
Rachel Sievers, Au.D., CCC-A
Arkansas Children's Hospital

CHARLIE
CARE PROJECT VIDEO

- https://www.youtube.com/watch?v=Z_y10sR_Apw

GRIEF IS REAL AND UNPREDICTABLE

*Grief is wild... It pays no attention to rules and doesn't follow directions, a map, or a schedule.*

Greg Adams, LCSW, ACSW, FT
Program Coordinator
AR Children's Center for Good Mourning

CHANGE OF PLANS...
Cochlear implantation at 2 years of age

The first 6 months were amazing!

Then…

CI COMPLICATIONS

When things don’t go as planned…
• Changes in skin flap
  • (Fluid, redness, bruising, hair loss)
• Changes in performance
• Pain
• Deactivating electrodes
AFTER REVISION - BANDAGE REMOVED

REACTIVATION – WE WERE SO EXCITED!

EXTRUSION

Fully inserted electrode array

Partially extruded electrode array
HERE WE GO AGAIN!

5 MONTHS POST REVISION
SILVER LININGS – OBJECTIVE

- Newer device – latest technology
- Tracking Speech Perception
  - 2 years, 6 months (6 months post original CI) – 72% WIPI
  - 3 years (during extrusion of array) – 44% WIPI
  - 4 years, 4 months (1 month post revision) – 68% WIPI
  - 4 years, 5 months (2 months post revision) – 72% PBK (open set / harder)

SILVER LININGS – SUBJECTIVE

- Charlie loves his super ear!
- We can talk to him on his “bad side” in a noisy environment and he
doesn’t hesitate to respond
- Very accurate localization

Phew! Finally, some affirmations!

LESSONS IN DELIVERING DIFFICULT NEWS
LESSONS IN DELIVERING DIFFICULT NEWS…

1. How a medical professional delivers the diagnosis can make or break their future relationship with the family. Ideally, it should set the stage for a relationship of mutual trust and respect.

LESSONS IN DELIVERING DIFFICULT NEWS…

2. No matter what the parent’s background or education level, KEEP THE MESSAGE SIMPLE! What are the results? What’s the plan? Send them home with written information, too.

LESSONS IN DELIVERING DIFFICULT NEWS…

3. Acknowledge that the information may be difficult to receive.
LESSONS IN DELIVERING DIFFICULT NEWS…

4. Body language is important; sit down and look them in the eye. Do not rush.

LESSONS IN DELIVERING DIFFICULT NEWS…

5. Give the family *time to process* the information, not just during the appointment but after, too.

LESSONS IN DELIVERING DIFFICULT NEWS…

6. Actively listen and allow silence.
LESSONS IN DELIVERING DIFFICULT NEWS…

7. Parents’ reactions to difficult news with differ across families and within families.

LESSONS IN DELIVERING DIFFICULT NEWS…

8. It’s ok to talk about GRIEF.

LESSONS IN DELIVERING DIFFICULT NEWS…

9. The parent is part of the managing team. TELL them this and be genuine about it.
LESSONS IN DELIVERING DIFFICULT NEWS…

10. Dress the part. Looking like a professional ensures the family doesn’t second guess your ability to care for their child.

THINGS I LEARNED (OR LEARNED AGAIN)

It’s REALLY hard to keep amplification on a young child.
Parents often worry if they're doing enough or making the right decisions.

**HOW THE PARENT MAY APPEAR IN THE BOOTH**

Is he not paying attention? Maybe he's tired. I should have put him to bed earlier.

Uh oh, my stomach growled. Maybe that's why he didn't hear that!

Maybe he's moving too much and messing up the test!

I heard a beep...did he hear a beep?...I heard a beep!

**WHAT'S REALLY GOING THROUGH THE PARENT'S HEAD**
AMPLIFICATION FITTING – LESSONS LEARNED

- Put the device on as early in the appointment as possible.
- Do the counseling and teaching after.
- Parents aren’t going to hear much of what you’re saying in the beginning. They are anxious to see what the device will look like on their child and observe how their child will react to it.

A PHOTO IS WORTH A THOUSAND WORDS

GIVE FAMILIES THE TOOLS THEY NEED TO SUCCEED

- Families don’t know what they don’t know.
- Don’t be afraid to discuss barriers to success:
  - Financial constraints
  - Retention
  - Transportation
  - Basic needs
  - Differing opinions at home
  - Limited availability of services close to home
  - Grief
RETENTION IDEAS - CLIPS

MAKE LEMONADE

KIDS ARE AMAZINGLY RESILIENT!
THE BLANKET PHOTO

GIVE FAMILIES THE SUPPORT THEY NEED

- Families need support beyond that which a medical professional can provide
- They need emotional support from others who have walked in their shoes
- Other families with children with hearing loss
- Adults with hearing loss
- Consider connecting them with counseling / psychological support

"WHAT WORKS FOR YOUR CHILD IS WHAT MAKES THE CHOICE RIGHT."
HANDS AND VOICES
www.handsandvoices.org
FAMILY SUPPORT

- The Care Project
  www.thecareproject.com
- Hands and Voices
  www.handsandvoices.org
- Boys Town “My Baby’s Hearing”
  www.babyhearing.org
- Supporting Success for Children with Hearing Loss (Karen Anderson)
  www.successforkidswithhearingloss.com
- Social Media Groups

DISCUSSION

Rachel Sievers, Au.D., CCC-A
Arkansas Children’s Hospital
501-364-1953
SieversRK1@archildrens.org