189)

## 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>
- ❖ Academic Consortium for Complementary & Alternative Health Care - <http://www.accahc.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, HPNF, HPC - <http://advancingexpertcare.org/>
- ❖ AETC National Resource Center - <http://aidsetc.org/>
- ❖ AgingCare.com: Connecting Caregivers - <http://www.agingcare.com/>
- ❖ Agency for Healthcare Research and Quality - <http://www.ahrq.gov>
- ❖ Aging with Dignity - <http://www.agingwithdignity.org>
- ❖ Aging Parents and Elder Care - <http://www.aging-parents-and-elder-care.com/>
- ❖ AIDS Answers - <http://aids.answers.com/>
- ❖ AIDS.org - <http://www.aids.org/>
- ❖ AIDS Healthcare Foundation - <http://www.aidshealth.org/>
- ❖ AIDS Info - <http://www.aidsinfo.nih.gov/>
- ❖ AIDSMEDS - <http://www.aidsmeds.com/>
- ❖ AIDS Official Journal of the International AIDS Society - <http://www.aidsonline.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 Hospice and Palliative Medicine (AAHPM) - <http://www.aahpm.org>
- ❖ American Academy of Medical Acupuncture - <http://www.medicalacupuncture.org/>
- ❖ American Academy of Pain Management - <http://www.aapainmanage.org/>
- ❖ American Academy of Pain Medicine - <http://www.painmed.org>
- ❖ American Academy of Pediatrics - <http://www.aap.org>
- ❖ American Art Therapy Association - <http://www.arttherapy.org/>
- ❖ American Assisted Living Nurses Association - <http://www.alnursing.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 Espanol)
- ❖ 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 -

[http://www.acponline.org/running\\_practice/ethics/issues/policy/caregivers\\_appendix.pdf](http://www.acponline.org/running_practice/ethics/issues/policy/caregivers_appendix.pdf)

- ❖ American College of Rheumatology - <http://www.rheumatology.org/>
- ❖ American Geriatrics Society - <http://www.americangeriatrics.org/>
- ❖ American Headache Society - <http://www.americanheadachesociety.org/>
- ❖ American Holistic Nurses Association - <http://www.ahna.org/>
- ❖ American Hospice Foundation - <http://www.americanhospice.org>
- ❖ American Hospital Association - <http://www.aha.org>
- ❖ American Journal of Nursing - <http://www.ajnonline.com/>
- ❖ American Massage Therapy Association - <http://www.amtamassage.org>
- ❖ American Medical Association - <http://www.ama-assn.org>
- ❖ American Music Therapy Association - <http://www.musictherapy.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>
- ❖ American Society of Regional Anesthesia and Pain Medicine - <http://www.asra.com>
- ❖ 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>
- ❖ Assisted Living Directory - <http://www.assisted-living-directory.com/>
- ❖ 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/>
- ❖ AVERTing HIV and AIDS - <http://www.avert.org/hiv-aids-help-and-advice-us.htm>

## B

- ❖ Bandaides & Blackboards - <http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/>
- ❖ Be Med Wise - <http://bemedwise.org/>
- ❖ Before I Die: Medical Care and Personal Choices - <http://www.thirteen.org/bid/>
- ❖ Be The Match: Bone Marrow Donor - <http://www.marrow.org/>
- ❖ Bereavement Support Group - <http://www.mdjunction.com/bereavement>
- ❖ Between a Rock and a Hard Place: Clinical Ethics in Action - <http://blog.nutritioncare.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/>

- ❖ Canadian Cancer Society – <http://cancer.ca>
- ❖ Canadian Society for Spirituality & Social Work – <http://w3.stu.ca/stu/sites/spirituality/index.html>
- ❖ CancerCare – <http://www.cancercares.org>
- ❖ CancerConnect.com – <http://news.cancerconnect.com/>
- ❖ Cancer and Careers – <http://www.cancerandcareers.org>
- ❖ Cancer Health Disparities – <http://www.cancer.gov/cancertopics/disparities>
- ❖ Cancer Hope Network – <http://www.cancerhopenetwork.org>
- ❖ Cancer Library – <http://www.cancer.gov/cancertopics/cancerlibrary>
- ❖ Cancer Hope Network – <http://www.cancerhopenetwork.org/index.php?page=home>
- ❖ Cancer.Net: Caregiver Support – <http://www.cancer.net/coping-and-emotions/caregiver-support>
- ❖ Cancer-Pain.org – <http://www.cancer-pain.org/>
- ❖ Cancer Pain Management in Children – <http://www.childcancerpain.org/>
- ❖ Cancer Pain Release – <http://www.whocancerpain.wisc.edu/>
- ❖ Cancer Support Community – <http://www.cancersupportcommunity.org/>
- ❖ Cancer Survivors Network – <http://csn.cancer.org/>
- ❖ Cancer Survivors Toolbox – <http://www.canceradvocacy.org/toolbox/>
- ❖ Cancer Treatment Centers of America – <http://www.cancercenter.com>
- ❖ Can't Believe I Have Cancer – <http://cantbelieveihavecancer.org/>
- ❖ Careforce – <http://careforce.com>
- ❖ Caregiver.com – <http://www.caregiver.com/>
- ❖ Caregiver Action Network – <http://caregiveraction.org/>
- ❖ Caregiver Resource Directory for Recovering Service Members – <http://warriorcare.dodlive.mil/files/2013/08/Caregiver-Directory-Printer-Friendly-8-5-x-11.pdf>
- ❖ Caregiving Resource Center – <http://www.aarp.org/home-family/caregiving/>
- ❖ Caregiving.com – <http://www.caregiving.com>
- ❖ Care Search: Palliative Care Knowledge Network – <http://www.caresearch.com.au/caresearch>
- ❖ Caring.com – <http://caring.com>
- ❖ Caring Connections – <http://www.caringinfo.org/>
- ❖ Caring for the Patient with Cancer at Home – <http://www.cancer.org/acs/groups/cid/documents/webcontent/002818-pdf.pdf>
- ❖ Catholic Health Association – <http://www.chausa.org>
- ❖ Center for Bioethics & Human Dignity – <http://www.cbhd.org/>
- ❖ Center for Bioethics and Medical Humanities – <http://www.mcw.edu/bioethicsandmedhumanities.htm>
- ❖ Center for Ethics in Health Care – <http://www.ohsu.edu/ethics/>
- ❖ Center for Healthcare Decisions – <http://www.chcd.org/>
- ❖ Center for Hospice Care – <http://www.centerforhospice.org/>
- ❖ Center for Medical Ethics and Health Policy – <http://www.bcm.edu/ethics/>
- ❖ Center for the Study of Bioethics – <http://www.mcw.edu/bioethics.htm>
- ❖ Center to Advance Palliative Care – <http://www.capc.org/>
- ❖ Centre for Pediatric Pain Research – <http://pediatric-pain.ca/>
- ❖ Chaplains on Hand – Providing Spiritual Comfort – [Chaplainsonhand.org](http://Chaplainsonhand.org)
- ❖ Child/Adolescent Health – <http://www.ahrq.gov/health-care-information/priority-populations/children/index.html>
- ❖ Childhood Cancer Guides – <http://childhoodcancerguides.org/>
- ❖ Children's Hospice International – <http://www.chionline.org>
- ❖ Children's Project on Palliative/Hospice Services – <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3409>
- ❖ Children's Organ Transplant Association – <http://www.cota.org>
- ❖ Chronic Nonmalignant Pain – <http://www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/psychiatry-psychology/chronic-nonmalignant-pain/>
- ❖ Clinical Communication Collaborative – <http://www.clinicalcc.com/>
- ❖ Communicating with Patients – <http://www.aha.org/advocacy-issues/communicatingpts>
- ❖ Cluster Headaches – <http://www.clusterheadaches.com/>
- ❖ Coalition for Compassionate Care of California – <http://finalchoices.org>
- ❖ Compassion & Choices – <http://www.compassionandchoices.org/>
- ❖ Compassion in Action - USA – <http://www.compassioninaction.us/index.cfm>
- ❖ Compassion and Choices – <http://www.compassionandchoices.org/>
- ❖ Compassion Books – <http://www.compassionbooks.com/>
- ❖ Compassionate Friends: Supporting Family After a Child Dies – <http://www.compassionatefriends.org>

- ❖ Complementary & Alternative Medicine - [http://www.cancer.org/Treatment/TreatmentsandSideEffects/Complementary and AlternativeMedicine/index](http://www.cancer.org/Treatment/TreatmentsandSideEffects/ComplementaryandAlternativeMedicine/index)
- ❖ Complementary Medicine/Alternative Medicine News - [http://www.medicalnewstoday.com/categories/complementary\\_medicine](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>
- ❖ Critical Path Project - <http://www.critpath.org/cpap/index.php>
- ❖ 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/>

## D

- ❖ Decisions Near the End of Life - <http://www.ache.org/policy/endoflif.cfm>
- ❖ 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>

## E

- ❖ 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/](http://www.aarp.org/families/end_life/)
- ❖ End-of-Life Care for Children with Terminal Illness - [http://kidshealth.org/parent/system/ill/bfs\\_hospice\\_care.html](http://kidshealth.org/parent/system/ill/bfs_hospice_care.html)
- ❖ End-of-Life: Exploring Death in America - <http://www.npr.org/programs/death/971106.death.html>
- ❖ End-of-Life Nursing Education Consortium (ELNEC) - <http://www.aacn.nche.edu/el nec>
- ❖ End-of-Life/Palliative Education Resource Center (EPERC) - <http://www.mcw.edu/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/>

## F

- ❖ Families Facing Cancer: Emotional & Practical Support - <http://familiesfacingcancer.org/>
- ❖ Family Caregiver Alliance - <http://www.caregiver.org>
- ❖ Family Caregiver Support Group - <http://www.caregiversupportnetwork.org/default.asp?id=1>
- ❖ Fibromyalgia, Chronic Fatigue & Central Sensitivity Syndrome Online Resource - <http://dewarlorx.com/fibromyalgia.htm>
- ❖ Fibromyalgia Information Foundation - <http://www.myalgia.com/>
- ❖ Fibromyalgia Network - <http://www.fmnetnews.com>
- ❖ Fibromyalgia Support Group - <http://www.mdjunction.com/fibromyalgia>
- ❖ Fibromyalgia Treatment Center - <http://fibromyalgiatreatment.com/>
- ❖ Finding Comfort in Spirituality - [http://www.nccn.org/patients/resources/life\\_with\\_cancer/spirituality.aspx](http://www.nccn.org/patients/resources/life_with_cancer/spirituality.aspx)
- ❖ For Grace: Empowering Women in Pain - [http://www.forgrace.org/women/in/pain\\_home/](http://www.forgrace.org/women/in/pain_home/)
- ❖ Frankly Speaking About Cancer - <http://www.cancersupportcommunity.org/MainMenu/About-Cancer/Frankly-Speaking-About-Cancer>
- ❖ Full Circle of Care - <http://www.fullcirclecare.org/>

## G

- ❖ GMHC - Fight Aids. Love Life. - <http://www.gmhc.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>
- ❖ Guide to Internet Resources for Cancer - <http://www.cancerindex.org/clinks1.htm>

## H

- ❖ HIV/AIDS - <http://www.publichealth.org/resources/hiv-aids/>
- ❖ HIV/AIDS Clinical Care - <http://aids-clinical-care.jwatch.org/>
- ❖ HIV/AIDS Nursing Certification Board - <http://www.hancb.org/>
- ❖ HIV/AIDS Program - <http://www.ihs.gov/MedicalPrograms/HIVAIDS/index.cfm?module=research>
- ❖ HIV Clinical Resource - <http://www.hivguidelines.org/Content.aspx>
- ❖ HRSA HIV/AIDS Programs - <http://hab.hrsa.gov/>
- ❖ Harvard Medical School Center for Palliative Care - <http://www.hms.harvard.edu/pallcare/>
- ❖ The Hastings Center: Promoting Ethics in Health, Medicine & Environment - <http://www.thehastingscenter.org/>
- ❖ Healing Beyond Borders: Educating and Certifying the Healing Touch - <http://www.healingtouchinternational.org/>
- ❖ HealthCare Chaplaincy Network - <http://www.healthcarechaplaincy.org/>
- ❖ Healthfinder.gov - <http://www.healthfinder.gov/>
- ❖ AllRefer.com: Health - <http://health.allrefer.com/>
- ❖ Help for Headaches - <http://www.headache-help.org/>
- ❖ Hopkins Opioid Program - <http://www.hopweb.org/index.cfm?cfid=3623510&cftoken=22742986>
- ❖ 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.ihp.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/>
- ❖ Inter-Institutional Collaborating Network on End of Life Care - <http://growthhouse.org/iicn.html>
- ❖ 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/ipcfrc/>
- ❖ International Society for Quality of Life Research (ISOQOL) - <http://www.isoqol.org/>

## J

- ❖ Joe's House: A Lodging Guide for Cancer Patients - <http://www.joeshouse.org/>
- ❖ Joint Centre for Bioethics - <http://www.jointcentreforbioethics.ca/>

## K

- ❖ Kids Against Cancer - <http://www.kidsagainstcancer.org>
- ❖ Kidsaid: 2 Kids, 4 Kids, By Kids - <http://kidsaid.com/>
- ❖ KidsHealth - <http://www.kidshealth.org/>

## L

- ❖ LIVESTRONG - <http://www.livestrong.org>
- ❖ Legal Side of Pain - <http://www.legalsideofpain.com/>
- ❖ Leukemia & Lymphoma Society - [http://www.leukemia.org/hm\\_lls](http://www.leukemia.org/hm_lls)

- ❖ Liam's Foundation for Pediatric Palliative Care - <http://www.liamsfoundation.org/>
- ❖ Listen with Your Heart - <http://www.cancer.org/treatment/understandingyourdiagnosis/talkingaboutcancer/listenwithyourheart>
- ❖ Living Beyond Cancer - <http://www.mskcc.org/mskcc/html/58022.cfm>
- ❖ Long Term Care Planning Network - <http://www.ltcplanningnetwork.com/>
- ❖ Loving Touch Infant Massage - <http://www.lovingtouch.com/>
- ❖ Low Cost Prescription Drugs: Patient Assistant Programs - [http://www.thelivingweb.net/lowcost\\_prescription\\_drugs.html](http://www.thelivingweb.net/lowcost_prescription_drugs.html)

## M

- ❖ MAGNUM: The National Migraine Association - <http://www.migraines.org/>
- ❖ Make A Wish Foundation - <http://www.wish.org>
- ❖ MDJunction: Support Groups for Your Health Challenges - <http://www.mdjunction.com>
- ❖ Medal Medical Algorithms - <http://www.medal.org/>
- ❖ MedicineNet.com - <http://www.medicinenet.com/script/main/hp.asp>
- ❖ Memorial Sloan Kettering Cancer Care - <http://www.mskcc.org>
- ❖ Mesothelioma & Asbestos Awareness Center - <http://www.maacenter.org/>
- ❖ Mesothelioma Cancer Alliance - <http://www.mesothelioma.com/>
- ❖ Mesothelioma Guide - <http://www.mesotheliomaguide.com/>
- ❖ Mesothelioma Treatment - <http://www.asbestos.com/treatment/>
- ❖ Minority Nurse: What Color is Your Pain? - <http://www.minoritynurse.com/nurse-led-interventions/what-color-your-pain>
- ❖ Mom Always: Help for Mothers Facing Terminal Diagnosis - <http://www.momalways.org/>
- ❖ Multicultural Health Care and Cultural Competence - <https://network-health.org/Providers/Programs-and-Services/Multicultural-health-care-and-cultural-competence.aspx>
- ❖ 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/>

## N

- ❖ National Alliance for Caregiving - <http://www.caregiving.org/>
- ❖ National Alliance for Hispanic Health - <http://www.hispanichealth.org/>
- ❖ National Association for Home Care & Hospice - <http://www.nahc.org/>
- ❖ National Association of Clinical Nurse Specialists - <http://www.nacns.org/>
- ❖ National Association of Social Workers - <http://www.naswdc.org/>
- ❖ National Brain Tumor Society - <http://www.braintumor.org/>
- ❖ National Cancer Comprehensive Network - <http://www.nccn.org/>
- ❖ National Cancer Institute - <http://www.cancer.gov/>
- ❖ National Center for Complementary and Alternative Medicine - <http://nccam.nih.gov>
- ❖ National Center for Cultural Competence - <http://nccc.georgetown.edu/>
- ❖ National Center for Health Statistics - <http://www.cdc.gov/nchs/>
- ❖ National Children's Cancer Society - <http://www.children-cancer.org>
- ❖ 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 Partnership, Inc. - <http://www.fmpartnership.org/>
- ❖ National Fibromyalgia Research Association - <http://www.nfra.net/>
- ❖ National Guideline Clearinghouse - <http://www.guideline.gov/>
- ❖ National Headache Foundation - <http://www.headaches.org/>
- ❖ National Health Council - <http://www.nationalhealthcouncil.org/>
- ❖ National Hospice and Palliative Care Organization - <http://www.nhpco.org>
- ❖ National Institute of Aging - <http://www.nia.nih.gov/>
- ❖ National Institute on Minority Health and Health Disparities - <http://www.nimhd.nih.gov/>
- ❖ National League for Nursing - <http://www.nln.org/>
- ❖ National Marrow Donor Program - <http://www.marrow.org/PATIENT/Caregiving/index.html>
- ❖ 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 Drug Handbook - <http://ndhnow.com/>
- ❖ Nursing World - <http://nursingworld.org/>

## O

- ❖ Office of Cancer Complementary & Alternative Medicine - <http://cam.cancer.gov/cam/>
- ❖ Office of Cancer Survivorship - <http://cancercontrol.cancer.gov/ocs/>
- ❖ Office of Minority Health - <http://minorityhealth.hhs.gov/>
- ❖ On Our Own Terms: Moyers on Dying in America - <http://www.pbs.org/wnet/onourown/terms>
- ❖ 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.osher.ucsf.edu/>
- ❖ Oxford Pain Internet Site - <http://www.medicine.ox.ac.uk/bandolier/booth/painpag/>

## P

- ❖ Pain.com - <http://www.pain.com/>
- ❖ Pain & Chemical Dependency - <http://www.stoppain.org/pcd/default.asp>
- ❖ Pain & Policy Studies Group - <http://www.painpolicy.wisc.edu/>
- ❖ Pain Action - <http://www.painaction.com/>
- ❖ Pain Connection - <http://www.painconnection.org>
- ❖ Pain Community - <http://paincommunity.org>
- ❖ Pain Medicine News - <http://painmedicineneeds.com/>
- ❖ Pain Research Forum - <http://www.painresearchforum.org/>
- ❖ PainEDU - <https://www.painedu.org/>
- ❖ Palliative Care - <http://www.growthhouse.org/palliat.html>
- ❖ Palliative Care Communication Institute - <http://pccinstitute.com/>
- ❖ Palliative Care in Cancer - <http://www.cancer.gov/cancertopics/factsheet/Support/palliative-care>
- ❖ 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>
- ❖ Patient Resource Cancer Guide - [http://www.patientresource.com/Cancer\\_Guides.aspx](http://www.patientresource.com/Cancer_Guides.aspx)
- ❖ Pediatric Art Therapy for Children with Cancer - <http://www.tracyskids.org/>
- ❖ Pediatric HIV/AIDS Care, Inc. - <http://www.k12academics.com/national-directories/volunteer-program/pediatric-aidshiv-care-inc>
- ❖ 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/>

- ❖ Provider's Guide to Quality & Culture - <http://erc.msh.org/mainpage.cfm?file=1.0.htm&module=provider&language=English>

## Q

- ❖ Quality of Life with Cancer Supportive Care - <http://www.cancersupportivecare.com/qol.html#TOC>

## R

- ❖ R.A. Bloch Cancer Foundation and Hotline - <http://blochcancer.org/>
- ❖ RSDSA: Supporting the CPRS Community - <http://www.rsd.org/>
- ❖ Remedy's Health Communities: Cancer - <http://www.healthcommunities.com/health-topics/cancer.shtml>
- ❖ Resources and Links for Patients and Families - [www.aosw.org/AOSW/AOSWMain/People-Affected-by-Cancer/resources-and-links.aspx](http://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/>
- ❖ Robert Wood Johnson Foundation - <http://www.rwjf.org>
- ❖ Rosalynn Carter Institute for Caregiving - <http://www.rosalynncarter.org/>

## S

- ❖ SAMfund for Young Adult Survivors of Cancer) - <http://www.thesamfund.org/>
- ❖ SHARE Pregnancy & Infant Loss Support - <http://www.nationalshare.org/>
- ❖ Shaare Zedek Cancer Pain & Palliative Medicine Reference Database - <http://chernydatabase.org/>
- ❖ Sickle Cell Anemia - MedLine Plus - <http://www.nlm.nih.gov/medlineplus/sicklecellanemia.html>
- ❖ Sickle Cell Disease - For Kids & Teens - [http://kidshealth.org/kid/health\\_problems/blood/sickle\\_cell.html](http://kidshealth.org/kid/health_problems/blood/sickle_cell.html)
- ❖ Sickle Cell Disease - March of Dimes - [http://www.marchofdimes.com/baby/birthdefects\\_sicklecell.html](http://www.marchofdimes.com/baby/birthdefects_sicklecell.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/>
- ❖ Spine-Health - <http://spine-health.com/>
- ❖ StopPain.org - <http://www.stoppain.org/>
- ❖ Stronger Together Cancer Digital Magazine FREE resources for ALL people touched by cancer - [http://mydigimag.rrd.com/publication/?i=250044#{%22issue\\_id%22:250044,%22numpages%22:1,%22page%22:1}](http://mydigimag.rrd.com/publication/?i=250044#{%22issue_id%22:250044,%22numpages%22:1,%22page%22:1})
- ❖ Strengthening the Spirit - [http://www.cancer.org/publications/56-strengthening\\_the\\_spirit](http://www.cancer.org/publications/56-strengthening_the_spirit)
- ❖ Suncoast Hospice - <http://www.thehospice.org>
- ❖ Supportive Care Coalition - <http://www.supportivecarecoalition.org/>
- ❖ Survivorship Center: Living Beyond Cancer - <http://www.mskcc.org/mskcc/html/58022.cfm>
- ❖ Susan G. Komen for the Cure - <http://ww5.komen.org/>

## T

- ❖ Tanenbaum: Combating Religious Prejudice - <https://www.tanenbaum.org/>
- ❖ The Body: The Complete HIV/AIDS Resource - <http://www.thebody.com/>
- ❖ The Cancer Journey - <http://www.thecancerjourney.com/>
- ❖ 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/>
- ❖ TIME: Toolkit of Instruments to Measure End-of-Life Care - <http://www.chcr.brown.edu/pcoc/toolkit.htm>
- ❖ Today's Caregiver - <http://www.caregiver.com/>
- ❖ Transcultural C.A.R.E. Associates - <http://www.transculturalcare.net/>
- ❖ Transcultural Nursing - <http://www.culturediversity.org/>
- ❖ Transcultural Nursing Society - <http://www.tcns.org/>



## U

- ❖ UCLA Cancer Center Survivorship - <http://www.cancer.ucla.edu/Index.aspx?page=6>
- ❖ Union for International Cancer Control - <http://uicc.org/>
- ❖ United Hospital Fund - <http://www.uhfny.org>
- ❖ U.S. National AIDS Hotlines & Resources - <http://www.thebody.com/index/hotlines/national.html>

## V

- ❖ Vital Options International - <http://www.vitaloptions.org/>
- ❖ Vulvar Pain Foundation - <http://www.vulvarpainfoundation.org>

## W

- ❖ WebMD - Health - <http://my.webmd.com/>
- ❖ Well Spouse Association - <http://www.wellspouse.org/>
- ❖ What Is Pediatric Palliative Care? - <http://getpalliativecare.org/whatis/pediatric/>
- ❖ Women, Children, and HIV - <http://www.womenchildrenhiv.org/>
- ❖ Women's Cancer Network - <http://www.wcn.org>
- ❖ Worldwide Congress on Pain - <http://www.pain.com/>
- ❖ World Institute of Pain - <http://worldinstituteofpain.org>

## Y

- ❖ Young Survival Coalition - <http://www.youngsurvival.org>