How to Use the Pediatric Comfort Care Kit

The materials in your Comfort Care Kit are designed to maximize the psychological, emotional, spiritual and physical comfort of seriously ill children and their families. Please use these materials as needed in the care of your patients.

Comforting children

**Hand/foot massage creams and instructional video**

Individual-sized containers of Lotus Touch massage cream. Friction warms the cream, making it more slippery. Hypoallergenic.

**Aromatherapy supplies**

Some essential oils have been combined with jojoba oil—these may be massaged onto the child’s feet or back. (Do not massage onto a child’s hands. If the child later rubs his or her eyes, the oils may cause irritation.) Other oils are used only as scents to be placed near the child. Both kinds of oil may:

- Enhance relaxation
- Reduce nausea
- Assist with pain control
- Counter offensive odors

**Flavored lip balm**

These can soothe the lips while covering the smell of plastic, cleaning products or medication associated with breathing masks and tubes.

**Therapy CDs**

Music CDs facilitate relaxation through deliberate keys and tempos. Other CDs use guided imagery to help the child relax.

Creating mementos

**Creative Memories memento box**

This is to be given to the family during the dying process or following a death. You may place the family’s mementos in the decorative box.

**Plaster hand mold kits**

Create a 3D mold of a child’s hand or foot. Suggest that the child hold a parent’s finger or hand in the mold to make the memento even more meaningful (and easier to create). Dental-grade materials offer extreme detail. Requires at least an hour of staff time to complete.

**Colored ink handprint posters**

Using a large sheet of paper, have the family make a circle of handprints around the patient’s prints. Each person may choose a different color if they wish. Fingers can overlap to show connectedness.

Afterward, let family members engage in the
intimate act of gently washing the patient's hand with warm water and a washcloth. Some people choose to write meaningful words next to their prints.

**Invisible ink handprint or footprint supplies (for infants)**

Invisible inks are used with “In Loving Memory” cards, which also include a space for a photo and an envelope for a lock of hair. The prints leave no ink on the child and take only a few moments to produce. If possible, take a 4 × 6 photo of the baby and its parents before the baby dies. Or, ask the family for a photo that they’d like to use. Include this in the card.

**Crayola Model Magic**

This modeling compound is used to make impressions of the child’s hands or feet. It requires no preparation and takes only a few moments to produce. It offers less detail than a plaster mold. It can be painted after the mold has dried.

**Hardbound blank books**

To be used as a journal, memory book or scrapbook. Children or family members can write about their experiences, starting with the diagnosis or any point during treatment. Families can create a scrapbook pertaining to a single event (such as transplant day, or the last day of chemotherapy). Staff can write down memories for a patient who has completed treatment or for the family of a patient who is dying.

**Creative art supplies**

For children who wish to express feelings and experiences that are hard to put into words. Not intended for general leisure.

**Card- and letter-writing supplies**

For patients or siblings who wish to share messages with loved ones. Especially helpful for siblings who want to say something to the patient but do not want to enter his or her room.

**Digital camera and photo printer**

It is important that families have the ability to take photographs of their child during meaningful moments. Photos capture the good times that occur in the midst of the difficult ones, and they provide priceless mementos. Digital prints offer greater detail, versatility and archival quality than Polaroid photos.

**Engaging siblings and other children**

If a sibling wishes, permit the child to provide comfort care to the patient. You might suggest that siblings fluff the child's pillow, choose a particular stuffed animal to place on the child's bed or select music to play in the child's room, for example.

When creating mementos, allow children to participate in decision-making and assert their preferences (what colors to choose, how to place artistic elements, what to do first). Encourage children to talk about their choices. These choices may reveal specific memories about the child who is dying.

Art and letter-writing materials are especially valuable for siblings who do not wish to spend time in the room of an ill or dying child. The art or letter may be kept private between the sibling and patient, or a caregiver can share the art or letter on the sibling’s behalf. Encourage siblings to:

- Draw a picture that honors or symbolizes the relationship that the children have shared.
- Write a message to their dying loved one to express favorite memories or feelings of love and affection.
• Express final words to address any unfinished conversations with the dying child.

During a funeral service, siblings can play a meaningful role by placing their art inside the coffin.

**Literature for children and parents**

**Understanding children’s reactions and concerns when a loved one is hospitalized**

*Kids Worry Too*

Practical suggestions to help parents understand children's concerns and cope with their fears.

**Introducing the concept of death**

*Things to Consider: When Your Child Has a Terminal Illness*

Very useful for parents. Explains concepts that parents need to consider when speaking with and caring for dying children. Offers good examples of how to start conversations with children and how to respond to some of their questions about death and dying.

*Lifetimes: The Beautiful Way to Explain Death to Children*

An excellent book for an adult to read to a child to introduce the topics of death and dying. A good way to start the conversation. Give this book to the family, so the child can revisit the book later when questions arise. Can be used with either a child who is dying or with the siblings of a dying child.

*The Next Place*

For starting a discussion about what happens after someone dies. Very useful for working with a patient who is dying or the patient’s siblings. This book evokes questions about what the family and child believe might happen after death. A gentle and peaceful way to initiate the conversation.

*I Miss You*

Primarily for explaining the death of an adult loved one, this book can also be used by the sibling of a young patient. Good for promoting conversations about death and about the feelings children may have after the death of a loved one.

*What Will I Tell the Children?*

Concise information about children's understanding of illness and death at different ages and developmental levels. Offers basic suggestions for responding to children's needs.

**Exploring events and feelings surrounding a death**

*Journey through the Dying Process*

A Fairview publication that describes the dying process. It prepares families for some of the physical changes they may see and for events that will take place. Also discusses some of the care decisions that need to be made.

*What on Earth Do You Do When Someone Dies?*

For older children and teens. Discusses typical emotions someone may have when a loved one is dying. Describes what happens when someone dies (to the body, during funeral services, etc.). Addresses grief issues and helpful ideas for coping after a death.

*What Will I Tell the Children?*

Helps parents understand children's feelings at different ages.

*I Miss You*

Primarily for explaining the death of an adult loved one, this book can also be used by the sibling of a young patient. Good for promoting conversations about death and about the feelings children may have after the death of a loved one.
When a Brother or Sister Dies . . .

Compassionate Friends brochure. For older children and adolescents, or for parents to read to younger children. Describes many of the feelings someone has when a sibling dies.

When Someone Very Special Dies

This is a workbook to be used under the supervision of an adult caregiver. It helps children use art to identify and express their feelings about a loved one's death. Children illustrate their book with their personal story.

Beyond the Rainbow

For children who are dying. This is a workbook to be used under the supervision of a professional caregiver. It elicits thoughts and feelings children have about their impending death. It may be easier to use portions of this book instead of the whole thing at once. Rather than give this book to the patient or family, we recommend contacting a trained staff person.

Coping with grief and bereavement

What on Earth Do You Do When Someone Dies?

For older children and teens. Discusses typical emotions someone may have when a loved one is dying. Describes what happens when someone dies (to the body, during funeral services, etc.). Addresses grief issues and helpful ideas for coping after a death.

Understanding Grief: When a Child Dies

Compassionate Friends brochure. A good first resource to give to parents after the death of a child. Introduces some of the feelings that parents may experience following a child's death.

The Grief of Stepparents: When a Child Dies

Compassionate Friends brochure. A good first resource to give stepparents after the death of a child. Introduces some of the feelings that stepparents may experience following a child's death.

Parents Who Are Now Childless . . .

Compassionate Friends brochure. A good first resource to give to parents whose only child has died. Discusses issues related to being childless, such as the question: “Are we still parents?”

The Sudden Death of a Child

Compassionate Friends brochure. Discusses some of the initial feelings parents experience after the unexpected death of a child. Introduces ideas for parents to consider over time.