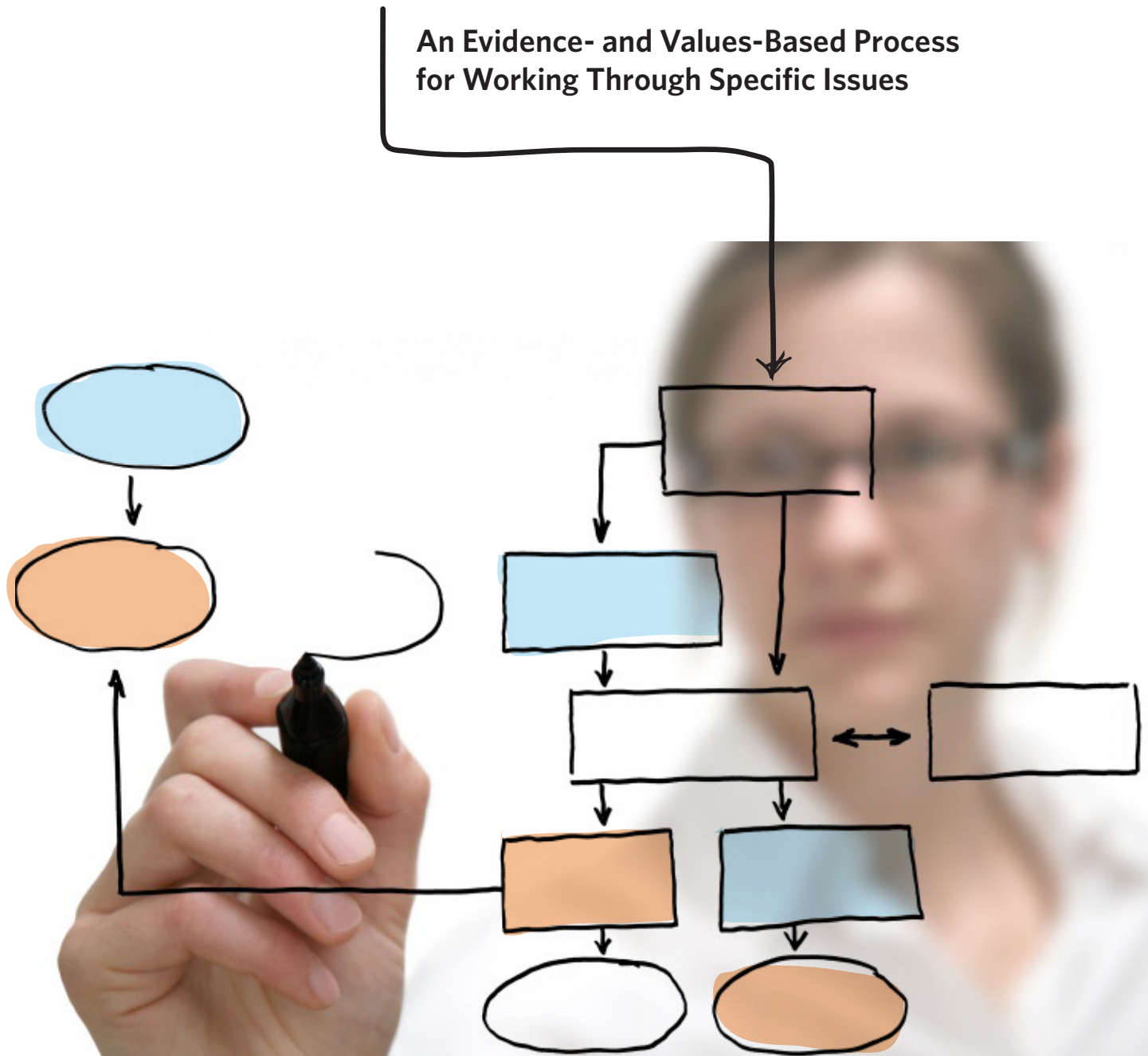


Ethics-Based Decision Process

An Evidence- and Values-Based Process for Working Through Specific Issues



Bashir Jiwani, PhD



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Jiwani, Bashir. (2013). *Ethics-Based Decision Process: An Evidence- and Values-Based Process for Working Through Specific Issues*. Surrey, BC: Fraser Health.

The Ethics-Based Decision Process:

HOW TO USE THIS TOOL

The document sets out a process that can be used in multiple ways, by individuals or teams.

INDIVIDUAL USE

- Simply work through the different worksheets in order.
- You will likely notice that there will be gaps in your information and in your understanding of what should matter.
- If this happens, work through Step 5, develop a plan to gather the missing information and to work out your thinking, and then come back and finish the process.

TEAM USE

- Identify a facilitator in your team, set up flip charts that correspond to each of the steps and substeps in the process, set aside 90 minutes and work through each question with a view to completing the exercise in the 90 minutes.

CLINICAL AND NON-CLINICAL APPLICATIONS

- The process works for almost any issue, personal or professional, clinical, administrative or otherwise.
- For non-clinical or non-health care uses, replace the headings in the worksheets with those appropriate for your context.

An elastic process that can be used in 30 minutes or over a greater period, depending on the care the users wish to take in making a decision and the time available to do so.

Step 1. What question are we trying to answer?

Step 2. What are the facts?

Step 3. What are the relevant values?

Step 4. In what order do we prioritize these values?

Step 5. Who do we need to partner with?

Step 6. What are the different possible answers to the question?

Step 7. How well does each possible answer allow us to live to our values?

Step 8. How do we describe and justify our approach?

Step 9. What are our next steps?

“The world we have made as a result of the level of thinking we have done thus far creates problems we cannot solve at the same level of thinking at which we created them.” –Albert Einstein

Step

Identifying the Key Question

THE KEY QUESTION

What problem are you trying to solve?

SAMPLE QUESTIONS

- “What should the goals of care be for Mrs. R?” (as opposed to “Should we insert a feeding tube for Mrs. R?”)
- “What should the treatment plan be for Mrs. R?” (as opposed to “How do we keep Mrs. R safe, keep the team safe, and provide the best care possible?”)
- “How should we respond to Mrs. R not following through on the care plan we have recommended for her?” (instead of “should we push Mrs. R to come in for her dialysis treatment?”)
- “How should the team respond when Mrs. R’s family brings her in for dialysis, she gently resists, is clearly in pain, and her family insists she gets dialysis with little pain medication?” (Instead of what do we do with this difficult family?)

* Patients, residents or clients.

- 1 Determine the question(s) the group is seeking an answer to.
 - The question you ask will determine the type and scope of answer you get.
 - You want to ensure that the group is working on the same problem and asking the best question to help solve that problem.
- 2 List each as a possible question that the group might tackle.
- 3 For each ask, if we get an answer to this question, will it provide sufficient direction for us to deal with the issue?
- 4 Select a key question from the list.
 - Many questions will present themselves; the challenge is choosing which should be addressed in the time immediately available.

TIPS FOR SUCCESS

- Focus on a broad question that, if answered well, will likely include more specific ones and will provide meaningful direction for moving forward.
- Some questions are really about missing information. Avoid these, we will get to them in the next section.
- Avoid yes or no questions to allow a broad range of answers.
- Questions that begin with “What should” or “How should” work well.
- Only include descriptors in the question about which there is explicitly shared agreement.
- Try to use honest and accurate, yet morally neutral, language — language that others will be able to hear without feeling threatened or judged.
- While this process looks linear, it does allow movement back and forth between steps. It is just fine to choose a key question, continue with the conversation, then return back to confirm and if need be, alter the question selected.
- Don’t worry if this step seems difficult — it is! Take the time to do this work first.
- It can be helpful for the leader(s) to think about this in advance and come to the meeting with one or two possibilities in mind.

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Step

Identifying the Key Question

Questions that need to be addressed:	The Key Question the team will focus on:
1.	
2.	
3.	
4.	

Step 2 Summarizing the Facts

A FACT IS A BELIEF THAT IS TRUE.

The more evidence that we have for a belief, the more likely it is a fact.

The quality of a belief will depend on the evidence we have to support it.

SAMPLE ENTRIES

- Mrs. R is an 80 year old woman.
- She is from Guatemala and speaks a dialect of Spanish that is uncommon.
- She has three children who visit her regularly.
- She defers to her family when it comes to making treatment decisions.
- She has end stage renal disease due to previous cancer.
- She experiences great pain when she's on dialysis.
- The family does not seem to accept that Mrs. R is dying.
- The team is having difficulty communicating with the patient and family.
- The team has no regular opportunity to come together and discuss challenging cases.

"It ain't what you don't know that gets you in trouble. It's what you know for sure that just ain't so." –Mark Twain



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- 1 List:
 - What we know for sure about the context.
 - The evidence we have to base this on.
 - The information that is missing, but that we can find out (and who will do this research).
 - The information that is missing, that we cannot know.
- 2 Develop a shared understanding of the context, including areas that may be unsettled or controversial.
- 3 Discuss the evidence:
 - Is there agreement about the sources of evidence?
 - Is there agreement about how this evidence is interpreted?
- 4 Ask specifically if there are any assumptions people believe are being made that are contentious or unclear and make these explicit.
- 5 Identify the source(s) of the disagreement and if consensus is possible.

TIPS FOR SUCCESS

- Ensure that you list beliefs about the world (things that are true or false – often declarative sentences) and not values (what is important to us – often imperatives – “we should”...).
- Evidence here can be technical (a patient's blood report details) or narrative (stories about the patient's life).
- Remember that reasonable people can understand what reality looks like and how to interpret evidence differently.
- If someone states a belief that is contentious, ask probing questions to understand the source of disagreement.
- Use qualifiers (e.g. *sometimes, in most cases*) to get to a statement everyone can live with.
- List disagreement about a fact as a fact itself (e.g. there is disagreement between the team and family about the patient's ability to interact with her environment.)
- Use the subheadings provided (e.g. patient's clinical condition, patient's identity, about the team, about loved ones, etc.).

Step 2 Summarizing the Facts

What we know for sure: About the **patient's identity**, who she/he is, what her/his values and beliefs are, what a meaningful life looks like for her/him, the significance of her/his illness for him

How we know this...

What we know for sure: About **the patient's medical condition**, treatment options, etc.

How we know this...

What we know for sure: About **the patient's family**, friends, and support people

How we know this...

Step 2 Summarizing the Facts

What we know for sure: About **members of the care team**, who's involved and what their perspectives are

How we know this...

What we know for sure: About **the system**, who else is affected, relevant policies, laws, etc.

How we know this...

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

Step 3 Determining What Matters

VALUE STATEMENTS DESCRIBE WHAT SHOULD MATTER IN THE DECISION WE MAKE AND HOW WE RESPOND

There are things we unreflectively want - they show up in our default behaviours.

There are things we believe we should want - these usually arise after we think carefully about things and talk them through with others.

SAMPLE ENTRIES

It is important that..

- Mrs. R is fully informed about her condition, including that she has cancer.
- We minimize Mrs. R's pain and suffering.
- We maximize Mrs. R's quality of life from her perspective.
- We maximize the amount of time Mrs. R is able to live.
- We don't cause Mrs. R pain or suffering
- We make decisions based on the son's values and beliefs.
- We make decisions based on the physicians values and beliefs.
- Family members are able to live with the treatment decision we arrive at.

“We humans can tolerate suffering but we cannot tolerate meaninglessness.”

.”—Archbishop Desmond Tutu

- 1 Brainstorm everything that is important that the decision should live up to (column 1).
 - Ask people to offer full ideas in answering the question “Whatever our answer, it is important that...”
 - All considerations should first be named and listed, regardless of degree of importance (so all responses should be accepted).
- 2 Prioritize this list (column 2).
- 3 Review the list and confirm the ordering.
- 4 Discuss the justification for the prioritization: why is it reasonable to prioritize and balance in this way?
- 5 Identify values about which there was disagreement and discuss how to address these.

The resulting list will be the criteria against which the quality of different options will be judged.

TIPS FOR SUCCESS

- Make explicit what matters in the situation.
- When a consideration is identified as important, explore whether it is important for its own sake or because it gives us something else of more importance.
- If the latter, be sure to capture both the instrumental and the intrinsic value on the list. For example, if it is important that “all team members clearly chart conversations with a patient about what is important to them while they are in hospital”, is this because it is important, “to minimize exposure to legal liability,” “to ensure consistency of care,” “to best respect the autonomy of the patient,” or “to assist family to understand the perspective of their loved one”? All of these may be important, but some will likely be more important based on the context. So all of the considerations in quotes above should be listed.
- Avoid one word values that are open to interpretation.

Step 3 Determining What Matters

Specific criterion: However we answer the question, it's important that...	This is important because...

Step 4

Determining What Should Matter Most

GETTING OUR PRIORITIES STRAIGHT

There are lots of things that are important in life, but not all of these are equally important.

What matters is getting clear on what our talk is so we can walk it. This requires having complex conversations, often in short spaces of time.

SAMPLE ENTRIES

It is important that..

- 3/5 We fully inform Mrs. R about her condition, including that she has cancer.
- 4/5 We minimize Mrs. R's pain and suffering.
- 5/5 We maximize Mrs. R's quality of life from her perspective.
- 3/5 We maximize the amount of time Mrs. R is able to live.
- 5/5 We don't cause Mrs. R pain or suffering.
- 2/5 We make decisions based on the son's values and beliefs.
- 2/5 We make decisions based on the physicians values and beliefs.



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*“Things which matter most must never be at the mercy of things which matter least.”
–Johann Wolfgang von Goethe*

HOW TO PRIORITIZE VALUES

Possible ways to do this exercise include...

- If the group is small enough, collectively give each value statement a score between 1 and 5, where 5 is crucial.
- Have each individual score each value privately on paper, collect and tabulate.
- Write each value statement on a whiteboard or flip chart, and have everyone write their score beside each.
- Give each participant 5 colours of stickers/dots, identify each one with a value between 1 and 5, and ask each participant to place one dot beside a value statement, then tabulate.
- Ask everyone to rate each statement individually, then have them work in groups to discuss their ratings and to identify: 1) a collective ranking where agreement was reached, and 2) values for which no consensus was reached.

TIPS FOR SUCCESS

- The objective is to arrive at a rank order of value statements where each value statement is listed in priority order and where each statement is rated by its importance.
- Justify both a) why the statement gets the rating it does, and b) why the value statements at the top of the list are more important than those below. Be able to complete the sentences:
 - › We have assigned this statement this score because...
 - › This statement is more/less important than those below/above because...
- Ensure your justification includes:
 - › Good reasons for your preferred values
 - › Descriptions that will make it easier for others to understand and engage your thinking
- If you have a better way at arriving at a summary of what matters most, use it.

Step 4

Determining What Should Matter Most

Specific criterion: However we answer the question, it's important that...	Priority:				
	Important 1	2	Very Important 3	4	Crucial 5
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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Step 5 Identifying Partners

CONSULTATION

Can take many forms ranging from providing information to seeking to gain information and to deepen understanding, and from partnership in decision-making to transferring decision-authority.

POSSIBLE PARTNERS INCLUDE

- Professionals from other disciplines.
- Professionals from other teams and services with relevant technical expertise.
- Professionals with past history of providing treatment or care for this patient.
- Family members the patient is or would be comfortable involving in decision-making about her care plan.
- Friends or acquaintances the patient is or would be comfortable involving in decision-making about her care

“...for many of our white brothers, as evidenced by their presence here today, have come to realize that their destiny is tied up with our destiny. And they have come to realize that their freedom is inextricably bound to our freedom.” – Martin Luther King Jr.

- 1 Make a quick list of people whose partnership is important for moving through this issue successfully and in an ethically justified way.
 - Consider who will be significantly affected by the decision.
 - Consider who has important insight into the various types of facts the decision analysis rests upon.
 - If the patient is unable to participate directly in her/his care, consider who has insight into the patient’s values and beliefs.
- 2 Seek out these individuals and ask their perspectives about the facts and values in the analysis so far.
- 3 Update and revise the tables in sections 2-4 as appropriate.
- 4 Determine the most appropriate way for these individuals to participate in the decision process .

TIPS FOR SUCCESS

- Partnership takes time and care. Because of this it may seem easier to move forward independently. Sometimes this is appropriate, for example when extremely quick treatment decisions need to be made. More often, there is time to build partnerships. When time is available, seek to build partnerships because if a decision is made poorly, short-term savings in time and resources can easily be outweighed by effort and energy that will be required to revisit decisions again.
- Be clear about the type of partnership you are seeking from people.
- When working with loved ones and family members, stay away from asking exclusively about their perspectives of what should matter. Instead, begin by asking what they think is important to the patient.
- For understanding a patient’s perspective, only include individuals whom the patient would like to have consulted.
- Remember people’s perspectives change over time. Don’t be angry or surprised when people change their viewpoints.

Step 5 Identifying Partners

Potential Partner	Contact Information

Step 6 Brainstorming Options

BRAINSTORMING

Is about pausing to let ideas flow. Just because an option is named, does not mean that it needs to be followed up.

This step is aimed at making room for creatively exploring what kinds of solutions, conventional or not, might meet the criteria indicated and answer the key question.

- 1 Have the discussion leader explain the brainstorming exercise.
- 2 Invite members to provide possible ways of answering the question.
- 3 List possible ways the key question might be answered on a flip chart.

TIPS FOR SUCCESS

- Do not evaluate options, simply list them.
- 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.

SAMPLE

The Key Question for which we are brainstorming:

How should the team respond when Mrs. R.'s family brings her in for dialysis, she gently resists, is clearly in pain, and her family insists she gets dialysis with little pain medication

Possible ways of answering the question:

Work with her family and push her to have her dialysis; don't offer pain medication.

Refuse to give her dialysis.

Bring in an interpreter, ask Mrs. R in private what she wants and act accordingly.

Bring in an interpreter, ask Mrs. R in the presence of her family what she wants and act accordingly.

Bring in an interpreter, ask Mrs. R in private how she would like her care decisions to be made and act accordingly.

Bring in an interpreter, ask Mrs. R in the presence of her family how she would like her care decisions to be made and act accordingly.

*"When the way comes to an end, then change - having changed, you pass through..."
-I Ching*



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Step 6 Brainstorming Options

The Key Question for which we are brainstorming:

Possible ways of answering the question:

Step

Analyzing Options

SYSTEMATIC ANALYSIS

Living with integrity involves:

- **Identifying** what matters the most,
- **Articulating** why this is so,
- **Carefully choosing** a course of action that best allows one to live up to what matters.

In this step we look at the possible solutions to see which ones best live up to the values that are most important:

- 1 List the highest priority values (from Step 4) in the top row.
- 2 Choose some of the options brainstormed (from Step 5) and list them in the first column.
- 3 For each box in the resulting grid, systematically discuss how well the option in question lives up to the value in question. If an option's consistency with a value depends on some other factor, make these contingencies explicit.

TIPS FOR SUCCESS

- Choose options that appeal to the group, but also one or two that at first glance don't look very good.
- When doing this as a group, put the list of prioritized values next to the list of possible options (flipcharts are helpful for this).
- Then pick an option and go through each of the prioritized values asking, "How well does this option live up to this value?"

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SAMPLE

List Options Here	List Most Important Values Here			
	Maximize QOL from Mrs. R's view	Don't cause Mrs. R pain or suffering	Minimize Mrs. R's pain and suffering	Family members are able to live with decision
Work with her family and push her to have her dialysis; don't offer pain medication.	no	no	no	yes
Refuse to give her dialysis.	no	maybe (may result in psychological suffering)	maybe	no
Bring in an interpreter, ask Mrs. R in private what she wants and act accordingly.	yes	yes	yes	maybe (depends on their comfort)
Bring in an interpreter, ask Mrs. R in the presence of her family what she wants and act accordingly.	maybe (depends on interpreter quality and how freely she answers questions)	maybe	maybe	maybe (more likely)
Bring in an interpreter, ask Mrs. R in private how she would like her care decisions to be made and act accordingly.	yes	maybe (may result in psychological suffering)	maybe (depends on what she chooses)	maybe (depends on what she chooses)

Step

Analyzing Options

The Key Question for this discussion is:

Blank space for writing the key question.

	List Most Important Values Here					
List Options Here						

Step 8 Deciding and Explaining

DECISION MAKING

Requires the thoughtful, careful, systematic examination of facts and values. Ideally, it should happen in the context of compassionate relationships that enable those involved to work together to understand the context and determine together what should matter most to all those involved.

- 1 Look at the analysis table from Step 7 and decide which individual or collection of solutions best lives up to what should matter most.
- 2 Complete the table on this list:
 - Describe the decision.
 - Identify the values the decision lives up to.
 - Identify what is important that the decision does not live up to.
 - Explain how this balancing is justified.

TIPS FOR SUCCESS

- Remember the analysis in Step 7 was not scientific - it was an effort to systematically reflect on the issue.
- Different options usually live up to different values. Creatively modify and combine the options to create a broad solution that lives up to as many of the high priority values as possible.

SAMPLE

THE QUESTION: when Mrs. R.'s family brings her in for dialysis, she gently resists, and is clearly in pain, the team should...

OUR SOLUTION: Bring in an interpreter, ask Mrs. R in private what she wants and act accordingly. We should also ask Mrs. R in private how she would like her care decisions to be made and act accordingly. And we should explain to the family that we have an obligation to honour Mrs. R's wishes

VALUES THIS GIVES: This will allow us to maximize Mrs. R's quality of life from her perspective.

WHAT THIS SACRIFICES: Depending on what Mrs. R indicates, this may result in her being in pain. Having the conversation itself may cause her emotional discomfort or pain. And depending on what the family understands their role to be, it might upset them as well.

JUSTIFICATION: This balancing is justified because our primary duty is to the patient. We want to be kind and compassionate with the family as well and assist them to serve their mother's interest. But we should do this in ways that give Mrs. R the greatest opportunity to guide her care to the extent she wishes.

RISK MITIGATION: We can minimize the risk of not living up to these values by explaining our thinking to the family, trying to understand their perspectives better and helping them to work through why we are moving in this direction.

*"You think that because you understand ONE you understand TWO, because one and one makes two. But you must understand AND.."
—Sufi proverb*



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Step 8 Deciding and Explaining

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...	
We can minimize the risk of not living up to important values by...	

Step 9 Putting a Plan in Motion

EXECUTION.

In order to live up to the values embedded in a decision, the decision needs to be implemented.

Decisions are based on factual assumptions about the consequences of our actions. Action needs to be evaluated to ensure it has brought about the desired state of affairs.

SAMPLE ENTRIES

- Social Worker (SW) to contact family and arrange meeting to discuss upcoming conversation with Mrs. R.
- SW to work with Most Responsible Physician (MRP) and Patient Care Coordinator (PCC) to identify a good time for a) a family meeting, and b) meeting in private with Mrs. R.
- PCC to contact interpreter services and arrange interpreter for meeting with Mrs. R.
- SW to write note in chart about outcome of family meeting.
- MRP to write careful note in chart about the outcome of the meeting with Mrs. R. with specific attention to how Mrs. R. would like care decisions made and what she indicates is important to her.

“There are risks and costs to action. But they are far less than the long range risks of comfortable inaction” –John F. Kennedy

- 1 Determine what next steps need to happen to operationalize the plan. For each step establish:
 - The specific action that needs to be taken.
 - Who will be responsible for the step.
 - Deadline by when the step should be taken.
 - How the result of the action will be shared with the team.
- 2 Determine when the team will reconvene to discuss the outcome of the various steps.

TIPS

- Include next steps for communicating the team’s thinking as well.
- Have someone write a note in the chart explaining the process the team went through to develop a solution, possibly including the decision workup document as well.



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Step 9 Putting a Plan in Place

Step	Team member responsible	Timeline	Communication Plan