

# Companioning Families Learning the skills

**Laura Hawryluck, MSc, MD, FRCPC,  
Physician Leader,  
Ian Anderson Continuing Education Program in End-  
of-Life Care  
Assistant Professor Critical Care Medicine**

**Kerry Knickle  
Special Projects Director,  
Standardized Patient Program,  
University of Toronto**

# What does Companioning Families mean?

- Sharing the grief, anguish and loss
- Listening
- Acknowledging and “giving permission” to express intense emotions
- Answering questions, responding to fears and anxieties
- Addressing issues of guilt, blame
- Respect for beliefs, values, culture, rituals



**Sharing the humanity**

# Companioning — The Importance

- First and foremost, sign of caring & compassion at time when need it most
- Defines quality of care
- Convey information and support
- Builds trust
- Helps in initial grief/bereavement
- Helps in decision-making re EOL care/organ & tissue donation

# Organ Donation Rates

- Current donation rates are clouded by poor data collection
- Reported as donations/million population
- Many hospitals do not keep track of all potential donors and consent rates
- Not clear if lower consent rates reflect
  - Missed opportunity to provide the option
  - Lower rate of consent
  - Less candidates for donation
- **Ontario has one of lowest rates in Canada**

# Challenges in discussing organ & tissue donation

## Medical literature

- A number of studies have examined the reasons for, or factors associated with, giving consent for donation
- These factors can be divided into 2 categories: unchangeable or changeable

# Unchangeable factors

- The brain dead patient's age
- Prior discussions and beliefs regarding organ donation
- Ethnicity
- Socioeconomic status and etiology of neurological death cannot be altered

Are these factors really NOT changeable?

- Lower rates of consent may reflect misconceptions and distrust
- Exploring such misconceptions, and sources of distrust, by skilled communicators may result in increased rates of donation in these groups

# Changeable factors

Can be divided into:

- 1) **who** discusses the possibility of donation
- 2) **what** is discussed
- 3) **how** it is discussed
- 4) **where** the conversations occur and
- 5) **when**



# TGLN telephone survey: What do we know about Ontario?

- 603 respondents from March 23 to 29, 2004
- 77% willing to donate own organs for transplant purposes
- 66% likely to consent to donating family member's organs even if unsure of family member's donation wishes
- 94% are either very likely (85%) or somewhat likely (8%) to donate a family member's organs when aware of donation wishes

## TGLN telephone survey: What do we know about Ontario?

- 38% believe they understand donation
- 69% are interested in learning more
- 53% report signing donor card
- 45% of those who have not signed say they would be willing to do so
- 96% believe in importance of telling family of wishes but only 44% report having a family discussion

## However...

- Clinical practice would refute claim that don't perceive additional pain as an issue
- Confusion about ethical and legal standards
- Lack knowledge of process

# Legal & Ethical Considerations

- Donation & transplant is at forefront of technology
- Forefront of ethics & law
- Lack structured teaching in ethics, law, culture
- Trillium Gift of Life Network Act and Health Care Consent Act must be understood
- Need for conflict resolution skills
- Need to develop abilities to think critically to face the challenges that lie ahead

# Current Teaching

- EOL care is not taught
- Not taught how to communicate about EOL issues
- Organ & tissue donation, if taught at all receive only passing mention
- Not seen as integrated part of EOL care
- Families report extremely variable levels of skill when communicating with healthcare providers on issues related to death and dying

# The Problem

- Lack training/poor role models
- Difficulties in responding to emotions
- Problems showing empathy
- Worsen in course of training
  - Not perceived as important
  - Not many effective role models
  - Emotional and physical fatigue

©Used with the permission of the Ian Anderson Continuing Education Program in End-of-Life Care, University of Toronto



# Why should we care?



- Research shows important unmet need of families
- Problems:
  - talking about end of life issues
  - responding to emotions
  - providing support
- Communication, accessibility and continuity rated more important than clinical skills
- May result in unwanted Rx, prolongation of dying

# Summary of current knowledge

- A number of barriers to obtaining consent for organ donation
- Reasons for, or factors associated with, giving consent for donation can be divided into two categories: unchangeable or changeable
- Communication skills are key to supporting decisions to donate organs and tissue



# 8 Steps to increase donation rates

1. Discussion occurs with intensivist & OPO
2. Know yourself: Personal values, beliefs & experience of individual seeking consent
3. Know cultural & spiritual beliefs
4. Show your caring and compassion
5. Clearly and gently explain neurological death
6. Explain what to expect, how will help others
7. Find a private, quiet location
8. Consider Time & Timing

# Goals

## To learn:

- How to communicate about neurological death, organ/tissue donation with substitute decision-makers
- How to address common barriers to donation
- How to provide emotional psychological support no matter what the final decision is re donation
- How to find the strength you need to carry on

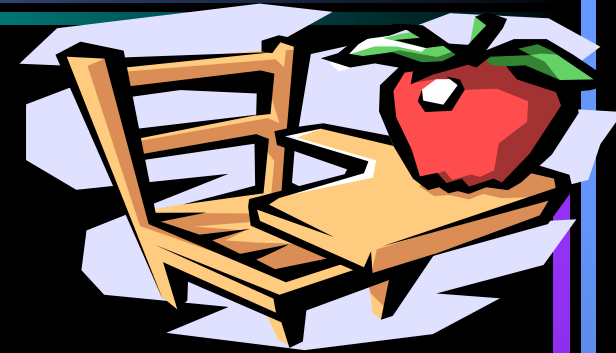
# Needs Assessment....

## Some helpful questions



- What aspects of communicating with patients and/or families are most difficult?
- What topics and/or emotions do you find difficult?
- What situations cause you the most discomfort? What is it that makes you so uncomfortable?
- How have your past experiences, professional and personal contributed to your discomfort?
- What skills do you wish to improve?

# Share personal experiences



- Share your own personal experiences:
  - Helps us find the strength to go on
  - Way of honoring people for whom things did not go well
  - Learn different approaches
  - Gain insight into why certain situations are particularly troublesome
  - May enhance abilities to improve skills
  - All of us make mistakes

# The Gift

- THE STORY OF A PERSON WHO IS LOVED
- The LOSS of this person
- Gift of ONE life to Others
  - in the purest sense of the meaning
- NOT a platitude
- A precious GIFT that MUST be honoured

# The Intensity

- The emotions are intense....
- Nature is very complex....
- You may never understand all of them –it may take years for families to sort through them
- Do not be afraid of this intensity
- Do not seek to repress
  
- IT IS NOT ABOUT YOU!!!

# The Family Perspective

- To begin to appreciate the family's perspective, must seek to understand:
  - the profound grief,
  - anger
  - blame
  - guilt search for meaning
  - questions of faith and
  - LOSS and emptiness

# The Family

- Intense emotions --?never before felt
  - 1) seeing loved one seriously ill AND
  - 2) understanding nature of illness, treatment options and
  - 3) making “best” decision
- Conflict/Torn
- Lack of support → CRISIS



Just WHAT are we asking them to do NOW??

- We ask them to tell us: “What their loved one would have wanted regarding organ donation if still able to tell the healthcare team”

# Time

- Do not rush the family!
- Its not about your time frame!
- DO give them a sense of when decisions need to be made
  
- Sense of time is one of your gifts to them
- Be prepared to change your agenda

# Timing

- Judge readiness of the family to hear information:
  - Is everyone present who needs/should be present?
  - Non verbal cues
  - Questions
  - Are they “not registering”?
  - Respect them when they say “Stop”
- May have to halt the meeting and return later
  - Ask them if they feel able/want to continue
- Do NOT abandon at signs of intense emotions

# Sharing the Humanity

- One of the most difficult things asked of us
- THE MOST IMPORTANT THING WE DO
- Sharing the emotions, the loss, the vulnerability and uncertainties
- Through the stories, getting to know, caring for someone who is already dead
- Getting to know , caring for and bonding with a family ones at a devastating time
- Abandoning your more public façade
- Acceptance and real meaning of dignity

# How can I help the family?

- Listen to the stories
- Accept their loved one, them, their relationship with each other
- Acknowledge & Respect the difficulty of their role
- Care for their well being
- Offer emotional and psychological support
- Offer to help in any way you can
- Offer to arrange for spiritual support
- Bereavement counseling resources

# How can I help the ICU team?

- Tell them what happened when you were with the family—WRITE it in the CHART!
- Emotions/dynamics/questions/ concerns
- Does the ICU need to clarify any aspects of care received?
- How can the team provide ongoing support?
- How can the team help facilitate goodbye rituals?
- Where do we go from here?
- Ask the team how they are coping?

# The Strength to carry on....

- Know yourself
  - Anticipate what will be hard
  - Try to understand “why”
- How do you relax? Find peace? Regain perspective?
  - Debrief
  - Collaboration/Teams (ICU/OR/Transplant)
  - Mentors AND Peers
  - Friends
  - Family?
- Focus on the meaning of what you do to donors, families, recipients

# Ethical, Moral and Legal Dilemmas

## Resources

- TGLN standards to common dilemmas
- Ian Anderson Program:  
[www.cme.utoronto.ca/endoflife](http://www.cme.utoronto.ca/endoflife)
- Joint Centre for Bioethics: [www.utoronto.ca/jcb](http://www.utoronto.ca/jcb)
- Caring for Donor Families
- Grief, Dying and Death — T. Rando
- Cultural Issues in End-of-Life Decision Making  
— Kathryn L. Braun (ed).
- Legal Advice — Hospital/TGLN



# TGLN Support in the Future?

- Challenge:
- Think about of what would help you?
- LISTSERV?
- Team Meetings?
- Case reviews/forums for discussion
- References for in depth reading

## Conclusion:

### 13 Steps to discussing Donation

1. Introduce yourself and explain who you are
2. Understand the GIFT and what you are asking
3. Explain neurological death
4. Explain Process of donation
5. Answer questions/address concerns
6. Respond to emotions
7. Help in decision-making

# 13 Steps to discussing Donation

8. Be sensitive to issues of time and timing
9. Share the stories AND
10. Share the humanity
11. Convey empathy, support and caring no matter what the decision is re donation
12. Support initial grief
13. Find the strength to carry on

# Always remember.....

- Life can change in a heartbeat
- It is a privilege to be a part of someone's life to hear the stories and share the sorrow — honor the experience
- The stories you will hear and the things you will see will teach you what is TRULY important in life
- It's a HARD road — sorrow and joy
- Bear Witness
- Learn.....