

What Do We Tell the
CHILDREN?

Talking to Kids about
Death and Dying

Joseph M. Primo



"..a must read"

- Kate Braestrup, *New York Times* Best-Selling Author of *How if You Need Me*

WHAT DO WE TELL THE CHILDREN?
TALKING TO KIDS ABOUT DEATH AND DYING

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C h a p t e r 1

Put On Your Own Oxygen Mask First

Before we can proceed to talk about children and their grief, we need to know our own grief story. Our interactions with grieving children, our presence and responses, are skewed by many variables: our age, previous losses, religious beliefs, cultural heritage, and, of course, our profession and social role. It is important to understand these prejudices because they will influence our expectations of how a child should grieve or what a child's grief looks like. This is true for each of us, and unless we are willing to dive into our own grief experience and reflect on our grief story, we will not be able to identify those feelings and discomforts that affect our perception of other people's stories. Through our own careful examination of our fears, preconceived beliefs, deaths, disenfranchised grief, and the ways in which each of us achieves emotional safety through ideas that can become rigid beliefs that are not applicable to everyone, we are able to better support the bereaved, especially children.

When I train facilitators of children's support groups, I never start the training with children's grief, even though that's the subject

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the facilitators have signed up to learn about. We never dive right into childhood development or what grief looks like for a kid. Instead, I dress up like a flight attendant and take out a mock oxygen mask. “When this thing spirals, folks, you’ve got to put on your oxygen mask first. Then you can help the child next to you.” Well, that makes sense to everyone. We all need to breathe, and it’s better for us to prepare ourselves first so that we can help the children. So, many thanks to whoever came up with that life-saving advice, because that same teaching is crucial for successfully helping adults and kids with their grief.

On the first day of training I have everyone create a loss line. It is a simple task that is full of emotion, memories, and sharing. No matter how creative someone is (or is not), each trainee sits down with a large poster board and maps out his or her grief story. The trainees make collages that map, from birth to the present moment, dreams that never came to fruition, loves that fizzled, parents who died, unwelcome moves across states that left friends behind, the deaths of pets and friends, job losses, and all sorts of other things that are a part of life. If you have never done this exercise, take some time and do it now. Create your own loss line. What memories are stirred? Are there any patterns? What other important life events followed?

This exercise exemplifies our grief story. Reflecting on life, seeing the years that were full of grief or hope, and returning to memories that time has since silenced, the trainees build on their empathy and can more clearly see the ways in which their story might lead to judgments and assumptions that would make them less effective with others. I call this grief work. And doing grief work leads to grief knowledge.

Grief work is so important because, for the most part, we’ve forgotten how to do it. We no longer have transference of grief

knowledge from our elders to the next generation. The knowledge has been lost because a discomfort with grief and a denial of our mortality have silenced our stories. Our lack of socially prescribed ways of dealing with death as a community directly affects each of us, especially our children. Kids look to adults in order to learn, acquire knowledge and facts, and better understand life. When a grieving child—or any child for that matter—looks to an adult to gain a better understanding of death but no one is able to provide honest or clear responses, it is unsettling for the child.

I believe our ability to honestly engage our mortality and grief has shifted dramatically in the last 150 years from an intimate familiarity to a disconnect and discomfort with death. Both our expectations and rituals have changed. Up until the twentieth century we were a primarily agricultural society in which children and adults were routinely interacting with nature and the cycle of life, watching animals give birth as well as die. It was a day and time when the sick were cared for at home and the death of both the young and the old seemed like an ordinary, albeit often unwelcome, part of life. Although medical science offers many blessings, it has also led us to create new expectations about death. Nowadays, we like to think that death is specifically for people over ninety or one hundred. We are OK with them dying. That seems natural to us. They lived a long life. We may miss them, but we are not surprised by their deaths.

In large part, this shift in attitude and experience can be attributed to medical advancements, but it also has something to do with the rapid change of our death rituals. Rituals are a crucial characteristic of how adults and children alike understand and comprehend death. The American Civil War, for example, drastically changed our death rituals and our vocabulary for talking about grief.

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During that war, Confederate and Union soldiers were embalmed and brought home for burial. This was a new practice, in which families could now expect their dead to be returned to them and buried in their family plot. Eventually, President Abraham Lincoln underwent the same procedure after his assassination. Everyone was so impressed that the new embalming practices allowed the president to be transported across the country. As a result, the practice's popularity increased, first among the rich and then among the masses. In a short period of time this led to the creation of "stand alone" funeral parlors, which replaced the parlor in the family home. No longer did the family care for their deceased; now strangers were responsible for the disposition of the dead for a fee, creating a new economy with its own ideas, agendas, and practices.

Funeral homes erased the smell and look of death. The dead looked lifelike and asleep, in what the funeral industry now calls a "memory photo." That's where a huge shift in our culture began. We transitioned from death to "a sleeping appearance." Our comfort and intimacy with death continues to be foreign. Funeral homes are staged to keep death tidy and to force us to control our emotions as lines form at the casket and the bereaved shake the hands of all those "paying their respects." The dead are made to look like the living, and this disguise affects our understanding of death.

Think about this. If you spend a Saturday afternoon watching a cooking channel on television, as I often do, you'll hear the chef say, "We eat with our eyes." He will then go on to talk about our senses and how our eyes, taste buds, and brains work together to create the entire, magical flavor in our mouths. Our eyes help us understand. They communicate with our brain. Our current funeral rituals have removed our ability to touch and interact with the dead and see them as they naturally are. Our senses aren't sending

honest messages to our brains and aiding us in our understanding of death.

I believe that our lack of interaction with the dead—death’s place as a taboo in our society—has affected our ability to talk openly about death and grief. Today, death is something that happens behind closed doors. Children do not often see it in real life, despite the fact that it is all over our television. Children understand dead squirrels on the side of the road, dead fish, and dead dogs. Parents tend to be comfortable with those teachable moments. But what about dead Grandma? Well, that’s when the folklore begins, which I will discuss shortly.

I view our mortuary practices, how we handle and deal with our dead, as interconnected with those taboos surrounding death and with our lack of vocabulary to talk about death and grief. The funeral ritual, after all, is an integral part to our good-byes and how we comprehend or process that a person has died.

Depending on the circumstances, anticipatory grief can begin as we first contemplate a loved one’s impending death. Grief can also launch into full swing when we learn about the death. It is then exacerbated during the funeral ritual when the living are reunited with the dead at a funeral home and see the dead for the very last time. These experiences can set us on a path, healthy or unhealthy, for our grief work. Our expectations about death and grief and the rituals surrounding them affect our grief work and healing.

Our grief work is an ongoing process that lasts a lifetime as we lose friends, family members, and even parts of ourselves (i.e., our own characteristics of a healthy body). Through this process we can build coping skills and resiliency, preparing us for future grief. We don’t have to be victimized or defeated by death.

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Our own stories, prejudices, and assumptions can dilute our thoughts and feelings about other people's grief, making it important that we take the time to understand the complexities of our grief and acknowledge our own emotional baggage.

Grief looks different depending on many variables, including culture. Although I advocate for everyone to have the opportunity to express his or her emotions, I am still surprised when I see people completely vulnerable in front of strangers. One morning during the summer of 2004, I was sitting at my desk and looking at Long Island Sound before making my rounds to visit hospice patients. It was a morning ritual, in which I reflected on the lives that had ended in the wee hours of that morning and I thought about the memories and love that would be shared that day. I suppose it gave me perspective on days when I found the institution dysfunctional and I hoped that, despite family dynamics and feuds, there would be a lot of beautiful moments and healing that day.

I got a call from the admission nurse asking for support. A twenty-nine-year-old mother of a two-year-old was en route to the hospice. She was being transferred from Yale-New Haven Hospital, which befuddled the staff since the patient was actively dying in the ambulance. Someone knowing that she has a terminal illness is quite different from someone actively dying. When we are actively dying, we are on our way out. Organs are shutting down, breathing is sporadic, and death is hours or moments away.

I met the patient at the front door. She was wearing an oxygen mask, and her skin was pale and frigid to the touch. Her eyes were fixed on the ceiling, and everything her body was communicating told us that she had only minutes left.

The usual routine for admitting a patient included a lot of paperwork, questions, and the introduction of nurses, doctors, a social

worker, and me, the chaplain. This mom, however, went straight to her room, and protocols were tossed aside so that doctors could ensure her comfort.

Shortly after her arrival, her family came to her bedside. Then her friends came; then her neighbors; then the neighborhood. Folk from the church came next, and then came death.

The wailing was so loud, so hysterical, and so chilling that nearby patients were moved to other rooms and musicians were brought in to fill the halls with sounds other than cries. It didn't stop there. Far from it! The patient was from an expressive cultural tradition, and as the mourners intensely experienced their grief, the nurses were alarmed by this reaction. Family members flung themselves on top of her lifeless body, and at one point, the patient's mother wrapped herself in the patient's arms and bounced up and down in the bed, tossing both herself and the body from side to side.

Witnessing this made my palms sweaty. I thought I was going to throw up from the intensity of it. I stood frozen at the back of the room. The nurses wanted the poor chaplain—poor me—to intervene. But they don't teach you that in seminary. What was I supposed to do? *“Um, ma'am, just wondering if you might get up and let us call the funeral home or something. Any interest in grabbing lunch from the cafeteria downstairs? The food is really tasty today. I think it is a new chef.”* What would that have looked like? It's not like she was hurting her daughter. Completely unsure of myself or the situation, I encouraged the staff to leave and stand outside the door. We did. Forty or so minutes later, after the musicians played a dozen songs, the family and the neighborhood emerged. They were composed.

The patient lay with a flower in her hands. They had brushed her hair and put a designer T-shirt on her so that she looked

like herself. Earlier that morning I had sat at my desk overlooking Long Island Sound, imagining a day filled with other people's grief. When confronted with something completely new, I had gotten out of the way and allowed it to be what it needed to be. I'm sure some other chaplain, nurse, or social worker would have dealt with this situation differently. However, for me, my decision was part of a paradigm shift in which I now firmly believe.

As a culture we tend to think that grief is something controllable and if we contain it we can get back to our lives quickly. Whereas, I think grief is something that is organic and spontaneous and if we let it be what it needs to be, then healing can happen and flow through that authenticity and vulnerability.

Grief is a normal part of the human experience. Allowing grief to be what it needs to be can enhance one's healing. Unfortunately, society is often uncomfortable with the ebb and flow that is grief.

We Americans, for the most part, like to think we are tidy. We spend billions each year on products to help us appear organized. Like many Americans, I buy plastic bins, shelving units, and closet organizers to keep up the illusion that my house will be neater, my life easier, and things a little more orderly. Grief is messy, and no matter how we look at its complexities, if we file it on a shelf in some stylish container, we will only stumble upon it at a later date when looking for something else.

In order to go any further in preparing ourselves to support a grieving child, we need to identify our grief triggers and prejudices and reflect on our own grief story. There in the depths of stories that have not been told in years, stories that may have become family secrets, aspects of a narrative that do not add up, and whatever fears surround our own mortality, we can better know ourselves

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and develop the empathy necessary to allow a child to fully experience his or her grief. Through that fully felt and supported grief experience, a grieving child can feel sadness and love at the same time, as he or she digests the complexities of death and finds hope in spite of it.

Practical tools, up-to-date research, humor, and helpful ways to create a safe space for age-appropriate grieving.

This wonderfully sensitive book is full of illustrative stories and gentle wisdom. Parents, teachers, and counselors will find it a necessary guide in engaging children in meaningful and needed discussions about death and loss.

--Kenneth J. Doka, The College of New Rochelle; Senior Consultant, The Hospice Foundation of America

The stories Primo tells are compelling and filled with many teachable moments about life and death. The book is encouraging for parents and others fearful of "doing it wrong" or (scarier still!) "having already done it wrong!" A must read for anyone caring for the grieving.

-- Kate Braestrup, New York Times Best-Selling Author of *Here If You Need Me*

This book is about the power of love and about overcoming our own anxiety, so that we can offer grieving children our compassionate presence and steady support as they create meaning in their own way and at their own pace.

--Deborah van Deusen Hunsinger, Princeton Theological Seminary

Joseph Primo's book should be given to every military household who has lost someone.

--Michael Anthony, Iraq War veteran and author of *Mass Casualties: A Young Medic's True Story of Death, Deception, and Dishonor in Iraq*

As a practicing physician and teacher working in hospice and palliative care, I believe that Primo provides a solid introduction for medical students and residents as they move into the responsibilities of supporting entire families, not just children, not just adults. I recommend *What Do We Tell the Children?* to those in all walks of life charged with the tough and tender task of supporting children in their grief. This will promote our work together for the children.

--Scott Long, Yale University School of Medicine and Physician at The Connecticut Hospice

Joseph M. Primo is Executive Director of Good Grief, Inc. in Morristown and Princeton, New Jersey, and President of The National Alliance for Grieving

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