

2 New Focus from Curing to Providing Comfort

New Treatment Plan

Together with the health care team (and perhaps _____
with your child) your family has decided to change _____
focus of treatments from curative to comfort _____
treatment. How will you and your child's team _____
accomplish this new treatment plan? _____

“No matter what the
outcome, parents will
be comfortable looking
back on their decisions,
knowing they were made
with both excellent
medical information
and excellent parental
wisdom” –From *Shelter
from the Storm*

"Second guessing" your choices

Other family members and friends may second guess your decisions to change to *comfort care*. Remember that he is your child and that you are doing the best for him, even if it means allowing him to die. To take the burden away, request that the medical team meet with your family members.

Write about how your family and friends are or are not supporting you and how this makes you feel...

"There is not one right answer which means there is no wrong answer either."—From *Shelter from the Storm*

Options

If you wish for your child to die at home, discuss the options with your health care team... what did they say?

What details would need to be worked out to allow your child to be brought home?

Options

Do you want to get into bed with your child – is this possible? Do you wish to hold your child in your lap – is this an option for you?

Do you and your family need some time alone with your sick child? Do you need to ask that phone calls be held, that visitors be limited or even stopped for a period of time?

Do you want time together with your child, family and friends? Can arrangements be made for a number of people to be present at once?

What else can be done to help you and your family?

“Remember that there are alternative death transitions, such as using harp music, special lighting, turning off certain monitoring machines and eliminating medications that are no longer needed. You have choices in these matters.”

– Robin

Talking to your child about death

It is important to recognize that all children are unique in their understanding of death and dying. This understanding depends on their developmental level. It is important to use care and judgment when explaining death to your child. The information on the following pages are for children between the ages of 3-18, but all children are different. It is important to consider your child's unique cognitive, emotional and developmental level before talking about death. Ask for guidance from trained staff if needed.

Developing an understanding of death

Infants: They may understand that you are sad, but have no real understanding of the meaning of death.

Toddlers: It is important to remember that toddlers cannot understand what they cannot see. They are affected by the emotions of those around them. They begin to possess early developmental understanding of grief and mourning, but perceive death as temporary.

Preschoolers: Death is not seen as permanent to this age group, but as reversible or temporary. It is important to talk in concrete, simple terms due to magical thinking. For example, they may think their illness/dying is punishment for something they have done wrong.

School-age: Children at this age start to understand that death is permanent. They understand cause and effect of death. For example, if a plane crashed, people could die. It is important to talk in concrete terms and provide realistic connections.

Teenagers: Most teenagers understand the full meaning of death. They know that death is final and that eventually everyone dies. Teens have a difficult time emotionally coping with death. They often withdraw from family and rely on their friends for support.

Talking to your child about death

Tips on talking to your child about death

- Talking about death does not make it happen.
- Allow your child to talk about fears, anger, and joy.
- Begin by asking your child, *“What questions do you have?”* and *“Is there anything you are afraid of?”*
- Listening is an important key in helping children cope with dying.
- Accept their feelings no matter how difficult it may be.
- Explain death to your child in a way that they understand and always be honest. If you are having trouble with this, ask if your hospital has a child life specialist or a social worker who can help you.
- Let her know you will be there as much as possible.
- Be consistent by showing your child affection and support.
- Ask her what wishes she would like fulfilled before she dies.

Involve your child in decision-making

Allow children to be part of the decision-making about their medical treatment and wishes. A simple example is: Do they want the red or blue bandaid? Children are very aware of their body and often know when they are dying even before parents and medical staff do. Your child knows what hurts and what is worth continuing to fight for. Decisions are best made with mutual respect and teamwork between child, parent, and the medical team. For example, a teenager may want to take control of her illness. Allow her to do this, as difficult as this may be, as it will be the only growing up she will ever do.

Allow your child to write a will to leave personal items for loved ones and friends.

Common fears and feelings your child may be experiencing

- Being alone at the time of death
- What will happen to the families they leave behind
- That they may be in pain

Talking to your child about death

- That their illness is a punishment for something they did wrong
- Burdening their family with emotional and financial stress

Ways to help children address fears

Take advantage of professionals who are trained to help children express fears. Child Life Specialists, Social Workers and Chaplains are all great resources when helping your child. Some great ways for your child to express fears are through talking, drawing, playing and writing. Reassure them honestly and in a comforting manner. Everyone should try to talk about their feelings and fears about the illness. Open discussion also allows the sharing of anxieties and the accomplishment of important goals.

Permission To Die

Children are very sensitive and aware of their parent's sadness. They worry about hurting loved ones who are left behind. As a result, children may cling to life. For some children, it is very important to receive permission to die and reassurance that loved ones will be okay.

Limit Setting

Continue to set limits with your child by parenting and keeping to the rules. This provides a sense of normalcy and discourages children from feeling a sense of being out of control.

Other ideas of talking with your child:

Making memories in the last hours

While your child is still alive, make memories

- Take a lot of pictures or videos
- Save a lock of hair or fingerprints
- Record her voice
- Have him draw a picture or write for you and do the same for him
- Invite friends in
- Tell favorite stories
- Ask if your child has things she'd like to do (talk with Uncle Steve, see her friend Grace, listen to the Dixie Chicks, meet with a spiritual leader... the options can be endless)
- Share your special memories with each other, the fun and favorite stories

Children need time to play.

Encourage and allow your child to continue with normal activities. Your child may want to fulfill a wish such as:

- Having a slumber party in his room
- A "picnic" with his friends

- Riding his bike one last time (even if it is with a lot of help)
- Drawing a picture and having it framed or seeing a special someone for the last time

Each child will have his own wishes and hopefully you can work with him to make realistic goals for his condition. Organizations such as *Make-A-Wish* 1-800 722-WISH are a great way for a child to make a wish come true.

Children as young as three years old are often aware that they are dying without having been told.

Writing a Will

For some children facing their own end of life, making some plans helps them feel in control of an event that they feel is out of their control. Some children feel comforted by planning whom they want with them, to hold them, possessions they want to hold, even what they want to happen to their toys/belongings after their life ends.

The following child “Stephanie” (10 years old) spent years in treatment for a brain tumor. When her tumor came back and the doctors told Stephanie the risks of surgery to remove it, Stephanie decided she didn’t want to continue with any more treatment. She wanted to go home. She asked her Child Life Specialist before she was discharged to help her write her will. They looked at a lot of different specialty

scrapbooking papers and she chose one that had a very subtle, airbrushed rainbow on it. She was very tired then and asked for help to work on the wording. However, the next day Stephanie had already written her will.

The following is Stephanie’s will to hopefully give you some guidance with your child...

Talking about death does not make it happen, though many people are afraid it may. Talking about death allows the child to complete important emotional tasks.

Writing a Will

My Last Will and Testament By Stephanie

To my Papa, I hand him down my Huskie Dog

To _____ my little sister I hand her down my toys

To _____ my big brother I hand him down my VCR

To my Dad I hand him down my DVD player

To my Grandma I hand down my stuffed animals

To my friend I hand down my CDs

To my Aunt I hand down my glass dolls

To my Grandma I hand down my jewelry boxes

To Uncle I hand down my Rose Bear

To my Mom I hand down my baby blankie

A few days after Stephanie wrote her will, she died at home.

Memories

Would you like to help bathe your child? You can bring in special soaps that remind you of your child.

What about a lock of hair, your child's handprints or footprints? Are these things you would like to have with you?

Would you like help in starting a memory album or journal for your child? _____

"A very special nurse gave me guidance as to how I could take control of Brita's final hours with us. After death is established, there isn't any rule that says you leave and the staff takes over. It is perfectly all right to pick up your child, hold them, rock them, etc. as long as you wish. There is a tremendous closure in bathing their body for the last time and actually touching the coldness and stiffness that is death. You are in control here, take as long as you need."

– Robin

Memories

How do these ideas make you feel? What can you cope with and what is too much for you?
 Know your limits and go with what “feels right,” not what is “expected.” It is okay to make your wishes known.

“Every once in awhile I pull out Lissy’s lock of hair when I can’t remember exactly the color. It was something I didn’t think I would want and a friend of mine encouraged me at the time of Lissy’s death. Now I am so grateful.”

–Resa

“A baby’s death is different than an older child’s because the only memories parents of infants may have are those created in the hospital.”

–Linda P

Tip: Talk to your child, cuddle your child and let her know you will be okay. It is so important for someone dying to know those they leave behind, especially their parents, will be okay.

Choices surrounding the death of your child

When you and the health care team have decided to allow a natural death you have choices.

Ask if the gowns and masks can be eliminated if these were previously needed for your child's condition.

- Can the lighting be turned down?
- Can favorite music be played?
- Can we decide who is present in the room?
- Can we stay as long as we want?

Would you like to be present when the machines and medicines keeping your child alive are stopped?

Your needs are highly respected during this time. Let your team know what you and your family's wishes are.

Tip: If you decide to be present, there will be someone with you to answer your questions. You may request a specific nurse, doctor, social worker, hospital chaplain, or personal spiritual counselor to be with you during this time.

Choices

47

During the death process you are in control about how much information you receive from your team. You can ask for step-by-step descriptions of what is happening with your child's body: Medicines being given to help keep your child stay comfortable, when medicines and machines are being stopped, how each change will affect your child.

Communicate your needs. What do you feel you and your partner would like?

What scares you the most about taking away life support?

“Zachary’s care had escalated so fast and we were completely out of control, not participating in the decisions about his care and unable to be an advocate for him. Now hospitals are attempting to include families as part of the team so there are more options for you. As an individual and as a couple, you must listen to your gut instincts about the amount of information you can handle and what you want to bear.”

– Linda C.

Choices

What questions can be answered to help you and your family through this time?

How is your health care team going to make your child comfortable?

My child's health care team

Name

How they helped my child

Tip: Have friends and family help you with this page so that you have the names of those who helped care for your child. You may want to remember or thank them later.