ChiPPS Pediatric Palliative Care Newsletter
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Edited by Charles A. Corr, PhD, Christy Torkildson, RN, PHN, PhDc, and Maureen Horgan, LICSW

Issue Topic: Understanding and Helping Fathers and Other Males

Welcome to the thirty-first issue of the ChiPPS electronic newsletter. This issue of our e-newsletter offers a PDF collection of articles that explore perspectives of fathers and other males in relationship to pediatric palliative and hospice care. Our primary goal in this issue is to honor and promote the perspectives of these men. At the same time, we also want to contribute to a better understanding of what it is like to walk in their shoes and how the assistance offered to them can be improved when a child is facing a life-threatening illness, is dying, or has already died. We hope that the voices of these men as they appear in this issue and the suggestions made for helping them will encourage greater recognition of how they can contribute and what they need in these difficult situations.

This newsletter is produced by ChiPPS (the Children’s Project on Palliative/Hospice Services), a program of the National Hospice and Palliative Care Organization and, in particular, by NHPCO’s E-newsletter Workgroup, co-chaired by Christy Torkildson and Maureen Horgan. Archived issues of this newsletter are available at www.nhpco.org/pediatrics.

Comments about the activities of ChiPPS, its E-newsletter Workgroup, or this issue of the newsletter are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues of this newsletter. Please contact Christy at christytork@gmail.com or Maureen at horgan.maureen@gmail.com.

ChiPPS is a program of the National Hospice and Palliative Care Organization. Learn more at www.nhpco.org/pediatrics.
Issue #31: Understanding and Helping Fathers and Other Males
(Click on the “bookmark” tab on the left-hand side of the PDF document for links to the following articles.)

Avian Nights
Sherman Alexie
In this poem Sherman, a Northwest award winning poet, novelist and filmmaker, shares a poem written about his son’s illness. We thank him for his courage to share with us all.

An Interview with a Dad Reflecting on Curative and Comfort Care for His Son
Mike Brown, MSW, CSW
A pediatric social worker at Hospice of the Bluegrass interviews a single dad whose 7-year-old son was on hospice. In this article Dad and Seth have agreed to be interviewed to share their experience of time in and out of hospice.

A Father’s Perspective on the Importance of His Presence in the Life of a Child with a Serious Illness
Don Hill
The best description of this piece is given in words written by Don himself; “We fathers are a troubled lot. We start the whole show and find it hard to stay connected. Even so we press in (at least at times). We hold our ground, sure enough. We keep ourselves in the game—most of us. We persist…. we are a presence in their precious lives.” This is much more than a therapeutic article for Don; it will touch a chord with many who read his words.

For the Love of Emani: A Father Transforms His Life to Care for His Daughter
Linda J. Chasteen, LISW
In this article, Linda interviews Timmy Johnson, a recovering alcoholic and single father to Emani. The love, pride, and work required to care for this special little girl comes through along with the help a palliative care team can provide.

Telling Him
Mark Nassutti
In another gut-wrenching article Mark shares how he was the one left to tell his 16-year-old son Andrew that he was going to die—there were no more treatments. Love, fear, pain, and incredible courage can be felt as we read his words.

Losing a Grandchild
Alfredo Santiago
Alfredo’s words are brief but powerful as he tells of learning his grandson’s condition following his birth, trying to help his own son, and then the loss of his grandson. The devastation of loss.

I’ll Never Find Another You
Alexander Peter
In sharing his poetry with us, Alexander’s words touch all of us who have lost a child, who remember the smiles and unconditional love, feel the emptiness of lost promises, and share the hope of meeting again.

Elijah – One in a Million
Michael Hillman
It is difficult to provide an introduction for Michael’s powerful words. They represent a fear most parents have; the unexpected loss of their child. Michael shares the life of Elijah, his son, who survived a congenital heart condition that required open heart surgery on the second day of his life to his death six and one-half years later—from a mosquito bite. You will need Kleenex.
To My Knees  
Kelly Farley  
Kelly shares the horror of losing not one but two children, 18 months apart. He describes the rawness of his grief and his fight not only to heal but to help other dads. Kelly’s words strike to the very heart of his grief: “[M]y response to these losses scared the hell out of me. I felt out of control—because I was out of control. I couldn’t change the fact that my children died. I couldn’t stop hurting. I didn’t just cry—I physically wept inside. There were times when there were no tears and it felt like I was convulsing internally.” This article is not just about Kelly’s losses; it is also about lessons learned and how to help others.

A Father’s Role in Palliative Care  
Marc Seymour  
Marc tells about his role as father and husband; the journey with his daughter Quinn, her rare and horrible disease. He writes eloquently of the challenge of grief, of being, of going on and the importance of being a dad.

Babylove and Babyloss: Some Personal Observations of One Dad’s Journey  
Ann Fitzsimons, BS & MBA  
Ann relates her observations of her brother-in-law’s response to the loss of his daughter and then his wife six years later. His response varies from those in earlier articles in this issue and may be more in keeping with the “generalized” belief about how men handle grief.

The Husband  
Brian Harrell  
This article hits close to home in the households of those who work in pediatric palliative/hospice care. It is also a perspective we have not had presented in the past. Brian is the husband of a palliative care physician. His words are a must read for all palliative care providers and their significant others!

Offering Men Space, but Helping to Heal Along the Way  
Rebecca Roberts Konarz, LMSW  
Rebecca, a trained bereavement professional, offers her insights about men and grief along with suggestions to support men who are grieving.

Helping Bereaved Men Heal  
Tom Golden, LCSW  
Tom has been a counselor for almost 40 years and many of those years focused on helping men heal from loss. In this article, he shares excerpts from his new eBook, “The Way Men Heal.” These excerpts come from a portion of the Introduction and one of the final sections of the book—Tips for Helping Men Heal. Tom is also the author of “Swallowed by a Snake: The Gift of the Masculine Side of Healing.”

A Hospital Support Group for Dads  
Scott Newport  
Evan’s dad, has been a frequent contributor to our e-Newsletter. In this piece, Scott, joined by Kelly Parent, Director of Patient and Family Centered Care at University of Michigan C. S. Mott’s Children’s Hospital, describes the start of a hospital support group just for dads. Practical guidance is offered on how to reach out to men and how they started the group. We are looking forward to hearing more as the group evolves!
Reaching Out to Fathers in the Community Palliative Care and Hospice Model  p. 44
Maureen Horgan, LICSW
Maureen offers practical suggestions on how to approach the men in the family, encouraging all team members to reach out to fathers and other significant men in the life of a family with a seriously ill family member.

Let's Hear It for the Dads: Resources for Supporting Fathers Through the Loss of Their Child & into Bereavement  p. 45
Compiled by Ann Fitzsimons, BS & MBA
As Ann writes, “In an issue devoted solely to “The Dads” we would be remiss to not include what resources we could find on helping fathers through their journeys with their children with life-limiting/life-threatening illness, as well as identifying those resources that can help support them in their grief.”

Items of Interest  p. 51
ChiPPS customarily shares items that may be of interest to our readers.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.
AVIAN NIGHTS

Sherman Alexie

wellpinit_junior_11@me.com

Starlings have invaded our home and filled
Our eaves with their shit-soaked nests. Rats with wings,
They are scavengers we pay to have killed
By the quick exterminator who sings

In Spanish as he pulls three baby birds,
Blind and mewing, from the crawlspace above
Our son's bedroom. Without a word,
the exterminator uses a thumb

And finger to snap the birds' necks—crack, crack,
Crack—then drops their bodies to the driveway
Below. For these deaths, I write him a check.
This is his job. He neither loves nor hates

The starlings. They just need to be removed.
Without guilt, the exterminator loads
His truck with dead birds and the tattered ruins
Of nests: twigs, string, newspapers. It is cold

When he drives away and leaves us, mother
And father of a sick son, to witness
The return of the father and mother
Starlings to their shared children, to their nest,

All of it gone, missing, absent, destroyed.
The starlings don't understand synonyms
As they flutter and make this terrible noise:
The screech-screech-screech of parental instinct,

Of panic and loss. We had to do this,
We rationalize. They woke up our son
With their strange songs and the beating of wings
Through the long, avian nights. Then, at dawn

The babies screamed to greet the morning light.
What could they've been so excited about?
What is starling joy? When a starling finds
A shiny button, does it dance and shout?

Do starlings celebrate their day of birth?
Do they lust and take each other to bed?
Are they birds of infinite jest, of mirth
And merry? How do they bury their dead?
We will never know how this winged mother
And father would have buried their children.
Our son almost died at birth. His mother
And I would have buried him in silence

And blankets that smelled like us. These birds
Don't believe in silence. They scream and wail.
They attack the walls. We have never heard
Such pain from any human. Without fail,

The starlings mourn for three nights and three days.
They fly away, only to carry back
Insects like talismans, as if to say
They could bring back the dead with bird magic,

As if their hungry children could cheat death
And suddenly appear with open mouths.
At birth, our son suffocated, his breath
Stolen as he swallowed his own shit. Faith

In God at such a time seems like a huge joke.
To save our son, the doctors piped the blood
Out of his heart and lungs, then through his throat,
Via sterile tube, via smooth cut

Of his carotid, then sent his blood though
The oxygen machine, before they pushed
The red glow back into him. This was new
Technology and he lived, though he crashed

Twice that first night, and spent the next five weeks
Flat on his back. His mother and I sat
At his bedside eighteen hours a day. Screech-
Screech-screech. We cawed and cawed to bring him back.

We attacked the walls of the ICU
With human wings. Screech-screech-screech. Grief can take
The form of starlings, of birds who refuse
To leave the dead. How much love, hope, and faith

Do these birds possess? They lift their faces
And scream to the Bird-God while we grow numb.
The starlings are odd, filthy, and graceless,
But if God gave them opposable thumbs,

I'm positive they would open the doors
Of our house and come for us as we sleep.
We killed their children. We started this war.
Tell me: What is the difference between
Birds and us, between their pain and our pain?
We build monuments; they rebuild their nests.
They lay other eggs; we conceive again.
Dumb birds, dumb women, dumb starlings, dumb men.

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AN INTERVIEW WITH A DAD REFLECTING ON CURATIVE AND COMFORT CARE FOR HIS SON

Mike Brown, MSW, CSW
Pediatric Social Worker
Hospice of the Bluegrass Cynthiana, KY
mbrown@hospicebg.org

In nine years as a social worker with Hospice of the Bluegrass, it has been my experience that when working with pediatric patients, fathers are rarely the primary caregiver or principal contact within the family and team. That is why I found my experience working with Miguel, a single dad, and his son, Seth, so helpful in learning more about fathers.

Shortly after Seth’s seventh birthday, he suddenly became severely dizzy and confused. He was rushed to UK hospital where he was diagnosed with Medulloblastoma and underwent several emergency surgeries. He began radiation and chemotherapy immediately, but the prognosis was bleak. Surgeries and treatments rendered Seth unable to walk, feed himself, or talk. Hospice was suggested, and Seth began receiving services from Hospice of the Bluegrass concurrently with his aggressive treatments.

Seth’s father, Miguel, quit his job to become a full time caregiver to Seth as a single parent. Neither Seth’s mother nor any other blood relatives were involved or supportive. Miguel and Seth moved in with a friend of the family, Marsha, who took on the role of Seth’s surrogate grandmother. Together they did a phenomenal job of loving and caring for Seth day and night for over eight months of treatments.

The treatments eventually worked. When his cancer was deemed to be in remission we were able to celebrate his “graduation” and discharge from hospice. He still struggles with the side effects of the treatments. Though he was once the top reader in his class, Seth now has difficulty walking, speaking clearly, and learning. The future is uncertain, but his dad, Miguel, continues to love him and help him in his long road to recovery. During the eight months that Seth was in hospice care, I got to know Miguel well and was very impressed by his steadfast love, enduring patience, and the bond that he built with Seth through a terrible ordeal. He is, to me, a model of caring and compassion. He graciously agreed to let me interview him for this article on hospice care and fathers. The following are some excerpts from that interview:

Miguel started by sharing his feelings about finding out Seth’s initial diagnosis. “I was proud that we found out the major problem very quickly because it was really scary not knowing what was going on. But at the same time I was really upset. I knew then that he had brain cancer, and I didn’t know if he was going to be okay. The hardest part was that the doctor told us that he might not even make it through the (initial) surgery.”
Seth interrupted saying, “I was scared too. When I went to the hospital I thought I might have to go up there,” he pointed, “up to God, but I wanted to stay here.”

Miguel continued by talking about some of the most difficult aspects of Seth’s care following his initial surgeries. After a couple weeks of radiation, Seth began moving more, feeling more, and started knowing what was going on. Then he started crying and was afraid to go to sleep because he was afraid of the radiation machine. Seeing him like that—it broke my heart. Because he was in pieces and I knew it must be really, really hard for him and what he was going through. Just thinking about it makes my heart ache.” Miguel got slightly emotional at this point in the interview. The task of taking Seth to his radiation treatments when he became scared was a tremendously emotionally difficult experience for Seth and Miguel. Miguel sometimes had to physically restrain Seth to get him to go or to keep him at his treatments. While the effort was a deep expression of his love for Seth, in that time it was heart wrenching for both of them and for everyone involved.

Miguel transitioned to talking about how he had taken on the role of dad, mom, and caregiver for Seth. Every child that goes through what we went through needs a mother and a father to help them. In this case it didn't happen. We did it, but there were a lot of times at the hospital when I saw other families that I was pretty upset because I was there—just me—trying to be dad and mom at the same time for my son. I went with him five days a week for radiation. He was in a wheelchair and I had to help him with everything. I was feeding him and changing him—he was in a diaper. I was proud of myself because I was there for him—helping him know that everything was going to be okay.

Miguel talked next about trust and hope. The doctors they told me that he was going to be speaking and walking within at least three weeks (of his initial surgery), but it didn't happen, and I wanted to know something to do about it. Then they got me more upset when they told me ‘Let's just wait another two weeks.’ This happened a couple times but this just got me more upset as the time went by and I was waiting for that moment. It didn't happen. I started thinking the doctors were not telling me everything.

Miguel's trust of the healthcare system eroded, and he wondered if he was being given all the information about Seth’s disease. Even more worrisome was a fear that Seth might not be receiving the full scope of treatments because he was not a native English speaker and because Seth had Medicaid. Miguel often felt that the doctors were telling him, “Everything is fine” when things were not. Marsha, Seth's surrogate grandmother, felt that they needed to push harder to find out answers to these questions. Miguel felt that pushing harder would only upset the medical staff and that they would not work as hard to help Seth. Interestingly, at the same time that he felt upset by what the doctors were telling him, he said, “Other people always told me everything is going to be okay. It will just take time. And that made me feel good because somehow it was giving me the hope I needed.”

When asked about his experience with hospice, Miguel said, “It helped a lot to have them coming to the house and always helping me make things better for my son. To me it was more than just people from hospice. It felt more to me like a closer friend because I know if I call them they will be there to help me and Seth. I thank hospice for being there.” When asked if it was scary to have Seth referred to hospice, he said, “No. I didn't know much about it, but when I found out how they could help me, I was glad. I hope that for other children out there that they have hospice to help them, too.”

When asked for advice for healthcare providers he explained, “Just help them—it doesn't have to be something big. Just be there. Because that is the important part. As a single dad I needed a lot of support, but with help I felt like I could do it. And I did.” His advice to other families going through similar struggles is, “Don't give up. Pray to be strong. Trust in God as he is the only One who can make things better.”

Miguel explained how he’d gotten through the worst parts of the ordeal. “First is my faith in God and
knowing that everything is going to be alright—and having other people and hospice around me for me and Seth helping us and praying for us and telling us that everything is going to be okay. That got me through one day at a time because there were some days that I was so upset that I thought I could not go through one more day. On those days I had to call one of these people to help me get through that day.”

We ended the interview with Miguel and Seth reflecting on their hopes and dreams for the future. Miguel shared, “My hope is that he can run and play a sport, be in school, graduate, and to not be sick—for the cancer never to come back.” Seth shared about his super soccer kick and said he dreams of the day he can play soccer again.
A FATHER’S PERSPECTIVE ON THE IMPORTANCE OF HIS PRESENCE
IN THE LIFE OF A CHILD WITH A SERIOUS ILLNESS

Don Hill
dhill@triadassociates.net

My son is in ICU at the hospital right now, he is chronically ill, he is categorized medically as “fragile,” he gets every breath from a ventilator, and he has Duchene Muscular Dystrophy (DMD). I was asked to write an article about the “father’s perspective who has a child with a serious illness” and I thought now would be as good a time as any to pound something out. I actually am mildly inspired but mostly it is therapeutic.

So what is my perspective while all this is going on? What is my view as I watch my son struggle? How do I still relish the joy of who my son is? From my perspective it is the one thing that love yields easily—presence!

All of us, or at least any of us that are worth our weight in salt, love our kids. And those of us that have a son with DMD are no different. When you go through the trauma of a diagnosis (we found out when Joey was 18 months old) you find that you still love your kid and don’t have a choice but to find a way to carry on. While we have been traveling alongside our son on this degenerative disease journey (he walked until he was 8 and he will be 25 next month) we can’t help but keep loving him. More particularly, from my perspective, we remain a crucial presence in his life. And probably most surprising, he has been a tremendous encouragement to me, my wife, and our two daughters, and, gee whiz, our whole family and many friends.

Technically DMD is not a disease but a gene deletion—our muscles replenish, theirs don’t. So over time Joey has lost all of his gross motor skills and his fine motor skills are almost depleted to nothing. He can’t hold his head up, he can’t breathe on his own, he requires 24 hours of care by his nurses (they are amazing) or me or my wife—she does the most. It, like other similar diseases, creates loneliness and isolation. We grind through each day typically desperate for something or other—sleep, medical appointments, urgent care, fix something, keep him warm, toileting, transfers, care coordination, answer questions—the list goes on and on. I usually am in reaction mode but sometimes I get perspective. Ironically while we are here in the ICU with lots of medical professionals and other nurses, there is a chance to find some perspective. As I look over this array of intervention and investigation I see again that my place in my son’s life is not just to help him, but also to hold him, to be present with him in his struggle.

We fathers are a troubled lot. We start the whole show and find it hard to stay connected. Even so we press in (at least at times). We hold our ground, sure enough. We keep ourselves in the game—most of us. We persist. But I think the kernel of my thought here is more than determination. Fathers have an obviously unique role. We are one of a kind. Only we have the unique position where we are not only present in our sons’ life but we are a presence in their precious lives. My goal continues to be for Joey to know my presence in his life. Only I can do that. Maybe you Dads out there know what I mean—maybe not.

Let me try to explain my point by recounting a past experience as a metaphor.

When learning to side houses and buildings when I was in the construction trade many years ago I had a mentor that taught me one thing while working on a construction site and while suspended on the sides of buildings—presence! He imbedded into me that being aware at every step on the construction zone and
up every level on the side of a building requires concentration and awareness. To remain productive and to be safe requires that every moment while you are thinking how to coordinate with your fellow-workers, how to cut and then place the wood on the wall, if you lose presence you may survive for a while but eventually danger will find you.

To extend my metaphor, we fathers are precariously perched alongside our kids and especially for those that have a degenerative disease. If we don’t pay attention—and believe me there are many who do not—we will probably fall by the wayside or get injured while working. Let’s face it. We live in a difficult world and it is even more challenging with long-term illness. Marriages fail, family relationships strain way too easily, and if we do not remain a presence in our disabled kids life, we will likely fall by the wayside. I don’t like that thought.

Presence is the one thing that I can bring. This is not to say that I am always loving and emotionally available—I fail on these regularly. But one thing is I consistently stay in the game. I may be overwhelmed (believe me this is not easy), I often get confused (you try to balance daily medications), and it goes without saying that my pride regularly gets me off course. I am often out of orbit—“knucklehead” comes to mind. Even so, being a presence for my son during our achingly difficult life and this particularly challenging time while Joey recovers is what I can do. Being present is what I would hope my fellow-sufferers would find a way to do as well.

Being a unique presence for Joey during our struggle is one thing but during his times of joy—now that is special! I have an example. I’m not sure it supports the point being made here but it was something really spectacular that happened recently. It is a long story so I will just hit the highlights.

Last year we moved into an apartment for 10 months while our home was remodeled—primarily for Joey’s needs. After the long remodel slog we moved back home, exhausted on a Saturday night, 10/21/12. Now the fun part. Four years ago Joey was able to meet Bill Cosby and we arranged another visit with him back stage at Benaroya Hall (home of the Seattle Symphony in Seattle) before Bill did his comedy “conversation” on Sunday afternoon, 10/22/12—the day after we moved back home. Though we were beyond exhausted, we got up and arrived at the Hall about 2 PM thinking Joey would visit with Bill for a few minutes then we would go back out into the audience, watch the show, and go home and crash. It didn’t go that way. Bill and Joey got to chatting and Bill realized that Joey knows a few of the particularly funny parts in some of Bill’s older routines (e.g., “The Dentist” and “Chocolate Cake”). One thing led to another and Bill had Joey go out on stage in front of the adoring crowd to introduce Bill and then they continued the conversation on stage where Bill had Joey do a few lines from both of those routines. The audience went wild and, when Joey left the stage, Bill and the whole crowd of over 3,000 giggling people gave Joey a standing ovation. This kid is unbelievable and I was there!

But that is behind us, now we are in the hospital. Now we struggle to find out why he is experiencing so much pain. Why is he so confused? How come he doesn’t know me when I walk in the room? We may never know, but for now I will continue to be with him. No matter what lies ahead for us I will be a presence in his life. That’s my perspective.
FOR THE LOVE OF EMANI:
A FATHER TRANSFORMS HIS LIFE TO CARE FOR HIS DAUGHTER

Linda J. Chasteen, LISW
Social Worker
Haslinger Pediatric Palliative Care Division
Akron Children’s Hospital
lchasteen@chmca.org

Timmy Johnson is known at Akron Children’s Hospital as a concerned parent who is the primary
caregiver for his beautiful daughter, Emani Renee. She is 5 years old with black hair, brown eyes, and a
smile that lights up the whole room! Timmy agreed to meet with me and tell us about his experiences of
being Emani’s dad.

Timmy, can you tell me about when Emani was first diagnosed?
― She was diagnosed with Cerebral Palsy at 17 or 18 months, but I knew something was wrong from the
very beginning. She didn’t cry when she was born and they took her straight to an incubator. At home
later, she did eat and take bottles, but she wouldn’t smile, crawl, or sit up when she should have. I have 3
other children so I knew she wasn’t developing right. She’s a miracle baby to me though.‖

How long have you been taking care of her by yourself?
― Her mother was unable to care for her almost from the very beginning. We split up when Emani was 3
months old and I knew that Emani would need me to take care of her. I am a recovering alcoholic and I
made a firm commitment to staying in recovery and putting Emani’s needs first in my life.‖

I commend you on your recovery. Did you become sober for Emani?
― No, I was sober for 6 years before she was born. I have two children, now in their 20’s, that I was not a
good father to because of the drinking. I say that I got to a point in my life when I ‘Hurt Right’ and that’s
when I made the choice to get sober and started with Alcoholics Anonymous (AA). Now I’m a better dad
to all my children, and the older ones have reconciled with me. The only relationships I need in my life are
with my kids and God.‖

Do you get any breaks in your care giving to take care of yourself?
― I have a hard time getting to my own doctor appointments because Emani has so many that I have to
take her to. She receives nursing hours to help me in the home, and I do still go to my AA meetings
regularly. I do that because I know my sobriety is the key to my being able to keep taking care of her. I do
have some family and friends that help on occasion. I’m very protective about who I leave Mani with
because she doesn’t talk. I quit my previous jobs as a cook to stay home with her.‖

Can you tell me what a typical day is like at your house?
― Well, I get up about 5:30 am and I get Emani up at 6:00 am, change her, give her medicines, and start
her tube feeding. She usually watches TV while she eats and then I get her ready for school. Some days
she has appointments with doctors or therapies that we go to instead. When she comes home, I feed her
again and she takes a nap, then when she’s up later, I let her play in the living room or watch TV again.
Then I feed her again, bathe her, give her medicines, get her ready for bed, and read to her.

How has the Palliative Care team been helpful for you and Emani?
― I found out about the Palliative Care Team in August 2012. Emani’s physical therapist, Kellie, referred
her. I was struggling with her nursing hours being cut and she needed a safer bed. With the team’s help,
we got both problems fixed. Also Palliative Care sponsored Emani for Christmas and donated many
presents to her and her 7-year-old brother. I couldn't believe that they even included my son. That helped me so much. Right now Emani is getting intensive therapy following heel cord surgery, and the Palliative Care Team helped me with parking passes because we are coming to Akron's Children's Hospital every weekday. I so appreciate their help and ongoing support.”

**What has been the most difficult for you?**

- It makes me sad seeing Emani on all that medication and having a G-tube. It's hard just knowing she will always need help. The hardest thing I have ever gone through was when my mom passed away from cancer. When I went to see her she told me, 'I'm at peace with God, Timmy. Take care of my grandbaby. I'm so proud of you and please quit crying.' So I did quit crying, but I still miss her every day. It does my heart good to know she was proud of me. My friends were surprised that I didn't drink when she died. I told them that will not happen because it won't change anything and it would put Emani at risk.”

**What brings you the most joy?**

- Seeing Emani smile brings me joy! She smiles now; she crawls, and tries to pull up to the furniture. Any accomplishments that she reaches make me happy. If I'm in the other room and I walk in by her, she lights up and she hugs me now.”

**What would you like to see for Emani in the future?**

- I just want her to reach her best potential and always have the care she needs. All these kids want is to be loved and they deserve that.”

Timmy and Emani have a large team of people who care about them and would very much agree that they all want Emani to reach her fullest potential. Timmy has learned a great deal about loving unconditionally and care giving in his role as a father. He loves all of his children, but he feels he has stepped up and learned the most about what being a great father can look like by caring for sweet Emani.
TELLING HIM

Mark Nassutti
mark@marknassutti.com

As a cold October sky hovers low over Seattle, I walk away from a tearful conversation with my son Andrew's high school homeroom class. I'd come on a mission. He wanted them to visit. So with my social worker, Bev, I'd come to deliver his invitation. I also had to prepare them for what they would see.

And now I have a problem.

Andrew, 16, has been fighting brain cancer for more than two years. The cancer has won. At yesterday's medical conference, the doctors said what amounts to "there's nothing else we can do."

I'm not sure how it happened, but Andrew wasn't in that medical conference room. He was almost always in the room, but this particular day he was down the hall channel surfing in the teen rec room at Seattle Children's Hospital.

As Bev and I walk away from that homeroom, she wonders aloud. "Does Andrew know as much, in concrete terms, about his situation as his friends do?" She's more than just a social worker. As of yesterday, she's my hospice case manager.

I have to consciously restart my breathing.

"We agreed Dr. Russell would tell him about the decision to stop treatments," she says, "but he got called away."

I'd made the invitation assuming Andrew had been told.

"No," I answer. The follow-up question hovers over us as we walk back to our cars. I already know the answer and I don't like the idea at all.

But here's the thing: I'm scheduled to pick him up this afternoon from his mother's house. I'll have him for the weekend. And the class visits Sunday.

I know that if I ask Dr. Russell to do it, he'll just tell me it should come from a parent.

I know Andrew's mother can't do it.

But if I do it, she'll hate me for it.

His mother and I divorced seven years ago. Pretty amicable until Andrew was diagnosed. Then, she stopped speaking to me. In medical meetings, she seems as impatient to get out as Andrew is. She does what she has to do but seems so angry. It's as if she doesn't want to touch any of it. That includes information. Since our parenting plan means I often have to endure 12 days without seeing Andrew, that's 12 days of information about medication changes, seizures, ER visits, doctor's appointments, and just generally how Andrew is doing. Twelve days of data she doesn't want to touch again.

Even when I quiz Andrew, which he hates, I'm constantly blindsided. Nothing fatal, just little mistakes that, when she finds out about them, set off new rounds of anger. Nothing fatal, but I need to know everything, so I can keep Andrew alive. No, check that. So that I can survive.
And another thing: I hear from several sources that she wants his friends to remember him the way he was, but she refuses to talk about that. So inviting them will throw gasoline on the fire.

But he needs that visit. So do they.

And telling him? I have no choice. He has to know.

Until yesterday, he'd seen every MRI and discussed every treatment. The potential benefits, the risks, the side effects. He'd been the decision-maker.

So he has to know. At the very least, or maybe most importantly, he needs time to prepare. I swore 18 months ago, when despite all my prayers no one would take the deal that I offered — me instead of him -- that if he had to die, he would not die in ignorance, he would not die in fear.

The least I can do is help him get ready. No matter what might happen to me.

I must tell him. The sooner the better. Tonight.

At dinnertime, we sit at my rough-hewn Mexican table. He's rolled up in his wheelchair. As I help him eat, he's wide awake despite the potpourri of meds that sometimes rob him of speech. Conversation flows. Then, despite a good meal, I feel a hollow form in my gut.

Now.

-Andrew. Has anyone told you the results of your last MRI?"

-No." He locks his eyes on mine.

-Do you want to know the results?"

-Yes."

-It's not good." I take his hand. —There's new tumor growth, in other parts of your brain." His eyes tell me to go on. —The doctors can't get at it with surgery, and the chemo has stopped working." I take a long breath. -# seemed to help for a little while, but not anymore."

-So I'm fucked." Dry, straight to the point, no sign of emotion, just a hint of anger, his eyes still locked onto mine.

I look down, feeling stupid and awkward and shaky. From a place far, far away, I listen to myself say the words —Yeah, I'm afraid so, Andrew." I meet his eyes again and search for something else to say, something to make it easier for him. Something that will break this increasingly awful silence.

-Dr. Russell tells us there's nothing more they can do. He said even if there was something, we probably couldn't get you into the trial because they have certain requirements that you don't meet anymore."

-So I'm fucked."

I shake my head, looking down. I take a couple of slow breaths. —Do you have any questions, anything you want to say?"
I remember something Bev had suggested. "We asked, I asked, well, when it happens, how it will happen. Would you like to know that?"

"You mean, how I'll die?"

"Yes." I can't believe I'm saying this.

In a completely calm voice, he asks, "When will I die?"

"Nobody knows for sure. Dr. Russell said it's very unlikely it would be less than two weeks, and it's very unlikely it would be more than six months."

He releases my hand to scratch an itch, then takes my hand again. "Okay, how?"

A warm eddy of calm flows around me. The tumor has affected your mobility. It's made it tougher to talk, putting pressure on parts of the brain that control those functions. What'll happen is you'll get sleepier and sleepier. Eventually the tumor will put pressure on the part of the brain that controls breathing. Your breathing will get more erratic, and then one day you'll just stop breathing."

"Will it hurt?"

"How long?"

"I don't know, Andrew."

After a moment, I ask again, "Do you have any questions? Anything you want to say?"

"No." His eyes still hold mine.

"Are you scared?"

"Yeah."

The silence feels unbearable. "Of what?"

He gives me that look that he always gives me when he's about to say "you are such a dork."

"Of dying."

"What do you think it's going to be like?"

"Scary." The look.

I feel like I'm in a fog. "Do you think you'll see anything or feel anything as you go through this?"

I hear a hint of wise-guy. "Scared."
My ears burn and I look away, but he still holds my hand. And he seems relaxed. I look at him. Is it the drugs? But I see that slight wise-guy grin of his, and his bright eyes, and I feel, well, soothed.

“I think,” I say, “I believe, that someone will be waiting for you on the other side. My grandpa Elmer. Elmer Andrew. We named you for him, remember?” He nods. I go on, telling him what I believe and why. He listens.

When I finish, I kiss him on the forehead. I roll him to the TV, then clear the table and do the dishes. At bedtime, after I’ve tucked him in, I say, just as I’ve said nearly 6,000 times before, “Good night Andrew. I love you. See you in the morning.”

Saturday passes with television, video games, and dinner at his favorite Mexican restaurant. As I’m making him Sunday morning pancakes, I find him looking at me with those beautiful brown eyes of his.

“Andrew, you’re looking at me as if you’re searching for something.”

“Uh-huh,” with that you-are-such-a-dork tone.

“So what is it?”

“The answer.”

“The answer to what?”

“Why?”

“Why what?”

“Why am I going to die before you? This is bullshit. The father is supposed to die before the son.”

Some tears come. I yield to them, but feel thankful that he can talk about it.

After breakfast, I bathe him, dress him, and do his hair gel just the way he likes it so he’ll look good for the girls. To probably any 16-year-old, friends seem to be everything. When I’d asked him if he’d like a visit, he lit up. I would risk the fires of hell to see that smile again.

When the homeroom bunch arrives, the boys shock me. They’d been sitting at their desks when I visited, so now, as they walk through my front door, I see how tall they’ve grown over the summer, how tan, strong, and healthy they all look. The contrast hits me in the gut.

Once they settle in, the mood turns lively and, frankly, loving. Andrew glows.

That evening, when I roll him out of the wheelchair van at his mother’s house, I kiss him on the top of his head. “I love you, Andrew.”

“I love you, too.”

On Wednesday, my wife, Madelyn, gets a call from the stepdad. She reports a crazed rant that I’ve killed Andrew. He broke down crying that morning, and when they asked him what was wrong he said, “Dad told me I’m going to die!”

Now I’m being blamed for Andrew’s death.
I just wish I could have been there when Andrew's tears came.

On a Wednesday two weeks later, I take Andrew to his favorite Mexican restaurant. He can no longer hold his head up, or feed himself. Between bites of honey-drenched sopapillas, he tries to say something, but I can't understand him. He tries again and again, and I shake my head in desperation.

As I drive him back to his mother's in the van, I hold his hand. The electric fuzzy dice he gave me for my birthday glow red under the rearview mirror. When I roll the wheelchair out of the van, I cradle Andrew's head in my hands and kiss him on the forehead. "I love you, Andrew."

-Love you too.”

-See you Monday.”

What had he been trying to tell me? More fajitas? Pass the guacamole? I think I'm done?

The following day, Bev visits me. She'd seen Andrew and tells me he's getting close. Hours, maybe.

She asks me if he's ready.

→Yes," I say, -yes. He's ready."

The next day, Andrew died.
I was a very happy camper when my grandchild was born. Thinking about all the things we are going to do: play baseball, football, to see what sport he would like, going to the park, etc.

Then I found out that he was born with a rare brain disease [olivo ponto cerebellar atrophy] and I was hurt just to know that he wasn't expected to live.

So came the pain, helping my son try to realize that the day will come sooner than expected. But my strong son didn't believe it; he was determined to fight for his son with articles in the daily newspaper asking for help to send my grandson to the Dominican Republic to receive stem cell shots. And that he did—they received money to go to the Dominican Republic. They went twice, but it didn't help my grandson's illness.

So with him getting worse and the sickness taking its toll, the day finally came. Five months after my mom died at 6:00 am in the morning, I received a call from a crying 33-year-old father/son telling me my grandson died in his sleep.

I rushed to get dressed and go to his house. And there he was, a little angel lying motionless in his bed in peace. . . . Not suffering anymore of going in and out of hospitals.

My insides were screaming of pain but I really knew he's at peace.

It was so hard to see him lying there. I couldn't believe it—his day has come . . .

You see when you know a family member is sick and will die, its fine. But when that time really comes it just rips everything you have inside of you.

The funeral was the hardest, looking at him in that little coffin. I really could not deal with it. Five months after my mother was in a funeral. It hit me hard, I was just devastated.
I’LL NEVER FIND ANOTHER YOU

Alexander Peter
alexandereb53@yahoo.com

Gone are the days we once shared
Together, happy memories we made.
Each day with you was always the best,
You celebrated life; there was no time to rest.

I remember there once was a time
When the sun was bright and it did shine
Like your eyes that gazed at me and smiled,
Saying, "Daddy, forever I want to stay by your side."

My dear one, when you were young,
For every song that you happily sung
Cloudy days became so much brighter,
Your endless love lifted my spirits higher.

The days that I held your hand,
It was hard for me to understand
That someday I would have to let you go
Without knowing you would never come home.

It's sad that time has come to pass,
You left me standing alone to ask,
"Why did she have to leave so soon?"
The days that pass are filled with gloom.

"Don't forget me," I hear you say
"Daddy, think of me each and every day,
You know that I wish you nothing but the best for you
So I'll send you a hug and I know you'd give me one too!"

I wish I could feel your spirit close by,
So forgive me if I shed the tears that I cry
Because you see, there will never be another you
That smiles, and hugs, and loves like you do.

You left my world too soon my dear,
It's sad and lonely without you here.
Come a day I'll knock on heaven's door
And then I'll see and be with you once more!"
ELIJAH – ONE IN A MILLION

Michael Hillman
michael.hillman@gmail.com

My son, Elijah, passed away July 2, 2010. His death was due to La Crosse Encephalitis which he picked up from a virus from a mosquito bite. And we are not talking about any mosquito, but from a daytime biting mosquito! After I found out what my son had passed away from, I did a little research on La Crosse Encephalitis. I found out that it impacts about 100 people a year and has a mortality rate of less than 1%. So, less than 1% from fewer than 100 people within the entire United States die from this virus. I think you have a better chance of being struck by lightning or even winning the Powerball than to catch this virus!

Elijah was a very happy and healthy six and a half year old little boy. He was not six and he was not yet seven – he was six and a half, and he was quick to tell you exactly how old he was! He was everything you would expect from a six and a half year old boy. He was so full of excitement and his curiosity was endless. Elijah was never happy with just a single answer to any of his seemingly endless questions. Oh how I wish I could just answer ONE of those questions now! One of the last things he was working on was learning to ride without his training wheels. He never had the chance to master it, but he promised – I will ride my bike when I am seven, Dad.” As we were remembering Elijah on his seventh birthday (he passed away two months before it), my sister called me to tell me that Elijah was riding his bike in Heaven and shouting –See Dad, I promised I would ride my bike without my training wheels!” It was a very heartwarming moment during a very tough day for me.

Elijah had just finished Kindergarten, and he was chosen as one of two kids in his class to receive the character award. Watching my little boy walk up to receive his award and the smile on his face as he held the certificate up for us to see was beyond words. Who could have ever imagined that less than two weeks after we hung his certificate on the wall, we would be attending his funeral?

Before Elijah was even born, he had been diagnosed with a congenital heart condition called Coarctation of the Aorta. What started off as a normal pregnancy full of hope turned into a roller coaster of emotions. My wife went from seeing her regular gynecologist to a “team of doctors” including a maternal fetal doctor as well as a cardiologist. We are very thankful for these doctors as they were able to determine the extent of Elijah's heart condition and prepare us for what to expect. Thankfully Elijah’s heart condition was not life threatening, but was serious enough that it would need to be monitored up until he was born and probably repaired through surgery. Although this was not the best case scenario, it helped to prepare me for what to expect….good or bad.

Due to his heart diagnosis, the doctors were prepared to examine Elijah immediately after he was born. We were not given the chance as parents at that initial moment for bonding. My wife did not get to feel that “skin on skin” bonding and I could not even hold, much less touch my first child. I was given a chance to look quickly at my son moments before he was rushed him out of the room for his examination. My next opportunity to see my son was through a transport incubator as he was being wheeled to the ambulance to go to the hospital. My only contact was to touch him with rubber gloves.

Elijah was going to require surgery to repair the heart defect. And this surgery was required as soon as possible to prevent further damage. So on his second day of life Elijah had surgery performed on his heart. So far, the closest I have ever come to surgery was stitches, and my son was having heart surgery! After what felt like a lifetime of waiting, I was finally told that the surgery was a success. Elijah would have to spend several days in NICU, but after that he would be going home. It was as if the world had been lifted from my shoulders. In my heart I thought God had actually answered my prayers and had brought Elijah and me through the toughest situation. Elijah’s heart was repaired, and there were no long term...
concerns to worry about. Sure, Elijah would continue to see his cardiologist throughout his young life, but he was not on any special medications or limitations.

From that day forward, life with Elijah was as routine as life with a young boy can be (which is not very routine).

As Elijah grew older, it was very obvious that he took after my wife's looks. But much to my wife's dismay, he was becoming more and more of a "Daddy's Boy." He was taking on more and more of my characteristics. He enjoyed being the center of attention and always had a great sense of humor. He was never one to shy away from anyone…and like myself, was sometimes very hard to keep quiet.

The summer we lost Elijah started out to be a fantastic summer. We had several family camping trips planned as well as reservations at a nearby water park. My sisters had plans to visit from Arizona in July. Elijah was going to go with me on my annual "Guy's Weekend Camping Trip" with my friends. It was going to be a full summer for us!

We went on our first and unfortunately only camping trip that summer right after school let out. It was a very memorable trip for me because Elijah wanted to do EVERYTHING with me. Wherever I would go Elijah wanted to go, even on hikes. I look back at this trip with happiness and regret because it was probably on this trip that Elijah was bitten by the mosquito that gave him the virus.

After the camping trip, everything was going great. Elijah spent his last week going to Vacation Bible School. The theme of the week was "Life as a Highway" and the church had a lot of road-themed activities. Elijah's favorite part was the 18-wheeler. The week started off great…but by Wednesday Elijah was starting to complain of headaches. He stayed home on Thursday because he was feeling sick, and that afternoon Elijah had a seizure and was rushed to the hospital. At the hospital they ran some tests but everything looked like it was a seizure caused by the fever symptoms he was having. Elijah was released from the ER. It was going to be a long night with Elijah. His fever symptoms did not get any better and my wife slept with Elijah in the spare bedroom so that I could get some sleep as I had to work Friday. On Friday my wife took Elijah to his pediatrician who sent my wife and Elijah back to the emergency room to get some additional tests done. It was there that I met up with them. They ran several blood tests and even did a spinal tap. Elijah was such a strong boy as they did the spinal tap right there in the room with one of the nurses holding him as the doctor inserted the needle. You could see the fear and the pain in his face, but he stayed still as he was told! We felt some reassurance when the doctor said the fluid was clear (it is typically cloudy if it has been infected). Obviously the real tests would be performed at the lab, but it still left us with a good feeling. Elijah ended up being admitted to the hospital where my wife spent the night with him. We were told that Elijah might have meningitis. So that night I read everything I could on this illness to help prepare myself. I learned meningitis comes in two forms, bacterial and viral. Bacterial meningitis can often be treated, but it usually leaves the person with some form of brain damage. And although viral meningitis has no known cure, it has a low "mortality rate." In fact many people may have had viral meningitis and never have known.

Based on the test results, we were told that Elijah probably had viral meningitis. Nothing was ruled out, but his symptoms appeared to be viral and not bacterial. Having done my research, this felt like some relief as it seemed to be the "better" of the two.

The next day Elijah was experiencing tremendous headaches and was placed on medication to calm him down. When the medication kicked in, Elijah was acting like my little boy. He had his sense of humor and was very talkative with everyone who came into his room. But when the headaches would come back, it was a different story. I felt so helpless as there was nothing I could do. As the day progressed, the headaches were getting more severe. It was during one of these bad headache spells that Elijah screamed out — "I am going to die! I am going to die!" What a shock! Those are not words you could ever
think of hearing from your own child. We held him close to comfort him and told him over and over that he was going to be all right.

As the headaches and pain became more intense, Elijah's brain reacted by trying to shut down. He became catatonic and did not even know we were there. We were reassured that these are "normal" symptoms for meningitis. So again, we had nothing to give us a real concern. We were told the infection was working its course and that children experiencing encephalitis or meningitis sometimes become catatonic or even aggressive as the brain heals itself. He had lost all control of his body functions and was wearing a diaper. Never imagining anything bad would happen, I kept thinking forward to when Elijah would be released from the hospital – I was going to tease him about wearing diapers because he was a baby.

It was that night that Elijah’s condition turned fatal. It was around 2:30 in the morning. I was spending the night with Elijah so that my wife could get some sleep. I had just walked away from holding his hand (I was hoping Elijah would know I was there even though he could not show it) when he went into a seizure and all the alarms started going off. Immediately the room was full of people and I was pushed to the outside. I was shaking from fear as I was seeing the numbers on his monitor skyrocket. One of the pastors from the hospital sat with me as I called my wife to tell her to come to the hospital immediately. As the alarms started to turn off, the adrenaline in the room started to go lower. I even started to feel better thinking he was pulling through. Most of the people had left the room and Elijah was lying in his bed resting. The numbers on his monitor "appeared" normal. Elijah was sent down to get a CT scan, and after that is when we found out what had happened. The virus inside Elijah’s brain had caused it to hemorrhage and the outcome was not very good. He was on life support as his brain was barely functioning.

The palliative care team was there in the room with us as well as the doctor to explain what had happened. I knew something was not right because why else would there be other people in the room with us? Nothing really "sank in" until someone from the palliative team asked who we should call. We did not have any close family members in Ohio. I am from Arizona and my wife is from California. I could not even dial the phone numbers. I needed help. When someone would answer the phone (we were calling them at 2AM), I would try to say something and could not get past hello. It was the palliative team that had to talk to our family. I kept thinking that my sisters were coming out in two weeks for vacation….now they would make plans for a possible funeral.

As I sat in the pediatric intensive care unit (PICU) with my boy on life support, I continued to pray to God to bring my boy back, to the same God who brought me a son and carried me through his heart surgery. I mean, why would God take my son from me? He could have taken him six and a half years ago – why now? The doctors told us there was always a chance, but it was extremely small. So I held tightly to that slim chance.

Elijah held on for three days after that. I was standing by his bed holding his hand when his whole body moved. It was not a "reflex" like we had seen previously—he actually looked like he was stretching to get more comfortable. Knowing the odds were not in his favor, I still got excited that he was getting better. But it ended up being just another unanswered prayer. The doctors performed a thorough analysis of his brain, and we were told he had about less than 1% brain functionality. My son was declared brain dead on June 30th, 2010. Our son would not be leaving the hospital at all.

Our families had made plans to come out as soon as they could, but they were not scheduled to arrive until the next day. The hospital agreed to leave my son on life support until they had the chance to say their goodbyes. I wanted my family to see Elijah as a "living boy." After our families arrived and said their goodbyes, Elijah was lying in my arms, surrounded by his mom and two older sisters, when we finally decided to remove the life support. Elijah died in my arms. I held onto him as long as I possibly could until
my arms were in pain. The nurses asked if I needed help with Elijah and I turned them down. I was going to stand up and lay my son down myself—I would never get another chance for this ever again. I had to turn away when they covered him up.

Losing my son really made me question my belief in God. How can God give me a son and bring me through so much, only to take him from me? I consider myself to be a religious or spiritual believer. Prayer and devotional time is a daily part of my life. I don’t just attend church regularly, but I choose to be very active in the church as well. But, when I lost my son, I felt as if God had abandoned me. Elijah’s life was an answered prayer and I felt so betrayed that God brought Elijah through so much only to take him from us by a mosquito virus. The “comforting” words I heard from others were of no comfort. They had not experienced what I had. I was told by many that God only gives us what we can handle. What we can handle? Who can “handle” losing their child? Or the best one: Elijah is in a better place. What better place than with his family? I could not force myself to go back to church and worship that God who took my son. One of the pastors in our church reached out specifically to us as he had unfortunately lost his son several years before. Meeting with him helped me —come to terms” with my feelings. I asked how a pastor who literally gave his life to serving God could get back on the pulpit. And to hear him describe the exact same feelings I was experiencing and how he learned to “manage” those feelings was a huge help. It took me several months, but I am now back to regularly attending service and being active. My wife still has a very hard time returning, however.

It has been almost three years since I lost Elijah, but emotionally it feels as if it were only yesterday. Some mornings I will wake up from having a dream about Elijah and I will think that his death was all part of that dream. It is as if Elijah is in his room across the hall. But then I quickly realize that it is not a dream and all those experiences start over. Other times I will see something on television or in a store and I will tell myself that I should pick that up for Elijah…only to realize I don’t have Elijah anymore. Those fatherly habits never go away. They will always be with me as a reminder of what I used to have.

Although I have not fully accepted my son’s passing away, I have accepted how others are around me. I know they mean well, and that I would probably be acting the exact same way if I were in their place. Most of my friends and family have learned to accept the “new normal” I have become. But not all have. Some, including close family (sad to say), are uncomfortable and avoid the subject. For those people, my relationship with them is not as close as it once was. I have learned who is there and who is not there for me.

Many grieving parents have said they would not change a thing when they look back. I am not one of those parents. My son lived a very happy and healthy life. If I had the chance to do it all over again, I would. I would relive it exactly as I had done EXCEPT his last few weeks. Knowing it was a mosquito virus that took him, I would not have let Elijah outside for a second. But I will not have that opportunity. So I live each day knowing that the pain I feel is so great because I loved him so very much.
I was lucky enough to live 35 years without having to deal with any adversity in my life. Yes, there were the normal bumps in the road that most people go through, but nothing that brought me to my knees.

In 2004 and right before my 36th birthday, my luck had run out when I lost my daughter, Katie. The death of my daughter dealt a blow that was staggering. However, due to my upbringing and how I thought I was supposed to respond, I refused to allow myself to feel the impact that had been inflicted upon me. Instead, I stood back up as quickly as possible before someone saw me in a moment of weakness.

I made a conscious decision to keep my pain and emotions hidden from others, but in order to do that, I had to force myself to bury them somewhere deep inside. I thought, if I could suppress them long enough, they would just go away. This strategy worked, for a while, but not without paying a high cost. I had no idea that I was teetering on an emotional collapse, complete with anxiety, depression, despair, anger, guilt, and profound sadness. These were all emotions that I had never experienced before, but there I was burdened with all of them at one time.

Shortly after the arrival of these new unwanted emotions, the unthinkable occurred again, the death of my son, Noah. Almost 18 months after losing my daughter, I stood face-to-face with the nightmare of burying another child. This time, I couldn't allow myself the luxury of ignoring a pain so acute that the thought of dying sounded like a pretty good option. This pain is so profound that words cannot explain it to someone who has not experienced it.

Although this pain would not be ignored, that did not mean I didn't try. I spent several months after the death of my son trying to figure out the right way to handle these losses. I was not equipped to deal with this pain. I had been taught my whole life by society that as a man, I was expected to "man up" and deal with it. I tried to carry on like a good soldier, but soon realized I was going to have to find another way if I had any hope of surviving.

I was slowly dying, I could see it in my eyes and in the way my body was changing. I had become a skeleton of my previous self because I stopped eating. I had no appetite and when I tried to eat, I couldn't keep it down. On days I could get out of bed, I would stand in front of the mirror and give myself pep talks. I was trying to convince myself to shake it off and move forward. Within seconds of my pep talks, I was holding my head in my hands bawling while I was patronizing myself for being weak. I refused to tell anyone of the nightmare I was living because I was embarrassed by my inability to control the situation.

To be honest, my response to these losses scared the hell out of me. I felt out of control—because I was out of control. I couldn't change the fact that my children died. I couldn't stop hurting. I didn't just cry—I physically wept inside. There were times when there were no tears and it felt like I was convulsing internally.

All of this scary stuff started to pile upon me and I had finally gotten to a place where I knew I needed help. I just didn't know where to look and what type of help I needed. I started a frantic on-line search for help, but I discovered that I was in for a surprise. Almost all of the resources I could find on the subject of grieving for a child were directed either toward women or "parents." I put "parents" in quotation marks, because in my experience, most of what I read for grieving parents was written by mothers, for mothers. If
I did come across something aimed at grieving dads, it was usually advice about how to comfort their wives.

So there I was, wanting help but unable to find any answers. It was on me to take control of my recovery from the aftermath of losing not one, but two children. I made a decision that I was going to find help somehow, someway. I reluctantly started to tell my story to counselors, my family doctor, child loss support groups, and strangers. I realized the more I told my story, the better I felt. A burden was lifted off of me each time I told my story. I got over being embarrassed to cry in front of others. I really didn't care what anyone thought anymore, I was doing this for me and my wife.

Once I started to seek help and the pain started to ease, I realized it was part of my responsibility to help other men through this horrific journey. In response to that realization, I created the Grieving Dads Project and wrote my book Grieving Dads: To the Brink and Back as resource for grieving men and the people that care for them.

I have spoken to hundreds of grieving dads and the one thing I have learned is people need to tell their story. Not only do they need to tell their story, they need to be allowed to share their emotions while telling their story. I often hear from not only grieving dads, but also their family members or care givers who want to know how to help these men. The following are a few ways to provide support to the grieving dads you may know:

1. Encourage them to talk about what they are feeling and thinking, even the really dark stuff. Some men may not feel comfortable with sitting and sharing, so be creative in finding environments/activities that may be more conducive to them sharing. Find a local counselor who is skilled and experienced in working with bereaved parents.

2. Remind them that they are not alone in their pain. Although they may feel this way, there are thousands of dads that are at various points along this path.

3. Do not try to solve their problems. It is human nature to want to help others and we often offer unsolicited solutions as a result. There are no solutions to this problem; they have to process this in their own way and in their own time.

4. Be a good listener. If you don't know what to say, say nothing. There is healing in silence, so it is better to sit quietly and listen than to fill the air with words that are not helpful.

5. Encourage them to find support groups for men in order to connect with others that are dealing with life’s adversity.

6. Do not push them through their grief. Allow them the time to process what has happened to them and their family. Dealing with the death of a child can take years.

7. Allow them to turn to or away from their faith as needed.

8. If they start to cry, let them, it helps cleanse the soul. If they try to apologize for crying, tell them no apology is needed.

9. Let them know you are there for them any time of the day; and mean it.

10. When they are ready, encourage them to find a purpose to honor their child. This is a key point in the healing process, but it may take time for them to build up the strength to get to this point.
Keep in mind that people that are grieving are ultra-sensitive so it is important to think before you speak. Understand how your words may be interrupted by the receiver.

It is important to deliver the message of “you are not alone.” They need to understand that other men have walked this path and survived it. If you can, try to find other grieving dads willing to work as mentors to the guys that are stuck or new to this journey.

Society needs to understand that it’s okay for a father to grieve the loss of a child. Society should not expect men to react differently than women. If we can get society to understand this, more men will start to open up about it, which will help others to not feel so alone.
A FATHER’S ROLE IN PALLIATIVE CARE

Marc Seymour
marc@quinnscrusade.org

When our daughter, Quinn, was just 9 days old, she was verbally diagnosed with Epidermolysis Bullosa (EB). It was later determined that she had Junctional Epidermolysis Bullosa-Herlitz (JEB-H). JEB-H is generally terminal before children celebrate their first birthdays. It is known as a skin blistering disorder, which is such a woefully inadequate description! It not only destroys the skin with the slightest friction, but it causes a host of internal problems as well. Another way that EB is described is as the worst disease you have never heard of.

It is quite a helpless feeling to have a child struggling with any disorder. With EB, the challenges are increased for a few reasons. One, it’s rare and many in the medical profession have had little to no experience with it. Two, people are afraid to touch your child (which is actually a blessing sometimes). Three, it means you as a parent need to become a skin and bandage expert as soon as possible.

The thing that worked best for my family was to figure out the roles we needed to play really early. Our son was two when Quinn was born. When his Mommy moved into the hospital that meant Daddy became a full-time parent. It also meant that I needed to find a way for my son and his mother to spend time together. This was an almost impossible task, when our infant daughter wanted to nurse every two hours or less. The only time we found that Mandy could be away from Quinn was during her bandage changes that were starting to last 2 hours or more. What this gave us was an opportunity to get Mandy out of the hospital.

Getting Mandy out of the hospital served several purposes. It allowed my son to spend some quality time with his Mommy. It let my wife spend some quality time with her son and escape the walls of a hospital. And, it allowed my wife to avoid seeing her daughter's horribly painful flesh—the flesh she was constantly touching when Quinn cried to be held.

My role was being defined for me. I was the skin and bandage man. I was in charge of learning everything I could about this horrible disorder. I was in charge of challenging the medical staff. I was in charge of investigating every possible option for Quinn's on-going care. It was my job to do my very best at being a parent to both of my children and taking care of my wife, too.

The most important job I could do as a father for Quinn, was to take care of her skin to the very best of my abilities. I took so much pride in doing it. I researched and talked to other parents to find new and better ways. While I learned technical precision, the best thing I did for Quinn's bandage changes was to listen to my wife. I listened to her requests for music while we did it. The music was so calming for Quinn—and for me!

Those bandage changes were the most difficult and rewarding times of my life. Quinn and I overcame so much together. We created such a bond through those hours of terrible struggle.

I have read that children spell the word -love" as -T-I-M-E." There has never been a truer statement.
Whether my children are healthy or sick, the best thing I can do as a father is spend time with them. The second best thing I can do is spend time caring for their mother, showing them how to put my 100% into a relationship with the woman I love.
My role continued to evolve during Quinn’s life and now after her death. It was important for me to be present, for me to deal with my own emotional needs. It was important for me to continue to focus on my relationship with my wife—as we struggled to raise our two children.

The most disappointing part of our experience with Quinn was the realization that so many men check out during the most difficult times for their children and families. It broke my heart to see so many mothers on their own raising children with special needs.

It is a father’s role to keep his promises. To love, to honor, and to give everything he has to his family. Being a father has turned out to be the most challenging role I have ever played. With a child struggling for life, the responsibilities are multiplied and magnified to levels no one can believe possible. You live every day surrounded by this horrible stress, making decisions you feel ill-equipped to make. You are battling your own emotions, pure exhaustion, and the realization that your child has it far worse than you. During those struggles it was very easy for me to slip into a state of grief—the grief of seeing your child struggle, the grief of thinking a normal childhood will never occur, and ultimately the grief of thinking this day may be the last you have with your child.

Fortunately for me, I was not alone. I had an amazing wife that reminded me how important it was that we not grieve Quinn while she was alive. And a wife that never let me forget that we needed Quinn to feel LOVE and HAPPINESS. Those would be the driving forces in her recovery.

Quinn's life was ultimately claimed by her fight with EB and the complications that come from bone marrow transplant. My role needs to change again. This next role may be the most difficult yet. It's trying to grieve and heal....while being present.....because I still have a son that needs his Daddy.
BABYLOVE AND BABYLOSS: 
SOME PERSONAL OBSERVATIONS OF ONE DAD’S JOURNEY

Ann Fitzsimons, BS & MBA
here4U, Inc.
Pediatric Palliative/Hospice Care Family Advocate
Anncomfortandjoy@aol.com

As I write this, the Diana Ross Motown song, “Baby Love” is playing in my head, as are the words…”Baby love, my baby love, been missing ya, miss kissing ya.” While the song wasn’t written about a dad losing a child, the words still apply here and are probably words a dad says to himself after a child has died, but very likely not words he speaks aloud to others. The literature shows that dads are often the forgotten mourners (as are siblings) when a child has died. Since, in many cases, mom was the child’s primary caregiver and “The Mom,” much of the attention is spent on supporting and consoling her. Society doesn't often think about what this is doing to dad, as he “suffers in silence.” My brother-in-law is one such casualty.

In mid-December, 1999, my niece, Riley Ann, was born prematurely with a malignant brain tumor that went undiagnosed in utero until a week before her birth. Seemingly it was a very aggressive cancer as four weeks earlier, there were no “telltale” signs of it on a routine ultrasound my sister had to check the baby’s size given her gestational diabetes during her pregnancy.

On the night of her birth, my brother-in-law, Doug, was allowed to be in the delivery room and when he came out, he looked beaten down, tired, and all he could say was –“Wow, her head is big.” There had been a lot of repair work required on my sister after the delivery and my niece was whisked to the NICU, so Doug was asked to leave the OR, a welcome respite, I think, from the look on his face. He sat on a bench for a few minutes and then said he had to go home to —“the boys,” their two sons, both under 6 at the time. I was beyond shocked, but said I’d stay with my sister and my niece, and then he left. At that moment, he left not just physically, but mentally and emotionally as he walked out the door, never fully to return to his daughter or wife again. You see, he is a firefighter—a person trained to rescue men, women, and yes, children, from burning buildings. He knew his family was in the midst of a fire, but he wasn’t sure he could save them, so he began to detach, to let go, as his training tells him to do when they lose someone in a fire. “Not your fault,” “You did all you could,” “You saved some of them”…I’m sure was what he was hearing in his head as he walked out the door of the hospital that night.

In the days to follow, Riley was transferred to a local children’s hospital, while my sister was stuck in the local suburban hospital until her OB would clear her to be discharged after her C-Section and all the repair surgery they had to do. I was designated —“Surrogate Mom”…that —“I knew what to do,” as my sister realized her husband could not play this role. My heart broke as I watched Doug further distance himself from his daughter…coming down on the day of her admittance, but only staying a brief time. He knew I —“had this,” while he went to be with my sister in her hospital room. You see, everywhere where he was, he felt guilty that he should be somewhere else—his loyalties were divided, but not surprisingly, primarily between his wife and his —“living” sons. He already knew before the doctors told us that his daughter would not live, so he focused on those who he could still help, those who would live, those he could still love; unfortunately, this wasn’t Riley.

Doug was antsy to get Maureen, my sister, discharged. He knew she was the strong one in their relationship—the one who could handle the situation—and he wanted her out and taking charge as soon as possible. She was eventually released and reunited with her daughter, but at great personal cost to her, resulting in an infection because she was overdoing it, spending so much time at the hospital when
she, herself, was still recovering post-operatively. Riley lived for two weeks, much longer than the doctors thought she would (we would only learn this later), and during that time, Doug did come to support my sister on some of her visits to the hospital. However, he always had an out, which was he had to go get "the boys"—this allowed him to leave and save face, something that was important to him.

There are beautiful pictures and memories of their days with Riley, but while her brothers and others embraced her, my brother-in-law always seemed distant, removed, almost "afraid" to let his heart open to this baby girl who was going to leave him too soon. It was more than he was going to be able to bear, and I suspect, that he thought (consciously or subconsciously), "If I don't get too attached to her, it won't hurt as much when she dies." It makes me wonder if other dads do the same—if the thought of losing their child is too much to handle, so against the order of nature, and such an all-out assault on their roles as protective fathers who can fix anything that happens in their family—that they just "leave" physically, mentally, and emotionally. While I've seen the opposite—dads fighting tooth and nail—opting for every surgery, treatment, chance to save their children—I think the ones who "opt out" while more invisible, are also there in our NICU's, PICU's, children's hospitals, and palliative and hospice care services.

Riley's nurses were treating her, and us, palliatively before there ever was such a "formal" service as perinatal palliative/hospice care. As such, they encouraged my sister to take her home for a little while...even a day...to spend time bonding with her brothers (and, I suspect, her Dad). My sister did, but Doug was adamant that we take her back to the hospital at the first sign of something going wrong. He had declared in no uncertain terms that he did not want that baby dying in the house—that he did not want his boys (and him?) to have to live with that memory in the house forever. Riley must have sensed this at some level, so she co-operated and ended up dying in the hospital, while both my sister and brother-in-law slept. When they realized she was gone, they let the nurses know, were allowed to ritualistically bathe and dress her, and then they left, their hearts broken, never to be fully-healed again.

After Riley's death, my sister sought out counseling for herself and her oldest son (aged 6). My brother-in-law never did. My sister struggled with this loss for a long time afterwards while Doug did what some men do—he moved on, went back to work, never really to talk much about his daughter's death again. Months later, my sister needed to know where he was with all this, and in one of his few candid conversations about the loss, he said there was a "forever hole in his heart" where Riley should be that would never be filled, but that it was too painful to talk about it, so he would just live with this hole for the rest of his days. While this admission made my sister feel better—that somewhere inside, he did have feelings and love for his daughter (despite his actions while she was alive), it made her sad that he would never do his grief work to process through this loss, and therefore, never would ever be "fully-whole" again.

Ironically, six years after Riley died, my sister Maureen also succumbed to cancer and was buried in the same grave as her daughter. As the cemetery workers dug my sister's grave, they scratched away dirt that revealed my niece's tiny white casket, which would now lie at the head of my sister's casket, the two joined to each other in death, their caskets forming the shape of a "T." As I looked around, I couldn't help but wonder how much bigger that hole in Doug's heart had gotten with this loss, and how, in the days, weeks, months to come, he would process (or not process) his grief, and that of his now three sons. Time would tell, but the pattern had been laid to not deal with this outwardly, to "suck it up" and tell the world he and his boys were fine." Years past both these deaths now, that would not be the case as both Doug and my nephews carry scars that can't be seen, but which are always going to be there—just waiting for the right triggers to rip them open again, bringing all their grief from these losses flooding back.

Having seen the damage that is/can be done with dads who either aren't supported well, who are not strongly encouraged to seek out help during or after the loss of a child, or for whom there may not be anywhere to refer them to or resources to make available to them, it is my hope that as professionals, we'll pay more attention to this sub-segment of our healthcare population. That we'll develop more resources for them that work with their processing/coping styles (e.g., perhaps more anonymous and
web-based), as well as strongly encourage them in our contacts with them to seek out help in some way/shape/form...to not go this journey alone. As they strive to resume their place in their families as husband, dad, provider, let it not be at the expense of pushing their own sadness, grief, and other feelings aside. Let them not remain invisible during their child’s illness and/or after their death.
Beep, beep, beep; the pager goes off again at 1:26 am. It not only wakes her from the deep slumber she finally attained after decompressing from the day's events, but it also jars me awake from my dream of hitting the game winning home run in game seven of the World Series, propelling the Cleveland Indians to victory.

Thus is the life of the husband of a palliative care physician.

When I met my wife, I had no idea what palliative care was. Sure, I had heard of hospice, but a “Palette of Care”? Can you imagine our first date. We met at a coffee house after she had been on call and at the hospital for more than 36 hours. She explained to me that it is not always about death and dying. Often, it is about pain management and making sure the patient and those associated with the patient are given accurate information, and, ultimately, being an advocate for their care. It also is about the emotional well-being of the patient and family.

This sounded wonderful to me. Only three years earlier, I had watched my bride of 4 years suffer and die after being diagnosed with acute lymphoblastic leukemia. Watching her endure the pain of the treatment left me with emptiness that still lingers. Night after night, I would page a doctor on call in order to ask how to provide adequate treatment to her. We had a case manager who handled the disease and appointment logistics, but we did not have anyone to provide the emotional stability that is needed when a loved one is diagnosed with a life-threatening illness. No one was concerned about what we would do with our one-year-old daughter during the next hospital stay, how we were managing to make ends meet, and how our faith was being sustained. Instead of straightforward medical care, we needed someone to care about our lives outside of the illness and outside of the hospital, and this was not provided.

As a man, it was extremely difficult not to fix the problem. Hand me a screwdriver and I will fix the lamp in the bedroom. But I had no tools to deal with cancer. Night after night, I would hear my cancer-filled bride cry herself to sleep, afraid of the next procedure or trip to the hospital. The Hematology and Bone Marrow Transplant doctors were great at what they did, but we did not get the overall support that palliative care provides.

When I learned, three years later, that such a program exists, I knew that any doctor who can help a family on that level had to be special.

Because of my experience with my deceased wife, the man I am would try to pretend as though I knew what I was getting into when we were married, and that it is always easy to share her with the hospital 24 hours a day — after all, I called on many doctors over the two years of suffering I witnessed. However, I soon learned I had no idea. The job is never done, and the minute I think we can take a breath, she is called upon to be there for another patient. Palliative care is a life, not a job.

I don't know how she does it. I am not very good dealing with emotions. I like everything to be black or white. When one brings in the emotional aspect of a disease, it is hard to comprehend. I learned that first hand. Seeing pediatric patients who have chronic and life-threatening illnesses and helping them, and their families, function takes a unique physician. She is often there to comfort a baby at the end of his life, and then give comfort to the family, while still performing other duties such as calling the medical examiner, palliating the staff, and doing memory-making activities. All the while, she is giving a kind word,
hug, or smile, when appropriate, to those in need. It is my job to try to help create a safe place, away from the craziness of the hospital.

That is not always easy for me. I am driven by my own occupation to succeed. My thoughts have always been that work must be a primary focus in our lives. I often come home thinking about the next day, and working on projects. As a husband, I must step out of the work role, into the comfort role, just as she does for the families she serves. I am not too proud to say that I am the cook in our house. I take pride in knowing my wife can come home to a home-cooked meal. And while the meals do not always taste like the recipe says they should, cooking is my way of showering her with love and a giving her a way to escape the job. The nights we have together, sitting, eating, and talking, cannot be replaced. We talk about work for a few moments, decompressing. I listen and enjoy hearing about her day. When the work conversation is complete, I know I must distract her from her thoughts.

While I want to understand, I cannot comprehend the pain she witnesses. I am not sure I need to. I must stand strong, holding her hand, knowing she is doing a job very few people can. Recently, we were watching a television show in which a 13-year-old girl was talking with her doctor. It was a moving scene, designed to evoke emotion from the viewer. I looked over at my wife and saw the tears streaming down her cheek. I asked what about the speech was most realistic. She just smiled and said, “All of it. My young patients are so afraid of the future, the pain, the unknown future they are a part of. This young girl encompassed the feelings of many. But, when she asked her doctor to shave his head with her, and he did, I can’t help but remember how many times I wanted to shave my head too.” I realized at that moment, I was crying too. It seems to me that the metaphor of shaving her head with her patients is truly what my wife does.

Recently, our eight-year-old daughter learned exactly what mommy does as a palliative care physician, and she summed it up better than I can. She said, “Mommy is able to share her love, not only with us, but to her patient too.” There are times I selfishly wish she was home when I got home, slept next to me every night, and that we did not have to plan our lives around the pager, but then she would not be the person I fell in love with, or the person I love deeper and deeper with every beep I hear. I am the husband of a palliative care physician. I am the lucky one.
OFFERING MEN SPACE, BUT HELPING TO HEAL ALONG THE WAY

Rebecca Roberts Konarz, LMSW
Board member, here4U
konarz5@att.net

Even as a trained bereavement professional, it may be difficult to reach grieving men, for many reasons, and on many levels. Messages sent from media and society surround the thought that women are far worse in their grief than men, and that the role of a grieving man is to pick up the pieces, be strong, and support his partner and children. In all reality, this is a far cry from the truth. Men need just as much support. However men and women are engineered very differently from one another. Brain research even indicates that male and female brains both develop and age at a different pace, as well as process language differently from one another. Therefore, since men process and express differently, so too does the support we offer to a grieving man differ on some level.

Unfortunately, society has made us believe that men are to be "strong" for the family following a death. Yes, being supportive and "strong" is helpful, but that strength is in expressing his grief openly and honestly when he is fully ready and with whom he undoubtedly trusts. Strength does not descend from holding back the tears, denying the right to voice his opinion about funeral arrangements, maintaining silence in a discussion surrounding the deceased, or ignoring those he loves the most as they approach him for a conversation of any topic. Strength is finding the courage to let others know what he needs, be it space, a shoulder to cry, a friend to golf with, or meals delivered. Voicing his needs are difficult for most, it shows vulnerability, but true strength lies in the courageousness of reaching out to those who love him.

Voicing needs, or lack thereof, and having meaningful conversation surrounding the death, leads to another area of concern for many. Friends, family members, spouses, and adult children always ask one question, "How can I get him to talk about it?" The truth of the matter is, just as each person is unique and individual so is their grief and how they choose to express it. While I fully agree talking with others about the death and circumstances surrounding the death is definitely a healthy, positive choice, it is not the only choice. While I fully agree talking with others about the death and circumstances surrounding the death is definitely a healthy, positive choice, it is not the only choice. In all honesty, there are many ways to "talk" through your grief that do not involve opening your mouth. One father told me, "I am just not a talker. I am doer. When I run, I grieve. When I drive to work, I grieve. When I hold my wife, I grieve. Why doesn't anyone get that?" Often men express their grief while "doing" something productive. It might be a sporting activity, a special hobby, or simply spending time alone outdoors doing mundane weekend chores. Those times and places offer security, consistency, and the idea of accomplishment. Grief is hard work and sometimes getting the everyday done, is difficult. So, if he is cutting the grass, do not get frustrated, he may be processing his grief with each row, not denying it.

There are no perfect words to say to someone following a death, and often not saying anything at all offers volumes. Quite frankly, very often for men a silent time side by side in a similar enjoyment, fishing, biking, running can offer more than any words a professional might speak. For example, inviting them to a simple last-minute activity, a round of golf, or going out on the boat, offers a "no-strings-attached" notion that men are seeking. In other words, planning a dinner with multiple couples, screams "CONVERSATION non-negotiable" to a man, where playing a round of darts in the basement sometimes sounds refreshing. In my experience, when a grieving person feels safe and in the company of those whom they trust, they tend to share outwardly and openly.

You can also help normalize someone's grief by openly and honestly expressing your own thoughts and feelings surrounding the death. This is helpful, in that, when we talk about our own feelings, our own loss of hope, our own struggles, we help others feel supported in knowing they are not alone. Professionally, I
have worked with several men, who remain on the *no talk-no share* side, in an effort to save those they love from feeling more sadness. One father stated, “I want to talk to her [his partner] but all she does is cry. I can’t make her cry anymore.” In reality, he was not making her cry; his words were music to her ears. Yes, her tears were of sadness, but also, as she stated, “We can relate on some level. I now know we are both sad by our situation. For a long time, I thought he was okay with this, but even in that one instance, I now know we are both hurting.” With that being said, it is also important to note that when we put ourselves out there, when we share, it may not be reciprocated. Supporters must work hard at not feeling offended if others choose not to share as well. The purpose of sharing in this instance is twofold, expressing your grief in a healthy way via talking and helping them feel supported.

In essence, the key to helping and supporting a grieving man is to remember that each person, young and old, will grieve in their own language, in their own space, in their own time, at their own pace, and each with their own unique expressions. Remembering that simply offering a listening ear, personally expressing your own grief emotions, rather than pressuring them to talk out loud, can do wonders for setting up a trustworthy relationship, where both parties feel open to express their grief.

Rebecca Konarz has been working with grieving families for over 10 years and remains very active in the hospice and palliative care community. She serves as a board member for *here4U*, a non-profit of families supporting other families of seriously-ill/dying children, as well as a guest speaker for many parenting support groups. She can be reached at konarz5@att.net.
HELPING BEREAVED MEN HEAL

Tom Golden, LCSW
Author of, The Way Men Heal and
Swallowed by a Snake: The Gift of the Masculine Side of Healing
golden@webhealing.com

The following are excerpts from Tom Golden’s new ebook, The Way Men Heal. This new ebook is an update from his previous book, Swallowed by a Snake: The Gift of the Masculine Side of Healing. Both books focus on understanding the uniqueness of men's grief. Golden makes it clear from the beginning of the book that all men don't grieve in a certain way and neither do all women. It's simply more complicated than that and the book helps explore this complexity. Our task is to find each person's uniqueness and being aware of the wide variety of ways to heal makes that task much easier. The book is divided into four sections: the first is an introduction that offers the basic information about men's uniqueness and how this impacts their healing. The second section explains why men's grief is less visible and so hard to spot. The third section focuses on the many ways that men (and some women) use action to facilitate their healing. It describes these actions and offers examples of numerous men and how they grieve including such notables as Michael Jordan and Eric Clapton. The final two-part section offers Tips for Helping Men Heal. One part is for the general public with ideas of how to help the men you love and the other is specifically for therapists helping men in a therapeutic setting. Golden has offered us two excerpts, the first is a portion of the introduction and the second is the beginning of the final section on Tips for Helping Men Heal.

FIRST EXCERPT

In the late 1970s, I had just gotten out of graduate school and was looking for a job at a counseling center. I wanted to finally put my years of schooling to work and start helping some folks. After 3 months I couldn't find a job. After 6 months, I couldn't find a job. After 9 months I couldn't find a job. And after a year I still couldn't find a job but I got an offer to work at a counseling center for death and dying. I didn't know a thing about death and dying but I said, ―Sign me up!‖ It didn't take long to notice some things about the center. One of the first things I noticed was that I was the only male therapist on staff. There were 17 female counselors and one man, me. Then after a while I started noticing that most of the male clients came to me. The women on staff didn't want to work with the men; they said things like ―men don't griee‖ or men ―don't deal with their feelings‖ or things such as that. ―Golden's a man, he can figure them out.‖ But Golden couldn't figure them out. I was saddled with a caseload of mostly men and I wasn't doing so well. What I had been taught at grad school was to sit and face each other and talk about the past. There were 17 female counselors and one man, me. Then after a while I started noticing that most of the male clients came to me. The women on staff didn't want to work with the men; they said things like ―men don't griee‖ or men ―don't deal with their feelings‖ or things such as that. ―Golden's a man, he can figure them out.‖ But Golden couldn't figure them out. I was saddled with a caseload of mostly men and I wasn't doing so well. What I had been taught at grad school was to sit and face each other and talk about the past. When I tried it with my female clients it worked wonderfully but with the men, not so well. I wondered if maybe the female therapists were right, there was something wrong with the men?

Finding Safety

What I have found out since that time is that eye contact means something very different to men and women. To women eye contact often means closeness or connectedness. This of course, is a good thing in treatment. When people feel connected and close they are more likely to feel safe. Feeling safe facilitates healing. But what about the men? I did my best to make eye contact with the men and it didn't take long to realize I wasn't making them feel safe at all, it was more the opposite. Men, I have since found, link eye contact, particularly with other men, as a sign of confrontation or challenge. Hockey has a "faceoff," boxers "face" each other, you "face" the competition. What I was doing wasn't helping these men feel safe, it was positioning them in a place of challenge. This of course is the opposite of what I wanted to do.
I started trying to understand where men did feel safe. I knew that men tended to form close friendships with other men in hierarchical professions such as the military, the fire department, police departments, or sports teams. These were all places that men were together, shoulder to shoulder, working on a common goal. The more dangerous the goal, the closer the men seemed to get. I started to realize that the men were more likely to feel safe and connected when they were shoulder to shoulder as opposed to the traditional therapeutic face-to-face mode.

SECOND EXCERPT

Tips for Helping the Men You Love

Our world is designed to offer safe spaces to those in need of healing that are usually feminine in nature. Whether it is a support group or some form of therapy, the world sees these interactive modes as the basis of healing. It is second nature for us to provide them to those in need. We don't even think about it. If you are upset, you are encouraged to talk with someone. But although I hope you can see that talking about it is a useful and effective mode of healing, it is far from the only mode. The masculine modes are little known and therefore simply not given the air time of the feminine. There are very few masculine modes of healing that are offered by our culture for those men and women who might want to put them to use. This leaves men at a distinct disadvantage since their natural ways to heal are unknown and generally not seen.

Without a well known healing model for helping men it becomes difficult to know what to do. Often we will try and get them to use a feminine mode and talk about things. This usually ends up being uncomfortable for both. The alternative is to simply leave them alone.

This section tries to help you deal with this dilemma by offering examples of ways I have seen men and women help the men in their lives. It is not meant to be a plug-and-play solution. It's meant to give you some ideas about what might work for the man you love. All men are different and your job is to understand the man in your life that you love and find ways that work for him.

Before we start offering ideas about how to do this, let's first think about four reasons that men's healing is invisible.

1. His emotions in public are taboo.

2. He is throttled by the provide-and-protect sex role that pushes him to not appear needy or dependent.

3. He lives in an invisible dominance hierarchy that moves him to view the world in a hierarchical fashion and strive to be as near to the top as possible and avoid appearing to be near the bottom.

4. He has important differences from women in his hormones and his brain.

These four factors give us a rough map of how we can be helpful to men. It should be obvious by now that if you want to be helpful you had best not expect him to appear dependent, at least not publicly. You will want to help him maintain his independence thus making things safe. You will probably want to honor or join in his action in some way or even start to heal yourself in a masculine manner since this harmonizes with his ways of healing. In sum, our goal is to help the man tell his story of loss without forcing him into an openly dependent mode and to help him feel safe in the process.

Let's keep in mind that there are likely 20% or so of men who will not be as impacted by the four factors we described above. They may prefer an interactive mode of healing and therefore want to talk about things and openly discuss their emotions. This is fine and with those men we need to use a more
traditional style in offering them our attention. There are also many who will appreciate a man's unique mix of the masculine and feminine. Even with this mix, I think you will find that most men will appreciate sensitivity to what we have outlined.

**What Fuels the Hierarchy?**

One of the things that very few people realize is that when we are living in a dominance hierarchy we take on a very different way to feel safe. Most people think what it takes to help others feel safe is to help people feel cared-for. Just look at the billion-dollar greeting cards industry. What do they do? They repeatedly offer words that make people feel cared-for. Who buys greeting cards and who receives them? According to the Greeting Card Association, 80% of those buying cards are women. They are very helpful in expressing the idea that the recipient of the card is a cared-for person. This is good. Knowing you are cared-for can bring a sense of safety especially for women, as the greeting card companies know.

But how about the men? In the dominance hierarchy is it important to know you are cared-for? Well, maybe yes, but it is likely more important to know you are respected and better yet, admired. Respect and admiration drive the dominance hierarchy. And what happens to men when they feel admired? They feel safer, and when men feel safer they are more likely to tell you about their failures or problems. This is very similar to how many women are able to open up about their difficulties once they are with someone who they know cares for them. Both create safe places.

Here's an example of using admiration: (only voice admiration if you really feel it, never BS, it won't fly with men.)

Wife: "John, I really admired the way you handled your father's funeral."
John: "Really?"
Wife: "Yeah, and the writing you did afterwards in his honor. That was powerful stuff"
John: "Yeah, that was really important to me."
Wife: "So how have you been since?"

This would first give John the sense that the wife thought highly of him and of the way he did things. It increases the likelihood of his responding to the final question. Then again, he may not respond. He might say ‘Oh, I've been fine’ and that is okay, too.

Now, compare that with a conversation with John that expects him to use the feminine modes.

Wife: "John, I haven't seen one tear or one word from you about your father's death. It makes me wonder if you care about him at all or are you just hiding how you are feeling?"
John: "Of course I care, get off my back."

The second interchange shows a good deal of judgment and basically lacks respect for John and challenges him while accusing him of hiding. It's grading him based on the feminine modes (talking and openly emoting) and when this happens he will not pass the test. It's likely John saw this as an attack. People generally don't open up about their vulnerabilities when they are feeling attacked. This sort of interchange will likely push him farther away and leave him angry and feeling misunderstood. We generally understand when a woman decides to not open up about her pain if she feels uncared-for. But do we have a similar understanding of men deciding to not open up if they feel that are not respected?

**Entering His Space**

The first thing to keep in mind is to find some alternative to the traditional face-to-face talking about things mode. Think about where he feels safe. Maybe going for a walk together, or shooting baskets, or going...
fishing. If you don't know how to shoot baskets or fish, get him to teach you. Going to a game together. Simply doing something shoulder to shoulder. Being with him. Women who are grieving like it when their friends or loved ones simply give them a place to interact. Maybe the grief doesn't even come up but the opportunity to interact is there and is appreciated. Just as some women may not discuss their issues of loss in a conversation, some men may not bring up their grief as you are doing something shoulder to shoulder. Remember, two men can stay silent all day in a fishing boat shoulder to shoulder and at the end of day feel very connected and close. They simply enjoy and are affirmed by each other's company. Keep that in mind as you join him in some shoulder to shoulder activity.

BIO -- Thomas Golden, LCSW is well known in the field of healing from loss. His previous book, Swallowed by a Snake: The Gift of the Masculine Side of Healing has been acclaimed by Elisabeth Kübler-Ross and others. Tom enjoys giving workshops in the United States, Canada, Europe, and Australia. His work and his web sites webhealing.com and thewaymenheal.com have been featured in the New York Times, the Washington Post, and U.S. News and World Report, as well as on CNN, CBS Evening News, ESPN, and the NFL Channel. He is in private practice in Gaithersburg, MD, and also enjoys doing Skype consults.
A HOSPITAL SUPPORT GROUP FOR DADS

Scott Newport
Scottandpenni@hotmail.com

Ok, I said it; I'm a man and understand how that can make things difficult when it comes to communicating except when you ask me about my first car when I was sixteen.

I guess the first thing I encountered about hospital dads was when Evan was born and some of the other fathers went- a-missing. –Hey Barb, when is Bob showing up?‖ I enquired. She turned toward her tiny premature baby, silent and tied down by wires and tubes, neatly wrapped in what looked to be cellophane, and whispered, –He had to work late.‖

At first I couldn't believe it. I mean, I was there every minute I could. In reality our fragile kids could die at any moment. Just the day before, the NICU became quiet as no one wanted to talk about the crack baby who was in the, -one room,‖ where babies went to die.

The farthest I ever escaped was the bathroom; I found that was a good place to hide and cry.

Since Evan's death at the age of seven I've had this driving passion to help other dads, you know the ones who are in our emergency rooms right now or are sitting in front of an ultrasound machine getting the bad news. I know some of these dads will have their children die early and some will spend many months pacing in a hospital room wondering why they couldn't fix their kids.

This past year my dream is becoming more of a reality thanks to an invitation from Kelly Parent, Patient and Family Centered Care director at the University of Michigan C.S. Mott's Children's hospital in Ann Arbor, Michigan. Kelly is a mother, her daughter is a cancer survivor, and we've had a shared mission for families for many years.

(A note from Kelly telling us why dads)

I have heard “Dad’s of Children with Special Health Care Needs” referred to as the “Forgotten Parent.” While no one intends to overlook fathers, our society is really good at avoiding them during times like these. Throughout my personal and professional experiences, I have noticed that people are drawn to showing more compassion with mothers of these special children (i.e., better eye contact, providing a gentle touch) and they directly ask mothers more questions about their child while fathers are standing silently aside. Additionally, the father is often the parent who returns to work first after crisis—mom is the stereotypical nurturer and dad stereotypically needs to “provide.” At work, Dad’s co-workers are quick to ask about the ill child, his wife, and the other children, but rarely ask how he is doing.

This is precisely why I felt the need to start a “Dad Advisory Council” at C.S. Mott Children’s Hospital. While dads are often more stoic and try to be the backbone of the family during these crises, inside they are being crushed by the same fear, isolation, and sadness that is crushing the rest of the family—but they are hesitant to talk about it. This proved to be 100% true. At the first meeting of the “Dad’s Council,” it took 85 minutes for 5 dads to share “their stories.” In mixed gender meetings, it has taken 5 dads less than 10 minutes to share the same stories. This first meeting immediately proved that dads of children with special health needs want to talk, and more importantly need to talk, but they first must recognize this need and then be offered safe places to talk. It is our hope that the “Dad Advisory Council” will provide opportunities for dads to reach out to other dads and provide the support that they need.
Our first dads advisory meeting went really well. The group had a diversity of diagnoses and some were new to the journey. As they told their stories I realized how much we had in common. If fact when it came to my turn, I said, “I won’t tell you my story because it’s the same as all of yours. My son’s name is Evan.”

By our second monthly meeting we decided to have an event to kick off our new initiative. You see, we all figured if we were to put out a flyer for a dads support group no one would show up, but if we had a competition of sort we would surely get a few guys excited. Our first event is going to be a bean-bag-toss, commonly known as, Corn Hole.

We are hoping to get dads connected as they stand by each other and compete. We’re hoping these connections will fill in the gaps that often occur in hospitals when trying to service the entire family.

During our second monthly meeting I opened by asking everyone to tell me about their first car. I’ve used this strategy for quite awhile when I first meet dads. I have found that everyone can remember their first car and is eager to share their story. Sure enough the stories were great and no one hesitated.

For all of us who work with dads I have found that you need to make a connection with the guys first before any effective coaching or positive impacts can be made.

In the future we are looking at starting an official mentoring program and sharing our mission with every service at C.S. Mott. We have already been invited to the Patient and Family Centered Advisory Committee to share our work.

I hope to write a follow-up story about how our first event went and look forward to hearing more about any other groups trying to reach out to the fathers who are way too often left crying in the bathroom alone.
REACHING OUT TO FATHERS IN THE COMMUNITY
PALLIATIVE CARE AND HOSPICE MODEL

Maureen Horgan, LICSW
Horgan.Maureen@gmail.com

I realized I was asking the wrong question. Instead of asking mom how dad was doing, I needed to ask mom what was the best way to talk to dad in the next couple of weeks. She might say, “he’s not a big talker” or “he’s too busy and I take care of this part of our lives.” My response was a gentle reminder that we supported all members of the family and that I would briefly reach out and let him decide if he wanted ongoing support and communication. In my 12 years of clinical work in palliative care both in the clinic and community setting it has been rare that a father declined ongoing check-in calls and he almost always has said, “Thanks for thinking of me too.”

I want to encourage team members and clinical managers to remind your team to reach out to fathers and other significant men in the life of the family with a seriously ill family member. When a team member is reporting on familial dynamics and structure of the family it is essential to inquire about the father’s involvement in the life of the family and patient. If that has not been assessed and there is a father in the life of the child the psychosocial assessment is not complete and needs ongoing attention.

I follow a general outline for the initial phone contact with the identified important male in the life of the family. After introducing myself, I ask “can you tell me about your son/daughter.” This lead-in question usually elicits some fun stories and unique descriptions about who the child is. The following inquires support relationship building and a more complete assessment:

- Inquire if the father has any questions about the service and what his hopes are for his family in the next couple of months.
- Acknowledge that every member of the family deserves support and that is why you are reaching out.
- Inquire about how he is coping and acknowledge/normalize that parents can cope very differently from one another.
- Inquire if father would like check-in calls from team members after visits (establish who from, often they request calls from the nurse); only offer if you can consistently deliver on this follow up.
- Inquire if father would like a weekly or monthly check-in call and clarify best time to call and at what number.
- Offer visits with father at alternate location, perhaps a quiet public location or meeting space at your office if distance is appropriate.
- Offer Skype type of technology check-in if the resource is available and the physical distance is an issue.

Divorce and or separation may create a more complex dynamic in the family experience. Identifying who is the family legal decision maker related to health care decision making is essential from the time that the family consents for care. Identify as appropriate father’s goals and hopes for child and the best way to support him from the suggestions above. Stepfathers, live-in significant others, and grandparents also need special consideration as they grieve and make sense of the family dynamics given their role. They, too, will forever be changed by the experience of a seriously-ill child. As appropriate based upon the initial assessment, they can also benefit from the support of the community palliative care team.
LET’S HEAR IT FOR THE DADS: RESOURCES FOR SUPPORTING FATHERS THROUGH THE LOSS OF THEIR CHILD & INTO BEREAVEMENT

Compiled by:
Ann Fitzsimons, BS & MBA
here4U, Inc.
Pediatric Palliative/Hospice Care Family Advocate
Anncomfortandjoy@aol.com

In an issue devoted solely to “The Dads,” we would have been remiss to not include what resources we could find on helping fathers through their journeys with their children with life-limiting/life-threatening illness, as well as identifying those resources that can help support them in their grief. Sadly, there was not a wealth of information out there on this subject or at least not that could be found in the “popular press.” This is indicative of a need for development of more targeted resources for the fathers—an often overlooked person in the “when a child is sick or dying” drama.

Outlined on the following pages, is a compilation of some books/booklets/pamphlets and a few websites written by, of, and/or for dads with seriously-ill children, or more notably, by those fathers who have had children die from a variety of causes including disease/illness, accident, suicide, and the like. Some poignantly chronicle the father’s journey through the child’s death and into grief, and for a lucky few, eventually into peace and acceptance; others share hard-won insights and strategies for fathers coping with a seriously-ill/dying/deceased child; while still others offer resources the authors found helpful in their own grief journeys after the death of their children.

Regardless of the age of the child, the cause of death, or how recent or long ago the death occurred, these fathers’ stories share many common themes of guilt, blame, anger, despair, disbelief, helplessness, failure, struggling to find their way back to their family as supportive husbands and fathers, and more. While these may also be emotions expressed by moms in similar circumstances, some of these feelings seem to resonate more strongly with fathers losing or who’ve lost children because they are supposed to be the “protectors of and providers for” their family, for their children. However, when a child is seriously ill or dying (or has died), it’s often difficult for a father to view himself as either a protector or provider (because he can’t/couldn’t “save” or “fix” his child), despite society expecting him to do so. He’s supposed to just keep moving and going, encouraging his family to move on from the loss, pushing his own feelings aside as he tries to be a supportive husband and father. Dads often have nowhere to turn for support—they don’t want to burden their wives, and other men who haven’t been through this simply wouldn’t understand—so they go it alone, often not getting any help in processing through this loss and what it means for them, as a dad to their child.

Thankfully, some dads worked through processing their feelings on having a seriously-ill or deceased child(ren) by writing and sharing their experiences, as in the books listed here. While not as complete as we’d like, these titles are a start at helping to “normalize” what it’s like for dads living with a seriously-ill child or who have had a child die, while offering helpful strategies and coping mechanisms that have worked for other grieving fathers.

It should be noted that many of these resources are available on Amazon.com, with some select books/booklets sold through The Centering Corporation’s website (www.centering.org) and/or through Griefwatch at www.griefwatch.com (books). Gunderson Health System’s Bereavement Services website (www.bereavementservices.org/catalog) also has an extensive collection of bereavement materials available, some with a father focus, especially in the area of perinatal and infant loss.
Books/Booklets/Pamphlets

- This book is a series of excerpts from this father’s journal after the loss of his 18-year-old son who was found dead in their home without any notice, but which later turned out to be due to complications from mono. The entries start from the day after his son died through the years after his death, and share this father’s insights and lessons learned on his grief journey.

- This is the story of how the author and his family coped with the loss of their two-year-old son, who died in an accident, from the time of death through all their re-entries into their “regular” life...all those “firsts” without him. It speaks to bereaved parents, and those who try to support the entire family—parents and surviving siblings alike.

- This father lost his 18-year-old daughter to a fall from a dormitory window at college after being served drinks illegally and given GHB, a date-rape drug, at a fraternity party. To help make sense of this tragedy, the dad began to write, exploring many aspects of this tragic death from his own story, his daughter’s story, to survival of those left behind, to warnings about campus drinking and much more.

- This book is a series of letters a bereaved dad wrote to his 9-year-old son after the boy died of a two-year battle with a malignant brain tumor. This father found writing these letters a valuable tool in helping to process his grief and let go.

- Written after the death of his only child, a 21-year-old daughter who died in an apartment fire, this book serves as a read for those who’ve lost a child and who can’t find consolation in prayer or sermons. Researching many cultures on this topic helped the author find peace and understanding, and it’s these insights he shares in this book.

- This dad, a therapist, has written a memoir of grief after the loss of his 22-year-old son in 1999. This book tackles the “institutional” tasks families encounter when such an unexpected death occurs (e.g., insurance claims, lawsuits, bank accounts, etc.) as well as the frustration and grief of having to deal with these tasks and a system that doesn't understand the state of bereaved parents. Helpful resources are also offered.

- A story of a father’s climbing back to life after the unexpected death of his son, with a renewed emphasis on what’s important in life and living again after this kind of loss.
Farley, Kelly. (2012). *Grieving Dads: To the Brink and Back*. Aurora, IL: Grieving Dads, LLC.

- A collection of heart-gripping stories from grieving dads which offers insights into what it's like for a dad to experience the death of his child. Candid, real stories of these men in their darkest moments of grief, they are representative of a cross-section of dads and childloss experiences from the male perspective. The author writes that “Any bereaved father will find brotherhood in these pages.”
- Note: See Author’s article elsewhere in this newsletter on his supportive blog for grieving dads, himself one.


- This dad chronicles the sudden death of his 30-year-old daughter as he tries to deal with what feels like a senseless tragedy. He was supported strongly by his community and was able to work through his grief and loss and now share the wisdom gained in looking for the answers to some of life's deepest questions around death (and that of a child) in this book.


- A father's memoir of his emotional journey from the death of his son during childbirth to the birth of his daughter a year later. An accomplished writer for ESPN and *Sports Illustrated*, this dad wrote this book to give hope to others that they can and will survive the loss of a child, especially when other children enter the family.


- After an accident, whereby two of the author's children are hit by an out-of-control car on their front lawn and where one child lives and the other dies, this dad writes about his heart-breaking journey through his sorrow in losing his son and in trying to reclaim the roles in his life as husband, dad, and protector. A story of a journey mixed with pain and grace, while bearing witness to God's presence in a situation of insurmountable loss.


- A book which offers insight into the masculine side of healing and how it differs from the way women heal. Using real-life examples (e.g., Eric Clapton and how he healed after the death of his 4-year old son), the book shows the many (and different from women) coping mechanisms men use to cope with loss and grief. The book has a section for those trying to help the suffering men in their life heal, as well as one for therapists working with these men.
- Available as a Kindle book only
- Note: See excerpts from this book in the Author's article elsewhere in this newsletter.


- A book for men to explore and find new ways to understand their grief and heal, as well as to examine how an individual's loss impacts the entire family.


- A pamphlet produced by The Centering Corporation, with helpful information for men as they attempt to cope with their grief after the death of their child. Also available in Spanish.

A memoir written by a father after the death of his 18-year-old daughter in a car accident. The book shares this dad’s grief from early after her death through years after her passing via emails, letters, and diary entries. The author helps the reader understand how men grieve differently after the loss of a child through this poignant and compelling story.


Losing his 19-year-old son to a car accident, this father confronts the harsh realities of a death like this, including living through the experiences at the hospital to the cemetery and beyond. This book describes this dad’s struggle to come to acceptance with his son’s death and the doubts he has about whether his faith path could provide him responses to help him move on from this tragedy.


Rabbi Kushner wrote this book years after his son, then three, was diagnosed with a degenerative disease (progeria) with a prognosis that he would only live into his early teens. As a result of that experience, he has contemplated the doubts and fears that people have when faced with a difficult situations (like illness/disease in their children) or tragedy. From the perspective of a rabbi and parent, the book offers guidance and consolation in times of grief and sorrow.


After losing a son to suicide, this dad (and former Family Therapist) had to confront his own feelings of grief, guilt, and failure as his family struggled to cope with this devastating loss. This honest and insightful book shares their journey to survive this loss and come to some sense of wholeness again.


A compilation of eleven men sharing their stories of tragedy, with each submission followed by advice to men on learning to communicate their feelings better and to overcome the harmful emotions of anger, bitterness, helplessness, etc.


A practical, straightforward guide on the basics of what a man needs to know when his child dies.


A bereaved father, this author shares his observations and conclusions about grieving the death of a child and outlines some techniques that helped him through his grief that he feels would be helpful to other bereaved dads. The book also lists a number of books that were helpful to the author after the death of his child.


A meditative picture book (think coffee-table book) compiled by a grieving dad after the death of his 9-year-old daughter to a brain tumor which matches color photographs taken by the dad with his writings as he journeys through his grief.


A dad shares what he learned in his grief process after all the formalities of the death of his child were over (i.e., the funeral, the family support, etc.). He shares his own insights, as well as the lessons learned from other grieving fathers in the support group, The Compassionate Friends.

- “A fatal disease, a father’s love, and a son’s courageous journey” is how this bereaved dad sums up what this book is about. At the age of nearly ten, this dad’s son was diagnosed with a tumor in his pelvis. The book chronicles what this journey was like for this dad as he watched his boy endure numerous surgeries and tests during his two-year battle, only to lose it. A story of a dad who walked it every step of the way with his son to death, and their strong faith in God.


- A collection of insights and helpful hints for fathers during their grief after the death of their baby.


- Losing his mother, wife, and young daughter in a tragic car accident, this author explores the depth of his sorrow and grief in an effort to come to terms with the losses and begin a new life with a deeper appreciation for what each of us are given in our daily lives.


- A dad (and a US Senator), this father retraces his son’s life as it led up to his suicide at 22. Having been adopted and having had struggles with learning disabilities and depression most of his life, this dad chronicles the sadness felt by him and his wife after his son’s death, but also speaks about how he returned to politics to become a tireless advocate for suicide prevention.


- A family loses a son to a freak traffic accident at 18 as the author recounts the incident and the shock and sorrow the family felt in the aftermath. However, the book also focuses on words of hope, support, and healing. Grief resources are provided, as is a chapter on the importance of sharing tragedy in a group setting through a group like The Compassionate Friends.


- This book deals with a father’s grief after losing an adult daughter who was killed when she lost control of her car in the rain in 1995. A wife, mother, daughter, sibling, and teacher, this dad opens us up to his agonizing grief and journey toward healing, and all the emotions that come with this, when a child (even a grown adult child) is taken too soon.


- This book is a candid account of a father’s struggle to save his son, born with a congenital heart defect which he survived only to be diagnosed with a new illness as a teenager, eventually losing his life at age 16. And while the book is a gripping, often raw tale of this dad recounting navigating these experiences—inside the healthcare system—and outside in the “real world,” it’s the epilogue where he begins to share his real grief work after this devastating loss.


- A booklet written by a dad to help other dads in their own grief work, as well as to be supportive of their wives after a loss due to miscarriage.

After losing his 25-year-old son in a mountain climbing accident, the author honestly and openly shares his struggle with this loss and trying to come to terms with his own grief and pain.

Web-Based Resources

www.GrievingDads.com
A website committed specifically to supporting Grieving Dads, it has opportunities for these dads to tell their story, learn about the Grieving Dads Project, and share their thoughts/feelings about the loss of their child/ren with other dads who’ve experienced the same thing. It gives them a "place" to grieve with other dads who "get it." The founder, a grieving dad himself, also blogs on his experiences in grief as a way to start/continue the conversations with these dads via this website.

http://www.youtube.com/watch?v=qdBJ1X33rXM
This is a video of a Dad, a comedian, who recounts what it was like when his world of being paid to "make people laugh" collided with his real world of living through the cancer diagnosis and death of his young daughter. In a raw, gut-wrenching monologue, this father lays his emotions, responses, and his grief bare for all to see so that viewers can truly understand how some dads cope with their own feelings when their child is seriously ill and then dies, from the anger, to regrets, to the intense sadness and grief. To quote this dad, "No one wants to see the clown in pain," yet viewers of this video will see a bereaved dad in the depths of his pain, underscoring how important it is to find ways to help these dads through their child's illness and death.
Items of Interest
In each issue of our ChiPPS e-newsletter, we offer additional items of interest.

1. There are Two Outstanding Web Resources for Fathers and Other Males that We Want to Bring to Your Attention. First, visit YouTube to view "The Moth Presents Anthony Griffith: The Best of Times, The Worst of Times." Using a familiar quotation from Charles Dickens as his theme, Anthony simply stands at a microphone and describes a time in his life when he was experiencing extraordinary tension between enjoying great professional success as a comedian invited three times to appear on "The Tonight Show" and challenges related to his young daughter's recurrence of her cancer, struggles with new symptoms and more intensive interventions, and her eventual death. Anthony shares his anger, raw grief, and efforts to come to terms with realities in his life.

Second, at www.GrievingDads.com, you can experience a safe place in which many fathers and others share their stories of loss and grief experiences. This website is a project of Kelly Farley, who describes his experiences as a bereaved father and his desire to help other bereaved dads in his article, "To My Knees," in this issue of our newsletter.

2. Subjects and Contributors for Future Issues of this Newsletter. In the many past issues of this newsletter, we have addressed a wide range of subjects. For future issues, we are thinking about addressing subjects such as differences between pediatric palliative care and pediatric hospice care, and concurrent care in the United States. If you know of good topics and/or contributors (including yourself) for any of these and/or other future issues of this newsletter, please do not be shy! Step right up and contact any of the following: Christy Torkildson at christytork@gmail.com; Maureen Horgan at horgan.maureen@gmail.com; or Chuck Corr at ccorr32@tampabay.rr.com. We will work with you!

In the meantime, you can visit archived issues of this newsletter at www.nhpco.org/pediatrics. Among them, you will find articles on bereavement, sibling bereavement, self care, ill and dying teens, perinatal loss, neonatal loss, spirituality, unsung heroes in the circle of care, pain and symptom management for children with life-threatening illnesses and their families, families experiencing transitions associated with pediatric palliative care, complementary therapies, examples of programs illustrating the current status of pediatric palliative and hospice care in the United States, memory building and legacy making in pediatric palliative and hospice care, examples of many programs offering this type of care in various parts of the world outside the United States, ethical issues related to pediatric palliative and hospice care, help and healing in relationship to bereavement perspectives, stress and moral distress (identifying stressors and supporting staff), using social media and electronic communications to network by families and practitioners, the role of pediatric palliative and hospice care in creating systems to support children, families, and the community, children are not little adults (i.e., respecting differences in providing pediatric palliative/hospice care), honoring volunteer perspectives, and perinatal palliative and hospice care.

3. Reader's Corner. Our occasional Reader's Corner column provides brief summaries and bibliographical information about journal articles and other publications that are important and likely to be of widespread interest to individuals who are involved or interested in pediatric palliative care, but that may not be known to all readers of this newsletter. Contributions to the Reader's Corner include an abstract of the publication, a description of the audience for this information, comments on what is special about the publication, and suggestions as to where and how this information can be applied. We welcome suggestions for publications to include in our Reader's Corner and/or summaries and comments on such articles following the model in this issue. Please send all such suggestions to Christy Torkildson at christytork@gmail.com.
4. “If Not Now, When?” Laura Rozo at TEDxUNC.
Laura Rozo, a junior at the University of North Carolina at Chapel Hill, died in the comfort and presence of her family and many friends on Thursday April 11, 2013. During her battle with cancer Laura shared her message of living life to its fullest at a UNC TedxTalk. Our thoughts go out to Laura Rozo's family & friends. In honor of her inspiring courage, please read more about Laura's inspiring journey and watch:

http://www.youtube.com/watch?v=X73qA-Q8_Qk

5. Two New Pediatric Care Modules Available on NHPCO's E-OL. The newest modules in the 10 module training series on pediatric palliative care are now available on NHPCO's E-Online education portal. Be one of the first to sign up for the latest module in the series that is designed to furnish you with the latest trends in pediatric palliative care provision.

- Module 8: Psychosocial Support of the Family and Patient
- Module 9: Pediatric Bereavement Care

As a reminder, here are the other modules in the Pediatric Palliative Care series:

- Module 1: Principles and Standards
- Module 2: Delivery Models
- Module 3: Ethics, Decision-Making, Advance Care Planning
- Module 4: Childhood Development in Health and Illness
- Module 5: The Spectrum of Complex, Chronic and Fatal Conditions in Pediatric Palliative Care
- Module 6: Assessment and Management of Pain
- Module 7: Pediatric Palliative Care - Symptom Management

6. Pediatric Continuum Briefing Available. NHPCO's Mary J. Labyak Institute is pleased to offer a pediatric-focused continuum briefing, Pediatric Concurrent Care (PDF), available free of charge online. The goal of the continuum briefing is to help providers work together to assure that each state’s most medically fragile children have the quality care they deserve.

7. NBCHPN: Two New Examinations. The National Board for Certification of Hospice and Palliative Nurses (NBCHPN) now has two examinations available for individuals who work with pediatric patients. The certification exam for perinatal loss care professionals is now available for the June 2013 testing window. Successful candidates will be granted the credential Certified in Perinatal Loss Care (CPLC) and may renew their certification every four years. This exam is designed for professionals working in a healthcare role which provides care to individuals experiencing perinatal loss that covers the content in the test content outline.
NBCHPN® also offers a Certified Hospice and Palliative Pediatric Nurse (CHPPN®) certification exam. Examination content is based on the competencies normally achieved through two years of practice in caring for children with life limiting illnesses and their families. Children are defined as perinatal, infant, pediatric, adolescent, or young adult patients.

Visit the website http://www.nbchpn.org/ and look under “Exams” for more details on either exam.

8. NHF Gala Focuses on Pediatric Care. The National Hospice Foundation's Ninth Annual Gala, hosted on April 26, 2013, honored and celebrated pediatric palliative care and hospice. The gala was held in conjunction with NHPCO’s 28th Management and Leadership Conference at the Gaylord National Resort and Convention Center at National Harbor, MD. Local ABC News Anchor, Greta Kreuz served as Mistress of Ceremonies for the event attended by over 500 guests. Three awards were presented to individuals who have contributed to hospice in significant and unique ways. Learn more about the gala on the NHF website.

Additionally, a live appeal was conducted during the gala to raise support for NHPCO's work on behalf of pediatric palliative and hospice care. A poignant video about pediatric care was shown to kick-off the live appeal and within minutes, $28,000 was raised on the spot. NHF and NHPCO thank all those who made this event such a success.

9. Calendar of Events. As a reminder, there is a calendar of pediatric educational opportunities on the ChiPPS section of the Web site, nhpco.org/pediatrics. ChiPPS is a program of the National Hospice and Palliative Care Organization. Please e-mail Christy Torkildson to have your pediatric palliative care educational offering listed.

Please note that the opinions expressed by the contributors to this issue are their own and do not necessarily reflect the views of the editors of this newsletter, ChiPPS and its Communication Work Group, or NHPCO. We invite readers with differing points of view to submit comments or suggestions for possible publication in a future issue.

Thank you for taking time to read this issue and for any feedback that you can offer us. Providing pediatric palliative and hospice care to children, adolescents, and their family members has made great strides in recent years, even though it is certainly not always easy and still faces many challenges and obstacles. We wish you all the best in your good work.

If you are not on our mailing list and received this newsletter from a friend or some other source, please send an email message to CHIPPSS2@NHPCO.org requesting to be added to our mailing list. If you are a member of NHPCO, the Solutions Center will be happy to help you adjust your communications preferences; contact them at 800-646-6460. Visit the ChiPPS Web page for further materials and resources of interest.