

## **LCC Session: Communicating Effectively with Families During Difficult Times**

**Presenter: Graeme Howieson, Father, Bereaved Parent, Member of the Provincial Paediatric Palliative Care Family Advisory Council (PPPC-FAC)**

**GOAL:** *The purpose of this session is to:*

- 1- *Become more comfortable communicating a prognosis that is difficult to hear and process for a family.*
- 2- *Learn how to approach families that have been in the hospital for a long time, but who are new to you.*
- 3- *Appropriately and effectively communicate with families going through Palliative Care/ End of Life Care with their child.*

### **PRE-SESSION MATERIALS**

#### **1. Required materials:**

- Personal Story – Please read mine and my wife’s personal journey (Appendix A) with our daughter Lidia.
- Personal List – Please read the included list (Appendix B) of helpful/ unhelpful ideas we found from our experiences with residents/doctors/ nurses when dealing with our family. (Please note: these suggestions are based on OUR experience; every family will be different)
- Video – Please watch the following video “Diagnosis: Anticipatory Grief”  
<https://courageousparentsnetwork.org/video-library/a-new-diagnosis/coping-with-the-diagnosis-grief-anxiety-worry>
- Photo – Please look at and consider how the photo below affects you as a professional. (Appendix C)
- Listen – Please take some time to listen to this short Podcast on a mother’s experience with Pediatric Palliative Care.  
<https://courageousparentsnetwork.org/podcasts/sarah-and-emerson>

#### **2. Additional task – please explore the following website if you are interested. It has been co-created by the Children’s Hospital of Eastern Ontario (CHEO) and parents. It is a practical guide to help professionals support parents of children with medical complexities:**

- Website – <https://ken.childrenshealthcarecanada.ca/xwiki/wiki/changingyourlens/>

**Questions to encourage discussion:**

- 1. How would you deal with family members asking medical questions about complex care/care outside of your expertise?**
- 2. How would you deal with a family member who becomes overwhelmed/incapacitated by devastating news that you have given them?**
- 3. Is it ok for a resident/ doctor to show emotion/ empathy/ sympathy toward family members as a means of support?**
- 4. What do you feel would be important to know about a family and their medically ill child before meeting them for the first time?**

## **Appendix A- Our Journey with Lidia**

Our daughter Lidia was born with a very rare genetic condition (Pontocerebellar Hypoplasia Type 7 or PCH Type 7), one of only twelve known cases in the world. We did not find out her genetic condition until after she had passed away. Even knowing her genetic condition before she passed would not have change her method of care.

Lidia was born at 36 weeks at McMaster Children's Hospital and we spent the first month and a half of her life in the Neonatal Intensive Care Unit (NICU) due to a variety of medical reasons. During this time my wife Lee and I became immersed in the medical side of Lidia's care. We were at the hospital every morning for rounds and became experts in Lidia and her medical condition. One of the scariest moments every day for us was walking into the NICU not knowing who our doctors and nurses would be and if we would have to explain every detail about our little girl over again. Also, during this time, after multiple rounds of blood work, CT Scans, MRIs, x-rays, and much more, we began to be told by our medical team what Lidia's life would look like. Hearing each piece of news, of things Lidia would never be able to do, was like grieving the loss of a piece of her life, every single time. Once we were discharged from the NICU and finally got the chance to go home, Lidia was making progress, and we felt like we were given hope by her medical team, that Lidia would live a long life with support from us. We later found out that this was false hope and were devastated to learn that what we had been told was in fact, incorrect.

We got a chance to bring our little Lidia home and were so very happy. But we quickly learned that her medical condition was causing multiple complications that began to put her life at risk. For the next 5 months, we spent much of that time in and out of the hospital. With her genetic condition she was only born with 50% of her brain mass and 30% of her cerebral mass. This meant she had many concerning medical conditions that began to take their toll on our beautiful baby girl. We found out from multiple appointments with her dietician, optometrist, audiologist, neurologist and many others, that Lidia had a sever allergy to cows' milk protein and soy, she could not see, hear, and she would never be able to walk or talk, due to her underdeveloped brain and lack of central tone. Each time we were told a new piece of news from her medical team, it was another devastating blow to our family.

As Lidia got older, she lost the ability to swallow and she began aspirating on her formula and saliva. At this point she was admitted to the Paediatric Complex Care Unit and introduced to the Complex Care team at McMaster University as she would need surgery to insert a G-Tube for her to survive. The doctors and nurses that were a part of this team became our family as we spent the majority of Lidia's last days with them. She also began to have Infantile Spasms and Focal Seizures, which began to damage an already underdeveloped brain. We tried every option the Neurology team gave us to correct the spasms, but they continued to get worse.

(Appendix A cont.)

At the age of 7 months my wife and I had to make the difficult decision to move our Lidia to End of Life Care under the care of the Quality of Life (QoLA Care) team at McMaster. The QoLa team was there very step of the way through our Complex Care journey to ensure our needs as well as Lidia's needs were being met. We were always given options and knew that the QoLA Care team had Lidia's comfort and best interest in mind. They guided us through the end of life process and after about a week, our beautiful Lidia passed away.

During the time she was alive and even in her afterlife, Lidia manage to touch so many lives and we always refer to the difference she made and continues to make as "Lidia's Legacy". Her medical team at McMaster, including the Pediatric Palliative Care doctors took such great care of her in her final moments. We have had to experience the worst possible thing any parent could ever endure, the loss of a child. Our goal moving forward is to continue to honour our daughter any way that we can. I come to share our story and our experience as a way to honour our little girl and to provide you with knowledge and expertise that you can hopefully bring to families going through similar situations.

## **Appendix B- Things to Consider as a Healthcare Professional When Dealing with Families and their Critically Ill Children**

- Ensure you know as much as you can about a new patient before speaking with the family
  - o One of the things that brought us the most anxiety was wondering if we would have to explain every detail of Lidia's story to a new doctor. Having a new doctor or nurse know as much as they could about Lidia before meeting us the first time put us at ease.
- Talk to the child like they are a person
  - o It made us feel like our daughter mattered if the doctors interacted with Lidia directly, even if she could not hear or see them
- Don't be in a rush
  - o Sometimes we felt like our medical team was in a rush to move on when we had questions or concerns. This makes the family and their child seem less important.
- Give time
  - o Take the time to sit with the family. Get to know them. Allow them to ask all the questions they need. This can be very helpful, provide relief and be therapeutic for many families going through the most difficult time in their lives.
  - o When giving potentially devastating news to a family, sit with them, given them time to process the news that is being given. Be available and prepared to answer any questions they may have.
- Be Honest
  - o When giving news to a family and their child, be as upfront and honest as you can. The family needs to hear the truth and not be given false hope.
- Never make assumptions about what families are dealing with and choices they are making
  - o We sometimes had doctors/residents question things we were/ weren't doing for Lidia. You don't always know why or what decisions the family has made.
- Provide Resources/ Social Worker Support
  - o When we were in the hospital, we felt like we were searching for answers much of the time. Whether it was having to make medical decisions for our daughter, or trying to navigate the home health care system, the more resources we were provided with, the easier many of those things became.
  - o Provide a social worker to take notes and provide support during difficult meetings.
- Make check lists/ next steps on the whiteboard in the room for parents because it can be overwhelming at times
  - o Often, there would be a lot of information/ results given to us on a daily basis. One of the things that would have been most helpful would be for our doctors or nurses to write out results/next steps on the board in our room, so we could be able to keep track of it all.
- Bring parents into the Rounds Meetings in the morning
  - o Being included in the daily rounds meetings was helpful for us to know where Lidia's progress was and allowed us to ask any questions if we had them.
- Check in with the parents and see what they need
  - o Simply asking a parent if they need anything or how they are doing can provide necessary support and comfort.
- Care doesn't end after the child passes away
  - o Some of the best care we received, was after Lidia passed. Doctor's and nurses were there as a support and continued to answer our questions if we had them.

## Appendix C- Something to Consider

**Are you able to recognize the signs/symptoms of medical PTSD in parents/caregivers of children with medical complexities?**

Flashbacks      Nightmares      Fight or flight response      State of hyperarousal      High anxiety

**What can you do as a Healthcare Provider?**

**Communicate**  
With family and other health providers

**Check-in**  
Ask parents/caregivers how they are doing and what is going well

**Come prepared**  
Read their chart before an appointment

**Respect**  
Trust that parents and caregivers are the experts on their child's health

**For more resources go to:**  
[www.changingyourlens.ca](http://www.changingyourlens.ca)  
[www.cheo.on.ca](http://www.cheo.on.ca)

**CHEO**  
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