



Bridge of Hope:
An Interdisciplinary Approach to Pediatric
Palliative Care



Bridge of Hope Pediatric Palliative Care Program Mission Statement

To celebrate the wellness of all children and families facing chronic, complex or life-threatening conditions by providing world class education, dignity and continuity of care.



MFCH provides advanced pediatric care within a special environment developed from the point of view of patients and their families as well as doctors and nurses. This special environment puts children and their parents at ease so the whole family gets better.



Family-Centered Care



The family-centered care philosophy is based on the belief that the health care providers, patients, and their families are partners, working together to best meet the needs of the child.

Recognized as a leader in pediatric care. Maria Fareri Children's Hospital operates under a "family-centered care" approach to treating children. This philosophy involves parents, siblings and family members in every step of a child's treatment, and is provided in a state-of-the-art building designed specifically from the point of view of children and their families. Our hospital philosophy is that family-centered care and active family involvement create an environment specially suited to enable medical specialists to provide the most advanced care to their patients and to facilitate the healing process, regardless of the illness.



I'm tired of being me
I don't want the world to see
The pain that fills me inside
It appears that happiness is not meant for me
Just tears
And fear
That's my frame of mind
I'll continue to cry
and wipe my eyes
My false smile like make-up covering
INSIDE....
The pain - both physically and emotionally
is becoming unbearable
God, please help me....

-Ariana S.



The Need for Pediatric Palliative Care

Approx. 53,000 children die in the U.S. annually

80% of those deaths occurring in hospitals

80% of those deaths resulted from chronic conditions

In any given day, 8,000 children benefit from pediatric palliative care services



8,000 children benefit from pediatric palliative care services



Why don't these children receive Palliative Care....



Education

not taught in medical school

not trained in residency

only 4 Pediatric Palliative Care fellowship programs in the United States



: Palliative Care texts

certification for Pediatric Palliative Care



Resources

- Funding / Support
- Not profitable for providers



Why aren't there more resources for children?



Palliative Care Resource Utilization



Pediatrics







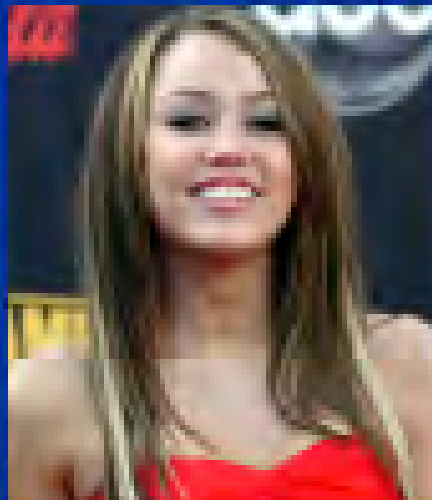
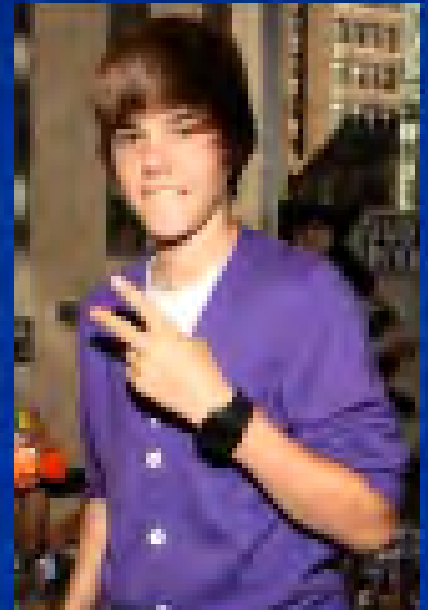
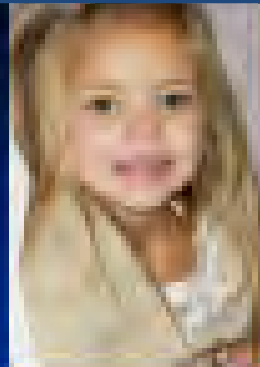
No word in English for someone
who has lost a child

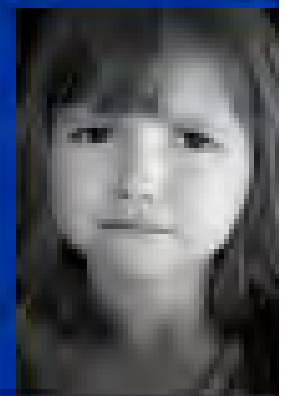
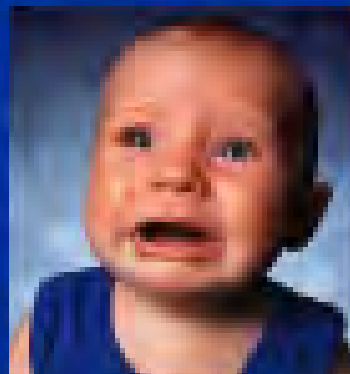
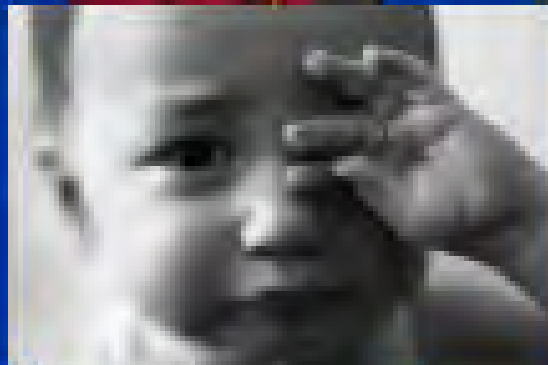
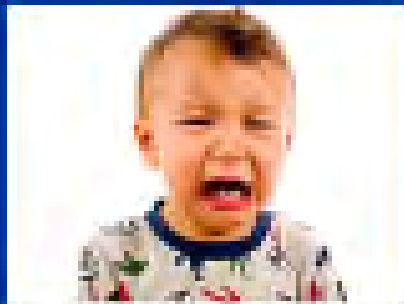
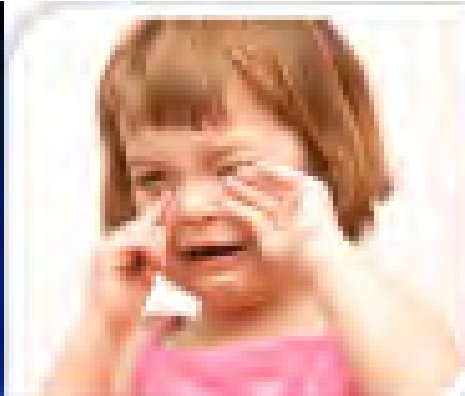


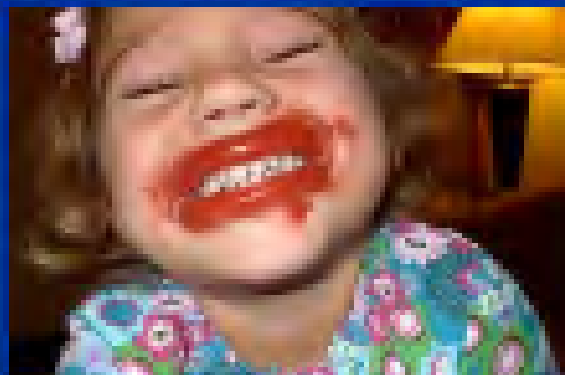
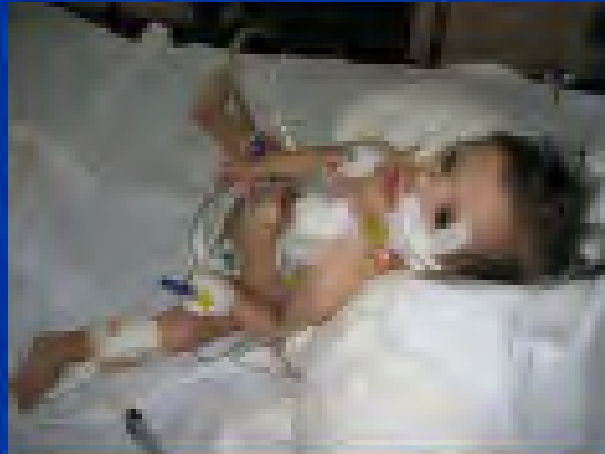
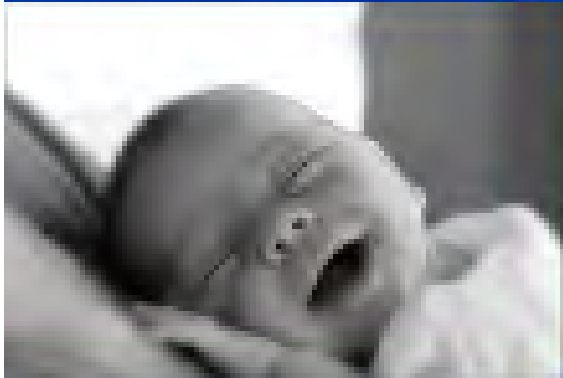
Who Provides Palliative Care ?

Child Life and Creative Arts Therapies
Family Support / Resource Center
Social Work: Hem-Onc, General Peds,
NICU, PICU and MSW Intern
Pain Service NP
RN's (PICU and Pain Resource)
Mental Health RN (C & L)
PICU RN
Metabolic NP
Chaplaincy
Ethicist
MDs: General Pediatrics, Pediatric Critical Care,
Neonatology, Metabolic/Genetics and
Child Psychiatry









Need for Pain Management and Palliative Care

- Pain is a multidimensional symptom that can overshadow all other experiences of both the child and family
- The management of pain in children with life-limiting illnesses is complex and unfortunately not often done effectively



Patient Presentation: Olivia B.



Gaucher's Disease

- In United States, 1:100 people are carriers
- Physical and mental impairments
- Painful bone lesions
- Autosomal recessive metabolic disease with shortened life expectancy







Nursing Role in Pediatric Palliative Care



Assessment

- Patient - age appropriate understanding of illness
- Family - Parents, siblings, extended family and the spokesperson
- Coping Mechanism any other crisis in past including death, divorce, or loss of employment
- Religion
- Collaboration with team members a plan on what the patient and family needs



Education

- Clarify diagnosis with family and their understanding
- Answer all questions when possible
- Educate family on DNR DNI
- Any Decision that they make is the right decision
- Use of drugs to alleviate discomfort



Education

(Continued)

- Remind families that they have Choices
- Educate nurses on the aspects of suffering families facing life threatening illnesses
- Use parents and children as our teachers
- We need to develop trust, respect, and caring within the family and the healthcare community



Goals of Child Life in Palliative Care

Involve children with life-threatening illnesses in decisions about their care, based on their developmental abilities.

Maximize the families involvement in care planning and decision making.

Provide opportunities for non-pharmacologic pain relief and distraction.

Offer children and their families opportunities for legacy building.

Provide bereavement support and information to the family.



What is Palliative Care Music Therapy?

Music Therapy is a research-based profession that uses music to reach non-music goals. Music Therapists use the patient's preferred music to address issues such as pain management, self-expression, agitation, isolation and spiritual comfort to achieve an increased quality of life.



Benefits of Palliative Care Music Therapy

Pain Management

Increased Socialization

Increased Relaxation

Facilitation of Legacy Building

Family Involvement (Parents, Siblings, Etc.)

Spiritual Comfort

Self-Expression and Communication



Major Fears of Hospitalized Children

INFANTS (birth - year)

- Separation
- Strangers

TODDLERS (1 -3 years)

- Separation
- Strangers
- Loss of control

PRESCHOOLERS (4 - 5 years)

- Loss of control
- Bodily injury and mutilation
- The unknown
- The dark
- Being left alone
- May believe hospitalization and treatments are a form of punishment



Major Fears of Hospitalized Children (cont.)

SCHOOLAGERS (6 - 12 years)

- Loss of control
- Loss of independence
- Bodily injury and mutilation
- Not being able to live up to the expectations of others
- Death
- May believe hospitalization and illness are a form of punishment

ADOLESCENTS (12+ years)

- Loss of control
- Loss of independence
- Altered body image
- Separation from peer group



Developmental Understanding of Death

Infant (0-2)

Concept of Death

- may not understand death
- will be affected by grief
- will sense changes in home

Grief Response

- may be irritable
- will respond/react to emotions of adults

Signs of Distress

- regression
- change in sleep/eating patterns
- may act out
- may be extra clingy
- Possible Interventions



Developmental Understanding of Death

Preschool (2-5)

Concept of Death

- may view death as punishment or abandonment
- view death as reversible and temporary
- may connect unrelated events to death

Grief Response

- very present oriented
- aware of change

Signs of Distress

- regression
- nightmares
- bedwetting
- change in sleep/eating patterns
- insecurity
- separation anxiety



Developmental Understanding of Death

School age (5-8)

Concept of Death

- death is reversible
- begin to understand finality
- may see death as contagious
- magical thinking
- may feel responsible
- may personify death

Grief Response

- May feel abandoned
- Repetitive question
- May reenact funeral

Signs of Distress

- Regression
- Nightmares
- Violent/aggressive play
- Change in sleep/eating patterns
- May have exaggerated fears
- Stomach aches/headaches
- Anger
- Concern about other family



Developmental Understanding of Death

Pre-Adolescent (9-12)

Concept of Death

- Death as punishment
- Fear of bodily harm
- Death is final, irreversible

Grief Response

- Questions about specific details
- Fears loss of other loved ones
- Some understanding of
- Mourning

Signs of Distress

- Regression
- School problems
- Withdraw from friends
- Change in sleep/eating
- Concerns with bodily harm
- Suicidal thoughts
- May be overly sad
- May hide their feelings



Developmental Understanding of Death Adolescent (12-18)

Concept of Death

- Death is universal
- Death is final and irreversible
- May be curious about death

Grief Response

- May try to care for others
- Depression
- Denial
- Often prefer friends over family
- Often reject adult rituals

Signs of Distress

- Regression
- Intense anger/guilt
- Acting out
- Changes in behavior



Chaplaincy and Social Work Together:

Addressing the
Psychosocial, Spiritual and Cultural
Aspects of Care



WMC/MFCH Chaplaincy Department

- 30 staff members both paid and volunteer representing variety of Christian denominations, Jewish and Muslim faiths
- Offers Clinical Pastoral Education with 15 interns annually

Chaplaincy strives to accompany patients & their families in the midst of their journey providing calm in the midst of the storm...



Chaplaincy as part of Bridge of Hope Team

- Honoring spiritual and cultural dimension of patient & their family
- Pastoral visitation—listen to, talk with and provide supportive presence to sick children & their families
- Pray with patients & family members
- Spend time to learn of individual spiritual journeys to assess how prepared patient & family are to embrace having a child living with a life limiting diagnosis
- Allow & encourage patient & family to express feelings toward God/Higher Power (ie, sadness, anger)
- Special insight into religious & cultural factors impacting how a child & family face illness and suffering



Chaplaincy as part of Bridge of Hope Team

(continued)

- Assist with End of Life discussions with patient and/or family
- Recognition of specialized needs of patient & family according to faith tradition: (ie, Baptism, Sacrament of the Sick, dietary restrictions)
- Provide appropriate religious literature & rituals
- Nondenominational chapel, Muslim & Jewish prayer rooms
- Daily worship services
- Collaborate with patient's & family's spiritual leader in the community
- Provide for the spiritual and emotional needs of staff



Maria Fareri Children's Hospital Social Work Presence

- 2 Pediatric Oncology Social Workers providing continuity of care in outpatient & inpatient setting
- 3 Inpatient Social Workers in the NICU, PICU and general pediatrics
- Director of Family Support and Family Resource Center
- 2 MSW social work interns



Social Work as part of Bridge of Hope Team

- Recognizing the importance of the family in treating the pediatric patient
- Appreciation for the socioeconomic, cultural, linguistic & spiritual dimensions of patient's and family's life & how they may impact medical treatment plan
- Expertise in helping patients & families maximize coping in crisis
- Intensive counseling to patients & families confronted by life limiting illnesses
- Spending time with patients & families being active listeners to their concerns & fears in order to help with normalizing what they are experiencing
- Help patients & families to formulate questions in order to gain clarity about medical status and medical treatment plan in order to assist with coping



Social work as part of Bridge of Hope Team

(continued)

- Advocate for patients' & families' individual needs
- Cognizant of treating family as well as patient
- Encouraging family members to take care of themselves in order to be present for their sick child (ie, go to Family Resource Center, participate in support group, walk around campus)
- Concrete referrals (ie, Ronald McDonald House, Friends of Karen, Cancer Care, American Cancer Society, JIMMY Fund, etc)
- Facilitate safe & appropriate discharge plan in collaboration with community based agencies



Key essentials for Chaplaincy and Social Work in providing Pediatric Palliative Care

- Spending time with patient & family
- Focus on active non judgmental listening to patient & family
- Celebrate with patient & family the simple triumphs & miracles
- Continued support upon returning home—phone calls, e-mails, home visits



Following the death of a child

- Provide memory boxes, bereavement literature and resources
- Follow up phone calls, e-mails to family
- Cards marking important dates (birthday, first year anniversary)
- Annual bilingual bereavement ceremony



Helpful Articles

"Family-Centered Care: A Resource for Social Work in End-of-Life and Palliative Care" in *Journal of Social Work in End of Life and Palliative Care*, 2006

"The Chaplain's Role in Pediatric Palliative Care: Mapping Model Programs" To be published in the June 2011 issue of the *Journal of Palliative Medicine*

"Factors that Distinguish Symptoms of Most Concern to Parents from Other Symptoms of Dying Children" in *Journal of Pain and Symptom Management*, April 4, 2010



Hope

Hope.

We all need you in our life.

Without hope we will be lost

It's so hard to live without hope.

Without hope we would all be in total darkness

So please just keep faith in what you do

And keep your head up no matter what happens

Things will get a lot better if you have hope.

Written by George Brown, age 17

