## Clinical Ethics-Based Decision-Making Issue Workup:

# The ethics-based decision process:

- 1. What question are we trying to answer?
- 2. What are the facts?
- 3. What are the relevant values?
- 4. In what order do we prioritize these values?
- 5. Consult appropriately to confirm and justify facts and values
- 6. What are the different possible answers to the question?
- 7. How well does each possible answer allow us to live to our values?
- 8. Make a decision and implement it.
- 9. Live with it & learn from it.

#### The story...

Joan is forty years old and is being cared for in your palliative care unit. She was initially diagnosed with cancer five years ago. This was treated successfully. The cancer returned one year ago and after ten months of active treatment, she and her partner agreed that she wanted to die peacefully and comfortably and made the decision to pursue palliative care.

Joan's pain is significant and the one thing she clearly asked for was to be as pain-free as possible. Currently she is receiving medication for pain that keeps her sedated most of the time. If she did not receive the medication, her pain would be so significant as to not allow her to make decisions for herself.

Joan is currently believed to be actively dying. Because she was expected to live for only a few days more, Joan's partner of two years, Carol, had asked that Joan's family in Vancouver be contacted. She asked the team to do this as she had not yet met the family.

Yesterday, Joan's mother and father, Joan's aunt and two sisters all arrived at the hospital. Joan's sisters and aunt live in Vancouver and have come to see Joan once in awhile over the last year. They have not been involved with Joan since the decision not to pursue aggressive treatment. Joan's parents have just flown in from Manila. They have not seen Joan for over a year. They are all very upset at seeing Joan like this and are asking why she her cancer is not being treated aggressively. They express their Catholic faith and indicate this is not an acceptable way to die. Joan's father demands that as the head of the family, he should be making all decicions about Joan's care.

Most distressing to the care team is that the family has pushed Carol out of Joan's room and are not allowing her to return. They did not know Joan was gay and had never met Carol before. They refuse to speak with Carol. When told about the great care that Carol has been showing for the last year, the family says they do not accept this as they believe Carol has been trying to brainwash Joan. As evidence, they point to the fact that Joan had mentioned some nonsense about turning away from her Catholic faith to become a born-again Christian – the same faith that they have learned Carol shares.

Carol is crushed and spends her time in a corner of the waiting room, praying and crying. Initially she had tried to have conversation with the family, but because they ended up shouting and being unkind to her, she has stopped this. She is concerned that this is just causing Joan additional distress.

The team is deeply distressed and is trying to determine the most ethically justified course of action. Many team members are angry at the family, are concerned about Joan's distress, and feel very badly for Carol.

## **Worksheet 1: <u>IDENTIFYING THE KEY QUESTION</u>**

What question do we all agree we are trying to get an answer to?

Explanation	Tips
• The question we ask will determine the	Design your question so that it allows for a variety of possible
type and scope of answer we get.	answers, not just yes or no.
• The goal is to ensure that the group is	• Questions that begin with "What" or "How" work well.
working on the same problem and	Only include descriptors about which there is explicitly shared
asking the right question to help solve	agreement in your question (e.g. "What should our human resource
that problem.	policy be during a pandemic?" instead of "should we force staff to
<ul> <li>Issues are often complex and this step</li> </ul>	come to work during a pandemic?").
involves clarifying exactly what work is	Pose your question in neutral terms (e.g. "how should the region
being done by the decision.	allocate resources", as opposed to "how can the region avoid
<ul> <li>There will be many questions that</li> </ul>	wasting resources on the elderly?")
present themselves; the challenge is to	Focus on the broad question which, if answered well, will likely
come to agreement on which of the	include more specific ones and will provide meaningful direction for
many questions should be addressed	moving forward (e.g. "what are the goals of care for Mrs. C?"
using this process.	instead of "What does Mrs. C want?").

Questions that need to be addressed
The Key Question, that if answered will provide the team appropriate direction for how to move
forward
?

## **Worksheet 2: <u>SUMMARIZING THE FACTS</u>**

The following are facts we assume to be true. It is important to ensure that we have a shared understanding of this list and that these assumptions are well justified. The extent to which they are, will in part determine how ethically justified our answer is.

Explanation	Tips
<ul> <li>Many beliefs make up any context. The idea here is to ensure everyone is working with the same understanding of the context. The goal is to ensure a shared understanding of the situation, including areas that may be unsettled or controversial, against which the decision is being made.</li> <li>Beliefs that are contentious or unclear should be made explicit.</li> <li>Points of agreement and tension should be named.</li> <li>A fact is a belief that is true. The more evidence that we have for a belief, the more likely it is a fact.</li> <li>The quality of a belief will depend on the evidence we have to support it.</li> <li>For the beliefs that are listed, explore what reasons people have for their beliefs.</li> </ul>	<ul> <li>Work hard to ensure that what gets listed here are beliefs (things that are true or false) about the world and not values (what is important to us).</li> <li>Beliefs usually involve declarative sentences with some form of the verb to be.</li> <li>Remember that the goal is simply to ensure that the team making the decision is on the same page, looking at the same picture.</li> <li>List only those beliefs about which it is important that everyone agree, including things that may be contentious and relevant (e.g. "All possible sources for ventilators have been consulted and all available resources are in the region's possession" and "The pandemic will come in multiple phases"; not necessarily "We have a publicly funded health care system").</li> </ul>

What we know for sure:	Evidence to support this
<ul> <li>About the patient's medical condition, treatment options, etc.</li> <li>About the patient's identity, what her values and beliefs are, what a meaningful life looks like for her, the significance of her illness for her</li> <li>About the other care providers, who's involved and what their perspectives are</li> <li>About the system, who else is affected</li> </ul>	
What we don't know but can find out	Person assigned to undertake the research
•	•

•	•	
•	•	
What we won't be able to know and will have to guess about		
•		
•		
•		
•		
•		
•		

#### Worksheet 3: <u>DECISION CRITERIA</u>, <u>IMPORTANT CONSIDERATIONS</u>, <u>VALUES</u>

What's important, why is it important and how important is it?

#### **Explanation Tips** This step is where values are made explicit. Try to use complete sentences in completing this step. Do this by answering the question, "Whatever our It involves brainstorming what is important in answering the key question. answer to the question, it is important that...". The values become the criteria by which the various Values can be instrumental (important because they give possible solutions to the question can be judged. us something of greater importance to us) or intrinsic At this point all important considerations should be (important for their own sake). When a consideration is identified as important, explore whether it is important named and listed, regardless of degree of importance. So a consideration offered by any group for its own sake or because it gives us something else of member should be accepted and listed. importance. The criteria should then be prioritized. If the latter, be sure to capture the intrinsic value on the The resulting list will be the criteria against which the quality of different options will be judged. Assign each item a numerical value reflecting its relative importance (e.g. 5=crucial, 1=important).

Specific criterion: However we answer the question, it's important that	Priority 5 = Crucial 3 = very important
	1 = important
We make decisions based on the values and beliefs of the patient	
Our decision advances the wellbeing of the patient, from their perspective	
We do not penalize patients for attributes that are beyond their control	
We do not cause harm to others involved in the situation	
The decision reflect the values and beliefs of family members	
We help families to help us understand the perspective of the patient	
We involve members of the family in the manner the patient does or would want	
We honour the integrity of the care team	
We pay particular attention to those who are vulnerable	
We do not cause harm to the patient	

## Worksheet 4: EVALUATING POSSIBLE OPTIONS

Possible responses to the question include...

Explanation	Tips
<ul> <li>At this stage different alternatives for answering the question should be entertained.</li> <li>This step is aimed at creating the room for creatively exploring what kinds of things, conventional or not, might meet the criteria indicated and answer the key question.</li> <li>Options should just be listed and not judged. Just because an option is named at this stage does not mean that it will be followed up.</li> </ul>	<ul> <li>Have the discussion leader explain the brainstorming exercise.</li> <li>Invite members to provide possible ways of answering the question.</li> <li>If anyone challenges an option or offers critical feedback, acknowledge the challenge but don't engage it; ask that this evaluation be held until the next step.</li> </ul>
<ul> <li>This step requires looking at the possible solutions to see which ones best live up to the considerations that are seen as most important.</li> <li>This should be done systematically, checking each of the reasonable/viable options against each of the most important criteria.</li> </ul>	<ul> <li>Put the list of prioritized values next to the list of possible options (flipcharts are helpful for this).</li> <li>Then pick an option and go through each of the prioritized values asking, "How well does this option live up to this value?"</li> </ul>

→ Possible ways of answering the question identified above include:			
1.			
2.			
3.			
4.			
5.			
6.			
7.			

#### Worksheet 5: ARTICULATING THE RESPONSE – A Preliminary Decision

The recommendations/ decision:	
This recommendation is based on the following values (listed in priority order)	
Values not supported by this recommendation include We believe this recommendation, and the balancing of values therein, is justified because	