

**CONTENTS and ANNOTATED BIBLIOGRAPHY  
PEDIATRIC END-OF-LIFE CASE STUDIES PPT**

<b><u>CONTENTS</u></b>	<b><u>SLIDE #s</u></b>
<b>INTRODUCTION</b>	<b>1 – 15</b>
<b>OVERVIEW</b>	<b>16 – 105</b>
<b>SECTION ONE: Children Who Suffer and Pediatric Palliative Care</b>	<b>17 - 32</b>
<b>SECTION TWO: Children Who Die and Hospice Care</b>	<b>33 – 48</b>
<b>SECTION THREE: Communication Along the Continuum Of Care</b>	<b>49 – 105</b>

**ANNOTATED BIBLIOGRAPHY**

**Introduction: Slide 9**

Korones, D.N. "Pediatric palliative care." Pediatric Review 2007 Aug;28(8):e46-e56.  
Morbidity and Mortality Weekly Report. Dec. 7, 2007;56(48):1257-1261.

**Introduction: Slide 10**

Docherty, S.L., Miles, M.S., Brandon, D. "Searching for 'the dying point:' Providers' experiences with palliative care in pediatrics acute care." Posted (<http://www.medscape.com/viewarticle/563199>): 10/10/2007. Pediatr Nurs 2007;33(4):335-341. © 2007 Jannetti Publications, Inc.

**Section One: Needs of children who suffer, Slide 18**

Wolfe, J., Grier, H.E., Klar, N., Levin, S., Ellenbogen, J.M., Schatz, S.S., Emanuel, E.J., and Weeks, J.C. "Symptoms and suffering at the end of life in children with cancer." N Engl J of Med 2000;342(5):326-333.

Himmelstein, B.P., Hilden, J.M., Boldt, A.M., Weissman, D. "Pediatric palliative care." N Engl J Med 2004;350(17):1752-1762.

**Section One: Needs of children who suffer, Slide 19**

Mack, J.W. and Wolfe, J. "Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis." Current Opinion in Pediatrics 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section One: Needs of children who suffer, Slide 20**

Feudtner, C., Hays, R.M., Haynes, G., Geyer, J.R., Neff, J.M., Koepsell, T.D. "Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services." Pediatrics 2001;107(6):e99. \* Note: This estimate spans an additional five years beyond the 0–19 age range provided earlier.

**Section One: What is pediatric palliative care? Slide 21**

Institute of Medicine (IOM). Committee on Palliative and End-of-Life Care for Children and Their Families. When children die: Improving palliative and end-of-life care for children and their

families. Behrman, R., and Field, M., (Eds). Washington DC: National Academies Press. 2003a:41-70.

**Section One: What is pediatric palliative care? Slide 22**

“Palliative care vs. other services.” Center to Advance Palliative Care. Accessed online on December 27, 2011 at [http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc/designing/presenting-plan/pc\\_vs\\_other/](http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc/designing/presenting-plan/pc_vs_other/).

“Financing pediatric palliative and hospice care programs.” A publication of the Catalyst Center: Improving financing of care for children and youth with special health care needs, April, 2011. The Catalyst Center is a project of the Health & Disability Working Group at the Boston University School of Public Health and is funded by the federal Maternal and Child Health Bureau of the Health Services and Resources Administration, U.S. Department of Health and Human Services, under grant #U41MC13618. Accessed online on Dec. 17, 2011 at <http://hdwg.org/catalyst/news/2011-05-19/2>.

**Section One: Palliative care is, Palliative care is not, Slide 23**

Diane E. Meier, MD. “The clinical essentials of palliative care.” *Slide 5*. Center to Advance Palliative Care in Hospitals and Health Systems. A *Robert Wood Johnson Foundation - Mount Sinai School of Medicine Initiative*.

**Section One: Benefits of pediatric palliative care, Slide 24**

Mack, J.W. and Wolfe, J. “Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis.” *Current Opinion in Pediatrics* 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section One: Benefits of pediatric palliative care, Slide 25**

“Palliative care improving clinical outcomes.” Center to Advance Palliative Care. Accessed online on December 27, 2011 at <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/outcomes>.

**Section One: The number of children receiving palliative care is on the rise, Slide 26**

Friebert S. “NHPCO facts and figures: Pediatric palliative and hospice care in America.” National Hospice and Palliative Care Organization. April 2009. Accessed December 18, 2011 at [http://www.nhpc.org/files/public/quality/Pediatric\\_Facts-Figures.pdf](http://www.nhpc.org/files/public/quality/Pediatric_Facts-Figures.pdf)

**Section One: Challenges to pediatric palliative care, Slides 27 & 28**

“Financing pediatric palliative and hospice care programs.” A publication of the Catalyst Center: Improving financing of care for children and youth with special health care needs, April, 2011. The Catalyst Center is a project of the Health & Disability Working Group at the Boston University School of Public Health and is funded by the federal Maternal and Child Health Bureau of the Health Services and Resources Administration, U.S. Department of Health and Human Services, under grant #U41MC13618. Accessed online on Dec. 17, 2011 at <http://hdwg.org/catalyst/news/2011-05-19/2>.

**Section One: Challenges to pediatric palliative care, Slide 29**

The Patient Protection and Affordable Care Act of 2010, Section 2302 “Concurrent care for children”.

See also the [Concurrent Care for Children Implementation Toolkit](http://www.dcppcc.org/professionals/implementation_toolkit.html):  
[http://www.dcppcc.org/professionals/implementation\\_toolkit.html](http://www.dcppcc.org/professionals/implementation_toolkit.html)

**Section One: Challenges to pediatric palliative care, Slides 30 & 31**

“Financing pediatric palliative and hospice care programs.” A publication of the Catalyst Center: Improving financing of care for children and youth with special health care needs, April, 2011. The Catalyst Center is a project of the Health & Disability Working Group at the Boston University School of Public Health and is funded by the federal Maternal and Child Health Bureau of the Health Services and Resources Administration, U.S. Department of Health and Human Services, under grant #U41MC13618. Accessed online on Dec. 17, 2011 at <http://hdwg.org/catalyst/news/2011-05-19/2>.

**Section One: Model pediatric palliative care, Slide 32**

American Academy of Pediatrics (AAP). Committee on Bioethics and Committee on Hospital Care. “Palliative care for children.” *Pediatrics* 2000;106(2):351-357. A statement of reaffirmation for this policy was published on February 1, 2007. {Online}. Available: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;106/2/351> [accessed January 5, 2008].

**Section Two: Children are not supposed to get sick and die, but some do, Slide 33**

Children’s International Project on Palliative/Hospice Services (ChIPPS), Administrative/Policy Workgroup of the National Hospice and Palliative Care Organization. “A call for change: Recommendations to improve the care of children living with life-threatening conditions.” Alexandria, VA. October 2001.

Institute of Medicine (IOM). Committee on Palliative and End-of-Life Care for Children and Their Families. *When children die: Improving palliative and end-of-life care for children and their families.* Behrman, R., and Field, M., (Eds). Washington DC: National Academies Press. 2003a:41-70.

Morbidity and Mortality Weekly Report. Dec. 7, 2007;56(48):1257-1261.

Friebert, S. “2009 NHPCO facts and figures: pediatric palliative and hospice care in America.” © April 2009, National Hospice and Palliative Care Organization.

**Section Two: Needs of children who die, Slide 35**

Mack, J.W. and Wolfe, J. “Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis.” *Curr Opin Pediatr* 18:10-14 © 2006 Lippincott Williams & Wilkins.

**Section Two: Needs of children who die, Slide 36**

Wolfe, J., Grier, H.E., Klar, N., Levin, S., Ellenbogen, J.M., Schatz, S.S., Emanuel, E.J., and Weeks, J.C. “Symptoms and suffering at the end of life in children with cancer.” *N Engl J of Med* 2000;342(5):326-333.

**Section Two: Needs of children who die, Slide 37**

Mack, J.W. and Wolfe, J. “Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis.” *Curr Opin Pediatr* 18:10-14 © 2006 Lippincott Williams & Wilkins.

**Section Two: Needs of children who die, Slide 38**

Feudtner, C., Hays, R.M., Haynes, G., Geyer, J.R., Neff, J.M., Koepsell, T.D. "Deaths attributed to pediatric complex chronic conditions: National trends and implications for supportive care services." *Pediatrics* 2001;107(6):e99. \* Note: This estimate spans an additional five years beyond the 0–19 age range provided earlier.

**Section Two: What is “traditional” children’s hospice care? Slides 39, 40, 41 & 42**

Morrow, A. "What Is hospice care? Hospice care promotes comfort and quality of life." Updated October 02, 2009. ©2011 About.com. All rights reserved. A part of [The New York Times Company](#). About.com Health's Disease and Condition content is reviewed by the [Medical Review Board](#). Accessed online on December 27, 2011 at <http://dying.about.com/od/whatishospice/a/whatishospice.htm>.

**Section Two: The number of children receiving hospice care is on the rise, Slide 43**

Walker, C. "Children’s hospice movement helps families overcome barriers." USINFO is produced by the Bureau of International Information Programs, U.S. Department of State. Web site: <http://usinfo.state.gov>. 12 Jan. 2007.

"NHPCO FY2009 national summary of hospice care." National Hospice and Palliative Care Organization © 2010 NHPCO.

**Section Two: Challenges to “traditional” hospice or end-of-life care, Slides 44 & 45**

Docherty, S.L., Miles, M.S., Brandon, D. "Searching for ‘the dying point.’ Providers’ experiences with palliative care in pediatrics acute care." Posted (<http://www.medscape.com/viewarticle/563199>): 10/10/2007. *Pediatr Nurs* 2007;33(4):335-341. © 2007 Jannetti Publications, Inc.

**Section Two: Legislative update, Slide 47**

NHPCO. "Concurrent care for children: Implementation toolkit released by NHPCO and DCPCC." Press Release. April 15, 2011. Accessed December 27, 2011 at <http://www.nhpc.org/i4a/pages/index.cfm?pageid=6485>.

**Section Two: Per the American Academy of Pediatrics, Slide 48:**

American Academy of Pediatrics (AAP). Committee on Bioethics and Committee on Hospital Care. "Palliative care for children." *Pediatrics* 2000;106(2):351-357. A statement of reaffirmation for this policy was published on February 1, 2007. {Online}. Available: <http://aappolicy.aappublications.org/cgi/content/full/pediatrics;106/2/351>. Accessed January 5, 2008.

**Section Three: Communication, Slide 50**

Korones, D.N. "Pediatric palliative care." *Pediatric Review* 2007 Aug;28(8):e46-e56.

**Section Three: Communication needs and concerns, Slide 51**

Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H. "Family perspectives on the quality of pediatric palliative care." *Arch Pediatr Adolesc Med* 2002;156:14-19.

**Section Three: Communication needs and concerns, Slide 52**

Contro, N., Larson, J., Scofield, S., Sourkes, B., Cohen, H. "Hospital staff and family perspectives regarding quality of pediatric palliative care." *Pediatrics* 2004;114(5):1248-1252,

DOI: 10.1542/peds.2003-0857-L. Online version:  
<http://www.pediatrics.org/cgi/content/full/114/5/1248>.

**Section Three: Communication needs and concerns, Slide 53**

Korones, D.N. "Pediatric palliative care." *Pediatric Review* 2007 Aug;28(8):e46-e56.

**Section Three: Communication needs and concerns, Slide 54**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 34.

**Section Three: Communicating hope, Slide 55**

Horgan, M. "Hope is the thing: communicating with families in the continuum of hope." *ChiPPS Pediatric Palliative Care Newsletter Issue #15: May, 2009*.

**Section Three: Communicating hope, Slide 56**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3): 359-366.

**Section Three: Communicating hope, Slide 57**

Horgan, M. "Hope is the thing: communicating with families in the continuum of hope." *ChiPPS Pediatric Palliative Care Newsletter Issue #15: May, 2009*.

**Section Three: Communicating hope, Slide 58**

Mack, J., Wolfe, J., Cook, E., Grier, H., Cleary, P., Weeks, J. "Hope and prognostic disclosure." *J Clin Oncol* 2007; 25(35):5636-5642, DOI: 10.1200/JCO.2007.12.6110. Downloaded from [jco.ascopubs.org](http://jco.ascopubs.org) on December 12, 2011.

**Section Three: Communicating hope, Slide 59**

Mack, J., Wolfe, J., Cook, E., Grier, H., Cleary, P., Weeks, J. "Hope and prognostic disclosure." *J Clin Oncol* 2007;25(35):5636-5642, DOI: 10.1200/JCO.2007.12.6110. Downloaded from [jco.ascopubs.org](http://jco.ascopubs.org) on December 12, 2011.

**Section Three: Communicating hope, Slide 60**

Horgan, M. "Hope is the thing: Communicating with families in the continuum of hope." *ChiPPS Pediatric Palliative Care Newsletter Issue #15: May, 2009*.

**Section Three: Communicating hope, Slide 61**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3): 359-366.

**Section Three: Communication & information processing, Slides 62 & 63**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3): 359-366.

**Section Three: Communication & information processing, Slide 64**

Mack, J.W. and Wolfe, J. "Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis." *Current Opinion in Pediatrics* 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section Three: Communication & information processing, Slide 65**

Korones, D.N. "Pediatric palliative care." *Pediatric Review* 2007 Aug;28(8):e46-e56.

**Section Three: Communication & culture, Slide 66**

Adapted from Ian Anderson Continuing Education Program in End-Of-Life Care. Communication at the end of life. Module 5. Slide 2.

**Section Three: Communication & culture, Slide 67**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 30.

**Section Three: Communication & culture, Slide 68**

Adapted from Ian Anderson Continuing Education Program in End-Of-Life Care. Culture in end-of-life care. Module 8. Slide 18.

**Section Three: Communication & culture, Slide 69**

Adapted from Ian Anderson Continuing Education Program in End-Of-Life Care. Culture in end-of-life care. Module 8. Slide 7.

**Section Three: Communication & decision-making, Slide 70**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3): 359-366.

**Section Three: Communication & decision-making, Slide 71**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3): 359-366.

Horgan, M. "Hope is the thing: communicating with families in the continuum of hope." *ChiPPS Pediatric Palliative Care Newsletter Issue #15: May, 2009.*

**Section Three: Communication & decision-making, Slide 72**

Ian Anderson Continuing Education Program in End-Of-Life Care. End-of-life decision-making. Module 4.

**Section Three: Communication & decision-making, Slide 74**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 47.

**Section Three: Communication & decision-making, Slide 75**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 18.

**Section Three: Communication & decision-making, Slide 76**

Ian Anderson Continuing Education Program in End-Of-Life Care. Communication at the end of life. Module 5. Slide 24.

**Section Three: Communication & decision-making, Slide 77**

Adapted from Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 6.

**Section Three: Communication & decision-making, Slide 78**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 39.

**Section Three: Communication & decision-making, Slide 79**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 40.

**Section Three: Communication & decision-making, Slide 80**

“My Wishes” Subcommittee of the Pediatric Palliative Team at Central DuPage Hospital. ““My Wishes.” Aging with dignity.” May 2006. [Online] <http://www.agingwithdignity.org/about.php> or call 1-888-5-WISHES. Note: “My Wishes” is based on the “Five Wishes” advance directive available from the nonprofit organization Aging with Dignity.

**Section Three: Communication & decision-making, Slide 81**

Korones, D.N. “Pediatric palliative care.” *Pediatric Review* 2007 Aug;28(8):e46-e56.

Spinetta, J.J., Jankovic, M., Eden, T., Green, D., Martins, A.G., Wandzura, C., Wilbur, J., Masera, G. “Guidelines for assistance to siblings of children with cancer: Report of the SIOP working committee on psychosocial issues in pediatric oncology.” *Med Pediatr Oncol* 1999;33(4):395-398.

**Section Three: Communication & ethics, Slide 82**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 19.

**Section Three: Communication & ethics, Slide 83**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3); 359-366.

Mack, J.W. and Wolfe, J. “Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis.” *Current Opinion in Pediatrics* 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section Three: Communication & ethics, Slide 84**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 22.

**Section Three: Communication & ethics, Slide 85**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slide 20.

**Section Three: Communication & ethics, Slides 86, 87 & 88**

Tulsky, JA. Beyond advance directives: Importance of communication skills at the end of life. *JAMA*, July 20, 2005;294(3); 359-366.

**Section Three: Communication & ethics, Slide 89**

Ian Anderson Continuing Education Program in End-Of-Life Care. Decision-making in pediatric palliative care. Module 12. Slides 21 and 22.

**Section Three: Communication & ethics, Slide 90**

Wolfe, J., Grier, H.E., Klar, N., Levin, S., Ellenbogen, J.M., Schatz, S.S., Emanuel, E.J., and Weeks, J.C. "Symptoms and suffering at the end of life in children with cancer." *N Engl J of Med* 2000;342(5):326-333.

**Section Three: Communication & ethics, Slide 91**

Mack, J.W. and Wolfe, J. "Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis." *Current Opinion in Pediatrics* 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section Three: Communication & ethics, Slide 92**

Singer P.A., Martin D.K., Kelner M. "Quality end-of-life care: Patient's perspectives." *JAMA* 1999;281(2):163-168.

Ian Anderson Continuing Education Program in End-Of-Life Care. End-of-life decision-making. Module 4. Slide 9.

**Section Three: Communication, Loss & Grief, Slide 93**

Horgan, M. "Hope is the thing: communicating with families in the continuum of hope." *ChiPPS Pediatric Palliative Care Newsletter Issue #15: May, 2009.*

Klass, D, Silverman, PR, Nickman, SL, Editors. *Continuing bonds: New understandings of grief.* Copyright 1996: Taylor & Francis.

**Section Three: Communication, Loss & Grief, Slide 94**

Klass, D, Silverman, PR, Nickman, SL, Editors. *Continuing bonds: New understandings of grief.* Copyright 1996: Taylor & Francis.

**Section Three: Communication, Loss & Grief, Slide 95**

Finkbeiner, A.K. *After the death of a child: living with loss through the years.* The John Hopkins University Press. May 18, 1998.

**Section Three: Communication, Loss & Grief, Slide 96**

Painter, K. "Complicated bereavement and the power of forgiveness." Corr, C.A., Torkildson, C., & Horgan, M. (Eds.) *ChiPPS Pediatric Palliative Care Newsletter.* May, 2011: #23.

Mack, J.W. and Wolfe, J. "Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis." *Current Opinion in Pediatrics* 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section Three: Communication, Loss & Grief, Slide 97**

Mack, J.W. and Wolfe, J. "Early integration of pediatric palliative care: for some children, palliative care starts at diagnosis." *Current Opinion in Pediatrics* 18:10-14. © 2006 Lippincott Williams & Wilkins.

**Section Three: Communication, Loss & Grief, Slide 98**



Painter, K. "Complicated bereavement and the power of forgiveness." Corr, C.A., Torkildson, C., & Horgan, M. (Eds.) ChiPPS Pediatric Palliative Care Newsletter. May, 2011: #23.

**Section Three: Communication, Loss & Grief, Slide 99**

ELNEC-Pediatric Palliative Care. Loss, grief & bereavement. Module 9.

**Section Three: Communication, Loss & Grief, Slide 100**

Jennings, F. "Deficit of care." Corr, C.A., Torkildson, C., & Horgan, M. (Eds.) ChiPPS Pediatric Palliative Care Newsletter. August, 2011:#24;10-12.

**Section Three: Communication, Loss & Grief, Slide 101**

Jennings, F. "Under pressure." Corr, C.A., Torkildson, C., & Horgan, M. (Eds.) ChiPPS Pediatric Palliative Care Newsletter. August, 2011:#24;17-18.

**Section Three: Grief Interventions for HCPs, Slide 102**

Adapted from ELNEC-Pediatric Palliative Care. Loss, grief & bereavement. Module 9.

Jennings, F. "Under pressure." Corr, C.A., Torkildson, C., & Horgan, M. (Eds.) ChiPPS Pediatric Palliative Care Newsletter. August, 2011:#24;17-18.