

## 'Dad's going to die'

### What to do when you have to tell kids about impending death.

Deb Thomas reads while Elizabeth, 8, does homework and Jesse, 4, plays. The family "clung together" after her husband, Jesse, died almost two years ago.

Edmee Rodriguez / News-Leader

Elizabeth and Jesse Thomas lost their father, Jesse, to cancer almost two years ago. Elizabeth, 8, holds a wedding photo of her parents taken in Jamaica in 1995. She finds comfort in pictures featuring both parents and keeps two in her bedroom. Jesse, 4, has few memories of his father, although he remembers a trip they took to Bass Pro Shops Outdoor World. Both children attend meetings at Springfield's Lost & Found to help them grieve.

Edmee Rodriguez News-Leader

Don Payne gives himself a shot while eating dinner with his family in Chandler, Ariz. He recently had to tell his two sons that his chemotherapy was not working and that he would die from pancreatic cancer. Bereavement experts say it is important to tell kids when a parent is going to die.

Pat Shannahan

### Coping with death by age groups

Children understand death in different ways. What to expect by age group:

#### BIRTH TO AGE 3

- View death as loss, separation or abandonment.
- Change in sleep, eating, mood.
- Need constant nurturing.

#### AGES 3 TO 6

- View death as reversible, believe people who die will come back.
- Belief in magical thinking.
- Might think they caused death, that death is punishment.
- Can't grasp abstract concepts.

#### AGES 6 TO 9

- Begin to view death as final.
- Sees death as accidental, something that happens to old people but not them.
- Increased curiosity about illness, its affect on the body.
- Worries about how the dead person eats, sleeps.

#### AGES 9 TO 12

- More aware of death's finality and their mortality.
- Delayed, strong grief.
- Concern about how the loss will affect them.

- Understand that they, too, will die.
- Interest in goodbye rituals.
- Questions about afterlife.

#### ADOLESCENTS

- Adult understanding of death as inevitable, universal and irreversible.
- Repressed sadness, feel confused, responsible, angry and lonely.
- Might see self as invincible.
- Might question meaning of life and religious beliefs.
- Might assume a more adult role.

#### WAYS TO HELP

- Use concrete terms for death — dead people no longer breathe, eat or grow.
- Don't say a dead person is sleeping, resting, lost or taking a trip.
- Prepare children for what to expect at the funeral or visitation.
- Maintain routine as much as possible.
- Use books on death and loss to aid understanding.
- Don't assume older children and teens can cope on their own.

Sources: Mayo Clinic, National Hospice and Palliative Care Organization and Hospice of the Valley, Phoenix

By Tresa McBee, News-Leader and Connie Cone Sextion, The Arizona Republic

Martha Payne wasn't exactly sure what she was going to say. She looked at her two sons, Josh, 9, and Jeremy, 5, playing in the family room and fought the urge to weep.

It had already been such a long day and she was running on little sleep. But there was no going back. She and her husband, Don, had agonized for three days about how to break the news to their sons. They sought advice from their doctor, from their pastor, from friends. It was time.

Don, 45, turned off the television and had the boys join him on the sofa. They huddled close, one on either side. Martha, 43, took a seat on the ottoman, facing them.

"Your dad doesn't have to take chemotherapy anymore," she said, quietly.

Josh excitedly gasped.

Martha's heart sank, realizing he misunderstood. "No, honey, the chemo's not working anymore."

Josh's smile vanished as the words hung in the air. He leaned forward. "Then, Dad's going to die?"

"Yes, Dad's going to die."

As Don's tears began to spill down his face, he pulled both boys close, and they buried their faces against him.

Everyone was crying, now.

As hard as it was, as much as Don knew that he was tearing their lives apart, the father wanted his sons to know the truth. When he and Martha shared their news that February evening, Don probably had a few months, maybe a year, to live. The boys needed to know.

His instinct was right, bereavement experts say. Children are extremely perceptive, says Barbara Volk-Craft, a nurse and director of the Health Care Decisions program for a Phoenix hospice.

Hiding news of a terminal illness may be impossible. Children might wonder why Mom and Dad are starting to whisper, why phone calls are suddenly cut short when the kids enter the room. The children watch and listen and try to guess, trying to piece it together. And sometimes they think the sadness that has settled into the house is all their fault.

"The child is waiting for you to talk," Volk-Craft says. "There is anxiety for the parent. They are afraid to tell their children what's going on. But children are very adaptable, as long as they feel support."

Deb and Jesse Thomas didn't hide that he would die. After the diagnosis of terminal cancer, the Springfield couple told their daughter, Elizabeth, then about 4, that daddy was sick. Little brother Jesse, then 10 months old, was too young to understand.

"When I look back, I feel like there was so much more I could have done to prepare them ... but I don't know what," says Deb, who was 38 when 48-year-old Jesse died Nov. 5, 2002.

Honesty is critical, because children will sense if adults' actions and feelings don't match, says Karen Scott, a Springfield licensed professional counselor and co-founder of the nonprofit Lost & Found, which helps children cope with the death of a loved one.

How much to reveal about the impending death of a parent depends on a child's age, emotional maturity and time until death, Scott says. Don't give more information than is needed at that moment.

"You should be guided by the questions your child asks," Scott says. And expect a lot of them. Children will process information at varying rates and return with more questions.

"Typically they'll think about that a day, a week, a month and then they'll come back," Scott explains.

Giving Josh and Jeremy as routine a life as possible has been Don and Martha's goal since they first learned in fall 2002 that Don had pancreatic cancer. But it's been tough. Don needed surgery to cut out a tumor, and he worked hard to keep up his energy to play with the boys as he endured radiation and rounds of chemo. But other tumors appeared.

The family had been through so much already. Josh was just 10 months old when Martha discovered she had thyroid cancer. Three years later, Jeremy was born with a cyst in his brain, so a shunt was surgically implanted to control the spinal fluid in his head. Without it, he could have suffered brain damage. The shunt was removed last year, but Jeremy is closely monitored.

It wasn't until February that it was time to tell the boys just what was ahead.

"How long have you known?" Josh asked that Friday night, the hurt in his voice apparent as he looked at his parents.

"Since Wednesday," Don said. "We were just waiting for the right time to tell you."

Jeremy was still wiping away tears. "I don't want you to die."

Josh, too. "No, you can't die."

The pleas, Don would later say, hit hard, like he'd been punched.

Josh began a volley of questions. "Why can't they fix you? Why can't they just give you two times the medicine? Why can't they put a shunt in you like they did for Jeremy?"

Don and Martha took each question, explaining that there are just too many tumors now.

Deb Thomas still takes questions. She and 8-year-old Elizabeth and 4-year-old Jesse talk about Jesse Thomas all the time.

They still ask why he's gone, although Elizabeth, who goes by Lizzie, understands more the permanency of her father's death. Sometimes Jesse will ask for his father's phone number or inquire if his dad can come down for a while.

"Lizzie remembers more and misses her father and talks about him a lot," Deb says.

Jesse Thomas took two years to die — a long goodbye, his wife says. But that allowed them to try to prepare their children. Deb credits her husband's strength — on which she leaned — for helping Lizzie and Jesse by talking about God and heaven and angels. They read books about death, and Deb tried to complement her husband's efforts as best she could.

"One thing my husband did, which was incredible, he got a Bible and highlighted scripture for the children as they got older," Deb says. "He took one day at a time, and he taught his children to also.

"I don't know of any quick remedies to prepare them. But certainly my husband has to be mentioned (for his preparation)."

About 1.9 million of the 40 million children living in the United States today have gone through what Josh and Jeremy soon will experience and what Lizzie and Jesse are dealing with. The 1.9 million have lost at least one parent and are receiving survivor benefits.

"The death of a parent for a young child is a little more frequent than we would like to think," says Jon Radulovic, vice president of communications for the National Hospice and Palliative Care Organization. "One out of 20 children will lose at least one parent by the time they are 20."

Steve Averill, coordinator of bereavement services at Arizona's Hospice of the Valley, said the surviving parent needs to provide continued support years after a death.

Children react differently, depending on their age and maturity, he says. With teenagers, grief can get mixed up with stress. They can get behind in their schoolwork, maybe get into arguments. By ensuring that they know what is happening, what has happened, they feel less alone, Averill says.

Scott agrees.

"Include them," she says. "Teenagers are so resentful if they feel like they're left out."

And always let children decide if they want to attend the funeral, Scott says. But they need to be told what will happen in order to make that decision. And if they decide to go, they should be accompanied by an adult who isn't grieving and can answer questions.

Security is a big concern, especially for young children, Averill says. "They're afraid that someone else in the family may die."

That response is normal, Scott says.

"What happens to children when someone dies is their assumptive world is shattered."

It's common, Scott says, for children to worry about three things: who could die next; what if the surviving parent dies; and who will take care of me if that happens?

"They worry about my life," says Deb Thomas. "They worry about whether I'm going to be around."

Amid chaos, children find comfort in routine because it offers safety when so much is unpredictable, Scott explains.

That's one reason rituals are part of the Lost & Found experience, says co-founder Shawn Askinosie, who's also a Springfield attorney.

"Rituals are very important," he says. "In fact, every meeting is built around rituals."

At the beginning of each children-only meeting — parents are required to stay in the building while their children meet — participants state their names, who died and how. Deceased loved ones are also acknowledged on significant dates like birthdays, holidays and death anniversaries, Askinosie says.

The Thomas family remembers Jesse on such days, Deb says. Elizabeth and Jesse write letters to their father, attach them to balloons and release them at his grave.

Because Jesse Thomas talked to his children about heaven, they associate the sky with the place their father went to. "That's how they feel like they communicate," Deb says.

She credits family, friends, her church and Ozarks Coca-Cola — where Jesse and she met and both worked — for helping her and the children through loss.

Deb also believes Lost & Found provides a unique place for her children to work through grief. Elizabeth has said there are things she can say at Lost & Found that she can't say anywhere else.

"Depending on the age of the child," Askinosie says, "the bottom line is they need to hear the truth. I think it's something parents need to think about when there's a death or a long-term illness."