

Changed By My Child

Lessons on Caring, Living, and Dying Well
by Lois Swope



Creative Health
Care Management
Symposium
June 21, 2017





Lois, Leah & Karly



Karly & Pokito



Karly,
5-6 years old



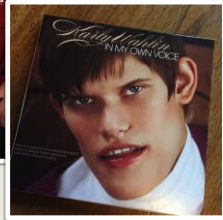


Amy & Karly

"That song changed my life... I was a composer! I was a musician. I had a voice that others could hear."
- Karly



Karly & Karen Bohnert,
music therapist



Everyone is more than their symptoms:

See the whole person, not just their diagnosis

Lesson 1

"Don't let
Rett Syndrome be
the only thing
said of me." - Karly





Karly &
Elizabeth



"Assume Intellect":

*Trust the experience of the
patient and their family*

Lesson 2

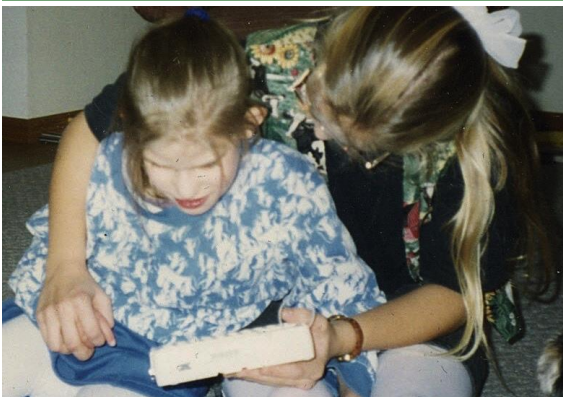
“Just because I’m silent doesn’t mean I’m ignorant.”

– Karly



“My brain is intelligent, my body struggles.” – Karly



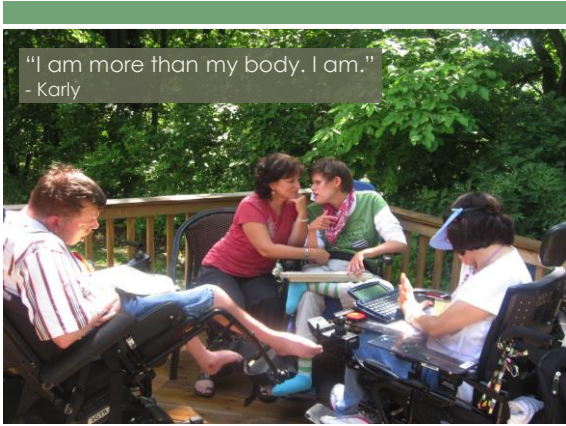








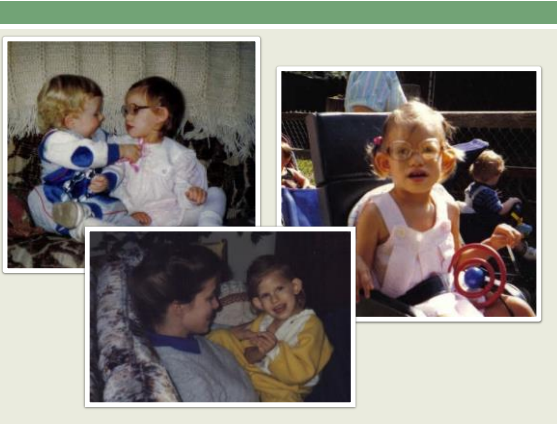
“Many of my memories of going to doctors and therapy visits are **painful to remember.**”
– Karty



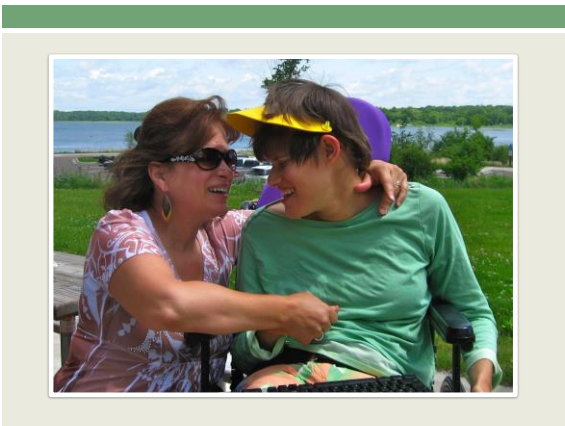


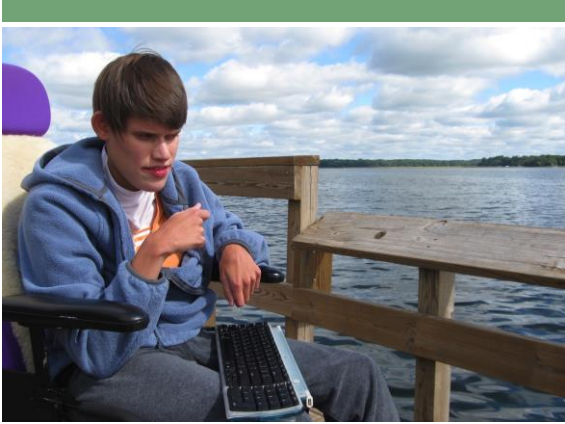
Every patient has a backstory:
Be curious and compassionate

Lesson 3







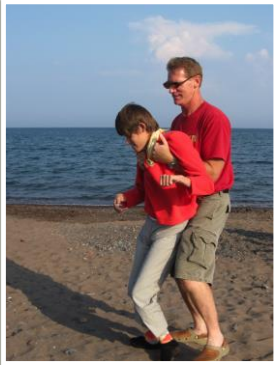






"The Cruel Stare"





Karly & Gregg

Death is part of life:
Accept that mortality is not failure

Lesson 4





"I've said yes to everything I was supposed to do here." - Karly







"My **favorite place on Earth** is on the back of a horse."

- Karly
Last ride on Chester



Thank you.

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