End-of-life concerns

If your child is approaching death, you may wish to make family memories while you can. If your child is old enough, he or she may wish to participate in end-of-life decisions, such as planning a funeral or memorial, making a will (choosing to leave favorite toys, photos, music, etc. to family and friends), choosing to die at home or in a hospice, or donating organs. You will have to decide how much medical care you want for your child, and how to cope with your own grief and the grief of your children. The hospital chaplains can help you think through these issues and express your wishes to the other people involved.

Making memories—
Even if your child is dying, he or she may not die today or tomorrow. While your child lives, make some memories together. A photo album of favorite pictures, a scrapbook of your child’s drawings, a baby book, a journal of your own thoughts and feelings about your child’s life, a videorecording—these are all ways to remember your child. Going on a special family outing, or participating in a special religious or spiritual ceremony may become a treasured memory. There is a long tradition of saving a lock of a child’s hair. Your child or teenager may want to make a card, scrapbook, video, or a mix tape of favorite tunes to give to special friends.
Some websites offer online space for memorials to children who have died; see the Kremer Family Resource Center for a list. If you kept an online Family Diary through Children’s Mercy Hospitals & Clinics, ask the Community Relations department about getting a copy of your diary to keep.

Medical decisions
Dying at home may be an option—discuss this with your doctor. Hospice care can offer the child and the family emotional support, comfort measures, and care; in Kansas City there is an excellent children’s hospice called Carousel.
Carousel (pediatric program of Kansas City Hospice)
12006 W. 87th St. Parkway
Lenexa, KS 66215
913-894-8228
http://www.kansascityhospice.org/
You may be asked to decide how much treatment your child should have, once the treatment can no longer help your child get better. You may wish to think about a Do Not Resuscitate (DNR) order, which will tell health care providers not to try to revive your child if he or she stops breathing. Some families will be asked to consider autopsy, the examination of your child’s body tissues after death, perhaps in the hope of learning how to understand your child’s illness and to improve the care of other children. Caring Conversations from the Center for Practical Bioethics (http://www.practicalbioethics.org/cpb.aspx?pgID=886) may help you to think about these choices.
The Kansas City Partnership to Advance Pediatric Palliative Care (http://www.practicalbioethics.org/cpb.aspx?pgID=888) is developing resources to support families of terminally ill children.
Some part of your child may be able to live on in another child. Consider organ donation.
Organ & Tissue Donation http://organdonor.gov/
Coalition on Donation http://www.shareyourlife.org/

Funeral planning—
MISS Foundation: Saying Goodbye to a Child (includes a Funeral/Memorial Planning Worksheet) http://www.missfoundation.org/family/funeral.html
Guidelines for planning a children’s funeral (for children to attend) by Helen Fitzgerald http://www.americanhospice.org/articles/childfuneral.htm
Suggestions for funeral directors . . . when a child dies http://www.compassionatefriends.org/Brochures/fundirec.htm
It is possible to plan a meaningful funeral or memorial service without spending thousands of dollars. To make sure your wishes are recognized, and you are not pushed into paying for more than you can afford, plan the funeral well ahead of the death.

Funeral Consumers Alliance (includes information on how to plan a funeral, including how to care for your own dead without using a commercial funeral home, explanations of costs, etc.)
http://www.funerals.org/

To plan a funeral in advance, and avoid unnecessary expense, a local resource is the Funeral Consumers Alliance of Greater Kansas City
4501 Walnut St.
Kansas City MO 64111
816-561-6322
http://www.funerals.org/KansasCity/index.html

Consider reading the book *Caring for the dead: your final act of love* by Lisa Carlson (Hinesburg, VT: Upper Access, 1998) which is available in area public libraries.

Consider also:
"Before you buy a casket from a funeral home" by Michele Baskin-Jones at http://dying.about.com/cs/funeralplanning/bb/BYfuneral.htm provides links to online discount casket retailers, and casket-building plans. A family member with carpentry skills might find that building a personalized casket is both therapeutic and a gift of love for the grieving family.

For free funeral planning information from the funeral home industry, try http://www.funeralplan.com/

**Grief and after care—**
 Turning Point offers programs for families facing cancer and other potentially terminal illnesses Including sibling support
8900 State Line Rd., Ste 240
Shawnee Mission, KS 66206
www.turningpointkc.org

Children’s Mercy Hospitals & Clinics offers an Aftercare Bereavement program for patients’ families; contact Janie Wood, Staff Chaplain, at 816-234-3911 for information.

Solace House (a center for grieving children and their families)
8012 State Line Rd Ste 202
Shawnee Mission KS 66208
913-341-0318
http://www.solacehouse.org/

Compassionate Friends (self-help organization for families grieving death of a child; there are several local chapters; for a chapter's contact number and meeting information phone 630-990-0010 or (toll-free) 877-969-0010.
http://www.compassionatefriends.org/

There are many organizations offering grief support for families who experience the death of a child in infancy or due to specific causes; see the Kreamer Family Resource Center for a fuller listing.

**Death certificates—where to get copies**

**Kansas**
Office of Vital Statistics
Curtis State Office Building
1000 SW Jackson, Suite 120
Topeka, KS 66612-2221
http://www.kdhe.state.ks.us/vital/death.html

**Missouri**
Missouri Department of Health and Senior Services
Bureau of Vital Records
P.O. Box 570
Jefferson City, MO 65102
http://www.dhss.state.mo.us/BirthAndDeathRecords/BirthAndDeathRecords.html