

## Best Evidence Statement (BEST)

**Date:** 6/7/11

### Sibling Support in End of Life Care

#### Clinical Question

P (population/problem) Among siblings of actively dying patients  
I (intervention) does sibling involvement and preparation at patient's end of life  
C (Comparison) compared to no involvement and preparation  
O (outcome) impact the siblings grief response?

**Target Population:** Siblings 3-21 years of age of terminally ill children at patient's end of life

#### Definitions:

**Sibling Preparation:** Refers to support and age appropriate information about the patient's end of life status; provide opportunities for the sibling to ask questions, to touch, hold, and visit; participate in any memory making activities such as hand molds and prints; describe what the child may see or hear, such as equipment and vocabulary, for example ascertain understanding of the "D" words- death, dying and dead;

**Grief Response:** Grief is the normal response to a loss or a significant life changing event. Reactions and expressions of grief vary at different levels of maturity. Common grief reactions in children can include but are not limited to: regressive behaviors, feelings of guilt, difficulty sleeping, emotional responses (sadness, irritability, anxiety, loneliness, turmoil, relief), physical responses (fatigue, stomach pains, appetite changes), changes in thought patterns (confusion, difficulty concentrating, dreams or thoughts of the deceased), and behavioral responses (crying, withdrawal, avoiding people or places that remind one of the deceased).

**Recommendation** (See Table of Recommendation Strength following references)

It is recommended that siblings of actively dying children be involved and prepared for their siblings' death to facilitate appropriate grief responses, (*Lauer, Mulhern, Bohne, & Camitta, 1985 [4a]; Freeman, O'Dell, & Meola, 2003 [4a] Pettie Michael and Lansdown, 1986 [4b]; Martinson, Gillis, Colaizzo, Freeman & Bossert, 1990 [4b]; and Nolbris & Hellstrom, 2005 [4b]; Bendor, 1989 [5a]; Heiney, 1991 [5a]; Carr-Gregg & White, 1987, [5a]; Duncan, Joselow & Hilden, 2006 [5b]; Giovanola, 2005 [5b]*).

#### Discussion/summary of evidence

One cohort study directly answered the PICO question (Lauer, Mulhern, Bohne, & Camitta, 1985 [4a]). This study examined the siblings' perceptions and involvement at end of life in a home care or hospital setting and correlated those factors to adjustment after death. The results indicated that siblings who were part of the home care group reported being more supported and involved than siblings in the hospital group. Siblings' recollections at the time of death in the home care setting and hospital setting were compared and showed that 84% of the homecare group and 29% of the hospital group were present at the time of death ( $P < 0.05$ ). During this time 79% of home care group were able to touch, hold and kiss their sibling compared with 38% of children in the hospital group. The hospital group reported more passive activities such as watching, waiting, and leaving the room, ( $p < 0.05$ ) then the home care group. At the one year follow up 79% siblings whose brother or sister died at home recalled comforting their brother or sister compared to

19% of siblings whose brother or sister died at the hospital. Significantly fewer children in the home care group (16%) compared to children in the hospital group (75%) described death itself as frightening. 85% of the home care group compared to 25% of children in the hospital group describe death as natural ( $p < 0.01$ ).

Two descriptive studies (Pettle Michael and Lansdown, 1986 [4b] and Freeman, O'Dell, & Meola, 2003 [4a]) report including siblings in the terminal phases of illness led to less behavioral and psychological disturbances after the death of their brother or sister. Freeman, O'Dell, & Meola, 2003 [4a] found when the patient was at the terminal phase of the illness the siblings were concerned about: pain palliation, their ability to comfort their brother or sister, not having enough preparation or information regarding the dying process, social support and family harmony.

Two qualitative studies also examined the needs and issues of surviving brothers or sisters of a child who died of cancer (Martinson, Gillis, Colaizzo, Freeman & Bossert, 1990 [4b]; and Nolbris & Hellstrom, 2005 [4b]). Martinson et al. (1990) suggested health care professionals and parents keep the siblings involved and interacting in as normal manner as possible, explaining changes and giving appropriate accurate information. Nolbris & Hellstrom (2005) stated that during the terminal period, the healthy siblings felt included, but not sufficiently prepared for what was happening.

Four expert opinion articles relating to sibling involvement at end of life also provided information relevant to the clinical question. All of these authors recommend advocating for sibling involvement at end of life Bendor, 1989 [5a]; Carr-Gregg & White, 1987, [5a]; Duncan, Joselow & Hilden, 2006 [5b]; Giovanola, 2005 [5b]. Open communication between parents and surviving siblings is critical to a child's bereavement process (Giovanola (2005 [5b]). Bendor (1989) suggests interventions must be age appropriate and reflect the unique relationships that siblings have with each other and encourages health care professionals to utilize their clinical expertise to enhance healthy sibling adaptation throughout the illness experience.

**Body of Evidence:** Moderate

### **Health Benefits, Side Effects and Risks**

Supporting siblings at the time of death of their brother or sister can promote normal growth and development and facilitate healthy adjustment to the loss.

No adverse reactions to any of the interventions were noted in any of the reviewed studies, Lauer, Mulhern, Bohne, & Camitta, 1985 [4a]; Freeman, O'Dell, & Meola, 2003 [4a] Pettle Michael and Lansdown, 1986 [4b]; Martinson, Gillis, Colaizzo, Freeman & Bossert, 1990 [4b]; and Nolbris & Hellstrom, 2005 [4b].

### **References** (evidence grade in [ ]; see *Table of Evidence Levels following references*)

Bendor, S. J. (1989). Preventing psychosocial impairment in siblings of terminally ill children. *The Hospice Journal*, 5(3-4), 153-163. [5a]

Carr-Gregg, M., & White, L. (1987). Siblings of paediatric cancer patients: A population at risk. *Medical and Pediatric Oncology*, 15(2), 62-68. [5a]

Duncan, J., Joselow, M., & Hilden, J. M. (2006). Program interventions for children at the end of life and their siblings. *Child and Adolescent Psychiatric Clinics of North America*, 15(3), 739-758. [5b]

Freeman, K., O'Dell, C., & Meola, C. (2003). Childhood brain tumors: Children's and siblings' concerns regarding the diagnosis and phase of illness. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, 20(3), 133-140. [4a]

Giovanola, J. (2005). Sibling involvement at the end of life. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, 22(4), 222-226. [5b]

Heiney, S. P. (1991). Sibling grief: A case report. *Archives of Psychiatric Nursing*, 5(3), 121-127. [5a]

Lauer, M. E., Mulhern, R. K., Bohne, J. B., & Camitta, B. M. (1985). Children's perceptions of their sibling's death at home or hospital: The precursors of differential adjustment. *Cancer Nursing*, 8(1), 21-27. [4a]

Martinson, I. M., Gilliss, C., Colaizzo, D. C., Freeman, M., & Bossert, E. (1990). Impact of childhood cancer on healthy school-age siblings. *Cancer Nursing*, 13(3), 183-190. [4b]

Nolbris, M., & Hellstrom, A. L. (2005). Siblings' needs and issues when a brother or sister dies of cancer. *Journal of Pediatric Oncology Nursing : Official Journal of the Association of Pediatric Oncology Nurses*, 22(4), 227-233. [4b]

Pettle Michael, SA, & Lansdown, R. G. (1986). Adjustment to the death of a sibling. *Archives of Disease in Childhood*, 61, 278-283. [4b]

**Note: Full tables of evidence grading system available in separate document:**

- [Table of Evidence Levels of Individual Studies by Domain, Study Design, & Quality](#) (abbreviated table below)
- [Grading a Body of Evidence to Answer a Clinical Question](#)
- [Judging the Strength of a Recommendation](#) (abbreviated table below)

**Table of Evidence Levels** (see note above)

<i>Quality level</i>	<i>Definition</i>
1a† or 1b†	Systematic review, meta-analysis, or meta-synthesis of multiple studies
2a or 2b	Best study design for domain
3a or 3b	Fair study design for domain
4a or 4b	Weak study design for domain
5 or 5a or 5b	Other: General review, expert opinion, case report, consensus report, or guideline

†a = good quality study; b = lesser quality study

**Table of Recommendation Strength** (see note above)

<i>Strength</i>	<i>Definition</i>
“Strongly recommended”	There is consensus that benefits clearly outweigh risks and burdens (or visa-versa for negative recommendations).
“Recommended”	There is consensus that benefits are closely balanced with risks and burdens.
No recommendation made	There is lack of consensus to direct development of a recommendation.

**Dimensions:** In determining the strength of a recommendation, the development group makes a considered judgment in a consensus process that incorporates critically appraised evidence, clinical experience, and other dimensions as listed below.

1. Grade of the Body of Evidence (see note above)
2. Safety / Harm
3. Health benefit to patient (*direct benefit*)
4. Burden to patient of adherence to recommendation (*cost, hassle, discomfort, pain, motivation, ability to adhere, time*)
5. Cost-effectiveness to healthcare system (*balance of cost / savings of resources, staff time, and supplies based on published studies or onsite analysis*)
6. Directness (*the extent to which the body of evidence directly answers the clinical question [population/problem, intervention, comparison, outcome]*)
7. Impact on morbidity/mortality or quality of life

**Supporting information**

**Introductory/background information**

The role of the child life specialist working in a pediatric hospice and palliative care setting is to provide appropriate interventions, resources and support for families of terminally ill children. While working in this environment it became apparent that siblings of brothers or sisters with a terminal illness seemed to be an underserved population. There are limited current resources available for this population.

**Group/team members**

Tina Ulanowski, M.Ed.; CCLS; Cincinnati Children’s Hospital Medical Center StarShine Hospice and Palliative Care; [tina.ulanowski@cchmc.org](mailto:tina.ulanowski@cchmc.org)  
 Susan McGee, MSN, RN, CNP, Division of Developmental and Behavioral Pediatrics  
 Barbara Giambra, MS, RN, CNP, Evidence-based Practice Mentor, Center for Professional Excellence, Research, and Evidence-based Practice

**Search strategy**

**Terms:** grief, children, sibling, death  
**Databases:** Pubmed, Medline, Google Scholar, CINAHL  
 No date limits used. Last search: 3/17/11

**Applicability issues**

Health care teams working with siblings of terminally ill patients may not have a child life specialist as part of the multidisciplinary group. Incorporating a child life specialist as part of the team would be optimal as their training uniquely qualifies them for working with this population. Due to budgetary concerns this may not always be possible, funding the position with Grant monies may be an option.

Copies of this Best Evidence Statement (BEST) are available online and may be distributed by any organization for the global purpose of improving child health outcomes. Website address: <http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/ev-based/default.htm>  
 Examples of approved uses of the BEST include the following:

- copies may be provided to anyone involved in the organization’s process for developing and implementing evidence-based care;
- hyperlinks to the CCHMC website may be placed on the organization’s website;
- the BEST may be adopted or adapted for use within the organization, provided that CCHMC receives appropriate attribution on all written or electronic documents; and

- copies may be provided to patients and the clinicians who manage their care.

Notification of CCHMC at [HPCEInfo@cchmc.org](mailto:HPCEInfo@cchmc.org) for any BEST adopted, adapted, implemented or hyperlinked by the organization is appreciated.

*Additionally for more information about CCHMC Best Evidence Statements and the development process, Center for Professional Excellence/Research and Evidence-based Practice office at [CPE-EBP-Group@cchmc.org](mailto:CPE-EBP-Group@cchmc.org)*

### **Note**

**This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.**

**Reviewed against quality criteria by two independent reviewers.**