Consent Leading Practice

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Conflicts of Interest

- I have no conflicts of interest to declare.
Objectives

• Review the Canadian Leading Practise Guidelines on Consent in Organ Donation.
• Discuss each of the 12 recommendations.
Developing Canadian Best Practise Recommendations

• Workshop held February 2014
• 44 Participants
• Exhaustive literature review/ Environmental Scan of current guidelines, legal review of Canadian Donation, consent and requesting legislation.
Recommendations 1.

• Effective Conversations with Families
  – Effective conversations with families of potential donors are collaborative, compassionate, and supportive, providing meaningful information regarding donation and its value. This supports families in reaching an **optimal and enduring decision** that is also respectful of the wishes of the potential donor.
Pre-Mentioning

- The pre-mentioning of organ donation is a distinct challenge in Canada at the present time.
- Pre-Mentioning is any discussion or offering of organ donation prior to the appropriate time, and done by someone not trained in organ donation.
- Pre-Mentioning leads to less organ donation via two pathways:
  - 1) Erodes trust
  - 2) Misinformation
2. Approach All Families

• Approach the family of every potential donor and offer the opportunity for donation.

• Notify the Organ Donation Organization as early as possible and before the initial donation conversation with the family.

• All families deserve an opportunity to make this gift of generosity.
3. Pre-approach Planning

- Elements of Pre-approach Planning
- Convene a team huddle with Organ Donation Organization donor Coordinator and key members of the health care team prior to discussion with families. At a minimum, include the donor coordinator, most responsible physician, and primary bedside nurse(s).
4. Topics in Pre-Approach Planning

- To ensure a well-planned approach, include the following topics in the team huddle.
  - Review information about patient, including medical status, eligibility, and prior donor registration/expressed intent to donate if available
  - Identify family members and related issues or conflicts that may impact decision-making.
  - Determine where and when the initial conversation should take place.
  - Determine who will lead the initial conversation with the family, who else will be in the room and what their roles will be.
5. Clear Communication of Grave prognosis and Death

- NDD- ensure the family has a clear understanding of neurological death, and has accepted the death before discussing donation.

- DCD- hold donation discussion after the consensual decision to withdraw life sustaining therapies is made.
  – Decouple if at all possible in DCD.
6. Information Provided to Family

- Provide the family with sufficient information, in a clear and comprehensive language to make an informed decision.
  - Be transparent about roles and responsibilities
  - Describe the value of Donation
  - Review Donation Registry/intent.
  - Describe the process, medical/clinical considerations and probability of Donation.
  - Describe any impact of funeral arrangements.
7. Communication Style

- When communicating with families, demonstrate sensitive, compassionate, and caring behaviour with a focus on family well-being.
  - Use a confident and positive approach, rather than a guarded or apologetic approach.
  - Do not use aggressive or coercive language, or strategies that polarize families.
8. Explore Family Reluctance

- Explore family reluctance to donate by sensitive discussing reasons, addressing medical, religious or cultural misinformation or misconceptions, and dispelling myths.
  - In the case of initial refusal, it is acceptable to re-ask for donation if the patient has previously registered intent to donate, if new information becomes available, if the family misunderstands the information or if there have been previous conversations by untrained staff that have provided incorrect information.
9. Supporting Families

• Support the family during and after donation discussions, regardless of whether they consent to donation.
  – Provide a dedicated, trained health care professional who focuses on family support throughout and after the process for the duration of family’s stay at the hospital.
  – Provide post-donation grief support/follow-up services and donor recognition.
10. Requester Skills and Characteristics

• The following skills and traits are essential in leading donation conversation with families:
  – Good communicator, listener, facilitator, with high emotional and cultural intelligence.
  – Open, honest, collaborative, and patient
  – Self-aware, non-judgemental
  – Comfortable in dealing with families in crisis
  – Trained and experienced in dealing with conflict
  – Compassionate
  – Passionate and knowledgeable about organ donation
  – Able to work well with a variety of personalities.
• Provide structured, formal training and competency assessments for individuals leading organ donation conversations.
11. ODO’s and Hospital Relationships

- Build a strong and trusting relationship between the Organ Donation Organization and the donation hospital and establish an effective donation environment in hospital:
  - Create a culture of organ donation, making organ donation an integral part of quality end of life care. Where not offering organ donation is considered a medical error.
  - Engage emergency departments
  - Make early referral a norm.
  - Provide health care professionals with continuing educations.
  - Ensure evidence based policies exist in the hospital.
12. Metrics to Measure

• Use the consent rate
  – Percentage of the number of consenting families over the number of families approached.
  – Recognizing the limitations of the consent rate as a measure of family satisfaction and well-being. A survey index should be developed to assess the impact of support provided to families.
Questions