

Helping Your Child When Death Is Near A Guide for Caregivers

Helping You Help Your Child

We know this is a most difficult time for you and your family. Throughout the coming days or hours, your child's body will prepare itself for the final stages of life. As a result, your child may experience some or all of the changes described here. Such changes won't occur in any prescribed order. Because they often signal that death is approaching, however, you may want to recognize and anticipate them.

Your physician and nurses are available to answer any questions you may have.

Temperature Changes

As your child's heat-regulating system fails, the hands and feet will cool first, becoming pale or blue. Your child's face may become gray, and the lips or nose may look blue.

Although most dying children don't feel cold, you might want to ask if a blanket would make your child more comfortable. In some instances, children may feel feverish and appear flushed. You can use cool washcloths to sponge them off.

Pulse Changes

As the heart weakens, the heartbeat often becomes irregular - rapid at times and slow at others. Pulse points, normally felt in the wrists and feet, may become faint. As the circulatory system slowly becomes less effective, your child's temperature and color may change.

Gastrointestinal Changes

The need for food and drink will decrease as the body begins to conserve energy. The muscles controlling the mouth, throat, stomach and bowel also will become less effective.

Often, the body doesn't need or tolerate fuel at this stage. If you want to feed your child, offer tea, juices, ice chips, frozen juice pops or sherbet as long as your child can swallow. Children also may find it comforting to have their mouth swabbed with a moist sponge.

Breathing Changes

If your child has difficulty breathing, you can help. Turning your child from side to side, elevating your child's head, propping up your child in a well-supported sitting position, or holding your child in your lap will relieve shortness of breath and provide comfort as well. You may want to consider using supplemental oxygen.

Breathing may become rapid, then shallow and irregular, with 10- to 30-second intervals between breaths. Maintaining a calm, reassuring atmosphere helps relieve labored breathing. You may want to encourage your child to imagine relaxing images or memories.

Eventually, your child may become too weak to swallow or clear excessive secretions from the mouth or throat. The secretions may cause a gurgling sound, which can sound disturbing but usually doesn't cause any discomfort.

Turning your child to the side, or keeping your child's head elevated, can help secretions drain. You may choose to use medication or suctioning to help clear the secretions, which might increase as death nears.

Alertness/Sleep Changes

Some children are alert and mentally clear until the moment of death. Others are confused, restless, sleepy or difficult to arouse. They may drift in and out of consciousness. Their speech can become confusing or difficult to understand.

Even if children cannot communicate in words, you can assume that they hear you, feel your touch or sense your presence. Hearing is believed to be the last sense remaining, so we encourage you to talk to your child and play soothing music. Maintain gentle physical contact. Sometimes nonverbal cues confirm that your child can hear. Children may move their eyebrows, change their facial expressions, flutter their eyes, grasp your hand, move an arm or leg, and change their respiratory rate and patterns. Familiar sounds, voices, touches and embraces will continue to bring comfort and security.

Pain Changes

Some children die without experiencing any pain at all. Others need regular pain medication. You'll be able to tell if your child is experiencing pain. Watch for nonverbal signs, such as grimacing, moaning, increased irritability, restlessness, interrupted sleep, and changes in breathing. Work closely with your child's physician and nurse to make sure your child is as comfortable as possible.

We're Here for You and Your Family

Nurses are available 24 hours a day to speak with you about any or all of these changes and to help you find ways to comfort and care for your child.

Some families want a nurse, social worker, child life specialist or chaplain present when their child is dying. Others view this as a private time and want to be alone. Please let us know how we can best support you.

Remember that you only need to do what is comfortable and right for you and your family. We're here to support you as you make decisions, plans, and arrangements.

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Make An Appointment **651-290-8707**

This information is for educational purposes only. It is not intended to replace the advice of your health care providers. If you have any questions, talk with your doctor or others on your health care team.

If you are a Gillette patient with urgent questions or concerns, please contact Telehealth Nursing at **651-229-3890**.