

Case 4: Mary's dialysis*

'Mary, Mary, quite contrary' she hummed to herself as she listened to Dr. Cheung, a nephrologist, drone on about her future need for dialysis. Mary is a 64 year old woman who has been diagnosed with renal failure. She was terrified when, two weeks ago, she was told how serious her illness had become. Based on what she has said to the care team in the past, she is a very independent person and fears the possibility of becoming 'disabled'.

Mary smiles pleasantly as the doctor outlines how dialysis works and the possibility of a kidney transplant. But at the end of this she tells him in no uncertain terms that she has no intention of ever going on dialysis. "Just let me die peacefully and with dignity," Mary says as she continues to hum 'Mary, Mary, quite contrary'.

Realizing that Mary seems distracted, Dr. Cheung comments, "You seem to have other things on your mind. Can you tell me how you are reacting to this kidney trouble?"

Mary, caught off guard by Dr. Cheung's change in direction, pauses a few moments, and replies, "Well, I don't like it one bit! But, I've had a good life and I will muddle through as best I can. I'm not ready to end my days attached to some infernal machine."

Dr. Cheung wants to explain to Mary the risks of not undergoing dialysis and that the treatment is a way to provide some increased quality of life despite the inconvenience and distress the treatment may bring. But Mary seems very clear that she does not want to undergo dialysis.

After Mary leaves their appointment, Dr. Cheung is left unsure whether he should spend more time trying to convince her to change her mind so he follows up with the rest of the care team to discuss what to do next.

Key Question

How should we approach supporting Mary?

(Completed) Ethics Decision-Making Framework

1. Key Question:

How should we approach supporting Mary?

2A. Facts:

- 64 years old
- Eligible for dialysis
- Kidney failure
- Has not been consistent in taking blood pressure medications
- Values her independence
- Wants to die with dignity and peacefully
- Has been seen by a nephrologist who recommends dialysis
- Stated she does not want dialysis
- Stated she has had a good life

2B. Missing information we CAN find out:

- What is important to Mary? Has anyone asked her? Perspective on the meaning of life/a good quality of life?
- What is Mary's understanding about dialysis/diagnosis/options?
- Does Mary need support, more time, or space, to think this through? What support does she need?
- Does Mary have any family/friends/support network?
- What is her living condition now and in the past?
- What are her past experiences with healthcare services?
- Why didn't she take her medication previously?
- What is her prognosis---will she go home?
- If Mary dies after refusing dialysis, will it have an impact on Dr. Cheung or others on care team, who should be supported?

2C. Missing information we CANNOT find out:

3. Values – it is important that...

1. Mary is the final decider on choices around her healthcare
2. We ensure Mary understands her treatment options and so can make informed decisions
2. Physician works to understand the reasons for Mary's mixed feelings
3. We understand why Mary is fearful around doing dialysis
4. We understand what Mary's goals in life/care are (i.e. what is important to her)
5. Mary is aware that she can change her mind later (within whatever the timeframe is)
6. We support physician and other care providers if Mary's decision has an impact on them

4. Possible Prioritization of Values:

1. Mary is the final decider on choices around her healthcare

2. We ensure Mary understands her treatment options and so can make informed decisions
2. Physician works to understand the reasons for Mary's mixed feelings
3. We understand why Mary is fearful around doing dialysis
4. We understand what Mary's goals in life/care are (i.e. what is important to her)
5. Mary is aware that she can change her mind later (within whatever the timeframe is)
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5. Brainstorm options:

- A. Get a second opinion on diagnosis and options
- B. Peritoneal dialysis (i.e. at home or clinic instead of in hospital unit)
- C. Request a social worker assessment to help understand Mary's values/beliefs and understand options
- D. Do nothing
- E. Put Mary in touch with someone else who is receiving dialysis
- F. Refer to Social Work –if we ask about Goals of Care
- G. Have a conversation with Mary asking:
 - What's a good life to her
 - Her goals in life/care
- H. Call a family meeting

6. Analyze options:

		OPTIONS →				
V		A	B	C	D	E
A	1	✓	~	✓	~	~
L	2	~	~	✓	✗	~
U	2	✓	~	~	✗	~
E	3	✓	~	~	✗	~
S	4	~	~	~	✗	~
↓	5	✗	~	~	✗	~

7. Make a decision: Dependent on knowing more details of each option – based on this it could be a bundle of 4 options together (everything except doing nothing)

The Ethical Decision-Making Process

1. Identify the key question
2. Identify the facts
 - a) What do we know for sure?
 - b) What don't we know that we can find out?
 - c) What information can't we know?
3. Identify guiding values – what matters?
4. Prioritize the values – what matters most?
5. Brainstorm the options
6. Analyze each option according to the prioritized values
7. Make a decision. Reflect and learn from it.

Find the complete ethical decision-making toolkit here:

http://fhpulse/clinical_resources/ethics_services/Pages/Default.aspx

Or contact Fraser Health Ethics Services at ethics.services@fraserhealth.ca

*SOURCE: Stewart, M. et al. (2014). *Patient-centered medicine: transforming the clinical method (Third Edition)*. Radcliffe Publishing. pages 119-120. No title in the original version. Adapted for FHES 2016 Conference by Allen Alvarez and Duncan Steele. Available at the FHES library at Central City Suite 400. Note: the book is CPD certified.