EXPANDING THE ROLE OF PALLIATIVE CARE IN ORGAN DONATION

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**Precipitating Event**

- Patient “A” is a young 21-year-old healthy male
- MVA
- Traumatic brain injury
- Registered organ donor
  - Family anticipated approach
  - Became suspicious at time of declaration.
  - Hostility directed at AV Hospital and One Legacy Staff
  - Verbalized accusations of “murder” in ICU and throughout the hospital
  - No evidence of peaceful decoupling
  - Family perceived poor continuity of care/support
- Palliative care not assigned for family support
The Palliative Care Paradigm

“Unity is strength... when there is teamwork and collaboration, wonderful things can be achieved.”

- Mattie Stepanek
Palliative Care Involvement

- Trigger for palliative care through the referral system by the OPO
- Trauma rounds provide briefing on patient case
- Initial introductions to the family
- Palliative care established relational support
- Palliative care positioned as liaison for One legacy
Informational Support

“Studies have shown there is a relationship between families’ consent, receiving understandable information about organ donation and brain death, and having been given sufficient time to make their decision.”

(Jacoby, Liva PhD and Jaccard, James, PhD, 2010)

Decoupling and Collaboration Result in Donation

- Knowledge deficits identified
  - Reinforce diagnosis/prognosis
  - Provide detailed information given regarding definition of brain death or DCD

- Identification of WHO the patient was
  - Functional abilities of patient before injury discussed
  - Patient and family quality of life values and beliefs
  - Reiterate total loss of function and brain death

- Promote acceptance of loss of life for effective decoupling

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Supporting One Legacy

- Regular email updates to the Organ Procurement Organization (OPO) regarding palliative care progress and family dynamics
  - Provide collaboration for more successful outcomes

- Notes are then added to the OPO charting system and distributed to all relevant OPO staff
  - Help to facilitate a successful approach

- Palliative care availability 24/7 for One Legacy cases
  - Build trust through continuity of care

- Pre-huddle with OPO before family approach
Supporting Your Hospital

The new palliative care model can help lower the average length of stay, increasing buy-in from your hospital administrators to support the program.
“HERO”

A person of distinguished courage or ability, admired for brave deeds and noble qualities.

A person who, in the opinion of others has heroic qualities or has performed a heroic act and is regarded as a model or idea

An ORGAN DONOR
Donor Families Top 5 Motivators

- Empathetic hospital staff presence
- Direct access to a familiar staff person(s) from time of admission to donation
- Feeling that they were “heard”
- Belief that their feelings were validated and normalized
- Grief support giving hope that they could “go on” without the deceased

“Reasons for not donating (organs) include emotional exhaustion and inadequate staff sensitivity and compassion.”

(Jacoby, Liva PhD and Jaccard, James, PhD, 2010)
Empathic Support

- Join to the family daily from day 1
  - Supportive Services Only
  - No goals of care discussion
  - Patient and family centered
  - Hearing their stories and grief

- Initiate Relationship
  - Identifying family values/beliefs
  - Honoring family culture
  - Identifying decision makers
  - Assessing/Overcoming Barriers

Standards in Practice

“Palliative care teams demonstrate empathy well and assist in complex communication interactions”

Caring Connections

➢ Between supportive care and family

➢ Between supportive care and hospitalists
  - Listening to and validating concerns
  - Normalizing feelings
  - Building a trusted relationship
  - Speaking honestly of death/ next steps

➢ Between supportive care and One Legacy
  - Huddling and re-huddling
  - Sharing family values and language
  - Collaborating to resolve barriers
  - Coordinating approach
The Power of the Spoken Word

Psychoanalysis is based upon the notion that when patients hear themselves tell their story, they gain insight into their problem and its reality, often bringing relief and resolution.


Communication involves more than just "saying something." Its real essence lies in "being heard."

- Susan J. Kline
Decoupling
Acceptance of the Loss

- Once families understand medically and emotionally that their loved one cannot survive, and have been allowed to grieve, they are better able to accept the loss and donation of their loved one.

- Families are presented respectful truth from a trusted source.

- Families are assisted for rituals, goodbye.

- The death becomes meaningful.

- One Legacy enters a warm room.

- No complaints makes happy administrators!

- It’s the right thing to do.
Proving the Paradigm

“However beautiful the strategy, you should look occasionally at the results.”
- Winston Churchill

The Palliative Care Team

- Bonds with the family as trusted caregivers and experts
- Identifies and overcomes barriers to donation consent
- Provides medical evidence and emotional support needed to gain acceptance and donor consent
- Allows time needed for family rituals and unity of decision
- Collaborates with One Legacy regarding shared goals, planned outcomes
- Creates a warm, welcoming room for the One Legacy team members
- Helps to secure lifesaving organs!
The Results Speak for Themselves!

Optimizes often under utilized palliative care teams

Improves donation statistics

**17 donors/50 organs/ 48 recipients ytd***

Brings families to an understanding of the prognosis and decoupling thereby avoiding conflict, lawsuits, loss of trust

Improves relational trust between the OPO and donor hospital administrators

Assists physicians and families with the difficult task of end of life conversations

Preserves the integrity of the mission and the messengers

Jacoby, Liva PhD and Jaccard, James, PhD, 2010: Perceived support among families deciding about organ donation for their loved ones. doi: 10.4037/ajcc2010396 Am J Crit Care September 2010 vol. 19 no. 5 e52-e61