Visionary Partnerships & Palliative Care
Together We Can Do Anything

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Meet my one in a million son, Austin and my daughter, Christina. When he was diagnosed with NBIA Disorders, our lives changed forever.
HE SAID:

“It’s a terminal brain disease.”

“He might live for two more years.”

“We will try to keep him comfortable.”

“Again, I’m sorry.”

“Please call for a follow up appointment in three weeks.”

“Merry Christmas.” (It was Christmas Eve)

“I’m sorry.”

I THOUGHT:

“Thank you.” I can see you’re saddened by the diagnosis and hate having to tell me this.

“TWO years??? Are you kidding me?”

“Right, wait for three weeks to understand what you are not telling me. NOT!”

“Merry Christmas? How am I going to be a happy Santa for my kids.”

“I can’t breathe and my head is spinning. Please don’t leave me yet.”

“Hang up. I want to crawl in a hole and pretend it was yesterday.”

“Thank you and God Bless YOU for giving me a diagnosis.”

“Oh, it’s Christmas... we’re having the family over in three hours.”
Eventually we went from...
And pain management became our focus. Fear-based communication and the “m” word:

- “Won’t it kill him?”
- “Won’t it make him stop breathing?”
- “Won’t he overdose?”
- “Isn’t it addictive?”
- “Don’t we have another choice?” (while sobbing)
What I learned from our experience with opioids:

- His personality returned

- Properly prescribed opioids allowed our entire family to have fun again, because they provided my son with comfort and relief from horrific pain

- That early communication on the positive effects of morphine would’ve helped us immensely. I would’ve fought back less... cooperated more.
Everything in life is a circle; Day follows night, spring comes after winter.

When a boat disappears behind the horizon, it is not "gone", just out of our sight.

God watches over everything that He created - the earth, the sun, trees, flowers and people who have to get through the school of life before they graduate.
...Because even us “big kids” need a little help sometimes. Our little ones however, are often so wise...

- When I go to heaven Mommy, will I run as fast as a jaguar?”

- “When I go to heaven Mommy, will you hold my hand?”

- He was only five years old, and we were in the car riding home from church. I had not told him he was terminally ill
Other children: What they know
Families like mine want to trust you and sometimes we (clinicians) have to do more to build that trust.

Besides, quite often, they want something good to come out of the tragedy they are experiencing. (Finding meaning)
Which means that how we talk to families is as important as what we say...

Everyone is a genius. But if you judge a fish on its ability to climb a tree, it will live its whole life believing that it is stupid.

-A Einstein
So how can we build that trust while enhancing communities of care?

By first understanding some of the outcomes of compassionate communication, which are:

1. Greater adherence to treatment plans
2. Better health outcomes
3. Increased patient satisfaction and loyalty
4. Reduced malpractice claims
5. Increased clinician satisfaction

*Marsha Levetown, 2012
Social Determinants of Health which teach us more about choice & preferences

Palliative care model: Patients AND Family Members

- Biology and genetics / Examples: sex and age.
- Individual behavior / Examples: alcohol use, injection drug use (needles), unprotected sex, and smoking.
- Social environment
- Physical environment
- Health services
The Core Social Determinants of Mental Health (the cause of the causes) of mental illness are:

- Discrimination
- Adverse early life experiences
- Poor education
- Unemployment
- Poverty
- Food insecurity
- Housing instability
- Adverse features of the built environment, and poor access to health care.
Why is understanding social determinants more important than ever?

- Because we are going to have to empower family members like NEVER BEFORE!
- From Stanford’s Clinical Innovation piece: “though the number of dedicated palliative care teams at larger hospitals is growing—from 53% in 2008 to 67% in 2015—less than half of the 8% of admitted patients eligible for palliative care actually receive it.
- We have to empower family members to do more caregiving and we need them to start asking -- no, demanding -- access to palliative care.
- So where do we start? By building a hammock of support by showing them what their own community of care may look like.
This Hammock of Support can teach families, that if one string breaks, you won’t fall through.
The Shortfall... Things That Broke My Heart

- Like many parent caregivers, I realized so much of life was boiling down to choices:

- Let my healthy child go for a sleepover (when I really wanted her with me)

- Letting her roam a little bit further than I was comfortable with on the playground, since I couldn’t keep her and my child (in a wheelchair) together

- Christmas cookies, class projects? I did my best but it was never at 100% as it might have been otherwise

- My undivided attention? Not nearly enough

- She simply saw “too much” because I was one parent, one caregiver. Who was there to hold her? I needed a volunteer.

- Besides losing my son, it is a part of the biggest heartbreak of the whole experience.
What about after the patient’s death? Why volunteers may be the most important person that family will know...

- BECAUSE LIFE MOVES ON...AND SO DOES THE CLINICAL TEAM

- Think about it... Where does the nursing staff/team go? Onto their next patient

- When does the bereavement team come onboard? Often, after the passing of the patient.

- Who can be the constant...the bridge? Volunteers
Also, we know that complementary care can be and often is an important thread in the Hammock of Care

- Reiki (including the neighborhood kids!)
- Healing touch (and included my daughter)
- Sermons at our church
- Prayer ceremonies in our home: four different religions
- Massage (For ex: Irene Smith here in CA)
- Music therapy (See www.room217.ca)
- Aromatherapy
- Friends!!!
- Meditation with Austin
Do we involve children?
A large community of care
It also included
What also was of the utmost importance, was that I grew to validate and depend upon my own team spirit. They became a part of my/our “hammock.”
What else is important in this Hammock of Support?

Technology: SKYPE, Facetime, WhatsApp and Facebook
Yes, it’s time to flip the care model upside down...
The story of Patient “M”
“If we, as members of the helping professions, can help the patient and his family to help get in-tune to each others’ needs, and come to an acceptance of an unavoidable reality together, we can help to avoid much unnecessary agony and suffering on the part of the dying and even more so on the part of the family that is left behind.”

~ Dr. Elisabeth Kubler-Ross
“In closing, our palliative care team created a roadmap for a healthier existence for all of us during Austin’s life and following his passing.”

I will remember our care providers for the rest of my life and I’m sure your patients will remember you, too.”

~ Dianne Gray