Enhancing Communication and Coordination of Care  
Guidelines for Physicians and Other Caregivers

Treatment decisions for seriously ill patients are often difficult for all those involved, especially patients and families. Many factors contribute to this difficulty, including among others: lack of understanding among the patient and/or family about the seriousness of the patient’s condition, ambivalence regarding just when to “let go,” uncertainty as to when or what complication will eventually lead to the patient’s death; inability of the patient to participate in decision making, lack of clarity about the patient’s wishes, no designated proxy decision maker or durable power of attorney for health care; disagreement among family members, complex family dynamics and unresolved family issues; and poor or inconsistent communication among and by physicians and other caregivers, and divergent opinions and lack of coordination of care.

Given the difficulty of these decisions, physicians and other caregivers need to approach such situations with the utmost sensitivity and skill, recognizing that these are incredibly important and complex interventions. Though there is no single, established method for how best to do this, what follows are some simple guidelines with proven tools developed by physicians and other caregivers throughout SSM Health Care to help improve the way we deliver care to seriously ill patients. The guidelines are designed to: enhance communication with patients and families as well as among physicians and other caregivers; improve the coordination of patient care across disciplines and different settings; and prevent conflict situations from arising that can divide patients/families and physicians/other caregivers, compromise patient care, and lead to much moral distress. The emphasis of these guidelines is on dialogue, shared decision-making, coordination of care, and patients’ best interests.

I. GUIDELINES FOR COMMUNICATION AND CARE COORDINATION

A. Communicate early and often with patients and families
Patients and families need to be informed early on about the patient’s diagnosis, prognosis, and treatment options. They also need to be updated frequently about any new developments in the care and condition of the patient, such as progress, setbacks, effectiveness of current treatment modalities, alternate treatment options, and necessary changes in the goals of care. Too often patients and families are left in the dark, informed too late about the patient’s true condition, and/or receive inconsistent information from the various physicians and other caregivers. As a result, they may form unrealistic expectations and misinterpret insignificant physical signs in the patient as genuine signs of improvement. Clear, consistent, and frequent communication with patients and families in language they can understand goes a long way in preventing this from happening.

B. Communicate early and often with other physicians and caregivers
Associated with this last point is the fact that physicians and other caregivers often do not communicate effectively or frequently among themselves. Not only can this lead to problems in the care of the patient but it can also be a significant source of confusion for patients and families as they are told different things by different caregivers. Physicians should be sure to talk often amongst themselves and with other caregivers about the patient’s situation so they can better coordinate the patient’s care. To avoid sending conflicting messages it is often best to designate a single physician (e.g., the attending or primary treating physician) to communicate on a routine basis with the patient and
family and, as appropriate, to relay the sentiments of the various caregivers back to
them. This not only enables more effective and consistent communication but also lends
itself to a more fruitful and trusting relationship with patients and families. For care
conferences (see below), however, it is essential that most, if not all, of the physicians
and other caregivers treating the patient are involved.

C. **Determine the goals of care and evaluate routinely**
Setting clear and realistic goals of care with patients and families and evaluating them
frequently is critical for all patients, especially those who are seriously ill. Only when this
is done can a care plan be developed that corresponds to the present reality of the
patient’s situation and her/his particular wishes and values. Additional benefits are that
patients and families gain a better understanding of what can reasonably be hoped for
through the care provided and physicians and other caregivers are able to come
together in establishing a more holistic and coordinated care plan.

D. **Make time for and participate in care conferences**
One tried-and-true method for enhancing communication and coordinating care for
seriously ill patients is to conduct a care conference early on in the patient’s admission
and as needed throughout the patient’s stay. Care conferences allow the patient (if
able), family members, physicians, and other caregivers to come together to discuss
important issues, such as: reasonable treatment options; patient and family values,
beliefs, and special needs; pain and symptom management; transition or discharge
plans; code status; palliative and hospice care options; and so on. Unfortunately, care
conferences are not a standardized, routine practice in medicine and are often only
conducted when conflict has already manifested. The main reasons for this are that care
conferences are seen by some as too time-consuming and it is difficult to get the various
physicians and other caregivers all together at the same time. Health care facilities that
do care conferences routinely, however, have found them to be very beneficial as time
spent up front is often time and heartache saved in the end. Moreover, clinical data from
recent studies indicate that care conferences are helpful in improving communication
with patients and families as well as among caregivers, achieving consensus around
reasonable goals of care, and avoiding intractable conflict. Palliative care physicians and
nurses, case managers, social workers, among others, are typically well-trained to
facilitate care conferences and physicians should utilize their expertise. In some cases
involving prolonged hospitalizations it may be necessary to have more than one care
conference and time should always be given to the patient and family to come to terms
with what is discussed no matter how many care conferences are held. For more
information on care conferences and tools to get started, see the materials provided at
the end of these guidelines.

E. **Exercise care in offering/discussing treatment options**
Too often patients and families are offered every treatment option possible and asked to
decide what they want. Fortunately, this approach works most of the time as patients
and families tend to make reasonable decisions after being given this inordinate amount
of power. When the patient or family requests treatment that seems inappropriate or
unreasonable, however, physicians object despite the fact they offered the option in the
first place. Not only is this a poor practice in medicine founded upon the false claim that
patients have absolute autonomy and physicians must honor any request no matter how
impractical, but it also puts the patient and family in a difficult position as all the
responsibility for treatment decisions shifts to them. A better practice, one built on the
concept of shared decision making, is for physicians to offer only those treatment
options that are reasonable and realistic in light of the patient’s overall condition and the
agreed-upon goals of care. With this comes the responsibility for physicians to engage
in honest dialogue about why such treatment options might benefit the patient and why other possible options will not.

**F. Address unreasonable requests up-front and candidly**
Patients and families have a right to participate in treatment decisions and to make requests for treatment. However, physicians are not legally or ethically bound to carry out every request made by a patient or family. This is particularly true if the request for treatment will extend or increase the suffering of the patient without conferring a proportionate benefit, is medically contraindicated because the treatment will be ineffective, and/or violates generally accepted medical standards of care and is inconsistent with professional experience. Too often in the end of life context physicians acquiesce to unreasonable requests for treatment for fear of legal liability. Not only is this an abdication of physicians’ responsibility to their patients, but it can also result in harm to the patient, moral distress in physicians and other caregivers, and the inappropriate use of limited health care resources. In addition to exercising care in offering treatment options, physicians need to address unreasonable requests up-front and candidly, accepting the responsibility that comes with their role as a medical professional and advocate for the patient.

**G. Ensure non-abandonment and quality end of life care**
As discussions are being held about treatment options for seriously ill patients, it is important for physicians to reinforce to patients and families that the patient will receive high-quality end of life care and not be abandoned if the decision is made to either withhold or withdraw treatment. Patients and families often think that once they decide against a more aggressive approach to treatment, the care of the patient will be compromised and they will be left on their own to attend to the needs of the patient. Unfortunately, this is sometimes the case in modern medicine and it is one reason why patients and families are inclined to press on with treatment against their better judgment. Physicians should be aware of the end of life care resources available to them, such as pain management experts, palliative care and hospice providers, chaplains, and bereavement support specialists. They should also call on these resources not only to assist them in caring for the patient but also as a sign that the patient will continue to receive appropriate care designed to promote comfort, dignity, and emotional/spiritual support. While it is important to enlist the help of others at this time, nothing can replace the presence and compassionate care of the attending or primary treating physician.

**H. Once the decision has been made...**
If the decision has been made to withhold or withdraw treatment and it is likely that the patient will die rather soon while in the hospital or other health care setting, physicians and other caregivers should:

- Be sure everyone involved in the patient’s care is aware of the decision
- Be appropriately present to the patient and family
- Attend to any requests of the patient and family that can be accommodated
- Address questions of organ and tissue donation as appropriate
- Discontinue monitors and alarms
- Cease any unnecessary treatments and assessments
- Move the machinery away from the bed
- Remove encumbering or disfiguring devices
- Have pain medications readily available so they can be provided as needed
- Attend to the psycho-social and spiritual needs of the patient and family
II. GUIDELINES FOR CONFLICT SITUATIONS

Even if all the above guidelines are followed, some situations will arise when patients or families (typically families) will request “everything be done” when empirical evidence and the collective wisdom of physicians and other caregivers suggest the request is unreasonable. When this happens physicians need to have a candid, direct, and structured conversation with the family before the situation becomes unmanageable. What follows are some basic guidelines for having such a conversation, which can be conducted by the attending or primary treating physician alone or with a small team of caregivers that also includes the primary nurse caregiver, the case manager or social worker on record, a chaplain, and the palliative care and/or hospice specialist.

A. Establish the setting
The attending/primary treating physician should ensure comfort and privacy, sit down close to the family, and introduce the issue by saying something like: "I'd like to talk to you about the treatment you are requesting and the possible implications of this."

B. Determine level of understanding
The attending/primary treating physician should ask open-ended questions to find out what the family understands about the patient's diagnosis and prognosis. Consider asking this question: “What do you understand about your loved one's health situation?” The attending/primary treating physician and other team members should fill in any gaps in the family’s level of understanding in clear and easy-to-comprehend terms and give them time to absorb any new information.

C. Clarify hopes and expectations
The attending/primary treating physician should talk to the family about the goals of care by asking questions like: “What do you think your loved one would want in this situation?” “What are your hopes and expectations if we provide the treatment you are requesting to your loved one?” If there is a sharp division between what is likely to happen and what the family hopes and expects to happen with regard to treatment, this is the time to express those concerns and clarify any misconceptions.

D. Discuss withholding or withdrawing treatment
The attending/primary treating physician should share with the family her/his thoughts about the lack of benefit regarding the treatment in question in language they can understand. This person should be firm, yet compassionate, in stating the reasons why she/he thinks the treatment would not promote the patient's overall best interests. Also, the attending/primary treating physician should point out the care options available to the patient (e.g., palliative and hospice care), and be sure to inform the family that withholding or withdrawing certain treatments does not mean abandoning appropriate care designed to promote comfort, dignity, and emotional/spiritual support. A palliative care consult should be initiated to further reinforce to the family that the patient will not be abandoned.

E. Respond to deeper needs
This is an extremely trying situation for the family, one that they are most likely facing for the first time. Beyond supplying important medical information, the attending/primary treating physician should also carefully listen to the family and try to determine the
underlying reasons for the family’s request to do everything. Often there is more than meets the eye and the attending/primary treating physician should seek help from pastoral care and/or social services to aid her or him in understanding and addressing the deeper motivations and needs of the family. For more information on understanding and responding to the underlying meanings of requests for “everything,” see Table 2 below from T. Quill, R. Arnold, and A. Back, “Discussing Treatment Preferences with Patients Who Want ‘Everything.’” *Annals of Internal Medicine* 151 (2009): 345-49.

<table>
<thead>
<tr>
<th>Domain</th>
<th>Concept</th>
<th>What “Everything” Might Mean</th>
<th>Questions to Ask</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective</td>
<td>Abandonment</td>
<td>“Don’t give up on me.”</td>
<td>“What worries you the most?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Keep trying for me.”</td>
<td>“What are you most afraid of?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I don’t want to leave my family.”</td>
<td>“What does your doctor say about your prospects?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I’m scared of dying.”</td>
<td>“What is the hardest part for you?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I would feel like I’m giving up.”</td>
<td>“What are you hoping for?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Do everything you think as a doctor is worthwhile.”</td>
<td>“What is your understanding of your condition/prognosis?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I really want every possible treatment that has a chance of helping me live longer.”</td>
<td>“What have they said the impact of these treatments would be?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I will go through anything, regardless of how hard it is.”</td>
<td>“Tell me more about what you mean by ‘everything’.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I value every moment of life, regardless of the pain and suffering (which has important meaning for me).”</td>
<td>“Does your religion (faith) provide any guidance in these matters?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I will leave my fate in God’s hands; I am hoping for a miracle; only He can decide when it is time to stop.”</td>
<td>“How might we know when God thinks it is your time?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I cannot bear the thought of leaving my children (wife/husband).”</td>
<td>“How is your family handling this?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“My family is only after my money.”</td>
<td>“What do your children know?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“I don’t want to bother my children with all this.”</td>
<td>“Have you made plans for your children (other dependents)?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“My husband will never let me go.”</td>
<td>“Have you discussed who will make decisions for you if you cannot?”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Nothing will bring me comfort.”</td>
<td>“Have you completed a will?”</td>
</tr>
</tbody>
</table>

**F. Devis e a care plan**

If agreement has been reached with the family about withholding or withdrawing treatment, the attending/primary treating physician should establish a care plan that addresses all agreed-upon items and any other aspects of care that correspond to the patient’s wishes, values, and beliefs and are necessary to maximize the patient’s comfort. The attending/primary treating physician should maintain open lines of communication with the family throughout the dying process and continually update and comfort them. Also, if possible, the attending/primary treating physician should be present and company with the patient and the family as the patient approaches death.

**G. Lack of agreement**

If agreement cannot be reached about withholding or withdrawing treatment, an ethics consult should be called and the hospital president or administrator on-call should be notified of the situation. Additionally, attention should now focus on restricting treatment options in light of the patient’s best interests with no treatment options being offered to the family that will extend or increase the patient’s suffering (e.g., amputation of a limb for a patient with end-stage illness) or are medically contraindicated because they will be ineffective (e.g., advanced cardiac life-support for a frail, elderly patient with multiple chronic conditions).
**G1. Offer time-limited trial**
If the treatment in question does not extend or increase the patient's suffering and could perhaps achieve its physiological end, the attending/primary treating physician could offer the option of providing the treatment for a time-limited trial. The attending/primary treating physician must delineate the therapeutic goals and the length of time the treatment will be provided to assess the effects of the treatment in light of the goals. In no uncertain terms, the attending/primary treating physician should point out that the treatment will be withdrawn if the patient does not achieve the therapeutic goals in the designated time.

**G2. Discuss alternate care options**
If, after the time-limited trial, the treatment is still considered unreasonable or inappropriate, it could be withdrawn provided there is wide agreement among the attending/primary treating physician, other caregivers, hospital president, ethics committee, and so on. If the decision is made to withdraw the treatment, the family should be notified promptly and given an appropriate amount of time to reconcile with the situation or make alternative plans.

**H. Documentation**
It is imperative that all discussions and decisions made with family be thoroughly documented in the patient's chart (paper or electronic). This includes but is not limited to the following: the proceedings from any care conferences; structured discussions regarding the family's request for everything; any informal or formal ethics consultations; and decisions about offering time-limited trials with precise dates regarding when the treatment was started, what therapeutic goals were agreed upon to measure the patient's progress, and when the treatment will be withdrawn if the patient's condition does not improve when measured against the agreed-upon therapeutic goals.

**I. Debrief with caregivers**
Since these situations are often stressful and difficult for physicians and other caregivers, a formal debriefing meeting should be conducted during and after the stay of the patient so the physicians and other caregivers can express their feelings and be supported in their roles. This can be done through the particular unit, the ethics committee, or a special ad hoc meeting group.
Care Conference Guidelines for Staff

**Definition:** A care conference is a meeting among the patient (if able), family, and health care team to facilitate communication about the overall plan of care, the needs and goals of the patient and family, pain and symptom management, and transition or discharge plan. A care conference can be conducted at any time throughout the patient's stay.

**Identifying Patients:** Patients who you wouldn't be surprised if they died in a year or less as well as patients with serious illness admitted to the intensive care unit are good candidates for a care conference. Care coordinators are the key staff responsible for identifying these patients, organizing the conference, and inviting the patient, family, and team members to the conference. Care coordinators should identify such patients and document their patient account number on the "Care Conference Record." This applies even to those patients who do not receive a conference. The information will be helpful for comparative purposes in terms of assessing patient satisfaction data and readmission rates among the identified patient population who did and did not receive a conference.

**Who Attends:** It is essential that care conferences be attended by the patient (if able), key family members and significant others identified by the patient, the attending/primary treating physician, primary nurse caregivers, the care coordinator, and a chaplain. Other team members involved in the care of the patient or whose expertise is needed may also be invited on an as needed basis, such as, specialist physicians, social worker, rehabilitation therapist, pharmacist, home care staff, clinical nurse specialist, and so on. No matter who physically attends the care conference, it is vital that all members of the care team provide their input and are apprised of the results of the conference. This will assure consistent information flow from caregivers to patients and families.

**Facilitator's Role:** Any member of the health care team who has group facilitation skills can serve as facilitator (e.g., care coordinator, social worker, chaplain). This should be determined in advance. Physicians generally should not facilitate the conference because this often interferes with their ability to present the medical information. The task of the facilitator includes:
- Welcoming participants and inviting them to introduce themselves
- Explaining the purpose and goals of the conference and outlining the format
- Setting the time limits (45-60 minutes maximum), and inviting initial questions or comments
- Following the format of the conference and facilitating discussion among those present
- Assessing the understanding of the patient and family, especially of medical terminology, and of the health care team as to the goals and resources of the patient and family
- Summarizing the discussion, identifying follow-up plan, and documenting the relevant information on the “Care Conference Record”

**Format of Conference:** Care conferences can be conducted in various ways that meet the particular needs of the institution and participants. Some of the key features include:
- Selection of appropriate setting that is conducive to a collaborative, respectful discussion
- Welcome, introductions, and reflection or prayer
- Discussion of purpose/goals of the conference, time limits, and other housekeeping issues
- Discussion of key considerations (e.g., medical status of the patient, patient and family satisfaction with current care plan, patient and family needs and goals, treatment options and goals of care, pain and symptom management, code status, psychosocial and spiritual issues, and transition or discharge plan)
- Identify outcomes, outline follow-up plan, and document proceedings on “Care Conference Record"
Care Conference Record

Part 1: Patient Information
Patient name: ___________________________  Patient account #: ___________________________

- How are patient’s wishes known?
  - Patient cognitive/verbal
  - Advance health care directive
  - Patient’s previous request

- Who is the decision-maker?
  - Patient
  - Parents (if minor)
  - Proxy (specify)

- Conference scheduled?
  - Yes
  - No (if yes, proceed to Part 2; if no, explain):

Part 2: Conference Proceedings
Conference facilitator: ___________________________  Conference date & time: ___________________________

Patient present: Yes  No  Attending/primary treating physician present: Yes  No

Health care team members:
(list name and role)

Family members:
(list name and relation)

Issues to be considered (check those addressed)

- Medical status of the patient
- Patient and family satisfaction with current care plan
- Patient and family needs and goals
- Treatment options and goals of care
- Pain and symptom management
- Code status (if not already discussed)
- Psychosocial and spiritual issues
- Transition or discharge plan

Discussion, outcomes, and follow-up:

Record updated to reflect outcomes of conference:  Date: ____________  Initials: ____________
Care Conference Q&A for Patients and Families

Q: What is a care conference?
A: It is a meeting where the patient (if able), family, and health care team come together to set up the best plan of care for the patient in light of the patient’s and family’s needs, goals, and resources.

Q: When is a care conference done?
A: There is no set rule. Ideally care conferences should be held early on when a chronically or seriously ill patient is admitted to the hospital. They should also be held when: there is a major change in the patient’s condition; the patient or family has concerns about the care being provided; the patient’s care plan needs to be revised or updated; or there is disagreement and not everyone is on the same page about the patient’s care.

Q: Who attends a care conference?
A: The patient (if able), key family members and others invited by the patient (such as, clergy person/faith leader or close friend), physicians, nurses, and others involved in the patient’s care. This might include a social worker, chaplain, rehabilitation therapist, pharmacist, or any other caregiver who can help in setting up the best plan of care for the patient.

Q: Who can request a care conference?
A: The patient, family, or anyone directly involved in the care of the patient may ask if a care conference would be helpful. The care coordinator, a registered nurse connected to a unit or patient group, is in charge of setting up the conference. The care coordinator invites the patient, family and health care team members to attend the conference at a time that is best for most of the people. In some cases, a social worker, chaplain, or other team member may set up the conference.

Q: What happens during a care conference?
A: The conference begins with introductions. The person leading the conference will state the purpose and goals of the conference and outline the format and timeframe for it. The patient, family, and others invited by the patient will have a chance to share their concerns, wishes, hopes, and goals. Physicians will explain the medical situation, reviewing the condition of the patient and treatment options, including the likely benefits and burdens of them. Other members of the health care team will share their views about the patient’s care and offer their insight as to how to provide the best care to the patient. If there are any decisions that need to be made, these will be listed. Everyone has a chance to speak. In cases where the patient is not able to speak, the choices the patient would have wanted will be discussed with the family members. This involves especially the person chosen by the patient to speak on the patient’s behalf (often called a surrogate decision maker, proxy, or durable power of attorney for health care). The person leading the conference will keep notes and make sure that any decisions made are written into the patient’s care plan and made known to all of the patient’s caregivers.