



Connections

Information + Support

Families of Children with Special Needs

Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, & Yancey counties

Fall 2013

FAMILY SUPPORT NETWORK™ - HIGH COUNTRY

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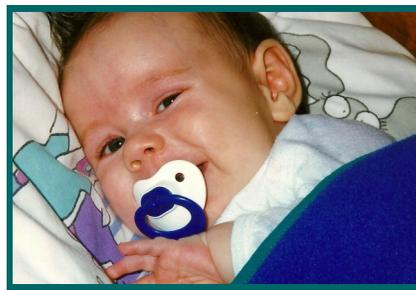
Friends of Family Support
Network™—High Country

Partnership for Children from:
Avery
Mitchell-Yancey
Watauga
Wilkes

Providing Comfort When a Child Dies

By: Helen Baldwin

In 1997, our two-month old baby, Jeffrey, was diagnosed with spinal muscular atrophy (SMA), a neuro-muscular/motor neuron disease and leading genetic killer of children under two. He died 3-1/2 months later, but our assignment was hardly over.



Jeffrey

Regardless of circumstances, grief is excruciating at best. The only guarantee is its unpredictability and propensity for making one wonder if it's possible to escape the abyss of heart-shredding despair. One baby step forward, S-L-I-D-E back, repeat... again and again. All 'firsts' are agonizing, and sometimes even 'twentieths' can blindsides those in grief.

There's no need to elaborate on the devastation of losing a child. Child death, obviously uncomfortable and rarely discussed, tends to send even family and good friends scurrying.

Input from bereaved moms might help change that.

Lindsay's son Emory, born in early 2008, was diagnosed at three days with Cerebrocosto-mandibular syndrome (his ribs were mostly cartilage), paired with micrognathia (recessed chin and his tongue set back); his was the 56th known case of this genetic condition in the *world*. Emory remained in the hospital for one month until life support was removed, and he passed away.

Lindsay's suggestions:

- *Allow the bereaved to grieve as long as it takes; don't try to push them through it. Friends and family who recognized the magnitude of my loss were the most helpful.*
- *Let the bereaved explore, question, and work through what makes sense to them in the area of faith.*
- *It's ok to not say anything; just know that I am sad, and that's ok as well.*
- *Just because I was laughing yesterday does not mean that I am healed and over the loss of my baby.*
- *Hearing others mention Emory after five years comforts me more than pretending he never existed.*

J's bright, outgoing 7-year old son was playing happily with a new friend when he became the victim of a tragic accident. While I was thankful we were 'prepared' for Jeffrey's decline, J said she was thankful her extraordinary son enjoyed life to the fullest right to the very end.

J's suggestions:

- *When speaking to the newly bereaved, it's okay to mention someone you've lost, especially a child, as it is comforting and also helps me identify those who are truly empathetic.*
- *It took a whole lot of grace on my part to respond kindly to frequent platitudes of 'comfort' that I questioned. However, I came to understand that most people have no idea what to say to someone who has just lost a child, and what comforts them is all that comes to mind. I'd certainly rather hear something spoken with kind intentions than be avoided.*
- *I often choose to be upbeat, positive, and even enthusiastic about life. That doesn't mean that I don't miss my son like crazy.*

- *I don't avoid saying my son's name or bringing up memories of him when one hits me. That makes some people uncomfortable, but I don't want his name to become taboo out of fear it will make me sad. The sadness of losing him is as much a part of me as the freckles and moles on my body that don't ever go away and occasionally multiply.*
- *Sometimes people who don't know how my son died bring up horrific stories of similar accidents and feel awkward when they learn my story. If this happens, acknowledge that you just learned about the circumstances, then sincerely express your sympathy.*
- *Above all, don't walk the other way when you see someone who has recently lost a child - you'll be noticed! Instead, kindly say hello and that you've been thinking about them, or just have a general conversation. I found that for the first month, there was so much support... then it was like I had the plague, and my son's name was avoided around me at all costs. I feel special warmth toward those who still mention him.*

In summary, some key elements of easing the grief journey: allow those grieving ample time and space (grief doesn't follow a playbook!), remember and mention the child, don't presume the individual is 'over it' because life seems good. I'd like to add *just listen*, as talking - and rambling - for the bereaved is extremely cathartic. And so are hugs and tears!

After Jeffrey's diagnosis and death, I relied on family, faith, and connections to other SMA families (primarily online) to stay upright. Some years later, I met Kaaren Hayes with Parent-to-Parent Family Support Network, a wonderful network for families faced with myriad 'special' circumstances. Teresa Emory, Outreach Coordinator for Mitchell and Yancey counties, helps lead a Compassionate Friends group, and there are also Supporting Families who have also lost a child who are a part of the program willing to talk one to one with anyone looking for the support and comfort of someone who truly understands.

Join us on Saturday October 26, 2013!!!

We are hosting our **3rd Annual Charles R. Duke Race: Making Strides for Families** at Greenway Trail - Clawson-Burnley Park in Boone, NC. Our race includes a certified 10K, a 5K, and a 1 mile walk/run/jog. You must sign up by October 9 to be guaranteed a T-shirt!!

Costume Contest!!

Price of the Event

10K w/FREE T-shirt - \$30 (\$35 day of race)

5K w/FREE T-shirt - \$20 (\$25 day of race)

1 mile fun walk/run/dog jog w/T-shirt - \$15 or w/out T-shirt - \$5

Activities for Kids!!

Schedule

8:30am: Same Day Registration, T-Shirt, & Packet Pickup

9:00am: 10K

9:30am: 5K

10:00am: Fun Walk/Roll

To register, please go to parent2parent.appstate.edu

COME JOIN THE FUN!!!



Volunteering Is Good For You!

- 92% of volunteers report that volunteering enriches their sense of purpose in life
- 68% of volunteers agree that "volunteering has made me feel physically healthier"
- 73% of volunteers agree that "volunteering lowers my stress levels"
- 34% of volunteers are considered to have an average BMI, compared to just 27% of non-volunteers
- 29% of volunteers who suffer from a chronic condition agree that "volunteering has helped me manage my illness"
- 81% agree that "volunteering with work colleagues has strengthen our relationships"
- 88% of all volunteers agree that volunteering provides networking and career development opportunities



Statistics taken from a 2010 survey conducted by UnitedHealthcare and VolunteerMatch (<http://www.unitedhealthgroup.com/news/rel2010/UHC-VolunteerMatch-Survey-Fact-Sheet.pdf>) and from a 2007 survey conducted by the Corporation for National & Community Service (http://www.nationalservice.gov/pdf/07_0506_hbr.pdf)



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