



Grief and Death in Epilepsy: Learning From Loss

On March 2, 2021, Partners Against Mortality in Epilepsy (PAME) held a webinar that explored grief among those who have lost a loved one to epilepsy. Three parents participated in the panel discussion and shared this advice for managing grief.

Sally Schaffer, parent

- Grief is more uncomfortable for those not sitting in it. Although all bereaved grieve differently, often pretending the passing never happened is not the right way to approach the bereaved.
- Often, people want to fill discomfort with words but often the only right words are “I’m sorry, I’m here to listen.” Sitting in the grief with someone without trying to fix it is one of the biggest ways to help.
- Grief morphs and changes throughout the years but many believe they are supposed to move through each and every specific stage, which isn’t the case. Give yourself grace. Be ok with saying no to things that might hurt. Understand grief is not linear and it does not follow a path.
- You need to feel it to heal it. Without feeling it all...including the pain, it is hard to move forward.
- While the loss of a loved one is the same, no two losses are the same (i.e., me losing my 7-year-old is not the same as someone losing their 30-year-old son. Or as someone losing a sibling).

Edana Perry, parent and Co-Founder of the Kayla Ross Perry Memorial Foundation

- Be kind to yourself on your journey and do not allow others to place expectations on you.
- Seek out healthy resources for comfort to find out what helps you, i.e, grief support groups, individual grief counseling, journaling, poetry.
- At your right time you will let go of the weight of your grief
- Do not suppress your pain, let it flow out.
- Turn mourning into mission (helping others)

Michael Schafer, parent and Co-founder of HOPE4SUDEP (website and fund-raising foundation in honor of Cameron Benninghoven); Lay Member Research Grant Committee for CURE

- I was out of the country on a surgical mission when I received the phone call that no one ever wants to receive...my stepson Cameron had died in his sleep two nights before. I was stunned with disbelief. It was inconceivable, incongruous with reality. A friend made arrangements for me to return home to Chicago immediately. I will never forget my partner’s words when she told me Cameron had died, in his sleep.
- I am strong in my faith and steeped in the philosophy that all things happen for a reason... but I had never been tested like this before. This would be a very real challenge to my spiritual moorings. I began to write my eulogy on the plane ride home. That helped.
- It is so important to share one’s grief; loved ones and friends want to be included in our tears. They can truly lighten the yoke of grief if we let them in.
- Families and persons who are grieving should let it be known that speaking of the loved one lost is welcomed (at least if it is welcomed); they should encourage others to speak the name of and be open about the one who has been lost to SUDEP or another form of epilepsy. Sort of communal remembering and celebrating.
- No one needs to suffer alone. We did not know of the epilepsy “family” when our son died, but quickly did afterward, and we sustained a lot of strength from others in the same circumstance. There are groups and agencies that could be of real service.

For more information on PAME, visit pameonling.org.