Building a Successful Pediatric Hospice Program

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Class Objectives

• State the decision process to begin a pediatric hospice program

• Identify and define the terms “Hospice” and “Con-Current Care” and “Partners in Children” used in Pediatric Hospice in relationship to eligibility and billing

• State two similarities and two differences in caring for pediatric hospice patients from adults
Class Objectives

- State the most common diagnoses in children on hospice
- List the most common pediatric calls
- Describe three internal challenges and practical resolutions in the implementation process
- Discuss common “fears” and apprehensions caring for pediatric patients
“We encourage people to live, really live, before they die. People think that hospice is about dying, but it’s really about celebrating life.”

~ Betty Bulen, Founder of The Elizabeth Hospice

- Introductions
- Opening Exercise
Initial Steps

• History of Pediatrics at TEH and in San Diego

• Developing a business case for providing a pediatric service
Initial Steps

• Internal Assessment
• SWOT Analysis
• Development of the Pediatric Resource Team
Initial Steps

- Leadership Approval
- Board Support
Developing Infrastructure

- Integration of Pediatric Assessment and POC into EMR
- Development of SOP
- Interdisciplinary Team Meetings
- Referral Process
Referrals

Pediatric & Perinatal Hospice Referrals
Serving Children and their families in San Diego

To make a referral (Monday through Friday) to The Elizabeth Hospice:
Call 760-737-2050 and ask for Samantha Heddy or call her directly at 760-796-3789

• Calls left on the answering machine on the Weekends or Holidays will be returned on the next business day (Monday through Friday).
• Fax all patient information/order to 760-431-1172
• Attn: Samantha Heddy/Michelle Goldbach-Pediatrics
Scope of Pediatric Services

- Traditional Care
- Concurrent Care/Shift Care
- Waiver program
- Other programs in California
Perinatal: Care Continuum - Before, During and After Birth

- Primarily MSW and Chaplain support
  Nurse plays a secondary role

- Birthing Plan - cornerstone of care support

- Support during pregnancy

- Support at Delivery

- Support of Hospital Team

- Possible Transition to Pediatric Team
Perinatal Hospice Experience
Pediatric Resource Team

**Facilitators:** Michelle Goldbach (Acting Supervisor)  
Liz Sumner

**Leadership:** Pattie Shader & Liz Sumner

**Medical Services:** Dr. G. Delgado, Dr. D. Calac, G. Atkinson, NP

**Clinical Team:** selected from across the service line

**Education:** Ann Sturley

**Admissions:** Beth Nido

**Bereavement:** Paula Bunn

**Volunteers:** Lena Rumps
Pediatric Team

- Two RNCM
- Five Per-diem RNs
- Four MSWs
- Two Chaplains
Community Outreach

- Reestablished relationships with key stakeholders in the community
- Developed informational brochure and referral process
Pediatric Providers in Care Team

- School staff
- Pediatricians
- Child Life Specialists
- CHAPLAINS
- INTERDISCIPLINARY TEAM MEMBERS
- Perinatologists
- PARENTS, CHILD, FAMILY
- MD Specialists
- Radiologist
- Family Doctors
- HOSPICE/ HOME CARE
- Transportation
- NICU/ PICU
- Infusion providers

The Elizabeth Hospice
Perinatal Providers in Care Team

- Genetic Counselors
- Perinatologists
- Midwives
- Geneticists
- Pediatricians
- Pregnancy Counselors
- Obstetricians
- Families
- N.I.C.U.
- Radiologist
- HOSPICE/HOME CARE
- INTERDISCIPLINARY TEAM MEMBERS
- Labor & Delivery Units/Birth Centers

The Elizabeth Hospice
Counseling & Bereavement Services

To make a referral to our Center for Compassionate Care of The Elizabeth Hospice for bereavement counseling or support groups call 760-737-2050.

Counseling on grief response to the illness of the child or possibility of losing their sibling, suggestions, resources, support and collaboration with schools.

Groups:
- Men’s Grief Support
- Living with Loss
- Loss of a Mother
- Loss of a Child
- After The First Year
- Perinatal Loss
- Loss and Celebration During the Holidays

To have a counselor contact you or for more information on Camp Erin or Wings of Hope, call AnnMarie Whitehead at 760-737-2050 ext. 2101
Davies, B. (1990) *Shadows in the Sun: The Experiences of Sibling Bereavement in Childhood.*
Initial Training

- Initial Training of Core Team
- Based Training on Pediatric ELNEC
- Developed two-day intensive Pediatric Training
- Integrated two Pediatric physicians and NP into the training curriculum
Staff Training

- Pediatric Hospice 101
- Online Training
- New Hire orientation
- Pediatric/Perinatal Modules
Resources

• Written Resources
• Telephone support
• Physician Support
• Pediatric Staff Support
• Clinical Staff Support
• Center for Compassionate Care
Coverage

What do we cover?
Equipment

• What equipment will I need?

• What if I am out in the field and need something?
Our Program Statistics

• Since November 2012
  o 23 referrals
  o 16 admits*
  o 2 pending admits
  o 1 revocation
  o 4 non admits (not ready for hospice or expired prior to admission)
  1 live discharge*
Our Program - Demographics

Pediatric Age Demographics

- Number of Patients

- Perinatal
- NB, less than 1 yr
- 1-4 yrs
- 5-9 yrs
- 10-14 yrs
- 15-20 yrs
- 20+ yrs
Our Program - Demographics

* 1 Congenital Heart had Trisomy 18
Our Program-Demographics

Patient's Ethnicity

- Caucasian: 8
- Hispanic: 10
- Black/African...: 2
- Asian: 1
- Portuguese: 1
- Native...: 1
- Unknown: 1
Common Calls

- What are the common calls
- Parents are the experts & your BEST Resource
- DNR/AND/Full Codes
- What if I don’t know something?
<table>
<thead>
<tr>
<th>P#</th>
<th>Admit Date</th>
<th>TOD/DC</th>
<th>Name</th>
<th>Age</th>
<th>Diagnosis</th>
<th>RNCM</th>
<th>Referral Name/#</th>
<th>MD/Contact</th>
<th>Parent Name/#</th>
<th>Status Summary Parent/#</th>
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<tbody>
<tr>
<td>29 weeks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Perinatal- trisomy 13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Delivered and expired at home</td>
</tr>
<tr>
<td>13 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Anoxic Brain Injury, NEC, TPN dep, Trach/Vent dep, narcotic dep.</td>
<td></td>
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<td></td>
<td></td>
<td>Patient passed at Rady’s</td>
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<tr>
<td>NB</td>
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<td></td>
<td></td>
<td></td>
<td>Anencephalic</td>
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<td></td>
<td>Born at PMC on 5/22/13. Died in the hospital at 0700 on the 23rd. MSW and Chaplain support provided. Siblings in the home</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Liver Failure</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Non Admit Expired at home</td>
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<tr>
<td>&lt;1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Reduction Deform, Brain</td>
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<td></td>
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<td>Expired in the home</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Metabolic Encephalopathy</td>
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<td></td>
<td></td>
<td>911 called by family for severe respiratory distress. Intubated at RCH. Extubated and expired at RCH (with concurrent care we didn’t need to discharge him)</td>
</tr>
<tr>
<td>13</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Lives in Valley Center. Mom does not want hospice at this time.</td>
</tr>
</tbody>
</table>
Challenges and Resolutions

• Culture Change/Resistance
• Training of staff
• Pediatric Resources
• After Hours, On Call staff

• Developing Infrastructure
• Dedicated Supervisor
• Communication
Challenges and Resolutions

• Unexpected growth
• Expanded service area
• Community Outreach
• Fund Development
• Marketing
Success Stories

“We were allowed to be parents”

“I just want to be a normal kid”
How I Feel......

• Open Discussion from list created by the group
Next Steps

• Creating a separate team

• Serving Pediatrics/Perinatal in expanded areas of Temecula

• Internal On call program
Resources for Pediatric Hospice Care

Nation Hospice and Palliative Care Organization - www.nhpco.org/pediatrics

Caring Connections - www.caringinfo.org

Children’s Hospice and Palliative Care Association - www.partnershipforparents.org

Children’s Hospice and Palliative Care Coalition - www.childrenshospice.org

Perinatal Hospice - www.perinatalhospice.org

Hospice and Palliative Nurses Association - www.hpna.org
We cannot live for ourselves alone. Our lives are connected by a thousand invisible threads, and along these sympathetic fibers, our actions return to us as results.

Herman Melville