

GOALS OF CARE/CONDUCTING A FAMILY CONFERENCE

Establishing goals of care for patients near the end of can occur in the inpatient or outpatient setting. Convening a family conference is necessary whenever there is a need for discussion between key members of the health care team, the patient and family. A successful family conference is more likely to occur if key steps are completed, in the correct order--a ten step process is outlined below.

1. Pre-Meeting Planning

- **Review Medical History:** review all pertinent medical facts including treatment options, prognosis, with and without treatment, and consultant opinions.
 - **Decide what is medically appropriate:** what tests/procedures/interventions do you believe will improve or worsen function, longevity and quality of life?
 - **Coordinate opinions:** contact consultants to coordinate key messages.
- **Advance Directives:** review any advance directive documents and bring them to the meeting.
- **Psychosocial data:** obtain all available information about the patient and family system. psychosocial status/issues.
- **Attendees:** Determine who you wish to have present from the medical team and invite the family to bring whomever they wish to the meeting. Determine whether there is a need for an interpreter for the patient or family members.
- **Meeting leadership:** designate one person from the medical team to serve as meeting leader.
- **Pre-Meeting:** convene a meeting of health professionals who will be present, immediately prior to the family meeting, to clarify leadership and meeting content.
- **Invite participants:** be sure to invite health professionals that you believe are necessary to help families with decision making: for example, for hospitalized patients, the primary care physician.
- **Determine if the patient has decision-making capacity**

2. Environment—find a quiet, private room; arrange chairs in a circle so each participant has a “front-row” seat; make sure the patient, if participating, will be as comfortable as possible.

3. Introductions—ask all participants to introduce themselves and their relationship to the patient. For large groups, set ground rules: everyone can speak, no interruptions. Identify the legal surrogate decision maker if available. Review your goals & purpose of the meeting; ask participants for their goals. Write names down if this is helpful to you.

4. Determine what the patient/family already knows. *"What is your understanding of _____'s present condition" or "What have you been told about _____'s condition".*

For patients with chronic diseases, ask about function and quality over the preceding 3-6 months and any changes or trends. Invite all participants to share their impressions.

"Tell me about the past few months—what changes have you noticed in your loved one's condition or function?"

5. Medical Review

- Provide a short synopsis of the current medical condition and how the current condition fits within the larger illness trajectory (for chronic disease patients). The synopsis should be very brief, focusing on the large overall condition; Avoid medical jargon.
 - *"Your father has pneumonia and kidney failure; despite 3 days of antibiotics, his condition is getting worse".*
 - *"Despite the chemotherapy, the cancer is growing, I believe your mother is dying."*
 - *"I wish things were different, but your heart condition is getting worse despite all the latest treatments."*

6. Allow silence, respond to questions and emotional reactions.

When the medical review has indicated that no further treatments are likely to reverse the disease process/the patient is dying, there are two common reactions. These two reactions represent a major branch point in the Goal of Care Discussion.

A. Acceptance—patients and families who understand and accept that death is approaching will typically ask or be thinking of the following questions and emotional reactions:

- How much time?
- What will happen?
- What do we do now?

When patients/families make these statements, you can usually move rapidly through Step 7 (answer the question about time) and then to Step 9.

B. Non-Acceptance—when patients or families are not ready to accept that death is coming, common statements include:

- How can you be sure?
- He was fine last week.
- We want a second opinion.
- There must be some mistake.
- Shifting focus by asking questions about a relatively minor aspect of care

All these statements represent potential conflict—Go to Step 8 to review the differential of conflict and learn strategies for conflict resolution.

7. Prognosis and Care Options

A. Prognosis: You will need to discuss prognosis to help patients/families decide among care options. A good entry to such a discussion is to discuss the future expected course of the illness and the estimated prognostic range:

“Has anyone talked to you about time?”

“Has anyone told you what to expect in the future?”

Guidelines on providing prognosis include: a) always ask if such a discussion is desired before providing data, b) provide data in a range (a few weeks to a few months), c) stop and allow silence after providing data to gauge any emotional reaction.

B. Discussing Care Options

“Things not going well--We are at a decision point

A. Continue interventions

Sustain life/hope for recovery or

B. Change focus to comfort, let nature take its course

Silence

Did your loved one ever talk about what they might want in this situation?

Review AD

1. Options can usually be divided into two major categories—patients and families can best make decisions if two “10,000” foot options are presented, rather than discussing more specific details:

- Continuing or expanding life-prolonging treatments with a goal of improved function, lengthened life, and/or improved quality, *versus*...
- Discontinuation of life-prolonging treatments, focusing on comfort with expected death.

2. Sample phrasing for patients receiving life-sustaining treatments (e.g. ventilator, dialysis, IV antibiotics for major infection, etc.) ...

At this time there are two broad options:

Option 1 is to continue the current treatments aimed at improving function and hopefully your loved one will improve.

Option 2 is to stop the current treatments and allow nature to take its course, I expect your loved one is likely to die within (x-x days/weeks)

Note: if you are unsure about the prognosis, and/or or if improvement after withdrawal of life sustaining treatments is a possibility (e.g. acute stroke) then you can add ...

although I believe your loved one is dying, it is possible that after we stop the (____) your loved one might actually improve—if that happens we will meet again and re-evaluate the plan.

Note: the same two-option approach is appropriate for patients who are not imminently dying, but the phrasing will need to be altered.

3. Sample phrasing for patients trying to decide whether or not to continue chemotherapy for metastatic cancer ...

At this time there are two broad options:

Option 1 is to continue chemotherapy with the hope that the next treatment will give you some additional time but without major side effects.

Option 2 is to stop chemotherapy and focus on other aspects of care that will help live as best possible.

4. When the patient can speak for themselves

- Ask patient what treatment he/she is considering in relation to their personal values and hopes
- Ask patient what type of support he/she would like from family members & health care team.
- Invite discussion from other family members about supporting the patient's decision.

5. When the patient can not speak for themselves

- Describe the goal of substituted decision making—to speak on behalf of the patient by making those choices we believe the patient would make if they could speak.
- Ask each family member what they believe the patient would choose if he/she were able to speak on their own behalf. ***“What would Dad say if he could tell us”***

C. Making a Recommendation

When patients/families struggle to make a decision, or you believe there is one preferred medical decision based on the facts, and/or your knowledge of the patient's wishes, ***make a clear recommendation***. Avoid statements such as: *“what would you like us to do?”* This type of statement only tends to worsen a families sense of guilt. Always try to make the recommendation based around patient/family stated values or goals...

Example: *“Based on what you have told me about your father and how he has lived, and what I know of his illness and expected future course, I would recommend we stop the _____, and focus on keeping him comfortable for his final days.*

8. Managing Conflict

Conflict is normal in high stress conversations concerning seriously ill patients and families. Common reasons for such conflicts include the following:

- **Information** -- incorrect, misleading, or conflicting information has been provided to the family by other health care providers.
- **Grief/Time** -- family members have not had sufficient time to psychologically adjust to imagining their life without the dying person.
- **Anger/Guilt** -- long lasting intra-family issues may disrupt or preclude logical decision making; in severe cases, the struggle you observe may be the result of long-standing serious family dysfunction—issues of past or current drug or alcohol dependence and/or physical, verbal or sexual abuse are common.
- **Trust** -- if a patient or family does not have trust in the medical team, it is impossible to work together to develop a treatment plan.
- **Culture** -- differences in culture, religion, socioeconomic status, etc. may all impede decision making.

Etiology	Intervention
Information	Provide honest information at the patient/family pace; Coordinate opinions between providers;
Grief/Time	Bedside counseling: education, normalization, reframing, empathy
Anger/Guilt	Bedside counseling: education, normalization, reframing, empathy Referral for counseling if needed;
Trust	Discuss trust openly; "I have the sense that you do not feel I am making the best recommendations for your loved one, can you tell me more?"
Culture	Ask open-ended questions to learn about particular cultural issues; Seek to find the common ground in decision making where the patient needs are at the center of decisions; Enlist assistance from individuals who can help bridge cultural concerns.

Key points in managing conflict

- Active listening—strive to maintain a civil discourse; ensure that your body language is open, conveying concern and empathy, re-state or paraphrase what people are saying to make sure you and others understand.
- Correct any factual misunderstanding.
- Provide an empathic statement; *"I can't imagine how hard this must be"*
- Keep the focus of the discussion on the patient's well-being.
- Recognize that time may be necessary—schedule a follow-up meeting;
- Establish a time-limited trial of continued life-sustaining treatments--establish clear goals and a time line (e.g. improved cognition, improved LFTs).
- Recognize that other resources may help the family: psychologist, spiritual counselor, palliative care team, ethics consultation.
- State directly that you (and health care team) will not abandon the patient and family, and will assure the patient remains as comfortable as possible.

9. Translate goals into a care plan

When a decision has been made to limit life-sustaining treatments, it is time to refocus the goals of care. Ask: *"knowing that time is short, what is important, what do you want/need to do in the time you have left"*. Typical responses are home, comfort, being with family, living until a particular life event.

Review the current medical tests, procedures, medications—decide which are helping to meet the patient's goals, which are providing no benefit. Key items for discussion at this time include:

- Future hospitalizations or ICU admissions
- DNR status
- Use of artificial hydration/nutrition, blood products or antibiotics
- Home support, Hospice

Develop a care plan that matches the patient/families goals, verbally summarize the care plan to ensure understanding and agreement. Caution against unexpected outcomes (e.g. if a dying patient does not die, as expected following discontinuation of treatment).

Note: Treatment goals drive our choice of diagnostic and therapeutic methods. When treatment goals change it is natural that diagnostic and therapeutic methods will also change—some will be

discontinued and others started. The phrase “withdrawing treatment” can have a powerful negative emotional impact upon a patient and family because it may suggest abandonment. For this reason the clinician should not use this term, but should instead speak about refocusing goals, of shifting from cure to maintaining comfort.

Note: The provision or discontinuation of certain treatments such as non-oral hydration and nutrition can have strong emotional meaning. Therefore the clinician should facilitate discussion of these decisions and explore their meaning with patients and families. Some issues are inherently more difficult than others to consider (hydration and feeding withdrawal are typically the hardest decisions for families). Be aware of cultural beliefs and attitudes that will influence decision-making.

10. Document, Discuss and Debrief
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- Discuss the meeting with health care providers who were unable to attend (e.g. the patient’s evening nurse).
- Provide concise written documentation of the meeting: Who was present; What was discussed; What was decided; What decisions were deferred; Plan of care; and, Next steps.
- Debrief the experience with colleagues: what went well, what could have been done better; process personal emotions.

Summary of Key Questions/Statements to Guide Discussion

DOMAIN	QUESTIONS
Assess understanding	<i>What have the doctors told you? or What is your understanding of the illness? What changes have you noticed in the last 3-6 months? (chronic disease question)</i>
Medical review	Describe current status/future in 2 sentences—Big Picture only.
Branch Point: Conflict or not: If conflict: empathic statement	<i>I can’t imagine how hard this must be</i>
Discuss prognosis if patient gives permission	<i>Has anyone talked about time-(pause) and what to expect in the future?</i>
Outline 2 broad care options	<i>There are two major options ... what approach fits best as you think about your illness?</i>
Patient unable to participate in decision making	<i>What do you think your loved one would say if he/she could be part of this discussion?</i>
If decision needed and making recommendation would be helpful ..	<i>Based on what you have told me, it seems that the approach that fits the best for you and your family is XXX</i>
Goal setting	<i>We have talked that time may be short, what is important, what would you like to do/spend your time?</i>

REFERENCES

- Curtis, J. R. (2004). Communicating about end-of-life care with patients and families in the intensive care unit. *Critical Care Clinics*, 20, 363-380.
- Curtis, J. R., Engelberg, R. A., Wenrich, M. D., Shannon, S. E., Treece, P. D., & Rubenfeld, G. D. (2005). Missed opportunities during family conferences about end-of-life care in the intensive care unit. *Am J Respir Crit Care Med*, 171(8), 844-849.
- Curtis, J. R., Patrick, D. L., Shannon, S. E., Treece, P. D., Engelberg, R. A., & Rubenfeld, G. D. (2001). The family conference as a focus to improve communication about end-of-life care in the intensive care unit: opportunities for improvement. *Crit Care Med*, 29(2 Suppl), N26-33.
- Lautrette, A, M Ciroldi, H Ksibi, E Azoulay. End-of-life family conferences: Rooted in the evidence. *Crit Care Med* 2006 34(11), s364-S372.
- Lilly CM, De Meo DL, Sonna LA et al. 2000. An intensive communication intervention for the critically ill. *Am J Med*. 109:469-475.
- Meisel, A & Kuczewski M. Legal and ethical myths about informed consent. *Arch Intern Med*, 1996; 156:2521-2526.
- Quill TE and Brody H. Physician recommendations and the patient autonomy: Finding a balance between physician power and patient choice. *Annals of Internal Medicine* 1996; 125: 763-769.
- Ruark JE, Raffin TA, et al. Initiating and withdrawing life support. *NEJM* 1988; 318:25-30.
- Weissman DE. Decision making at a time of crisis near the end of life. *JAMA* 2004; 292: 1738-1743.
- Family Meeting Fast Facts #222-#227. www.mypcnow.org