

As Death Approaches: *Changes You May See in Your Child*

Death comes differently for every person, and your child's death will be unique. However, there are natural and expected changes that happen as the body's systems fail. You may see some or all of these in your child.

This handout explains some of these changes and gives ideas about what you can do to provide care and comfort. Your child's comfort is the main goal now, and it may help to know that **most children can stay comfortable with medications that relieve pain and anxiety**. These medications may need to be adjusted frequently, but increasing dosages won't shorten your child's life.

Changes you may see, things you can do

This section describes physical and behavioral changes that are commonly seen in the dying process. Your child may not go through all of these changes, or at least not at the same time. But it may help you to know a little about what you're seeing, what your child may be experiencing, and what you can do to help.

Appetite, ability to eat and drink.

Your child may not need or want much food or liquid. This is a sign of the body's gradual process of shutting down. Right now, eating and drinking aren't essential. (In fact, you may want to talk to your child's care team about stopping any hydration and nutrition through a tube. Since the stomach and intestines stop working well at this point, continuing can be uncomfortable for your child.)

- Offer your child favorite foods and drinks and allow them to choose what they might enjoy. Don't insist that they take food or fluids.
- Offer small sips of fluid that can be sucked from a toothette sponge or a moist washcloth.
- To ease dryness, gently wipe your child's lips with a cool moist washcloth. Use an oral moisturizer on the teeth and gums. If your child is on oxygen therapy, use a water-based product (like K-Y jelly) on dry lips and nostrils — otherwise, you can apply small amounts of ChapStick or Vaseline to ease dryness.



Sleep.

Over time, your child will sleep more and more. The sleep may seem deeper — it may be difficult to wake your child. This change signals a slowing of the body's metabolism.

- Notice if there are times of the day when your child tends to be more alert and has more energy. Try to plan visits and activities for these times.
- Realize that your presence is comforting, even if your child is asleep or can't talk.
- Talk or read. Play music or sing quietly. Your child may hear your voice and find it soothing.
- Reach out. Hold your child's hand. Stroke their hair or rub lotion on their hands. If your child withdraws, remember that this is simply part of the dying process, not a rejection. Your caring touch can comfort your child and express your connection.

Body temperature, skin changes.

Your child's hands, feet, and limbs may become cool to the touch. You may also notice that the skin is splotchy and very pale grey or dusky purple. It may be darker on the underside of the body. These changes are signs that your child's circulation is slowing down.

- Don't use an electric blanket or heating pad. Because circulation is slow, your child's skin can easily burn.
- Use blankets, socks, and slippers. These may help prevent your child from feeling cold.
- Keep in mind that even though the skin feels cool, your child may feel hot and want to kick off the blankets. In this case, don't insist on blankets. Do what you think brings the most comfort to your child.

Bladder and bowel changes.

You may notice that your child has fewer bowel movements and doesn't need to urinate as often. The urine will have a darker color and a stronger smell. This is normal — as your child takes in less fluid and food, there's less waste. Also, the kidneys may be shutting down. It's also common for a person to begin to lose bladder and bowel control.

- If necessary, use disposable diapers and bed pads.

Seizures.

Although most children don't develop seizures at the end of life, a child with a brain tumor or metabolic problem may. Also, a child with a seizure disorder may have seizures more frequently at the end of life. (In this case, adjusting medication may help — talk to your child's caregivers.)

- If your child has a seizure, try to stay calm. Turn your child to the side. Don't try to insert anything into the mouth. Seizures can be hard to watch, but a child typically doesn't suffer and won't remember them.

Awareness and mood.

Your child may become increasingly confused about time, place, and people. Some children have trouble recognizing close friends and family members. At times, your child may also seem restless or upset — picking at the sheets, changing positions a lot, seeing things that aren't there, and so on. These behaviors are caused by changes in the body during the dying process, such as less oxygen to the brain, less fluid in the body, and lower kidney function. Medications can also be a factor.

- As often as needed and as long as it seems comforting, talk about how much you love your child. Speak in a gentle, reassuring tone.
- Don't insist on "correcting" your child. Don't argue or try to reason with them.
- Sit next to the bed or cuddle with your child. Your close presence can help orient and soothe your child.

As time becomes very short

In your child's final hours, you may notice that the changes described above are even more pronounced. Continue the comfort measures that feel right to you. As your child's breathing becomes more labored, you may want to raise your child's head and body with pillows. Turning your child partly to the side may allow secretions to drain.

Care and comfort for both of you

You already know many of the things you can do to comfort your child. They may be things you have always done — sitting close, listening to music or a video, talking, singing a lullaby, reading a favorite story, cuddling. Familiar things may be especially comforting now.

Your role at the bedside may come naturally to you, but taking care of yourself might not. You can easily become exhausted. This can make it harder for you to care for your child in the ways you want to. What can you do? Conserve your emotional and physical resources with a few small actions:

- **Schedule breaks.** Have someone take your place at the bedside if you're reluctant to leave your child alone.
- **Get outside every day, if only for a brief walk.** A few minutes of fresh air can soothe and center you.
- **Get enough sleep and rest.** You may need to leave the hospital or home for a few hours.
- **Eat regularly and focus on healthy foods.** You need good fuel during this stressful time.
- **Find a time and place to cry, complain, shout — to express the intense feelings you may be holding inside.** An understanding listener can help.
- **Be gentle with yourself.** The end of life will come in its own time, in its own way. You're not in control, but you can better comfort your child by caring for yourself.

As your child draws close to death, you may see these changes:

- **Louder breathing.** Your child's breathing may become louder, more ragged or gurgling. It may sound like snoring. This happens because saliva is more dry and thick now, the throat muscles more relaxed. It's not distressing or painful to your child.
- **Pale, bluish lips and nail beds.** This is a further sign of slowing circulation.
- **Half-open eyes and mouth.** Near death, some people's eyes remain partly open and look glassy. Their mouths may fall open.
- **Stop-and-start breathing.** Your child's breathing pattern may change, and there may be very long periods between breaths. This interrupted and irregular breathing is very common in the final hours of life. When your child stops breathing and the heart stops, there may be a final long sigh or gasp of breath. Your child may also pass urine or stool at this moment of death.

After your child's death, you may choose to spend time at the bedside with your family. Take as much time as you need to hold and talk to your child, bathe and dress your child, or do religious or spiritual rituals that are meaningful to your family.