



Natural Transitions

Volume 2, Issue 2

Conscious, holistic approaches to end of life

Loving Enough:
Releasing My Dying Child

The "Passing-through" Spirits:
Miscarriage

A Picture Worth a Thousand Words:
Memories of Sons and Daughters

Awakening to Energetic Parenting
in the Cycle of Life: Qigong



Children and Death



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Children and Death: The Toughest Topic

by Karen van Vuuren

A frail, exhausted octogenarian dies and we muse on his consummate life. He's made it through childhood to old age, and the finishing post is death. Grief and sadness arise, but he had a "good inning" (or that's the hope). Not so with the demise of a child. We expect our progeny to flourish, to enter adulthood, to thrive and outlive us, and when they don't, the natural order of things is undone. It's a generalization, but that's mostly how we see it.

Our editorial team braced itself for tears with this issue of NTM. If death is still largely a taboo topic in this culture, child death is probably the hardest to broach. Bereaved parents often feel the discomfort of others who don't know what to say or do around them.

It's not just lay people who don't know what to do or say when a child is dying or has died. Many healthcare professionals, including hospice staff, feel inadequately trained to serve terminally ill children and their families.

In research for this issue of NTM, I came across the work of Children's Hospice International (CHI), whose mission is to encourage the inclusion of children in hospice, palliative, and home care programs. The organization provides invaluable education and training to enhance services to families with terminally ill kids. In 1983, when CHI began, only four hospices in the US accepted children. Now, most hospices are at least open to serving children. Unfortunately, many hospices still do not feel well equipped to deliver pediatric care.

Getting families with dying children to even consider hospice is another monumental challenge. If choosing hospice means handing parents an ultimatum to stop treating their child's disease, hospice frequently doesn't stand a chance. Families of very sick children most desperately want them to live. Terminally ill kids generally receive more aggressive treatment than adults with similar diseases. Moreover, physicians often find it difficult (medically speaking) to hand out the six-month prognosis of probable death that is typically required for hospice eligibility.

CHI has been instrumental in promoting the option of concurrent curative and palliative care from the time of diagnosis, available through the Medicaid waiver. (See our article *Entering the Mainstream: Pediatric Palliative Care Comes of Age*.) A gifted palliative care team can act as a bridge to hospice, introducing the hospice concept, helping families to evaluate treatment options holistically (for example, their impact on quality of life), and even introducing the "what if" scenario of death.

This issue of NTM isn't just about child death; it's also about how children experience the deaths of others. Intuitively, I've always felt this hinges a great deal on how we adults deal with mortality. Read our contributors' views on exposing children to the way of all things—death. And then read how we can help them to experience healthy grieving.

For this NTM issue in particular, we welcome your feedback, and we thank you for walking with us as we explore this most sensitive of subjects.

Karen van Vuuren



Natural Transitions

OUR VISION

- Acceptance of death, loss, and grief as a natural part of life

OUR MISSION

- To share holistic approaches to end of life
- To provide a forum for end-of-life caregivers and educators

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Molly O'Brien

Kirsten Savitri Bergh was 17 years old when she and her best friend, Nina Dietzel, were killed in a car accident. Both girls were boarding students at Hawthorne Valley Waldorf School in Ghent, NY, and Kirsten's mother, Linda, the sole survivor of the crash, had come to visit. Just the year before Kirsten had experienced the death of her father and other personal life challenges. Linda Bergh says of her daughter, *"Poetry was Kirsten's way to penetrate her grief and confirm that love is the strongest thread in life."* Bergh left a legacy of paintings, drawings, and poetry, which she wrote during her high school years. NTM is honored to share some of her artwork (illustrations throughout) and poetry (Last Words: Papa) in this issue. For more information visit: www.beholdingthethreshold.org.

*Cover photo: David in his father's hands
Courtesy of Now I Lay Me Down to Sleep*

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Loving Enough: Releasing My Dying Child

by Dianne Gray

*“That which does not kill us makes us stronger.”
~Friedrich Nietzsche*

For years, I begged God not to put me through the gut-wrenching experience of having to remove nutrition and hydration from my terminally ill son, Austin.

You see, Austin was diagnosed at age 5 with a rare neurodegenerative brain disorder, one that by age 9, left him locked in his body, totally unable to move, but with his cognitive processes intact. Austin was helpless but not powerless.

It's hard to describe this exactly, except to say that when Austin could no longer walk, move his arms, and speak, I watched the subtleties in his face for clues to what he wanted, and I could fulfill his requests based on my mother's intuition and our new method of communication. Like many parents of seriously ill children, we developed our own language that consisted of my asking a question, then listening to his breathing pattern or watching his beautiful, blinking green eyes for a response. One blink meant “no,” and several consecutive blinks meant “yes.” This “language” between us became a cornerstone to my ability to manage his comfort. While he had no control over the horrible writhing of his body due to dystonia (a neurological movement disorder), he *could* have a “voice” in the management of his pain.

One fall night in Florida, when Austin was 9, he experienced excruciating pain that seemed to appear out of nowhere. I'd never seen anything like it. It was the kind of pain that leaves an indelible print on your soul forever. I begged for a cessation to the torture he was enduring. The pain stopped hours later, but I remember praying that my son would never, ever experience anything like

that again. And on that night I agreed to hospice and palliative care in our home.

Hospice was a good fit for us, though it took a toll on our privacy, our family life, our sense of well-being. Who adjusts easily to the invasion of nurses, medical equipment providers, social workers, and other hospice team members? Our home was once a place where laughter flowed easily and neighborhood children built forts in the living room during sleepovers. With hospice in our home, it seemed that each delivery person intruded on our happiness.

What good mother withholds nutrition ... from her child?

But in short order it became clear that without hospice we would be lost in a sea of physical and emotional pain and suffering. The hospice team, especially the case manager, became our life raft when it felt as if we were drowning under the pressure of life and death decision-making about issues that were way over our head. I was 39 years old and had to think about morphine, methadone, my 10-year-old son's impending death, as well as the emotional wellbeing of my healthy daughter, Christina, who was then 6.

One day our hospice case manager casually mentioned that, at some point, I might have the option of ending Austin's suffering by removing nutrition (he had a feeding tube) and hydration. Under certain circumstances, hospice considered this removal an acceptable practice.

I'll never forget that conversation. It became a benchmark moment in my life. What good mother withholds nutrition

(in motherspeak, life itself) from her child? I looked at the case manager as though he were the one taking narcotics, not my son, and quickly dismissed him from my presence. Was I rude? You bet! Someone responsible for coordinating my son's care had suggested (a) ending his life and (b) that I make the decision to do it by (c) not feeding him. “He's insane!” I thought.

Five years of at-home hospice care passed and Austin battled intermittent acute pain from dystonia. Our existence transitioned into what felt like a

“healthcare hurricane.” In the eye of the hurricane, we would settle nicely into a routine, and we all three knew what to expect: meds, breakfast, meds, Christina off on the school bus, meds, day at home

caring for Austin, meds, Christina home from school, Christina's homework. There were times when we got outside of the hurricane's eye and into the turbulent winds; everything that was our “norm” became undone when the pain from dystonia came again and each quarter hour became frantic. Each time this happened, our team came to Austin's rescue with increased doses of morphine, Ativan, and other medications. And after a few days or sometimes weeks, we would all settle back into a new “norm.”

This hurricane pattern repeated itself over and over during our five years with hospice—until the last time. A non-hospice visiting nurse had turned Austin, probably to reposition or change him, and after that, he was in the most horrific pain, the worst I had ever seen. Could it have happened to anyone caring for Austin, even me? Probably. He'd been in distress even before this incident occurred.

Fortunately one of our amazing long-time team members happened to be at the house at the time. I don't know what I might have done if she had not been there. Screamed at the nurse? Kicked her out of the house? I remember asking my non-verbal son to blink for me to tell me something about his pain in that frantic moment. He did, and I clearly understood that we were now in uncharted waters with his pain management.

For eight days our hospice team rallied like never before. Doctors visited and prescribed new and additional medications. Nurses stepped in with extra hours. Chaplains and other community clergy held vigil on a daily basis. Yet nothing, absolutely nothing, worked to stop Austin's suffering. These were uncharted waters for him as well. We discussed whether it was perhaps his time to go to heaven, to be free from the pain and the suffering. He blinked that he heard me and that he understood. Somehow he knew beyond his 14 years exactly what would happen.

I took a little longer to get it all figured out. Was he dying? I called the best clinician in the country for Austin's disease, and she said, "yes." I asked our medical director who also said, "yes." After 8 days of watching my son suffer in excruciating pain, and after putting myself through an intense ethics process with both hospice and my church, I accepted what our medical



Austin and Christina: Unconditional love

team suggested. It was time for Austin's suffering to end.

So on a day in February 2005, our family once again hit the eye of the healthcare hurricane. All became extraordinarily, eerily still as Austin began the horrible, yet peaceful process of a hospice-supervised removal of nutrition and hydration.

It felt like I was dying alongside my child. I felt sick to the core of my being every single minute of every day. Nauseous, I felt nauseous and as though my womb was nervous. I also felt that we were exactly where we were supposed to be in the journey of Austin's life. The phrase, *What you most fear, most likely presents* kept running through my mind.

I grew to see that Austin was profoundly suffering and that no amount of medication and no amount of treatment could stop his incurable disease. Even though I had prayed so desperately for a healing every single day and every single night for 12 years, had pleaded, bargained, and sought forgiveness to the depth of my soul, and still he was not physically healed, I felt strangely at peace with God. And after an 18-day process of life without nutrition and with only minimal hydration, my 14-year-old son died a peaceful and beautiful death at home, surrounded by love and guided by his little sister and me.

I share with you this quote from Mother Teresa: "I have found the paradox, that if you love until it hurts, there can be no more hurt, only more love." In loving Austin enough to help him through his dying process, I hurt so much I thought surely I would die. Yet, paradoxically, I found that it was the most loving thing I could do—and that love sustains me even now.

Dianne Gray is president of Hospice and Healthcare Communications (www.hhcommunications.com). She is an international hospice advocate who serves on the boards of numerous foundations to further pediatric hospice programming. She still sits at the bedside of dying patients to share unconditional love.



*A Picture Worth a
Thousand Words:*

Memories of Sons and Daughters
by Karen van Vuuren



NILMDTS

Photos: Left: Rob and Gina adoring David
 Top: David in the blanket his parents have never washed and have kept as a precious memento

In the latter 19th and early 20th centuries, death was a domestic affair. Families donned their Sunday best to pose with their dead in rituals of post-mortem picture-taking. Recording life's obvious end via the new technology—the *camera obscura*—was often the *only* documentary evidence of an individual's existence. In those days photography was expensive, so families used the significant occasion of death to create family portraiture. These images became prized mementoes, appearing on walls, on cards sent to relatives, and encased in precious locketts. They were part of an outward show of bereavement that included the wearing of special clothing and jewelry, particularly by the women of that era whose children and infants frequently succumbed to an early demise. Over the course of subsequent generations, remembrance photography became an outmoded, unpalatable practice to a modern society, which chose to institutionalize death and remove it from the family fold.

While post-mortem photography is still largely anathema to today's Western cultures, there is renewed interest in its ability to facilitate healing, particularly

for families dealing with the death, actual or imminent, of a baby. Inspired by their personal experience around the death of their child, Cheryl and Sandy Haggard created an organization—Now I Lay Me Down to Sleep (NILMDTS)—to preserve pictorial memories of the brief lives and early deaths of babies.

The Haggards' baby, Maddux Achilles, died on February 4, 2005, from a condition called myotubular myopathy that prevented him from breathing, swallowing or moving on his own. On his sixth day of life, his parents made the painful decision to remove him from life support. But before they did, they called Littleton, Colorado, photographer, Sandy Puc, to take black and white portraits of them cradling their son. "That night was the worst night of my life, but when I look at the images, that's not what I'm reminded of. I'm reminded of the beauty and the blessings he brought," said Cheryl.

NILMDTS, named for the well-known children's bedtime prayer, is a non-profit organization offering free remembrance photography to parents of babies who are stillborn or at risk of dying as newborns.

However much parents try to remember every moment and every feature of their child, a tidal wave of grief can wash away many of the details. Gina Harris, executive director at NILMDTS, tells parents they don't ever have to look at the photographs of their child. She said, "Some parents wait quite a bit of time to even look at the images, if they look at them at all. Whether they look or not, these images are a way to walk through the grieving process."

Do families ever regret inviting a photographer to share in this intimate time? It turns out the biggest regrets come from families who don't document these precious moments. "We've received feedback from a large number of parents who chose not to receive our services," says Harris. "You can't get that moment back."

Harris does not know of any studies that show how remembrance photography promotes healing, but shared, "I personally have experienced losing two boys. We were able to receive images of my son David, but not of my son Ethan. Grieving the loss of our boys was unimaginably difficult, but I will say,



NILMDTS

Baby David

having the images of David helped our grief process more than not having the images.” (See story: *Gina’s Babies*).

Although some of the 12,000 professional photographers in more than 40 countries who donate their time have experienced loss of their own, Harris describes most as simply “kind-hearted people who want to use their time and talent to give back.” These dedicated individuals also carry the message of NILMDTS and its services to hospital staff. Word also gets out through mothers’ groups and other medical professionals. “Typically a labor and delivery nurse will tell families about our services,” said Harris. Whereas some hospital staff might be reluctant at first, “once they see our work and how much it helps families, they are more comfortable sharing about our services.” Whatever the hospital staff feels, photographers are allowed to be present in the hospital environment as a guest of the family.

NILMDTS currently has enough volunteers to serve only families with newborn infants, but the non-profit hopes to expand to provide services to families with older children, children and families who would otherwise never benefit from a professional photography

session. Anyone can request the services of a professional photographer by going to the organization’s website. NILMDTS provides parents with a CD of images of their baby and a copyright release. These photos often take pride of place on walls,

in wallets, on desks at work—as any photo would of a child who had thrived.

Gina Harris is the executive director of Now I Lay Me Down to Sleep www.nowilaymedowntosleep.org.

Gina’s Babies

In 2007 I was pregnant with my first baby. Shortly after we found out we were having a boy, we learned that our baby had not formed kidneys. We made the decision to carry our son until he came naturally. Almost 34 weeks into the pregnancy, David, the name we had given him, was on his way. Thankfully, I had heard about NILMDTS from a friend. So when I went into labor, we called Sandy Puc, one of the co-founders, to take photos of our son. These photographs have become our most prized possession. His cute little face puts a smile on my face despite the tears in my eyes.

My husband and I were told we could probably still conceive a healthy child, and not long after David, I became pregnant again. According to our doctor, we would know at 16 weeks whether our child had formed kidneys. The ultrasound showed his kidneys were there, but he had cystic hygromas and hydrops. (The former results in the formation of large cysts around the neck, and the latter is extreme fluid build-up around all the organs.) We were informed that most babies with these conditions tend to miscarry. Each week, the physician checked our son’s heartbeat and it was strong. As time went by, I started believing that he would be healed. Then, at 24 weeks, his heart stopped beating and my labor was induced. We named him Ethan and held our very sick little boy as long as we could. This time, because we were in such shock after all we had been through over the course of the year, we did not call on NILMDTS. It is the biggest regret of my life. I know the healing power of the images provided by NILMDTS.



Before Their Time

CD Project Provides Solace after Suicide

by Lee Webster

In 1994, cabinet and casket maker Michael Whitman was on vacation with family in Maryland when he learned of his 23-year-old son Breck's death by suicide in southern California—abrupt, inexplicable, unfathomable. While he was en route to Breck by way of his home in New Hampshire, neighbor Sydney Long called and said, "Please come up. I have something to give you."

What she gave to Michael, his wife Lynn, and two younger sons, Tobin and Alec, was *Breck's Song*. As she described it, upon hearing of Breck's death, Sydney was immediately "drawn to the piano, sat down and played the opening verse of the song. The music and lyrics came to me in completed form ... as if from a source outside myself."

*I wish I could have held you.
I wish I could have taken your hand
And kept you safe with my love
From your darkness.*

—from *Breck's Song* by Sydney Long,
Before Their Time, Vol. I

Listening to a cassette recording of the song on the long plane ride west, with his 7-year-old's head in his lap, Michael found the will to meet what was waiting at the funeral home.

"We're used to warm bodies, and his was cold. There was his sweet face ... I kissed him goodbye." Each member of the family had brought a precious item—a Christmas ornament, hockey and ski medals, a quilt—to add to the casket which a friend had arranged to be sent on ahead from Michael's workshop. "Most comforting for the boys was to see the familiar casket out there, to know their brother was in familiar territory."

The family returned home and Michael began to ask the questions that haunt all parents: "Why did this happen? What was the final straw? What was so wrong that it couldn't have been prevented? What could I have done? How could I not have

seen it coming? Why didn't he talk to me?" And, most painful of all: "How could I have failed to protect my child?"

*A lifetime lived out in a moment
And a moment that changes everything.
If there was one thing that I could've said
to you,
What would it take to change your mind...
What would it be, what would it be,
What would it be?*

—from *Stillness of the Night* by Anke
Summerhill, Before Their Time, Vol. II

There was nothing that could explain the inexplicable. Michael, who has been an activist for adolescent (ages 10 to 24) suicide prevention ever since, says that in nearly two-thirds of all suicides, there is no note. "I've come to believe that there is a large measure of impulsivity in adolescent and teen suicide, because they don't stop to think about what they're doing. They don't have the life experience to understand that most problems can be either solved or at least improved or mitigated. They can't imagine getting away from the pain.

"In 90 percent of all suicides, depression, drugs, and alcohol are factors," he states. "What most people don't understand is that depression can be a fatal disease. And we weren't aware at the time of the part genetics plays." In Breck's case, alcoholism and addiction were unidentified players in both family histories.

While understanding what the risk factors are may aid in preventing future suicides in adolescence, recovery for parents is a long road fraught with sorrow, guilt, anger, and loss that is not like any other.

"I hear it from parents all the time. A normal, natural, old-age death is in the correct order. This is not the natural order of things." Michael lost his own father and stepfather in the months following Breck's death. "Losing a child is just totally different from losing a parent. It's the worst thing that a parent can go through.

"When you lose a parent, you lose something of a link to the past. When you lose a child, you lose part of your future. There won't be a graduation, there won't be a marriage, there won't be children. I read about my child's classmates' weddings and children. ... It's just not there for me anymore."

*Hearts are broken and dreams are lost
But I made a promise to love at any cost.
Little did I know the price was so high,
Losing forever in the blink of an eye.*

—from *Somewhere between Heaven and
Earth* by Cindy Bullens, *Before Their
Time, Vol. II*

It's not surprising that Michael eventually found solace in comforting other bereaved parents. The need to do something was there, percolating just below the surface, but the *how* and the *what* didn't come quickly. "Four years later, while I was driving home from work, it happened.

"The idea for *Before Their Time* sprang fully formed. And that's how many of the songs on the CDs were written as well. That's how it came to me—fully formed, title and everything. It's more like it came *through* me.

"I knew that I loved music, had always loved music, and Sydney's song had helped me so much. I wondered if I could make a CD that would provide as much comfort as that one did for me? Poof! Yes!"

The *Before Their Time* project has become three volumes of music compilations intended to uplift and bring hope to the survivors of youth death, especially to parents who have lost children to suicide.

"Right away I started to find songs, and other people started suggesting songs. I got on the national Folk Music DJ online discussion list and began seeing titles: Tom Paxton's *No Time to Say Goodbye* and Kate Rusby's *Who Will Sing Me Lullabies?* They just started coming in."

*It was a phone call in the night—
The kind you hear before it rings.
It was a phone call in the night,
When you can hear an angel's wings.*

—from *No Time to Say Goodbye* by Tom Paxton, *Before Their Time*, Vol. I

When professionals in the music business told him it couldn't be done, that getting the rights to use the music and then the rights to recordings of the music would be a nightmare and take forever, Michael didn't give up. He learned that the first thing he had to do was find the right person and that "the higher up the chain of fame, the harder it is to get to them."

But what happened next continued to happen: Friends of friends knew someone who knew someone who could help. His old college girlfriend, for instance, knew someone in her North Carolina chorus who handled John Rutter's US permissions, and six weeks after writing to him, Michael received a handwritten note from London with permission from Rutter himself to use his requiem's final movement, "Lux Aeterna."

*I heard a voice from heaven saying unto me,
Blessed are the dead who die in the Lord,
For they rest from their labors: even so saith the Spirit.*

—text from the Anglican Church's Burial Service (1662 Book of Common Prayer, slightly altered)

And musicians from all genres kept saying yes. Out of 120 requests, only three didn't work out. All the rest were offered freely, and with appreciation for being included.

The project's \$100K production costs were eventually funded entirely by donations and grants, and all proceeds from sales continue to be donated to New Hampshire and national hospice and suicide-prevention programs. The CDs are also provided free of charge to grieving families by hospices, mental health agencies, churches, and other helping organizations throughout the country.

For some parents, projects such as *Before Their Time* become their own lifeline; one of the myriad responses to child loss is contemplation of suicide by family members themselves, parents included. The book, *A Broken Heart Still Beats: After Your Child Dies* by Anne McCracken and Mary Semel, is one such project, chronicling over 300 authors—famous and little known—who have taken up the

work of capturing the language of grief in stories, poems, and memoirs. (See review page 25.)

At some point, the need to tell the story in some form, to surrender to narrative impulse, is cleansing and cathartic. Michael said, "Working on something to help other parents in the grief I knew they were suffering contributed to my own healing because I was *doing* something. I was drawn to a music project because I've always been involved in music, but others who undertake their own projects choose something close to their heart or that springs from their own forms of creative expression."

The loss of a child leaves parents with the unimaginable task of knitting together the hole that their child's death has created in the fabric of their lives. Michael recalls wondering for weeks if the day would ever come when Breck's death would not be the first thing he thought of upon waking.

"There are issues with loss by suicide that aren't there when a child is lost to illness or accident or some other means. But I've learned that people find ways to cope. I found a way. And I hope it inspires others to find their own path."

Michael Whitman of Lyme, NH, may be reached through his website www.beforetheirtime.org or at michael.whitman@valley.net.

Lee Webster, a green burial advocate and home funeral guide active with the National Home Funeral Alliance, writes and edits from her home in Plymouth, NH. Her website is www.turningleafhomefunerals.com.

For more information on *Before Their Time* CDs visit www.beforetheirtime.org.

Other Resources:

The Suicide Paradigm:

www.lifeguard.tripod.com

A site for those who have experienced suicide loss and those who want to know more about suicide and its aftermath.

The American Association of

Suicidology: www.suicidology.org

A site providing how-to information for people who want to start a Survivors of Suicide (SOS) group in their area.

Parents of Suicides Memorial Sharing:

www.pos-ffos.com

A site for parents, family, and friends to share remembrances and to connect with others who have experienced the loss of a child through suicide.



Michael and Breck 1978

From the Cradle On

The Perspective of a Pediatric Hospice Nurse

by Elaine Farnsworth, RN

I've worked in hospice pediatric care for the last 25 years and I've been a registered nurse for 40 years. When I look back, I think I've always been a hospice nurse. I just didn't know it for a while.

I started my career in the Neonatal Intensive Care Unit (NICU), and even then, if a baby wasn't doing well, it was "my baby." One was a baby born with a hypoplastic heart (the left side of the heart hadn't developed normally). The baby was transferred to another hospital and the mother stayed behind with me. Her child died, but many years later, the mother reappeared in my hospital to have another baby. I recognized her name, and when I walked into her room, she said, "I was hoping you'd still be here!" Even when I was a hospital administrator and when I trained certified nurses' aides, I always taught them about death and dying, and grief, and loss. That wasn't common in those days.

At my hospice, we provide hospice care for pediatric patients and palliative care through the Medicaid waiver program for kids with chronic disease who will most likely become hospice patients within a year. The latter allows us to do things like bring in music therapists and art therapists for chronically sick kids and their siblings who are Medicaid-eligible.

Most commercial insurance plans have a hospice benefit and, in recent times, some insurance companies have been willing to go beyond that to ensure children get the additional services they need. For example, insurers may authorize radiation or chemotherapy concurrent with hospice care, allowing us to come on board earlier in the disease process.

Some of our pediatric patients become long-term patients. We get babies with genetic diagnoses with a prognosis at birth of six months who are still with us two or three years later. Our pediatric cancer patients often have a much shorter

prognosis. A few months ago we had a little girl who was with us about a year. She had a brain tumor and had some radiation while she was on hospice. She experienced some good quality of life during this time because the insurance company allowed us to deliver palliative care under hospice.

[The parents] said, "She's an old soul," and they let her decide.

All said, I don't think we've made the same strides in pediatrics as we have in adult end-of-life care. We still tend to get pediatric patients who are really end-stage instead of earlier in their journey. That's because families are still seeking aggressive and curative treatment for their kids. We *are* seeing changes at the oncology clinics where some now have social workers to help families to find the right care. This provides more continuity between ongoing treatment and hospice services. The handoff to hospice should be gradual and gentle, not simply, "We're stopping treatment, so now you're on hospice."

When our pediatric patients come into hospice, we explore their goals of care, what's beneficial, and the costs and benefits of any interventions. As I've explained, children tend to receive more aggressive treatment than adults with similar diseases.

When providing care to a minor, parents are the decision-makers. It's up to them how much to involve their child. At the same time, the healthcare team will also consider whether to bring the child into the decision-making process. This is a move away from the practice of not telling them anything. Recently, we had an 11-year-old whose parents let her choose whether to receive more radiation. They said, "She's an old soul," and they let her decide. Kids who've been through

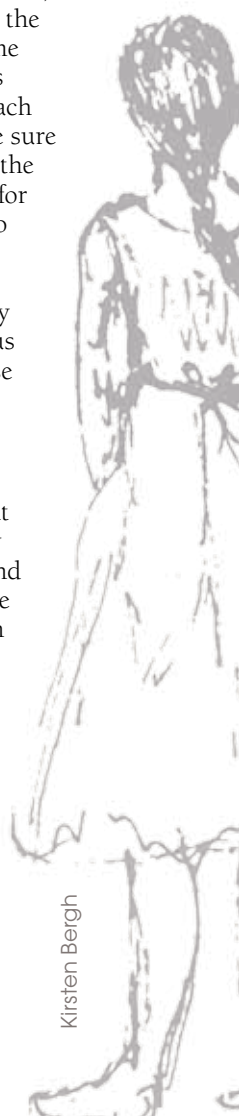
atrocious treatment, who've been in life and death situations over and over again, often have a deep understanding of what's going on and a maturity beyond their years. One little girl of 10 or 11 wrote a book about her journey during the last months of her life.

In pediatric care, we have to be especially clear about maintaining boundaries with our vulnerable child patients and their families. Many times I've seen nurses without boundaries work with long-term with patients, and the dynamics between the provider and patient become strange and difficult. That's why we have a team approach in hospice, so we can make sure we're doing what's best for the family and not what's best for us. As caregivers, we're also very clear about our days off. Families can get really dependent on their primary care nurses. When one of us needs a break, someone else covers.

When providing care to terminally-ill children and their families, it's important to remain grounded. In my case, my spiritual beliefs and our great team of nurses are sources of strength. Within the team, we can verbalize how things are going and discuss the issues. Despite the challenges of being a pediatric hospice nurse, I enjoy my work. In fact, I can't imagine doing anything else.

Elaine Farnsworth is a pediatric hospice nurse with The Denver Hospice www.thedenverhospice.org.

Kirsten Bergh



The “Passing-through” Spirits: Miscarriage

by Sobonfu Somé

Sobonfu Somé, international teacher and author whose name means “keeper of the rituals,” shares the rich cultural and spiritual perspective of her native country, Burkino Faso.

Miscarriage among the Dagara people in my country is often compared to lightning striking a tree at its core. It hits both the couple and the community in its most vulnerable place, putting the future of the village in jeopardy. The Dagara people’s understanding of miscarriage lies in their knowledge of the universe and the interplay that exists between the dimensions. It is a process that brings concrete evidence of a mythical dimension. In the indigenous world of Africa, the term *miscarriage* is defined as a powerful and major event in life. It is the cancellation of a long-planned travel arrangement, leaving people at the destination heartbroken and grief-stricken. It is also a message from the spirit world and a life-transforming experience.

From the African perspective, miscarriage is a direct or indirect intervention of God or some dimensional beings who travel the galaxy known as the *chiékuo* (pronounced chee-ay-koo-oh). They have been referred to as the “travelers” or the “passing-through” spirits. Strangely, they like the idea of going to a place, but they don’t like staying in one place for any length of time. They have difficulties letting go of their worlds to come into this world, which is different from what they know. When a *chiékuo* decides to enter a womb, chances are the pregnancy will end in miscarriage, in a stillborn baby, or in sudden infant death syndrome (SIDS).

A special ritual is often required to trick the *chiékuo* into staying among us. Though their actions are not appreciated, they are in fact child advocates—teachers who suddenly appear and usually bring specific messages. Their role is to call our attention to the importance of children and to remind us how susceptible and vulnerable we can be to losing our children. Though this message is sent through a couple or a family, it addresses the community at large. It usually alerts

people to the importance of strengthening their relationships with their children and of creating protective force fields around them.

In Africa, people always keep an eye on the *chiékuo*. In fact, they will try to find out before conception if the village might be subject to these beings. They are not uncommon—I myself am a *chiékuo*. I am an example of how these beings can interfere with the birth process and how, with commitment from the community, they can be persuaded to stay. Somewhere in the depths of my being, I can still remember the times my mother was pregnant with me and had to miscarry simply because I was not here to stay. When I think about it now, I can’t imagine the amount of pain she must have experienced.

...[M]iscarriage is a way for us to listen to the key spiritual truths bring brought to us.

My mother miscarried me twice. The third time she conceived me, she was able to carry the pregnancy to term and gave birth to a girl. I lived for six months as a fine baby. The day I decided I had had enough of this world, my mother said I had been sleeping, then I woke up and was playing and laughing. In fact, she says I was unusually happy. She watched me play, and then could tell something was wrong. Indeed, something was wrong: I was dead. And it all happened in one moment, just like that. In medical terms, this is called SIDS, but in village terms this is defined as a *chiékuo* who is returning home. Unfortunately, such a return home leaves the village in grief and turns life upside down for everyone.

I continued to try to find ways to leave this world and return to the world I knew so well, but the last time I was conceived, each attempt resulted in doors being shut to show the determination of my people to keep me here. I was about 6 years old when I finally decided to put an end to the process of trying to leave. Although it was a long and emotionally intense

process that led to my staying here, my mother befriended me in a special way and made me promise to stay. Now that I am here, it is bizarre to think about leaving.

At the first sign of miscarriage, a divination is done to bring insight about its source and prevent future miscarriages. Indigenous people believe there are other reasons for miscarriage similar to the *chiékuo*. Another theory is that the baby who is miscarried is actually an ancestor bringing a message. For instance, upon leaving human form, the ancestor finds its human family in constant disagreement. The miscarriage then becomes a way for the ancestor to bridge the difficulties in its family and to make peace. Through the tragedy of miscarriage, the family is brought together when they find the message of peace through divination. For the most part, miscarriage is a way for us to listen to the key spiritual truths being brought to us.

Miscarriage can also be viewed at certain times as self-initiated.

Sometimes there are those who want to find ways to initiate contact with, or to break through to, another dimension. It starts with the willingness of the woman (or the couple), whether consciously or unconsciously, to experience something deep, profound, and life-altering. An agreement is made with beings from the other side to experience something of unknown design that will open her to the mysteries of the universe.

Grieving the Loss through Ritual

Grieving is a soul-cleansing ritual, with an energy capable of cleaning away lingering clouds and festering wounds in one’s life. Over the centuries it is one of the ways the Dagara people have used to make peace. While a woman is miscarrying, she is surrounded by other women of the village who not only support her, but witness and go through the experience with her. After she miscarries, depending on her state of health, an intense grieving ritual can last 72 hours and allows her to go through the pain of her loss with her community.



This experience is usually so draining that it takes all her energy and leaves her nothing to do but rest. If she is too weak to partake of such an activity, a more moderate version allows her to deal with the loss without losing herself in the midst of it. In this less draining version, people come to her sickbed and hear her tell her story as they grieve together. The presence of other people supports, witnesses, and affirms the pain of a sister who has been chosen as the vessel for a message that addresses the whole community.

I remember when my aunt miscarried and we participated in her ritual. At that time she spoke some words that stayed with me. She said that her heart and soul were being watered by the presence of all her loved ones, that she did not have much strength to share, but that she had a few words to share with the spirit who had left her belly:

*Spirit of my Ancestors, Spirit of the Kontombile,
Spirit of the chiékuo and of the mysterious world,
It is to you I am calling, it is to you I am talking.*

*I have seen much pain,
I have lived through the unthinkable.
But what happened to me today
Was something I awaited.*

*I wished it not on me, not on anybody.
How come you let me down, my mothers?
Why did you forsake me, my fathers?
I feel betrayed and unworthy.*

*The spirit I awaited left me in a vortex of
grief, anger, sadness.
And without a good-bye, my home is
wrecked,
My spirit in great turmoil...*

Before we knew it, we were all grieving. My aunt's speech sent a shock wave through the room that brought her pain and grief to our already fragmented hearts. From then on the grieving process took its own course. At the center of the room was a clay pot where the blood of the miscarriage had been collected before the ritual began. Things that reminded people of the pregnancy were also put in the pot with a prayer.

Toward the end of the ritual, gifts were added to the pot, just as you might send some presents home with a dear friend who came to visit you. Certain things are required of the deceased baby. For instance, someone might say, "I give you this gift. On your next trip back, I need you to commit to staying so we can grow together and let our spirits bloom together." The important thing is to tell the miscarried baby that miscarriage and

grieving are not at all fun to be going through and we want it to stop now. When we voice our concerns, it makes the spirit realize that it has to be cautious and that it can't just use the body of this woman to go back and forth between dimensions.

After everyone has spoken, the clay pot is sealed with leaves and buried. During the next full grieving ritual, the woman's miscarriage pain and grief are added to that ritual, and the whole village joins her to mourn her loss again.

In many countries when a woman of modern society miscarries, the involvement of the community is insignificant. The experience then lacks validation, and the wisdom that comes as a gift is often not discovered and therefore not valued. Without acknowledgement, the experience leaves the woman and her family empty-handed, without anything palpable.

People say, "Don't worry, you can have another child. This was just a passing experience; don't let it bother you." As a result, the psyche interprets this experience as completely valueless. If it wasn't valuable, if there was no reason for it, the woman so often comes to feel that, in some way, she must have done something to cause it to happen.

It is important to feel from the heart—to go through the grieving process. Then we can truly begin to heal.

Sobonfu is one of the foremost voices in contemporary African spirituality. She is the author of several books including Welcoming Spirit Home: Ancient African Teachings to Celebrate Children and Community, from which this article is an edited excerpt. To find out more about Sobonfu Somé, visit www.sobonfu.com.



Companioning the Grieving Child

by Alan D. Wolfelt, PhD



Kirsten Bergh

I've always found it intriguing that the word "treat" comes from the Latin root word *tractare* meaning "to drag." If we combine that with "patient," we can really get in trouble. "Patient" means "passive long-term sufferer," so if we treat patients, we drag passive, long-term sufferers. That's not very empowering.

On the other hand, the word "companion," when broken down into its original Latin roots, means "messmate": *com* for "with" and *pan* for "bread." Someone you would share a meal with, a friend, an equal. I have taken liberties with the noun "companion" and made it into the verb "companioning" because it so well captures the type of counseling relationship I support and advocate. That is the image of companioning—sitting at a table together, being present to one another, sharing, communing, abiding in the fellowship of hospitality.

The companioning model of grief care, which I created some years ago, is anchored in the "teach me" perspective. It is about learning and observing. In fact, the meaning of "observance" comes to us from ritual. It means not only to "watch out for" but also "to keep and honor," "to bear witness." The caregiver's awareness of this need to learn is the essence of true companioning. Companioning the bereaved is not about assessing, analyzing, fixing, or resolving another's grief. Instead, it is about being totally present to the mourner, even being a temporary guardian of her soul.

If your desire is to support children in grief, you must create a "safe place" for them to embrace their feelings of profound loss. This safe place is a cleaned-out, compassionate heart. It is the open heart that allows you to be truly present to another human being's intimate pain.

In sum, companioning is the art of bringing comfort to another by becoming familiar with her story. To companion the grieving person, therefore, is to break bread literally or figuratively, as well as listen to the story of the other. This may well involve tears and sorrow and tends to involve a give-and-take of stories: I tell you my story and you tell me yours. It is a sharing in a deep and profound way. Of course, children often convey their stories through play more than they do through words.

Finally, companioning is much different than traditional treatment. While treatment works to return the mourner to a prior state of balance (or an old normal), companioning emphasizes the

transformative, life-changing experience of grief (the new normal). Treatment also attempts to control or stop distressful symptoms. Companionship, rather, demands observing and bearing witness. As companions, we are not experts who have the answers; we look to the bereaved child to teach us about his grief. We do not control his journey by creating a treatment plan; we simply show up with curiosity and a willingness to learn and listen.

My Personal Tenets of Companioning Grieving Children

1. *It is my helping responsibility to create a safe environment for the grieving child to do the work of mourning.* (A bereaved child does not have an illness I need to cure.) I collaboratively work with the bereaved child. I do not assess, diagnose, or treat him. The traditional doctor-patient model of mental health care is grossly inadequate. Why? Because it creates expectations of external cures that involve the grieving child and family only minimally in the helping process. To be effective with bereaved children, I must see them as *active participants* in the work of mourning. I'm a caregiver, not a cure-giver!

2. *A grieving child's perception of his reality is his reality.* A "here and now" understanding of that reality allows me to be with children where they are, instead of trying to push them somewhere they are not. I will be a more effective helper if I remember to enter into a child's feelings without having a need to change those feelings.

3. *Each grieving child I meet is a unique human being.* A child's intellectual, emotional, and spiritual development is highly complex and is shaped by many interrelated forces.

4. *While I believe children are able to experience feelings similar to adults', their thought processes are quite different.* A child's understanding of death depends upon his or her developmental level. As children mature, they may need to mourn in a new way based on these normal developmental changes. Therefore, helpers to bereaved children must stay available to help them for years after the event of the death. Mourning is a process, not an event.

5. *The relationship developed between counselor and child forms the foundation for all the work they will do together.* Empathy, warmth and acceptance are

essential qualities for the counselor working with grieving children.

6. *Play is the child's natural method of self-expression and communication.* To work effectively with bereaved children, I must keep my own "inner child" alive and well.

7. *Bereaved children use behaviors (regressive behaviors, explosive emotions, etc.) to teach me about underlying needs (for security, trust, information, etc.).* I have a responsibility to learn what those underlying needs are and help the child get those needs met.

8. *Children are not only thinking, feeling, and doing beings; they are also spiritual beings.* Not everything we observe in children can be precisely measured or construed. As a helper to bereaved children, I must remain open to the mystery that children keep alive in their young worlds.

9. *While the major focus in working with grieving children is on the present and future, I must encourage them to remember their past.* This historical approach aids in understanding the nature of the relationship with the person who died. It is in embracing memories of the person who died that the child discovers hope for a new tomorrow.

10. *While much of the grieving child's behavior and view of the world is determined by personal history and influences beyond her control, the growth process requires a hope for healing.* I have a responsibility to help the bereaved child not simply to reach homeostasis but to discover how the death changes her in many different ways. As a growth-oriented grief companion, I work to help bereaved children not just survive but also learn how they are changed by this experience.

11. *I must work to create a social context that allows grieving children to mourn openly and honestly.* It is through this social context that the child can work on the six reconciliation needs of mourning.

12. *Some children do the work of mourning in the safety of a group experience.* The commonality of shared experience that comes from a support group can provide a sense of belonging and help normalize the grief process.

13. *While I am responsible for creating conditions for healing and growth in grieving children, the ultimate responsibility for healing lies within them.*

I must remind myself to be responsible to bereaved children, not to be totally responsible for them.

14. *Right-brain methods of healing and growth (such as intuition) should be used more with grieving children than they have been in the past and integrated with left-brain methods (intentional, problem-solving approaches) if counseling bereaved children is to become more growth-oriented than historical mental health models of care have been.*

15. *The companioning approach to counseling grieving children sees children as possessing a wealth of strength, assets, and resources.* As I companion the bereaved child, I help her discover and make use of these strengths as she begins the lifelong process of mourning losses.

Alan D. Wolfelt, PhD, is an author and educator on the topics of companioning others and healing in grief. He directs the Center for Loss and Life Transition and is on the faculty at the University of Colorado Medical School's Department of Family Medicine.

This article is excerpted from his new book *Healing the Grieving Child: A Soulful Guide for Caregivers*. Dr. Wolfelt's other bestselling books include: *Healing Your Grieving Heart for Kids*; *Healing a Child's Grieving Heart: 100 Practical Ideas for Families, Friends and Caregivers*; and *Healing Your Grieving Heart for Teens*. For more information about Dr. Alan Wolfelt's work, visit www.centerforloss.com.

Dr. Wolfelt's Six Reconciliation Needs of Mourning

Need 1. Acknowledge the reality of the death.

Need 2. Move toward the pain of the loss while being nurtured physically, emotionally, and spiritually.

Need 3. Convert the relationship with the person who has died from one of presence to one of memory.

Need 4. Develop a new self-identity based on a life without the person who died.

Need 5. Relate the experience of the death to a context of meaning.

Need 6. Experience a continued supportive adult presence in future years.

The Young and the Old, the Quick and the Dead: Together in Nature

by Daniel Dancer

“It’s an odd thing to describe, that we run a summer camp alongside a cemetery,” says Shonie Schlotzhauer, director of Sacred Earth Foundation. “We’re really careful not to get too graphic, but we’ve found that it’s a wonderful thing to share with children. They seem to have a level of comfort with the existence of the cemetery—and the reality that there are real people buried there, re-composing into trees and flowers—that many adults don’t have. If only we could all have that level of innocent ease. I hope we are helping these kids retain a comfort with death and dying and an affinity for doing it in a natural, simple way that will last into their adulthood.”

White Eagle Nature Preserve Cemetery in Washington state was begun when Ray Mitchell died suddenly at age 62. He was the visionary founder of Sacred Earth Foundation, the non-profit land trust that owns the cemetery and all the land around it. Ray started the foundation 40 years ago with 160 acres of land and gradually added more as he developed a small, off-the-grid community, horse and buffalo ranch, and summer horse camp for children. The ranch—known as *Ekone*, which means “land of the good spirit” in the native Klickitat tongue—offers summer horse camps for children.

Ray was a horse whisperer, charismatic leader, community builder and lover of children, and the Sacred Earth Foundation and Ekone Ranch are a physical expression of his beliefs. His passing was a complete surprise as he was a healthy and vital individual. One close friend speculated, “It must have been kryptonite.”

The children are always more comfortable with the answers than the adults think they will be.

A half-dozen men probably called Ray their best friend, and I was one of them. He and I often discussed the idea of one day establishing a natural burial ground

on the ranch out by the canyon. That “one day” came all too soon. Myself and other friends kept his body refrigerated in the local funeral home for four months while we jumped through all the hoops to get our cemetery license. On the weekend between his birthday and Earth Day in 2008, we inaugurated the cemetery with his body, the first burial. We are now a Green Burial Council-certified conservation burial ground, the “greenest” a green cemetery can be, and I am the general manager.

White Eagle is quite likely the country’s only wilderness cemetery. It’s a place of remarkable ecological health and beauty. Its 20 acres are set within 1100 acres of permanently protected oak and ponderosa forest, meadow, and steppe on the edge of

spectacular Rock Creek Canyon near the Columbia River Gorge National Scenic Area. Deer, coyote, cougar, eagles, steelhead in the canyon creek, the occasional bear or lynx—all are present here. There are no invasive weeds, no fences, no noise, and not much evidence of humans other than the little road that takes you to the edge of the cemetery grounds. Our mission is to nourish this land while keeping it wild and to provide an all-faiths natural burial experience to any who choose us.



Ray Mitchell’s cowboy hat, adorning a tree near his grave

White Eagle Memorial Preserve

During the summer camp season, kids can often be seen in long lines riding horseback through the cemetery entryway or sitting on the giant handcrafted bench overlooking Ray's grave next to the cemetery's beautiful southeast boundary marker. Numerous loving comments decorate the bench; some are faded while newer ones have been added. Campers that knew Ray for many years tell stories about him and remember what he taught them. An increasing number who never met him circle his grave quietly and ask questions: "Why's he buried here? What do you mean this is a cemetery? It doesn't look like a cemetery to me."

The children are always more comfortable with the answers than the adults think they will be; the intersection of summer camp and cemetery tends to be quite beautiful. When burials happen in the summertime, the burial procession elicits a moment of silence from any campers or staff on its route.

The adults who come to White Eagle are also entranced by what they find. "It's so beautiful here. I can't wait to die so I can be here forever," Louis said jokingly. He and his wife, a Harley Davidson riding couple, came out to select their gravesites a year after we opened. It's a powerful and comforting thing to get to know the little ecosystem that one's body will eventually nurture. Burial sites are 20 feet by 20 feet in size, small ecosystems with their unique arrangements of rocks, bushes, trees, and wildflowers. We affectionately refer to our cemetery as an *afterlife community* and have begun hosting yearly events every Memorial Day so loved ones of those whose bodies have been buried at White Eagle, along with staff members and sometimes even campers, can all get to know one another.

Children are an intrinsic part of our community at White Eagle. A good example is the Bartus family and their two children who came all the way up



Kayla covering Grandpa Martin's grave

White Eagle Memorial Preserve

from Grass Valley, California, to help bury the shrouded body of their father and grandfather, Martin. Martin's body had arrived earlier that morning via a transport service offered by their local funeral home. I had communicated with Martin during the weeks when death was imminent, and he had asked me to pick out a spot in a grove of ponderosas, trees he had always loved for their elegance and for the song the wind sang as it blew through their needles. I sent him a picture of the site and hoped it would comfort him to know exactly where his body would be buried when he departed this world.

Children are an intrinsic part of our community.

Usually, the bottom of each grave is decorated with sage and pine needles and whatever might be blooming at the time. When we buried Martin, the aroma seemed to permeate the little grove in which we stood. As we gently lowered his body into his grave, his grandchildren watched, first in silence and then in fits of crying. They tearfully leaned down and placed their drawings and letters for Grandpa upon his shrouded body. When

they had recovered a bit, I carefully handed Kayla, age 9, one of our white homing pigeons to release. We all counted to three, and when she tossed the bird up into the sky, we all cheered as its white wings flew powerfully through the ponderosas. It circled high above and then soared away westward as everyone waved goodbye with huge smiles on their faces. Then we all took turns shoveling, the kids insisted on being included. Once we were finished, everyone gathered various kinds of seeds from nearby plants and scattered them over the grave. The kids collected pinecones and outlined their grandfather's grave with them. Martin's youngest grandchild later remarked,

"Grandpa is making the tree stronger!"

Do our bodies belong to us or do they belong to nature? At White Eagle we believe our bodies are a natural resource. We believe that when we die our bodies should be gifted back to nature to further the cycles of life. Ray Mitchell of Sacred Earth Foundation was known for a lot of things; one was a particular saying he used at poignant moments. I could imagine him uttering it as everyone stood and held hands around Martin's beautiful grave in the midst of the ponderosas: "Just when you thought it couldn't get any better!"

Daniel Dancer is the general manager of the White Eagle Memorial Preserve in the state of Washington. Find out more at www.naturalburialground.com.



Like the Rainbow Bridge: Children and Death

by Nancy Jewel Poer

In over 40 years of aiding the dying and their families in all aspects of home death and in helping found threshold groups across the country, I have held to some spiritual ideals which have been my guiding inspiration—like a lode star in the night. They give me the determination when I am awakened at midnight to drive long hours to a house where the “big journey” is happening. They give me the patience to work through a tangled bureaucracy of permits and death certificates, or to gather the materials to care for the body while striving to keep an artistic mood of dignity for the family. They uphold my belief that it matters if we can bring a mood of calm and peace to the dying one and the family. The consciousness with which we hold the dying matters, as they labor through the “birth” into spiritual existence. It matters how we honor their lives and accompany them with loving prayers on their journey to the other side, whether we are nearby or far away when they pass over.

Ultimately, it matters greatly how we stay connected after they are in their new state of spiritual existence where, filled with an awakened perspective we cannot know here, they can inspire us for creative work here on the planet. We can send them support for their journey in spirit with our heartfelt gratitude and loving remembrances of the life we shared with them. These spiritual ideals have upheld my work and my world view, and I have lived long enough to experience their truths.

We shall all, child and adult, have our individual response to death, but most always this experience is a defining moment in our lives. How a child reacts to death is greatly influenced by the responses of the adults around him or her. If there is overriding fear, it will be mirrored to the child. Likewise, a deep understanding that death is a part of life and there are resources and faith to meet it in spite of all the trauma, that will be conveyed as well. Yet every individual is endowed with a unique soul, and even a young child can come to us with complex issues around death. The sensitive parent

is open to this multi-layered reality. (See the book *Soul Survivor*.)

Though children’s reactions to death are varied, the adults around them can do wondrous good for the children if they can live their lives as though death is not the end of our existence but a transition to another state of being—if they can affirm for the child, through their wholesome embrace of life, that the relationship we share with those we love continues. The presence of our loved ones in spirit can be there wherever love and grateful memories flow. My mother, Lola, lived her life with such enthusiasm and conviction in the reality of the spiritual world, that when she passed on, our adolescent son said what we all felt: “We loved her and will miss her, but how can we be sad? Grandma is just saying ‘Whoopee!’ ”

When death enters life, security is the primary need of the child.

My husband and I felt very strongly that our six children should understand that death is a natural part of life. We also wanted to support the lives of our parents and grandparents, and for their final bedridden days, we nursed them in our home. Our children were all part of the caring process: feeding them, taking them outside, singing and visiting with them, being there with us when they died. All of our children have become deeply appreciated helpers with deaths in their communities because they had such grounded, practical experience growing up.

It is only natural to want to shield our young children from traumatic situations. The great paradox now is that young children are exposed to thousands of cruel representations of death as entertainment in the media. Ironically, the same parents who allow exposure to this are the ones who do not consider having their children experience a real-life dying or see a dead body in real life. Yet the latter is far more merciful and authentic. My husband and I chose to protect our children from violent media as they were

growing up and also to accept death as the natural course of life and destiny.

For children and adults, any participation in the after-death process is a healthy response and helps the participant(s) to deal with grief. Offerings of art, flowers, little treasures—all can be encouraged. Our children made the caskets for their beloved grandparents and were very proud to honor them so. They felt their grandparents would take heartfelt and grateful pride in their gift.

With regard to children attending wakes or funerals, we cannot know what will live in each child. A thoughtful explanation, so he knows what to expect, and intuitive questioning without imposing an outcome, help the child to let us know the extent to which he is ready to be involved.

When death enters life, security is the primary need of the child. Children need stability as much as possible. When a parent dies, their world is rocked out from underneath them. Ideally, caring adults will sustain healthy, familiar routines in the home. When children focus on food and mundane activities, this does not mean they are indifferent to the suffering and loss, but rather are in need of reassurance that the world will go on and that there will be people to care for them. *Who will be here to love me?* This is the poignant inner question for them. We all hope there will be loving relatives and caring friends who can be there for all such children.

It is important for the child to have adults around who truly carry a spiritual picture of life, adults who carry a certainty that the spirit of the grandparent is still present for him and loving him even though not in physical existence. With such faith to support the child, the angry, self-enclosing walls of feeling oneself an abandoned victim can transform to a growing realization that a vital link has now been created from this world to the next through a loved one on the other side. Many people slowly realize over a lifetime that the sister, the uncle,

or parent who died has been working to inspire events in their lives. Looking at the unfolding of destiny, one can gradually realize the ongoing care that is there all along, like guardian angels. This bond can be strengthened. (See *Staying Connected* by Rudolf Steiner.)

When we speak of children and death, it is essential to remember children do not see the world through our world-weary eyes. For them, life is all new, and many can still experience the spiritual world from which they have just recently come. They can certainly be wiser than many adults around them. This spiritual perception is most often strongest up to age 7. Between ages 8 and 11 our youngest son, an exuberant lad with unshakable spiritual confidence, experienced the passing of three grandparents. The first beloved grandmother died far away and suddenly. As our family held each other in a group hug on receiving the shocking news, he danced out of the embrace with the cheerful words, "Grandma died, but she's alive!"

...like Grandma's little boat to heaven...

His petite, bright-eyed great-grandmother died next—at home with us. We had her body taken to the undertaker in preparation for shipping out of state as her sister wished. And when the body came home for the vigil, I was concerned for my son's feelings. When I inquired how he was doing, he cheerfully replied, "Grandma is just up in heaven looking down on her little old bones!"

He was always in and out of the room of his invalid grandfather who lived with us for almost two years. The day the old patriarch lay dying, this grandson burst in with his usual enthusiasm and declared, "Have a good time in heaven, Pappy. I love you!" He then bounced outside to practice his basketball moves on the courtyard just outside the bedroom window.

Our dear Grandma lay in state in our big old family home and gave a first experience of death to over a hundred people, including many children, all taking place in a homey setting devoid of the imposing, somber mood of a funeral parlor. A woman in the community came to pay her respects but was nervous about facing death and certainly wanted to shelter her 2-year-old son from it. She parked her car with him inside right by

the room where Grandma lay. As she entered the vigil space with tremulous, hesitant steps, the boy adroitly escaped and came bounding into the room after his mother, grabbed the handles of the casket and tried to rock it. I assured the embarrassed mother it was indeed like Grandma's little boat to heaven, and her son was just fine. The child careened around the room, happily examining the crystals, flowers, and pictures. When the mother felt it was time to leave, she picked the boy up in her arms, and for the first time he could see the body. He gave it a cursory glance, and instead looked upward to where he knew the expanded loving spirit of Grandma was. With shining eyes he waved heavenward and piped his sweet "Bye bye." His mother was astounded. I was delighted.

Young children can give us startling and matter of fact insights of such spiritual truths. When asked if he knew what a funeral was, one kindergartner replied nonchalantly, "Sure, it's like the rainbow bridge when we come down to earth, only you are going back the other way!" A 7-year-old girl, wise far beyond her years, told her mother when her father died, "Mama, you don't need to cry. Daddy has finished all his tasks on earth and brought them up to heaven as gifts."

Anyone with an awakened awareness of the times we live in can realize that we are at a major threshold in civilization with regard to our planet and its resources and to our ways of living, being, and doing business. The underlying principles of our humanity, our ways to be here for one another and the world, are awaiting the courageous, the far-seeing, and uncompromising stand of those who feel we are here to serve compassionately, to live lives of meaning, and not of endless self-serving materialism. The strength and determination to do so will be greatly supported by the spiritual inspiration coming from ever-present help of the spiritual world at all levels. Many of our young children today know and live this. They know death is not the end. We are called upon to live our lives with the same joyful affirmation they can exude, knowing death marks the beginning of life in spirit. As we lovingly remember our loved ones, they can be ever-ready

to inspire, strengthen, guard, guide, and treasure us. For it is together we shall do the work of bringing enlightened consciousness, of bringing the love and wisdom from the spiritual world and the angels to the planet. With our gratitude for all they have given us, we can build a connecting bridge to the holy center of things from which springs the source of



universal goodness and healing deeds for the world.

Recommendations for Reading:

Soul Survivor: The Reincarnation of a World War II Fighter Pilot, by Bruce and Andrea Leininger, Grand Central Publishing (formerly Warner Books), 2010.

Staying Connected: How to Continue Your Relationships with Those Who Have Died by Rudolf Steiner, Rudolf Steiner Press, 1999.

Nancy Jewel Poer is one of the pioneers of the home death movement. She is a founder and faculty member of Rudolf Steiner College and author of Living into Dying: A Journal of Spiritual and Practical Deathcare for Family and Community. Poer produced the documentary The Most Excellent Dying of Theodore Jack Heckelman about conscious dying and has written a book for children about death called: The Tear: A Story of Transformation and Hope When a Loved One Dies. For more information, visit www.nancyjewelpoer.com.

Entering the Mainstream

Pediatric Palliative Care Comes of Age

by Leif Wellington Haase



In 1980, when her daughter Kristie was dying of leukemia, Laurie Kotas remembers how few were the places she could turn to, for either medical care or emotional support. “There was really very little in medical care for terminally ill children. It took many years just to get to borderline inadequacy.” Kotas now runs a Southern California foundation devoted to children with life-limiting conditions.

Twenty-five years later, pediatric palliative care—the specialty of caring for children with life-threatening conditions, relieving their pain, and helping them live as long and as well as possible—has achieved a new status, accredited by the Joint Commission, the gold standard of professional recognition in healthcare, and certified (since 2006) by the American Board of Medical Specialties (ABMS) as a sub-specialty.

Knowledge of pediatric palliative care is now required of doctors to pass their board exams in pediatrics. A small and dedicated group of doctors, both in California and nationally, has expanded the presence of palliative care for children in hospitals across the country.

Perhaps most encouraging of all, the mission of pediatric palliative care—the relief of suffering for patients and their families and ensuring the best possible quality of life—has made headway in public policy. In 2005, Florida received a federal waiver allowing children with life-threatening conditions to receive hospice and palliative care services in their homes without giving up curative treatments. The program, Partners in Care, is now

available in most Florida counties. California launched a similar program in 2008, and it has now been implemented in eight counties, most recently in Los Angeles and Fresno.

Provision 2302 in the Affordable Care Act of 2010 states that electing hospice care for a child does not preclude payment for curative services. This means that reimbursement decisions are less likely to dictate the difficult choices that children and their families must make.

To sustain this momentum, these promising new policies need to be clarified and implemented, more doctors and hospice programs need to be brought into the field, allies must be found both inside and outside organized medicine, and the mission of palliative care needs to be entrenched in American medicine and culture. While each of these trends is positive, staking out a permanent presence for pediatric palliative care may be as challenging as gaining traction in the first place.

Passing New Laws: Policy Matters

Changes to payment and reimbursement policies, especially by public programs such as Medicare and Medicaid, typically have tremendous influence on access to care and on the settings in which care is offered. Provision 2302 allows children enrolled in Medicaid and the Children’s Health Insurance Program (CHIP) to receive reimbursement for curative and hospice care simultaneously, though the life expectancy of these children still must be estimated at 6 months or less.

The significance of Provision 2302 is considerable. Most important, it makes the hospice benefit available, at least on paper, to many children who previously were not able to access it because they were still receiving curative treatment. Lower-income children and their families are especially likely to benefit.

Provision 2302 should also influence the benefit policies of private insurers who cover seriously ill children. Already many insurers have been demonstrating flexibility by covering both curative and palliative care in individual cases. Broader and more consistent payment policies should also encourage hospices to accept children.

By not forcing parents or providers to choose between relieving pain and offering hope, the changes to payment rules should also help lessen the stigma surrounding the death of children that continues to hinder the expansion of palliative care. As Frank Deford, the sportswriter whose 8-year-old daughter Alex succumbed to cystic fibrosis, wrote: “It’s different, a child dying. It isn’t just that children are supposed to keep on living. . . . They carry the hopes of all of us when they go off.”

Provision 2302 also complements the ongoing demonstrations in Florida and California that allow children with Medicaid and with certain life-threatening diagnoses to receive home and community-based care and life-prolonging treatments. Similar programs have been introduced in a number of other states, most successfully New York





and Massachusetts. While Provision 2302 is more restricted than these programs in retaining limits on a child's eligibility due to the 6-month life expectancy requirement, how this law is interpreted in practice remains to be seen.

People and Institutions: Gaining a Foothold

In addition to finding ways to pay for care, the main challenge for this emerging field is finding enough qualified physicians, nurses, hospice workers, and social service workers to care for more than a fraction of those children in need.

Pediatric palliative care is a team effort that begins at the time of diagnosis, takes place in multiple settings, and continues for an indeterminate length of time. A recent study of 6 of the largest hospital-based programs in the US found that their young patients lived longer than their adult counterparts, showing both the vital need for pediatric palliative care and the unique challenges it poses.¹

In many respects, the spread of pediatric palliative care parallels the effort to make hospice care available for older Americans. In the 1960s and 1970s, seniors had few options other than dying at home or in miserable circumstances in nursing homes that barely deserved the name. A series of exposés and testimony by senior rights groups helped shift opinion in Congress, and a hospice benefit was added to Medicare in 1982.

While the numbers of children needing palliative care are heart-wrenchingly high—estimates of the number of

children who suffer from conditions that could qualify for treatment range from one half to one million—they are still not large enough to make a culture of caring well for seriously ill children a priority at most hospitals and in most communities. Bringing together a team of doctors, nurses, and social service workers to treat them and their families properly, in multiple settings, is expensive. There are persistent gaps between the revenues the care can attract and patients' needs.

While caring for children with life-threatening illnesses takes place both inside and outside the hospital, the growth of hospital-based programs has been vital. Most programs are of recent vintage. When Dr. Stefan Friedrichsdorf of the University of Minnesota became a newly-minted fellow in pediatric palliative care in the 1990s, he could count his colleagues on the fingers of one hand. Minnesota saw its first palliative care patient in the late 1970s and now handles up to 90 children at a time with 35 full-time staff. Along with Akron Children's Hospital and Children's Hospital Boston, it is one of the largest programs in the country. While many existing programs serve inpatients only, Minnesota and Akron Children's serve inpatients and outpatients alike.

Dr. Friedrichsdorf compares building a palliative care program to "building a new lane on the highway." He notes that once hospital administrators overcome their initial denial of the importance of these programs, they tend to steer the most socially disadvantaged and ill children in this direction. Because pediatric palliative

care programs are labor-intensive, serve a relatively small number of patients, and are rarely profit centers, forging alliances with administrators and with other departments is critical.

Thanks in large part to changes in licensing and certification boards of internal medicine, pediatric palliative care has become more common in hospitals. According to San Francisco-based pediatric nurse and activist, Christy Torkildson, "The benefits of this model are much more accepted now. Most children's hospitals now have palliative care in some way... just not a hundred percent." Roughly three-quarters of US hospitals have at least one staff member dedicated to pediatric palliative care, along with an estimated 80 percent of large hospitals, which now support palliative care departments of some kind.²

This effort to integrate pediatric care with palliative care is being led by champion physicians nationwide—many who, like Sutter Health's Dr. Lorry Frankel, came to realize the gaps in their pediatric specialty training and became devoted to building the field. Dr. Frankel notes that doctors typically "hope for the best, but don't plan for the worst. No child should die. But despite our wonderful medical interventions, children do die." He stresses the need for a genuine contingency plan for the treatment of every child with a life-threatening condition: "Physicians need to have a care plan that includes palliative care and hospice as part of the treatment. They don't necessarily have to carry out the plan, but it needs to be one of the





options.” Such plans invariably need to include pain management, a goal critical to gaining the trust of patients, their parents, and fellow doctors alike.

For aspiring doctors in palliative care, roughly 80 percent of the board exam remains devoted to adult palliative care, but some knowledge of palliative care is now required for all aspiring doctors. The numbers of those certified in palliative care continues to grow: 47 doctors were certified after the first ABMS board exam in 2008 and 1274 physicians through other boards in that year alone. It is important to note that the grandfather clause that allowed certification in the field of palliative medicine without fellowship training is set to expire in 2012.

According to Frankel and other doctors, receptivity to this goal has been increasing even as the resources available to treat terminally ill children outside the hospital have remained flat or even declined. For instance, the number of hospices with services for children has grown to roughly 450 nationwide (from just 4 in 1983), but the number of service providers has shrunk during the recession. Because of California budget cuts, for example, there are no providers of hospice care for children in either Alameda or Contra Costa County, and caregivers travel 20 to 50 miles from Marin County to serve these patients.

Hospital-based programs have been successful in getting philanthropy to begin institutionalizing their mission. For instance, Akron Children’s Hospital has created an endowed chair based on a \$1.2 million gift from a family foundation. The University of Florida, Jacksonville, has recently inaugurated an endowed professorship in pediatric palliative care on the basis of a similar gift.

However, a simple increase in numbers of caregivers is not necessarily enough to meet the need. As Terri Warren, executive director of Providence TrinityCare in Torrance, CA, one of the state’s largest hospital-affiliated hospices points out: “I believe that a highly competent social worker can bridge the needs of adult and pediatric patients well, but their level of experience and comfort with children really determines if they can be effective at their job.”

Reducing the shortage of professionals and institutions for the diagnosis and treatment of orphan diseases will continue to depend heavily on the parents and relatives of children with life-threatening illnesses. The advocacy work of these parents has been critical both to changing laws and to changing attitudes. But as Laurie Kotas puts it, “Families are petrified of the word ‘hospice’ when it describes a child. We are trying to make the word and the experience more palatable.” Doing so is imperative for raising money from the government, foundations, and individual donors to keep services available for those in need and to expand them geographically.

Concrete positive examples of how existing programs and policies are working are imperative for both parents and primary care physicians. With this in mind, it will be critical to expand and stabilize the networks of caregivers outside the hospital so that doctors who have previously been reluctant to make referrals have a regular connection to hospices.

Moreover, the fate of federal health reform depends on building networks of coordinated care among physicians themselves and among different types of institutions devoted to acute, palliative, and long-term care. Demonstrating

successfully how to build teams of physicians and allied personnel—the rock on which pediatric palliative care is founded—will be a vital example for the payment and workforce reforms expected in the broader US health system of the future.

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This article is an edited reprint of the 2012 edition of HOPE Magazine, a bi-annual publication of Children’s Hospice and Palliative Care Coalition (CHPCC). CHPCC is a California-based nonprofit organization dedicated to ensuring that children with serious illness have access to compassionate, home-based palliative and end-of-life care. For more information on CHPCC or HOPE Magazine, visit www.chpcc.org.



Book Review

A Broken Heart Still Beats: After Your Child Dies

by Anne McCracken and Mary Semel

Reviewed by Lee Webster

“When Mary and I first met, we had two things in common: We had lost our sons and we had lost our way,” explains Anne McCracken. In addition to participating in grief support groups, they had each read self-help books, memoirs, and collected essays about losing a child. Some of these were comforting, some were recognizable, but most lacked universality and, ultimately, healing. What moved them, they discovered, was the literature of loss and grief. “We wanted inspiration. We wanted permission to hope. But we *craved* validation of our feelings.”

Their collection of writings—*A Broken Heart Still Beats*—by authors, poets, philosophers, and essayists from Sophocles to Mark Twain and Stephen King delivers all three. Weaving their own stories throughout this compilation of excerpts written about the loss of a child (or in the case of Robert Frost, four out of his six children), McCracken and Semel have accomplished what they set out to do—go beyond cliché and platitude to places only master wordsmiths can take us.

Each chapter is thoughtfully grouped, consolidated by theme in a manner the grieving will understand—“A Storm in the Heart,” “Especially Bad Days,” “Time Moves Differently Now”—and prepares the reader to delve in, to participate fully in a search for common ground.

Some authors write from personal experience, some fictionalize their search for meaning in the deaths of children and siblings and those whose losses have struck them to the quick. In either style, the words speak eloquently and directly to the core of shared yet deeply personal experiences.

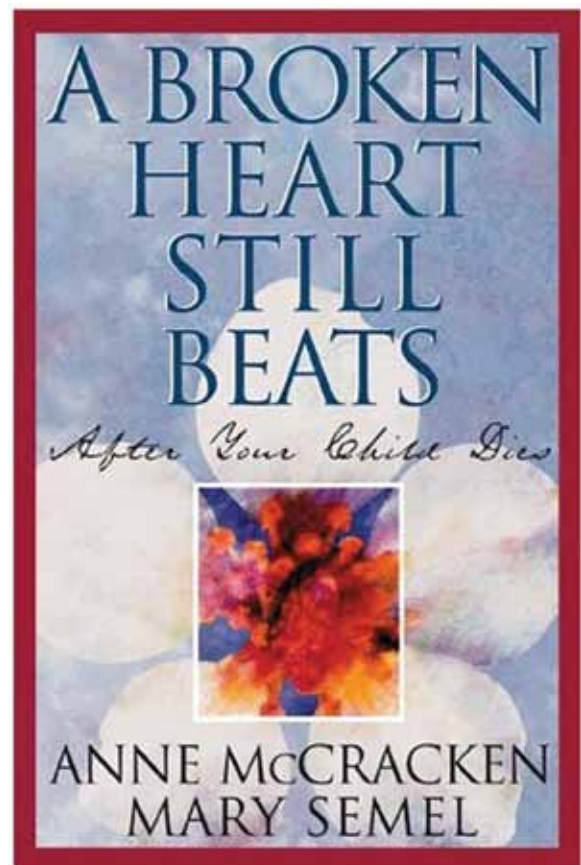
A Broken Heart Still Beats provides solace to grieving parents, as each vignette (of a length a grieving person has the capacity to absorb) offers a new shock or insight, a new wave of despair, anger, love, acceptance, or most importantly, a new understanding that resonates in the space between the readers’ memories and those of the authors.

A rich exploration of the grieving process and its aftermath, this anthology alternately offers total immersion and respite. There is no quick fix, no anesthetic, no single word of wisdom. Instead the reader will find timeless echoes of the familiar spoken through writers who are not afraid to walk the long road from devastation to resolution.

Friends make pretense of following to the grave, but before one is in it, their minds are turned and making the best of their way back to life and living people, and things they understand.

– Robert Frost, from his poem “Home Burial”
on the rippling effects of his 2-day-old child’s death

The common denominator is survival and, beyond that, finding a way to live again.



A Place to Heal A Children's Grief Camp

by Kristy Mitchell

By the time they graduate high school, 1 in 20 children will experience the death of a parent. One and a half million children under the age of 18 have lost an immediate family member. These numbers are especially disturbing because young people are at much greater risk for depression, suicide, poverty, and substance abuse. After losing someone they love, children often feel isolated in their grief, but it's rare for them to receive formal grief counseling.

The Camp Erin nationwide network of free bereavement camps for children and teens from ages 6 to 17 provides safe and comfortable places for children to express their grief in healthy ways. The Moyer Foundation, established by All-Star baseball pitcher Jamie Moyer and his wife, created the camps and continues to fund them. Moyer, who currently plays for the Colorado Rockies, recently made history as the oldest pitcher ever to win a Major League game. That record came the same year Moyer fulfilled his other big goal—establishing a Camp Erin in every Major League city.

The children who attend Camp Erin have all experienced the death of someone close to them. Over the course of a weekend, campers participate in traditional, fun camp activities combined with grief education and emotional support facilitated by grief professionals and trained volunteers. They learn coping skills that can be used long after camp is over. Often these bereaved children feel lonely and isolated. They're the only one in class who has lost a mom or a dad, a brother or a sister. As one 12-year-old camper put it, "I learned I am definitely not alone."

The camps are named in memory of Erin Metcalf, a remarkable young woman who developed liver cancer at the age of 15. Karen and Jamie Moyer met Metcalf through Make-a-Wish. During her hospitalizations, Metcalf showed

compassion for other children and their siblings she met, who sometimes received little attention.

Some of the activities at Camp Erin include fishing, swimming, canoeing, arts and crafts, nature walks, remembrance activities, and a very popular challenge course. When the campers decorate luminaries, light them, place them on a raft, and launch them into the lake, it's a very powerful moment of joining together and remembering. "They gave me a place to have fun and remember," said one 9-year-old participant.

*"It has let me see the many faces of grief."
Arden, age 12*

At Camp Erin, it's comforting for campers to know there are others who've faced similar situations and can understand just what they are feeling. Typically there are few avenues through which children can effectively express their grief. It's often challenging for them to find ways to honor and remember those they've held dear. At Camp Erin, they might think they're just having a good time. But through all the drama, arts and crafts, creative writing, and physical activities, they're "getting their feelings out" and remembering those they love. Maybe unbeknownst to them, they are on a path to healing.

In the case where one parent has died, the surviving parent is often at a loss over what to do to help the children. According to the father of two Camp Erin attendees, "No kid wants to be alone, and losing a parent puts them completely out of touch with other kids. This [camp] made them feel special in a whole elemental way."

Another father mentioned that his children don't always open up to him, but "they open up to other kids, and my daughter and the other girls in her group really bonded. It also helped me because it made me realize I'm not the only parent going through this experience."

Up to age 6, a child's concept of death is that it is temporary and reversible. Between ages 6 and 9, children begin to think about the finality of death. Around age 9 or 10, they have very little capacity to recognize that the feelings they have are grief-related. From ages 9 to 12, they develop an understanding of the finality and universality of death. Even as they grow older, they have shorter attention spans than adults and can experience brief grief reactions several times a day. It may take between 2 and 5 years for children to review and reevaluate the loss at each new stage of their development. Their main focus is on three basic questions, which will occur whether they mention them or not: "Did I cause this to happen?" "Will it happen to me?" and "Who will take care of me now?"

Normal Grief in Children

Most behaviors grieving children display are an expected response to loss. Some typical ways children express their grief are:

- Asking the same questions about the deceased over and over
- Playing death themes, e.g., funerals, experimenting with toys "dying," things coming back to life
- Laughing hysterically, hyperactivity, or emotional outbursts
- Difficulty concentrating in school
- Wanting to be alone more or to be with friends instead of family
- Wanting to be close to their caregiver, including wanting to sleep in the same bed



At Camp Erin, grieving kids find out they're not alone

Complicated Grief in Children May Include:

- Destructive behavior – towards self, property or others
- Excessive high-risk behaviors – drinking, sex, driving fast
- Extreme or extended withdrawal from things that used to give the child pleasure – friends, extra-curricular activities, family
- In younger children – inconsolable feelings of distress

While many Camp Erin participants take away tools to help them cope with everyday life, others start attending grief support groups. One young girl found a unique way to help herself and others who had lost a loved one.

Callie (not her real name) attended Camp Erin in 2010, about a year after the traumatic loss of her sibling to suicide. She was 10 years old and had just started 6th grade. She and her brother had shared a close relationship, and Callie was experiencing a sense of isolation, loss of concentration, and bouts of anger. One of her school counselors suggested Camp Erin, and she, along with her stepbrother, decided to give it a try.

Callie says that attending the camp helped her gain confidence. She particularly appreciated meeting other children who were grieving a loss, who listened and understood. Previously, when she had talked about her brother's death, she had been subjected to cruel comments. Callie stays in touch with two new friends who attended camp with her. Their reunions take place at Rockies games and they pick up like they had just left camp yesterday.

Kristy Mitchell is a communications specialist for HospiceCare of Boulder and Broomfield Counties of Colorado.

The above article includes edited excerpts from *Grieving Patterns by Age Group* by HospiceCare of Boulder and Broomfield Counties of Colorado (www.hospicecareonline.org).

To learn about Camp Erin throughout the US, go to www.themoyerfoundation.org.

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Awakening to Energetic Parenting in the Cycle of Life: Qigong

by Damaris Jarboux



Birth and death are the natural bookends of the human life cycle. Those who observe this process closely, such as midwives and hospice workers, can perceive the transition from the world of spirit into our world at birth and then back again at death.

From a Taoist perspective, birth and death are expressions of the polarity of yang and yin or expansion and contraction, a cycle expressed everywhere in our world. As our energy-body contracts in the yin state, it expands in the yang state, as in a natural breathing rhythm. Five major principles of yin-yang describe their interactions: Everything has a yin and yang aspect; every yin and yang can be further divided; yin and yang create each other; yin and yang control each other; yin and yang transform into each other.

We experience this every night as we sleep (if our energy-body is fluid enough) when our consciousness moves out of the physical third dimensional body (*jing*), which becomes yin, and gathers into the emotional fourth dimensional body (*chi*) in the dream state, which becomes yang and may even proceed on into the continuum of mind or fifth dimensional body (*shen* or spirit). We bring back our nighttime experience into the chi/soul body before settling back into the physical body upon awakening. If we are conscious enough in the middle state, we can gently gather at the edges of the dream state and bring it down into our waking consciousness in the material world.

These different levels, all part of our individualized nature (our personality), are not separate but are connected through our energy-body; indeed we always live in all three realities, whether we are aware of it or not. The only difference at death is that the “cord” connecting the chi and shen bodies is severed from the physical. Our consciousness then lives in the chi/soul level until our process there is complete

when it moves on into the shen/spirit level and on into the “great mind” of Oneness. If one accepts reincarnation, then one can appreciate that the journey back into the world of substance is the reverse of the journey out, gathering back together our energy-body. This cycle is called “Jacob’s Ladder” and is common to many religious or spiritual philosophies, viewed from different cultural perspectives.

If one sits in a centered, aware state with a dying friend, one can perceive the life-forces gathering into the chi body. As we feel the physical body becoming more yin (contractive), we also perceive the energy-body becoming more yang (expansive). That is why the most helpful therapeutic we can offer is energy—not physical—work. Indeed many dying people prefer energy work to massage or other physical therapies. This preference signals this ongoing transition. The other loving service we can offer a dying person is helping her review her life story, which is happening on an inner level. This review is most helpful to her soul and spirit. In fact, she is practicing living in her other body, and the observant helper can tell when her consciousness leaves and then falls back into the physical body. If you ask her where she was immediately when she returns, she will often remember that she had been in a different place (spatially), often saying good-bye to someone living far away. This is similar to “false labor” as a woman’s body prepares for the process of birth.

Children naturally embrace the process of birth and death if their parents do. *How* the parents go through these transitions is the strongest determinant to *how* the children will do so because the response of a child to anything in the environment or any new experience is based on his perception of the parents’ experience. A child (infants to about age 12) will look at the eyes of the parent to immediately *know* the “survival value” (healthy or unhealthy) of anything he is experiencing; we are biologically encoded to do this

from birth. Science tells us that thoughts in the head express directly into the body, affecting the self on all levels and continuing beyond us to influence anyone in our field. All facts of life and death are a direct download from parents to their children. The participation of children in the process of death (and birth) requires parental discretion because it is important not to expose a child to aspects of these experiences that he cannot yet understand (and may misinterpret), especially if a parent is struggling to cope herself. If there is a great deal of pain, bleeding, physical symptoms, or bodily distortions, the child can be traumatized if the parent is not accepting, at peace or coping well with the experience. If the parent is not coping well, it is better to remove the child from the field until she can regain ground. If the parent is coping well, then the child will also be at peace and will experience it as part of life and part of nature. I have witnessed both birth and death as profound learning experiences for children whose parents have found an inner confidence in their natural relationship to these life portals.

My 3-year-old daughter provided wonderful, sweet, and gentle help to me when we were hanging out in our backyard redwood hot tub during the first stage of my second labor, but when the labor started to become more intense for me, I knew her best place was with her grandmother. The next day, having participated to the degree that was appropriate for her, she patiently stood by the window for 2 to 3 hours, waiting for her little brother to be brought home.

During labor, a fully dilated mother in the transition stage is very exposed because a lot of her consciousness is out of her physical body and gathered into her fourth dimensional body for the purpose of generating enough chi there to push the baby out. If we consider that this woman is also very connected to her child—who is participating—then we might see that she could inadvertently draw that child



Damaris teaches William Goldman to do the solar plexus eye practice on daughter, Joselyn

out of the physical with her. In fact, if one gets close *behind* a woman and hugs her while she is struggling with this last stage of labor, it is possible to channel one's own chi from the middle *tan tien* (heart energy center) straight into hers to provide support. This is usually best achieved accompanied by the single word, "ppppuuushh," full of vitality and will.

The same principle applies if a child is really close to the dying person. I have seen children who were very close to a grandparent become too affected energetically from the drawing out of the grandparent's energy-body from the physical into the chi body. Children are trying to incarnate, not excarinate. As caring adults, we are trying to help them slowly awaken in the physical without losing too many of their mystical-magical qualities.

The questions to ask are: "Should my child participate in this?" and "To what degree?" If we are willing to accept yes or no, then we know that our ego is not too involved in the decision.

Babies and young children have naturally good energy if nothing interferes with it before or after birth. Children do a lot of natural Qigong.* They do, however, rely on the general energy field of their parents and extended family to protect their energy-body and keep it strong. Often the best Qigong for the young child is to reinforce that general field they are held in and fed from; to make gentle, small adjustments to their energy-body to keep it as open and strong as possible; and to give them a good baseline to return to as they get older.

All children experience some stress, trauma, and shock to their energy systems as they grow up. Their reaction to it is reflective of their constitution, temperament, and character, all of which are expressions of their energy-body. While some wounding is inevitable—

Hagan Caldwell

and thinking holistically may even be desirable—they can still come through it with their systems clear, open and strong. This positive response has a lot to do with what the young baby and child do *not* do, since, left to themselves and given good choices, they stay very healthy. Children have an abundance of free physical energy and, as documented in Chinese research, until about 18 months, the energy center in their forehead is relatively open, so they can actually see past the material world. After that it is thought to close until about age 12 to allow them the opportunity to get well grounded in the material world. How can we best support them?

In the womb, the developing child is held tightly and protected; his whole world consists of that sense of ultimate closeness. After he is born, things change quickly. The physical umbilical cord to the mother is cut, an energetic one remains to feed the baby from the mother's energy field. The father holds his own larger sphere of protection and direct heart connection for the entire family field—a role that is vitally important in today's world. The energetic cord to the mother is fully intact until the child is in his teens. It is the job of the teenager to thin the cord and the job of the mother to let him. The cord should be totally severed by the mid-twenties or there will be an unnatural overdependence. The young person relies on this energetic nourishment and protection until he is 12 to 14 years old, by which time his personal energy field has grown much stronger. The parents cannot project a balanced field to the child if they don't have one. Qigong (energy cultivation) of some kind for parents is of great benefit to children and might be considered part of a healthy lifestyle.

Every spring there is birth in nature, fullness in summer, death in the fall, and rest in winter—the great wheel of the seasons—and children naturally learn from this if their parents are attuned. There are also many deaths in life to allow the birth of something new: new siblings, friends moving away, pets dying, changing houses or towns. Change is the only constant in life. “Letting go” is one of the five great themes of humanity and nature as understood in Taoism, but it is the hardest for the Western world, as our motto is more likely to be “just do it” than “just let go” or “just cry it out.” Tears are the natural help our body provides. The biochemistry of tears changes depending on what is moving through our emotional body: joy and laughter, tender-hearted

sadness, abject grief. One should never stifle tears that help a child learn not to suppress this natural expression of letting go. There might be much less depression in our world if people simply cried when they felt like it.

In conclusion, the best energy work for the child is the personal development of each parent and the relationship between them. Also important is early bonding with both parents (even if there is not a lot of play) and a constant loving, touching, caregiver, when the parents are absent. Some natural and gentle energy practices can help in any situation, no matter what the stress or trauma, because they can also calm the parent. A child who grows up with energy consciousness will naturally incorporate it into play and daily activity.

Energy Practices for Parents to Help Their Children

Harmonizing the field

It is a common practice among indigenous mothers to put their children to bed after smudging them with copal sage or cedar to clear the day's events. Parents can do this with the energy of their hands by slowly moving them down the child's field (3 to 6 inches above the body) from head to foot. Use both hands—one hand if you are holding the child—and do it front and back. This smoothes out the energy field; it is very relaxing, good for any stress, and children love it.

Tummy rock

For stomach upset in newborns or small children, move your hands side to side over the abdomen, 3 to 6 inches above the body.

Solar plexus eye

On all babies and children, moving your hands clockwise (up their right, down their left) over their solar plexus will greatly relieve common stress or the shock of any trauma or sports injury. You can even do this with your mind if you don't have access to the child.

Natural regulation

Move hands clockwise over the belly of a constipated child and counterclockwise over the belly of a child with diarrhea.

Western science, through EEG studies, also gives us invaluable insight into the world of children when considering their experience of death and birth and how we might best teach, hold, nourish, and protect them. From 0–2 years old they experience delta brain waves (considered

deep sleep for an adult), meaning they are not connected to the outer world in the same way as adults. From 2–6 they experience theta brain waves, mixing an imaginary state with the outer world (in adults theta brain waves are associated with our magical abilities). From 6–12 children experience alpha brain waves, signaling the centered, meditative state of consciousness that bridges our inner and outer worlds. Then from 12 years and older, they are developing the conscious mind through the many levels of beta states: focused, linear, logical. This explains why babies and children under 12 learn by modeling parents and caregivers, because they are in a hypnagogic trance state observing and downloading directly into the subconscious. Science has proven the subconscious is a million times more powerful at processing information than the conscious mind. This is why a child under age 3 can learn three different languages and keep them completely separate, as they are downloaded directly into the subconscious habitual mind, a feat that is nearly impossible once the conscious mind is fully developed. Therefore, if a parent wishes to help a child under age 12 experience death in the most balanced way, he or she will not treat the child as a small adult but as a child, with an open mystical magical subconscious. Comprehending these aspects of consciousness and the energy-body provides deeper understanding, not only about the process of birth and death, but as a blueprint on how to live life.

*Qigong or Chi Kung (energy cultivation) is an ancient Asian healing art that has always been both a personal practice (energy cultivation of many kinds) and a clinical practice (treatment by a practitioner that is based on an assessment of the individual's energy-body). Qigong is the grandparent of acupuncture, Tai Chi, and the martial arts.

As a registered nurse, Damaris Jarboux moved from the world of high-tech medicine to hospice, where she worked during the early days of the movement in the US. She is internationally recognized as a master Qigong practitioner and teacher and has undertaken a deep study of Western and Eastern medicine. She is a founding member of The National Qigong Association and has created an advanced Qigong healing program. For more information about Damaris Jarboux and Qigong, visit www.thecenterplace.com, or the National Qigong Association at www.NQA.org.

Rupie's Gone Night-Night

by Isabel Stenzel Byrnes

When I first met her, Sylvia was a very sick little girl. I was 6 years old, and we shared a hospital room. She was about 10 but didn't look much bigger than I was. The adults around me spoke with excited tones, because she also had cystic fibrosis (CF). She coughed much harder than I did. She seemed tired and withdrawn. I remember her parents talking to mine about how they did their treatments and what machines worked best.

I remember when, months later, my doctor told me about Sylvia. His eyes sagged, and he spoke in a whisper, "Sylvia didn't make it." Immediately, I thought: *Huh? Didn't make it? Make it where?* As the doctor spoke in his serious voice to my mom, I imagined this was not good.

In the next few years, as my illness worsened, I suffered from anxiety-attacks. I was scared to sleep in my own bed. I developed compulsive habits in an

attempt to soothe myself. Things were churning inside my head. I asked for a Bible for Christmas.

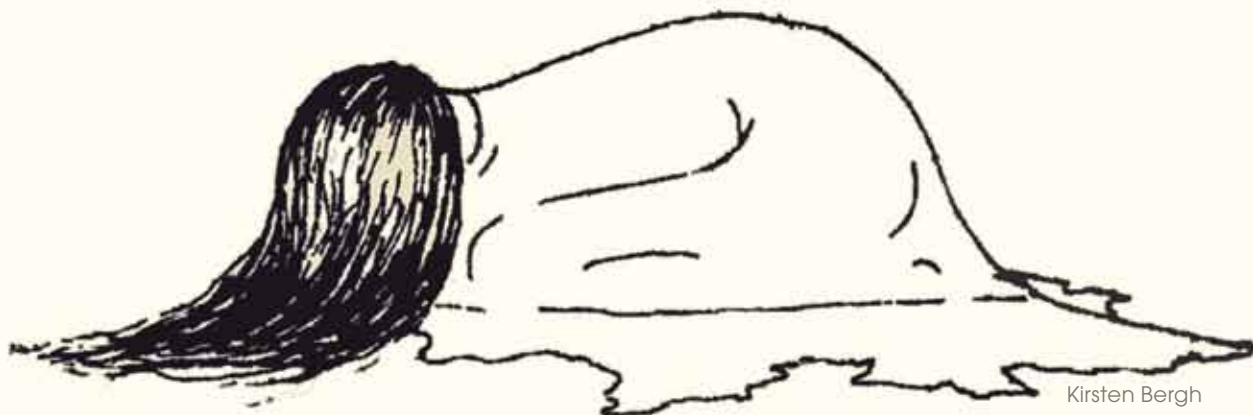
The names of the children who had died were read aloud.

Now flash forward to my first week at CF summer camp when I was 11. One night as the campers and counselors gathered around a campfire, the usual laughter and high-pitched voices hushed to a respectful silence. The names of the children who had died were read aloud. All around me people started to cry. I listened as the close cabin-mates of the deceased trembled while they told stories about years past. I thought about how sad it was—to lose a friend—but I didn't feel that sad because I didn't know these kids. In fact, I didn't know anyone else who had died of CF. But then it hit me: Sylvia.

Right then and there I finally absorbed that Sylvia had died—of the same disease I had.

Such is childhood grief. It starts off mysterious and obscure. It can remain buried and suppressed for years, only to be triggered by other losses or traumas. Sometimes these griefs accumulate and can be released in psychosomatic ways or through mental health issues. I wonder to this day: What if I had had someone to talk to about death? Would my childhood understanding of life and my illness be better? Or worse?

It's funny, the words that adults use to talk to kids about death. A few months after my dog died, my older brother and my 2½-year-old niece were sitting together looking at pictures. "There's Rupie," announced my niece, pointing to the photograph of us all gathered for a picnic in the backyard.



Kirsten Bergh



“Yeah, that’s right,”
my brother said.
“Where’s Rupie now?”
he asked, to generate
the kind of thought and
response to stimulate a
toddler’s language skills.

Without losing a beat, my niece
said, “Rupie’s gone night-night.”

“That’s right,” said my brother. “Rupie’s
gone night-night.”

I rolled my eyes. Grief 101
says not to tell children that
people go to sleep when they
die. Just say it: Rupie died.
She got a sickness and died.

It was awful. We miss her and feel sad. It’s
hard to lose someone you love. We want
to protect our little ones from sadness and
concern: that there is an end, that anyone
can die, that sometimes death happens to
people (and dogs) whom we care about.
Just as there is an instinct to grab our kids
as they wander across a busy road, we
wish to grab their emotional wanderings
and protect them from the difficult
feelings of sadness, fear, anxiety, regret,
guilt, and so on. Childhood is seen as a
carefree time, and introducing a difficult
topic like death is sometimes perceived
as taking that innocence away. However,
a child lives in fantasy. If not informed
about a big topic like death, sometimes
what a child can imagine can be far more
troubling than the reality.

Clearly, how a child understands death
and grieves depends on the child’s
developmental stage and age. Children
under age 2 may not have the words yet
to understand death, but they are keenly
aware of the emotions around it. They
can benefit from maintaining the routine
they had before the loss, as well as from
receiving touch and affection, which give
them a sense of security. Children under
age 5 can be very egocentric. Their first
response to a loss may be: “Well, since
Grandpa died, who is going to play ball
with me now?” They want to know how
the death is going to affect them. And

they may have a hard time grasping the
permanence of death: “Maybe Grandma
is just on a vacation but she’ll be back.”
Because young children exhibit magical
thinking, they are at risk of developing
erroneous ideas about the death, for
example: “My sister died because I didn’t
let her play with my toys.” Children
at this young age are susceptible to
experiences of guilt for causing the death,
as well as a fear of dying themselves

... make grief an unashamed, accepted, “normal” part of family life

and anger at the deceased for leaving. It
isn’t until around age 8 to 10 that a firm
understanding of the finality of death
emerges. However, the understanding is
not always personalized: “Death happens
to others, but it won’t happen to me or
those I love.”

By the early to middle teen years,
an adolescent become capable of
abstract reasoning and can understand
the universality, irreversibility, and
permanence of death. Young people
of this age are ripe with introspection,
existential and spiritual awakening,
so the concept of death can greatly
influence a teen’s worldview and sense
of self. Because peer relationships are so
critical at this stage, the death of a peer—
including a sibling—can have a lasting
and profound impact on a teen.

Clearly, there are many other factors
besides age that can influence how a
child understands death and grieves. The
family communication style—how open
or hushed the family is after a death—will
impact a child’s knowledge of death and
experience of grief. A family who creates
rituals, talks about the deceased loved
one, and shares feelings openly is likely
to make grief an unashamed, accepted,
“normal” part of family life.

Past experiences with illness and loss will
also impact how a child grieves. A child

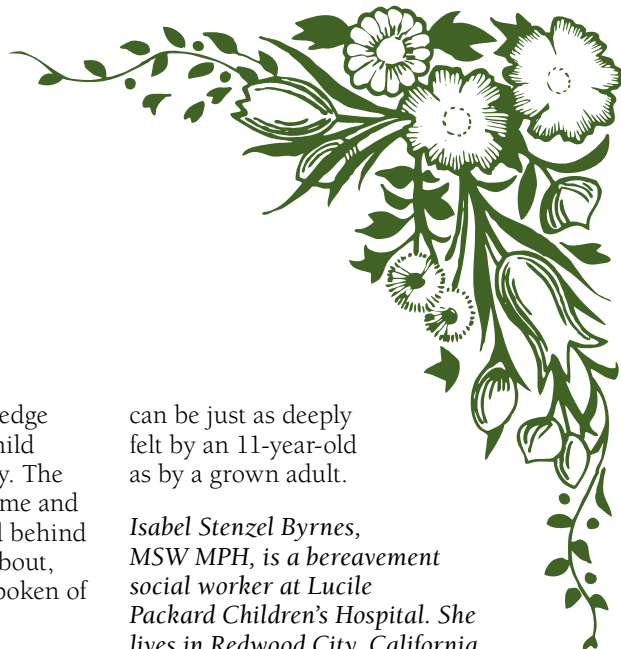
with cancer or other life-limiting illness
like CF, who has had years of experience
with medical care, is capable of having
a precocious understanding of his or her
prognosis. A child who has been to a
funeral and has seen how people react,
what happens to the body and coffin, and
what follows in the weeks and months
and years afterwards, will clearly know
what to expect in future losses and future
ways of grieving.

Keep in mind, a child
who has experienced a
death will be impacted by
the death throughout her
lifespan. A 4-year-old, who
loses her baby sister, will
experience this loss differently when she’s
8, 12, or 20. The meaning of the loss will
change depending on her developmental
understanding of what happened.
Further, exposure to how other people
are grieving the loss through time will
influence a child’s long-term grief. For
example, in the case of the 4-year-old,
if this child’s mother goes through
depression and “complicated grief,” the
child will be parented differently, and
the impact of losing a sibling will persist
years later.

Similarly, as a child matures, he or she
absorbs the familial and societal messages
about death. As kids become teens, they
learn it’s okay and not okay to talk about
death or grief in certain circumstances.
They become self-conscious about sharing
feelings surrounding the death of a loved
one. Sadly, boys are often encouraged to
be strong, hold in feelings, and “move
on” after a death. As kids grow into
adulthood, they develop the coping
skills and defense mechanisms to protect
themselves from the painful hurt that
death causes.

Given our society’s attitude towards
death and a learned tendency to be
uncomfortable talking about death,
talking to a child about death can be
one of the most difficult conversations
any adult can have. However, when
a child asks questions, she is ready





for honest, age-appropriate answers about death. When a child mentions the name of someone who has died, it is an invitation to talk about her grief. Understandably, sometimes it can be too painful for a parent to talk to a child about death or grief (especially when the parent is grieving). If that is the case, it's important that there are other adults (teachers, counselors, clergy) with whom the child is comfortable and who is available to talk about these issues with the child. Encouraging a child to maintain a relationship in mind, spirit, and heart with the deceased loved one can also be a big help, one that grows and accompanies the child throughout

her life. It's important to acknowledge that, just like with adults, each child will grieve in her own unique way. The feelings surrounding grief will come and go and change through time. And behind grief is love. Love can be talked about, remembered, held in the heart, spoken of safely.

Talking to children about death is an opportunity to normalize this fact of life. It's a chance to bring an awareness of the preciousness of life, even to young children. I left that campfire memorial with my eyes wide open: "This is it. I have one life to live, and I'm going to make the most of it. Each day is a gift." These words

can be just as deeply felt by an 11-year-old as by a grown adult.

Isabel Stenzel Byrnes, MSW MPH, is a bereavement social worker at Lucile Packard Children's Hospital. She lives in Redwood City, California. She is also featured in the award-winning documentary The Power of Two about her journey with cystic fibrosis. More information is available at www.thepowertoftwomovie.com.

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Papa

by Kirsten Savitri Bergh

Did I swallow your spirit
When my mouth was open and dry
From the wails of despair that shook my body?

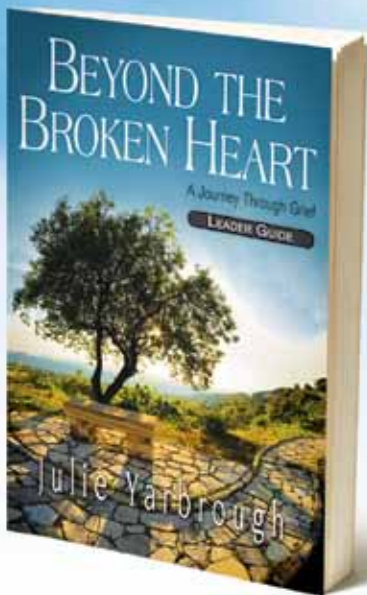
Did it slip through your soft dying fingers
That I held like cool shells
In my own hands, not daring to let go,
And mix with my blood?

Did it seep into my every pore
Like your living odor, when I held you
In my arms and listened to your fading heartbeat?
Was it in the air I desperately breathed
When I sang all our old songs to you
Until my body tingled and collapsed?

Did it fill me like a dream, like a new love,
Like a baby that is the new me, the you-me,
Who laughs and dances and embraces living?
Are you the stream of joy in my thoughts?
The laugh tickling my throat,
The lightness in my heels?

So, I carry you in me,
Not as the fading memory of a father,
But rather as a growing, glowing child,
Until we become one,
And I can let you go.

Kirsten Bergh was 17 when she died suddenly in a car accident with her best friend, Nina Dietzel. "Papa" is in memory of her father who died a year before Kirsten. This poem and illustration by Bergh are from She Would Draw Flowers, a book of Bergh's art and poetry published posthumously. To find out more about Kirsten Bergh, visit www.beholdingthethreshold.org.



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About the author:



Julie Yarbrough. Inspired by her personal experience after the death of her husband, Dr. Leighton Farrell, senior minister at Highland Park United Methodist Church for many years, Yarbrough established a support group for widows and widowers and began writing for persons who are grieving. She is president of Yarbrough Investments and lives in Dallas, Texas.

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