Discussing neurological death and the option of donation
(including ethical and legal considerations)

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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

Where do you begin?

- Ask the ICU team about the person
- Ask about the history — story of illness
- Ask about the family
  - Who are they? What is the dynamic between them?
  - When did they find out that their loved one was admitted to hospital to the ICU?
  - Were they with him
  - How are they coping?
  - Are they in different places emotionally?

Then…

- Ask the ICU team their perception of how the family feels re donation
- Ask the team if they can introduce you to the family AND stay for the meeting
- Find a private place….

Introduce yourself

- Be VERY CLEAR on who you are and what your role is:
  - "My name is Sara. I am an organ donor coordinator from the TGLN
  - I am here to talk to you about the possibility of organ donation and to help you decide if this is the right choice for you and your loved one
  - I am also here to help and support you in any way I can in this very difficult time…"

Show empathy and caring

- "I am so sorry to be meeting you like this…."
- "I can't imagine what a shock this must be…"

- Very important
- First step to show you care about the family and their loved one
- Last thing you want to do is launch into explanations of organ donation – conveys message that you ONLY see this person as a repository of organs

AVOID

- I KNOW
  - How you feel…..
  - How hard this is for you….
  - How confusing this is….
  - How strange this is……

YOU DO NOT KNOW!!!

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Timing

- “Is this a good time for us to talk about organ donation or would you like me to come back later?”

- Allows the family to indicate whether they are ready
- You are a companion —

  Neither in front, nor behind

Who is here?/ Who needs to be?

- “Is everyone here that you would like to be here?”

- Often families will not say anything unless asked:
  - They do not want to delay you
  - They know you are busy
  - They are afraid you will vanish…never to be seen again

Initial questions

- Crucial to convey/reinforce empathy & caring—THEY matter to you…NOT a formality
- See and match the language they use
- Gauge understanding
- Clarify misconceptions & correct mistaken information re illness/care to date
- Gauge emotions and family interactions
- Re-address critical issue of

  “What is neurological death?”

What do they know and understand?

- “I would like to start by asking if you have any questions about what the ICU team has told you?”
- “About the care he/she has received?”
- “We share a lot of information when somebody is in the ICU. Many families find it confusing and overwhelming. Is there anything that isn’t clear in what you have been told? Anything you would like us to go over again?”

Answering initial questions

- Crucial to know the story!
- If you don't know about something
  - ADMIT IT
  - Develop a strategy to find out
    - Asking the ICU team
    - Tracing details down from records/EMT/other hospitals
  - DO NOT FLUB IT OFF — "I can't answer that/ Its not my area/ I was not involved in that part of his care"

“Tell me about your son…”

- Some characteristics may become apparent as they answer your initial questions
- If not, ask….
- DOES make it harder to fulfill your role
- Get to know and like the person who is now brain dead
- Helps you remember the reality and power of of the GIFT

The stories —
“He sounds like a wonderful, special person”

- Many families will feel a need to share the stories of their loved one
- Way of keeping him close and real
- Way to hang on
- Way to reassure they will NEVER forget
- Way for them to make you understand HE is A PERSON
- Important to know you care about him
- Way to start grieving

Encourage the stories

- Do NOT interrupt
- Do NOT rush reminiscing
- Do not impose your agenda or time schedule

- May find yourself laughing — this is normal
- May find yourself crying — this is normal
- It is OK to laugh and cry WITH the family….

Encourage questions

- “I want you to feel free to interrupt me AT ANY time if what I am saying is not clear or if you have any questions as we go through this….”
- “There is no such thing as a question that is not worth asking”
- “Many people find that questions only occur after they have had some time to think and talk about the information that I am going to share with you… Please write down any questions that come up. I will be happy to answer them when we meet again…”

AVOID

- Euphemisms
- Jargon
- Diversions
- Withdrawal

} to escape the INTENSITY

- Language you would use with a colleague
- Talking down to family

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Neurological Death

- Needs to be crystal clear
- Often will have had a confusing explanation from the health care team:
  - "We will withdraw life support and let him die"
- Often will be confused because loved one
  - feels warm
  - looks unchanged
  - heart beating, lungs are moving, monitors record normal vital signs

Neurological Death—Where do I start?

- Explain 2 main parts of the brain:
  - Cerebral cortex: part that lets you think, talk, write, that makes you the person you are
  - Brainstem: The part that controls your breathing, your ability to be awake, that keeps your body in balance

Neurological Death

- Explain degree of damage
  - neurological death means the brain has been so severely damaged that it will NEVER recover
  - Brad will never be the person you loved
  - neurological death means that both parts of the brain are not receiving any blood flow or oxygen — it does mean that the brain has died

Neurological Death vs. Coma

- Explain the differences
  - In a coma specific parts of the brain either in the cortex or brainstem have been damaged or affected by things like drugs
  - Depending on the cause, you MAY recover from a coma. If you don’t you can live in a comatose state because the parts of the brain that control your breathing, that keep your body on even keel are not damaged
  - If you wake up, you may become the person you were before or may wake up with problems that affect your quality of life

Neurological Death vs. Coma

- In neurological death you will never wake up
- Because the brainstem is so damaged even the machines and the drugs we have in the ICU will not be enough to keep you alive beyond 1-2 days at the most
- It is for this reason that neurological death is felt to be the same as death
- Saying “neurological death = Death” is NOT helpful UNLESS you explain WHY
- Mention ethics/law perspectives IF you are asked

Watching Neurological Death Declaration

- Important for some families
- May offer it if think would help the family
- Must prepare them for each test of brainstem function — Tell them what they will see
- Explain how pain will be inflicted and why
- Explain spinal reflexes

- Provide emotional support throughout

Non-Verbal Aspects

- Facial expressions
- Gaze — where are they looking?/eye contact
- Head movement — nodding/shaking
- Posture — leaning farther away from you?
- Interpersonal distance — moving away?
- Touch — welcome or not?
- Voice — holding back tears/growling?

Adapted from Hall JA, Affective and Non-Verbal Aspects of the Medical Visit, The Medical Interview, Lipkin M Jr, Putnam SM, Lazare A eds., Springer 1994 p. 499

Miracles- MAYBE he will wake up? CAN THE DOCTORS BE WRONG?

- Myths/Real stories of people waking up after years in coma
- Gently convey that this is not true here
- “The entire team… everyone looking after your son would love to be able to tell you that they could save your son…. BUT we can’t… There is nothing we can do to save him… There is no chance that he will come out of this or that he will live”

BUT the nurses still talk to him….

- ICU team will often talk AND encourage families to talk to loved one even when brain dead
- Keeps team aware that caring for a PERSON
- Fulfills need to say things left unsaid, to ensure last words are not angry ones
- Most important thing we can do is to help people say "I love you"
- On some level — maybe not in traditional sense — MAY still hear us: when people love connection goes beyond physical presence

How much Oxygen is he on?

- ICU team will have provided explanation of illness/life support — “crash course”
- Many families fixate on details e.g. PEEP/ 02/ creatinine without fully understanding implications for big picture
- Way of trying to grasp Rx of critical illness, of controlling spiraling world
- Way of holding on to hope

The Donation Process

What is involved?

- What happens if you decide donation is the right choice for you?
- Which organs can be donated?
- How do you know his organs can be used?
  - Explain testing/evaluation process…serology/individual organ evaluation
  - Are the tests 100% accurate? i.e. are organs ever rejected at time of surgery?
  - What happens to organs that are not used?

TGLN Step-Specific SOP's

- The TGLN is the provincial organization responsible for all aspects of the donation process from identification of potential donors, through surgical recovery, to the after care of donor families
- The TGLN has created a 12-step diagram to illustrate the process of organ and tissue donation (next two slides)

Step-Specific SOP's

1	Referral and Preliminary Assessment
2	Determination of Death
3	Donation Request and Consent
4	Donor Screening and Testing
5	Preliminary Organ Recovery Planning
6	Organ Placement Process
7	Final Organ Recovery Planning
8	Tissue Placement and Recovery Planning
9	Organ Recovery Process
10	Tissue Recovery Process
11	Donor and Family Aftercare
12	Case Follow-up and Closure

Introduction

This 12-step diagram represents the sequential activities involved in the process of organ and tissue donation. Standard Operating Procedures (SOP) have been organized within this framework, thus, documents relevant to any step may be accessed by clicking on that step in the diagram. General documents not pertaining to a specific step may be accessed by clicking on the most relevant of the six categories featured below. You may also search by keyword or view the Table of Contents directly.

General SOP's & Other Documents

Overview of the Donation Process

Management of the Potential Donor

Database and Waiting Lists

Hospital, Program and Supplier Profiles

Administration

Forms Catalogue

Keyword Search

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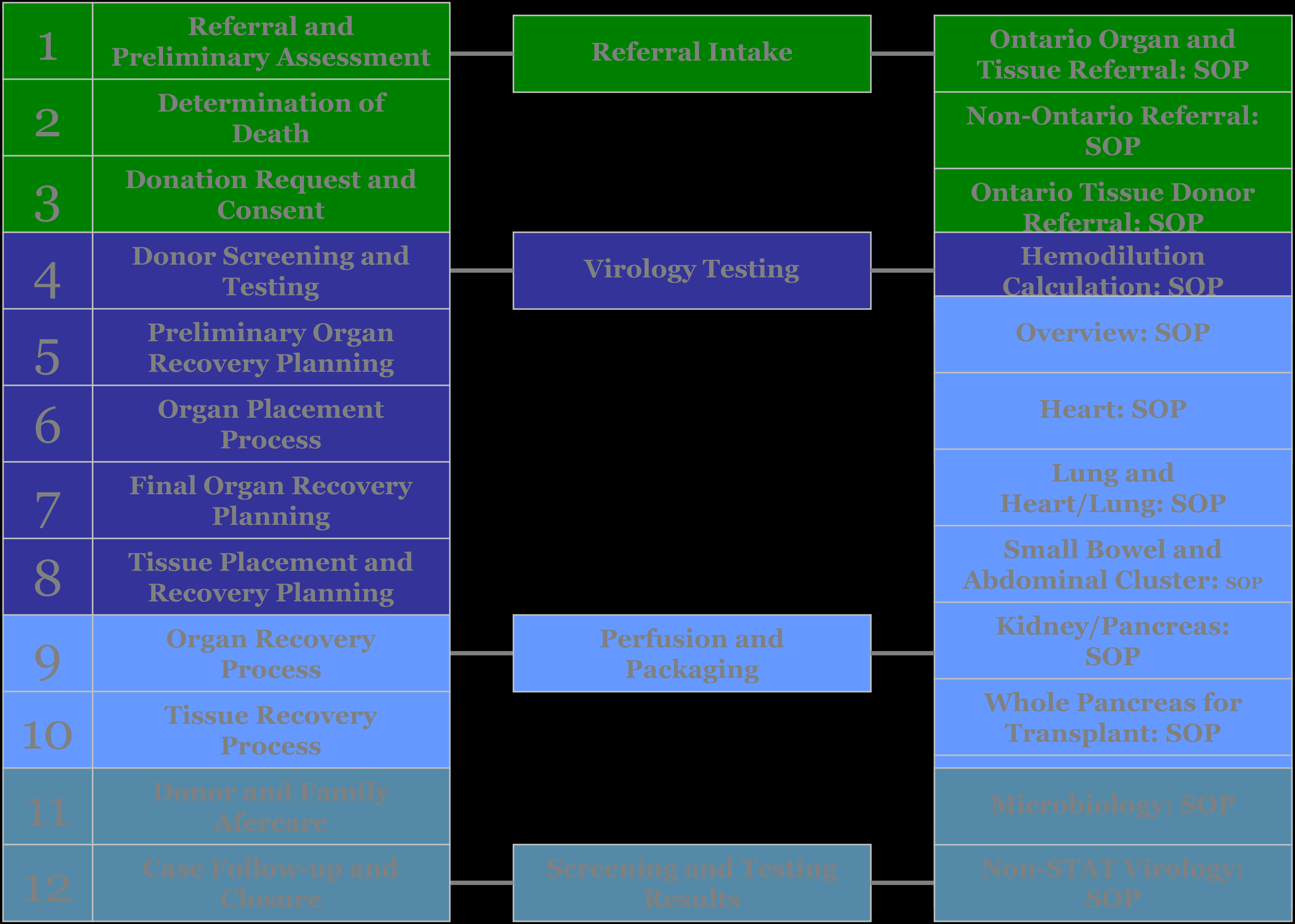
Step-Specific SOP's



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Referral Intake

Virology Testing

Perfusion and Packaging

Screening and Testing Results

Ontario Organ and Tissue Referral: SOP

Non-Ontario Referral: SOP

Ontario Tissue Donor Referral: SOP

Hemodilution Calculation: SOP

Overview: SOP

Heart: SOP

Lung and Heart/Lung: SOP

Small Bowel and Abdominal Cluster: SOP

Kidney/Pancreas: SOP

Whole Pancreas for Transplant: SOP

Microbiology: SOP

Non-STAT Virology: SOP

Questions to address

- Does donation seem to fit with his prior wishes, values and beliefs?
- When will you know if his organs can help someone else?
- What about tissue donation? Which tissues can be used?
- What is involved in tissue donation?
  - Eyes (NOT corneas)/bones/skin/valves
- Options of restricting donation to certain organs/tissue

Questions to address

- Who does the surgery?
- Does he have to be sent to another hospital for surgery?
- How long will all this take?
- What happens to him in the meantime?
- Can we stay with him?
- When do we have to leave?
- Ask about any ceremonies or rituals they may want to hold at the bedside
- Offer to help facilitate this

Questions to address

- How are the recipients chosen?
- Can we contact the recipients?
- Can we decide who/what kind of person will get his organs?
- Will we hear anything about the recipients?
- What does this mean for the funeral?
- What happens if we say “No”?

Explaining YOUR role

- What will you be doing during this process?
- What role do you play?
  - Organization/Coordinating
    - Bloodwork, tissue typing/ancillary tests
    - Calling Trillium Gift of Life Network (TGLN) to find recipients
    - Coordinating and working with ICU/ORs teams
  - Companioning family and ensuring their needs are met

Address their concerns

- Encourage questions
- Recognize need to repeat some information
- Normalize need to hear information several times
- Avoid jargon
- Express care, compassion and empathy throughout — loved one will be treated with RESPECT and DIGNITY
- Emphasize that the care will not be affected if answer is “No” — they will not be abandoned!

Consent

- 3 components:
  - Capacity — must understand & appreciate
  - Disclosure — how much info do they need?
  - Voluntariness
- Waiver
  - Waive desire to disclosure — TENUOUS
  - Explore and make sure this is what they want to do
- Therapeutic privilege
  - Disclosing info would upset them — NEVER take this stand

Disclosure:
How much information to give?

- First, need to know this is an option: There is a choice
- What would a reasonable person need to know in this situation — modified objective standard in legal terms
- Answer all the questions described in previous slides
- Answer any additional questions they have
- What is the alternative? Withdraw life support — what does this mean? How ?

How much information to give?

- Palliation — how will this be achieved?
- Dying process
  - What will happen?
  - What can they expect to see?
  - Will their loved one stay in ICU?
- The team's and YOUR availability to help them through this

AVOID

- Information overload — be sensitive to the family's responses and readiness →

  Goal is not to dump information on family in a mechanical way

- Too technical language
- Rushing the family to keep to your time schedule
- Any misconceptions of who you are/what your role is

How much time to they have?

- Need to know they do NOT have to give you an immediate answer
- Encourage them to take time and talk about donation among themselves
- May leave them with information pamphlets re donation
- Do give them a sense of time frame in which you need to hear from them

How will they let you know?

- Tell them you and the ICU team will be available to answer any questions they may have
- Tell them how they can reach you
- Tell them how/who they contact re their decision

The Family

Acute Family Emotions

- Shock
- Grief
- Fear
- Guilt
- Anxiety
- Anger

- Over-dependency
- Shielding
- Disbelief
- Denial
- Depression

Adapted From Buckman R., *How to Break Bad News: A Guide for Healthcare Professionals*, Johns Hopkins University Press Baltimore 1992

Shock/Disbelief/Denial

- Silence, Not registering, “No!”
- It CAN’T be happening → It ISN’T happening
- Surreal

- Coping Mechanism
- Does NOT mean they have not heard you or are not listening/understanding
- Empathize
- Normalize
- Go gently and give them time

Anger

- Most complex and difficult emotion
- Anger can be directed at their loved one, themselves, healthcare team/system
- Can be a ploy to mask other reactions
- Can be a way of trying to regain control when life seems to be spinning out of control
- Can be a way of asserting/seeking power when feel disempowered

When faced with Anger…

- Do not RUN or PANIC!
- Give them permission to express
- Explore causes, convey empathy:
  - “You seem angry…. I would like to talk about this…. Can you tell me what has happened or what is causing you to feel this anger?”
- Normalize:
  - “If I was you, I would be angry too!”
  - Many people feel angry at their loved one when something like this happens…. Its normal…it’s a sign of how much we love them, how how much we wish this just wasn’t happening

Is their anger appropriate ?

- Anger may be completely justified
- Sometimes it may result from misunderstanding of the care received → clarify and re-explain
- Sometimes, things do go wrong → may not be anyone's fault….be honest, apologize
- Acknowledge imperfect system
- No need to tow "White Line"
- If need information, if perceive a problem or are concerned re quality of care received, offer to explore it…

What isn't allowed!

- It is NOT permissible for them to scream at you, threaten you, or throw things/destroy property
- If this happens tell them:
  - this behaviour is not allowed
  - excuse yourself and
  - offer to return later when you can have a calmer conversation

Guilt or Self-Blame

- Hidden emotion
- Can drive requests for Rx and denial of reality
- May be great reluctance to share
- Confessing or verbalizing their “role” in loved ones illness→ increases vulnerability

When faced with guilt…

- Ask about it if you think it might be a problem:
  - Some people feel that this would not have happened if only they had convinced him to see a doctor sooner. Do you feel this way?
- Explore causes
- Normalize and convey empathy
- Reassure:
  - “ We can’t tell you the outcome would have been any different” Sometimes, even when people come to the hospital sooner, this cannot be prevented”

Blame

- Search for meaning — some way to explain WHY….
- Blame their loved one, healthcare team, system, God
- Did something really go wrong?
- If “medical error”, acknowledge it, tell them you will help them look into it (contact Patient Representative), apologize
- However, need to talk with them about what to do now…in current situation….

When faced with blame..

- Explore their feelings/perceptions
- Be empathetic and supportive
- Normalize:
  - "I can understand you feel this need to blame someone…to hold them responsible. I think I would feel the same way…."
  - "However, no one is to blame here…This is something that could not have been foreseen or prevented…" (Say this only if it is TRUE)
- Offer to involve Chaplaincy, Social Work

Fear/Anxiety

- Very common
- World is spiraling out of control
- Fear “giving up too soon” or “he has suffered enough”

- Explore causes
- Normalize
- Empathy and support
- Offer to arrange counseling if needed
- Social work support

Overdependency

- Over-reliance on healthcare team
- "You know best…"
- Seeking security

- Need to make sure they understand
- Trust is good
- Not ensuring they understand and appreciate choices because they will agree with you to donate is BAD

Shielding

- “We can’t possibly tell Mom… it will kill her”

- Gently explore reasoning
- Develop a plan together: how can you tell her together with supports in place?
- Cannot shield someone from the pain of LOSS no matter how much you would like to
- Respect different cultural approaches…
  - share the information you need to convey and
  - ask them how best to do this respecting their cultural beliefs….

Children

- Families almost always want to shield
- Can be more frightening to the child if don’t see their loved one — imagination
- Miss an opportunity to say goodbye
- May feel they caused their loved ones illness: “Magical thinking”
- May stifle their own grief for their parents
- May feel they have to assume place of loved one to help parents heal
- May feel unloved, in the way…..

When family member is a child…

- How are they coping? Eating? Sleeping? School? Ask about nightmares?
- Educate re grief in children and unique perspectives e.g.“magical thinking”
- Offer help of Children Services now and/or in future
- Talk about bringing the child to the ICU with support to visit their loved one as an option
- Grief kit: Teddy bears/information pamphlets?
- Respect parents feelings re appropriateness

Things to remember….

- Don’t be afraid of silence
- Don’t be afraid of intensity —
  ITS NOT ABOUT YOU!
- Don’t be afraid of getting to know the people involved — It’s most special and rewarding experience you will have!
- Don’t abandon
- Don’t make promises you can’t keep
- Recognize the power of non-verbal communication

Getting back to the ICU team…

After your meeting, tell the team what happened:

- What did you say? How did they react?
- What questions did they have?
- Were there any misconceptions?
- Emotions/Interactions/dynamics
- Need for ongoing support: other team members
- Ceremonies/rituals/leave taking rituals
- What is the plan?
- WRITE IT DOWN IN THE CHART

Common Questions

Will he feel Pain?

- Likely a lot of pain involved prior to neurological death
- Related to “He has been through enough”
- Spinal cord reflexes — if witnessed — may be taken as a sign could still react to pain even if understand brain is dead
- Anesthetists report increases in BP/HR during incisions in OR
- Commonly give anesthetics in OR — make sure you know practice in your institution

Can I have his sperm?

- Sometimes wives or long term partnerships make the request
- Goal: In vitro fertilization and children in the future
- The retrieval of sperm is no longer possible in accordance with new laboratory policies

Can we stay with him?

- Open visiting in ICU — no restrictions
- Can accompany to OR doors
- Can see him post-op after the donation is complete
- NO obligation to stay —
  - Many families feel cannot stay
  - Many do not accompany if has to be transferred to another hospital
  - Encourage them to do what is right for them

What about the funeral?

- Open casket is still possible — would not be able to tell donated organs
- Organizing donation process may delay funeral slightly
- Funeral homes — once chosen — coordinate arrangements with the hospital
- There is no rush to find funeral home
- Need to take time to find the right place for them

“What would YOU do…?”

- Acknowledge the difficulty of the decision
- Emphasize that this is a personal decision which is different for everyone
- There is no right or wrong answer
- May say
  - “I honestly don’t know what I would do in your situation…. It is a hard decision… let’s talk about it some more… What do you think would make this decision easier for you?
  - I would donate…. But that is a decision that is right for me. We need to figure out together what is right for Brad and you

“He has suffered enough…”

- Fear more pain will be involved…
- Fear will suffer as body is maintained on machines until donation
- Fear long delay
- May be a sign that the family feels THEY have gone through enough
- VERY common reason that people say “NO” to donation

What can I say when I am told: "He has suffered enough"?

- Normalize this feeling
- Ask the family to tell you what THEY mean by the statement
- Clarify any misconceptions re pain/suffering — he will NOT feel pain
- Gently explore whether they feel donation
  - would be something he would value
  - something that would be important to him
  - Ask about prior wishes — would this be a way of honoring what was important to him?

Responding to a "NO"

- Be gracious, respectful and unprejudiced
- Be caring & empathetic
- Remember: Its OK to say "No"
- ITS NOT ABOUT YOU!
- You are not on commission
- Ensure family is not left feeling guilty that they did/can not consent
- Do not abandon — offer your ongoing support… "Is there anything you can do to help them?"

Common Ethical / Legal issues

Signed Donor Card

- A signed card is legally binding under *Trillium Gift of Life Network Act*
- May be a problem if family
  - does not know of prior wishes
  - does not appreciate importance
  - does not agree with loved one
- May be a source of conflict
- At this time, family as substitute has never been challenged if refuse consent in presence of signed card

Signed donor card — AND family says “NO”

- Troubling if consider not respecting a known prior wish and if strongly support donation
- Ethically dilemma:
  - Are these wishes still valid?
  - Do we respect wishes or respect substitute interpretation of wishes now that neurological death has occurred?
  - What of effect on substitute’s grief?
  - What of impact on future donations?
- At this time family wishes still would prevail

Waiting for Neurological Death

- Person may not be brain dead but may have a high likelihood of becoming brain dead
- Do we continue life support with SOLE goal of waiting for neurological death so can donate organs?
- May be a way of respecting known wishes
- Suffering? Conflict of interest? Resource issue?
- Varying policies — some place will, others won’t — Know your institution
- Negotiate on individual case basis

Tissue Donation & Discrimination

- Contraindications to donation exist for medical reasons, e.g. sepsis, cancer, HIV…
- Some contraindications are discriminatory
- Based on international tissue bank standards
- Based on resource issues
- Its not JUST!
- Can admit such policies are not fair…
- Can offer to write a letter to standards cmte
- Will take time and decreasing stores to change if EVER do!

Non-Heart Beating Donation

- Currently occurs in USA and parts of Europe
- NOT in Canada
- Need to thank family for their offer, for the gift that such a donation would be…
- THEN explain that this is not currently an option in Canada
- If pressed can say there are ethical and legal issues surrounding this type of donation that must be discussed and agreed upon before we decide to proceed with NHBD in Canada

Positive serology: what do you tell?

- The reporting of positive donor serology for communicable and reportable diseases is the responsibility of public health
- All donor laboratory results are part of the TGLN donor charge and not the property of the donor hospital
- TGLN has a policy outlining the process for reporting the results (go to the TGLN website for further information)

What do you do if SDMs of equal legal rank disagree?

- Assess their decision-making capacity
- Do NOT take sides
- Ask them how they arrived at their conclusion: assess reasoning
- Ask if anyone had spoken to him about his thoughts on donation
- Does anyone know his prior wishes
- Ask them to talk about whether donation would fit with his values, beliefs

10 Practical Pearls for Conflict Resolution….

1. Create understanding environment
2. Set ground rules — no yelling/insults
3. Make decision-making a shared purpose
4. Place decisions in context of values history
5. Listen & look for and explore emotions

Adapted from Conflict Resolution, Dr K. Bowman, © Ian Anderson Continuing Education Program in End of Life Care, University of Toronto

10 Practical Pearls for Conflict Resolution

6. Do not try to resolve past disputes
7. Assess reasoning
8. Clarify misunderstandings/misconceptions
9. Be non-biased
10. Encourage self-awareness: YOURS & theirs

Adapted from Conflict Resolution, Dr K. Bowman, © Ian Anderson Continuing Education Program in End of Life Care, University of Toronto

Contact with recipients

- Often desired by families
- Way to know “their loved one lives on”
- Can see if recipients have characteristics of their loved one
- May look for his eyes smiling out of another person’s face
- May only want contact with recipients of certain organs, e.g. heart
- May be a way for them to make sure recipient is taking good care of their organ(s)

What do I say if they want to contact recipients?

- No contact with recipients is permitted
- No identifying information about recipients is ever released to the donor family
- No information about recipient illness is given
- Recipients may write a thank you letter to TGLN, which can be passed on to the family — identifying information will be removed
- No obligation on the recipient to write a letter

Your personal views

- If asked, you CAN SHARE your views on difficult ethical issues
- AS LONG AS YOU EMPHASIZE THESE ARE YOUR PERSONAL VIEWS
- You are a representative of TGLN and need to act accordingly
- You are NOT OBLIGATED to share your views

The coroner and the police

- Inform the family if you need to call the coroner and explain why…
- Last thing the family needs is to be surprised by a call or visit from the coroner or police