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Acute Care Decision Sheet

As a caregiver you will most likely need to respond to an acute medical condition requiring care in the hospital. It is important for you to discuss the situation and develop an action plan with your medical team. Please remember interactions, interventions, and resources vary from pediatric to adult hospitals; however, the end goal of a multidisciplinary approach to care is the same. The differences between adult and pediatric hospitals might stem from the following: patient acuity level, patient-to-nurse ratio, and availability of specialized equipment. Nevertheless, hospitals and their employees are still compassionate, goal-oriented, and family-centered. They value and appreciate input on how to interact with your loved one, and some adult care processes can be requested by family members. As a caregiver, be direct, clear, polite, and straight to the point with the healthcare team regarding the medical issue and treatment.

Initiate a meeting to establish (and update) a care plan

Request a meeting to discuss family goals for care – include the attending physician, nurse practitioner, nurse manager, social worker, case manager, other key healthcare team members, and other specialists. This meeting helps develop an agreed plan of care.

- This can be held as often as possible and are typically arranged by the unit or floor social worker or case manager.
- You can request to have outside services or advocates such as a family member, patient advocacy representative, or outpatient provider. These participants will help you better understand the discussion and articulate your thoughts to the medical team. Often these participants are on the phone.
- This is a forum to discuss any issues in care, expectations of care, or interventions that could or should be carried out.

Discussion topics to consider with your healthcare team

- What is the acute illness (reason for admission) and is it reversible?
  - How long will this acute illness last with current care plan?
  - What to expect in “good” and “bad” days
  - What does it mean if there aren’t any changes in symptoms? Would that be expected, or is that a sign of something else that might require additional intervention?
- What are the underlying comorbidities that might increase the chance of a poor outcome?

    - Are those underlying issues worsening during this acute illness?
    - Neuro-relevant questions:
        - Has there been constant status epilepticus? If so, how long?
        - What are the underlying cognitive changes that are being seen by the medical team either by diagnostics or by physical exam?
        - Are there changes in behavior or communication?
    - Kidney questions:
        - Are renal issues acute or are the kidneys functioning stably?
        - **NOTE**: If your loved one is receiving organ-saving acute hemodialysis, it is not considered to be end-stage renal disease unless the kidneys have not started to work after six months.
        - Is this a quick fix that will most likely resolve in an outpatient setting or are there other severe acute issues such as other organ failure?
    - Lung questions:
        - Are there respiratory changes?
        - Is oxygenation required to sustain acceptable levels?
        - Does their breathing look labored, difficult, uncomfortable?
    - Other health related issues such as a heart attacks or stroke are all important to consider.
        - How does this change the baseline and function of your loved one?
        - Does it impact the quality of life that you seek for them?
- Will any of the comorbidities permanently affect the quality of life?
    - This is always difficult in critical care as “time” is usually the only indicator if one will improve or not.
    - Remember: At baseline, your loved one has an incurable disease, and some healthcare providers might not understand goals of care and what is an acceptable change from this baseline.
        - **NOTE:** It is very important to have clear established understanding with your healthcare team of what is the ongoing quality of life that is effective and OK for your loved one.
- Are pain and quality of life being balanced?
    - Those who have loved ones who are nonverbal or with a lower cognitive function can find these times more difficult during an acute situation. Having a discussion with your healthcare team or having a list available to discuss ways to interact, communicate, and pick up on their verbal and non-verbal cues as to whether they are hurting is very important to the bedside nurses as well as the overall healthcare team.
    - Resources such as communication boards or a quick reference guide (e.g., a poster board to hang on the wall that shows certain types of verbal sounds or movements your loved one makes when in distress or pain) is invaluable to the medical team and should be discussed as soon as admitted.
- Understanding the risk of death if changes are not implemented.
    - **EXAMPLE:** Is a breathing tube or other form of life support required to maintain life?
    - This can be a very difficult question, and the younger the age the more difficult it is to address openly with parents from a healthcare perspective.

    - If you are faced with end-of-life consideration, medical professionals (e.g., hospice team, pain management team) are available to assist during these times. These teams typically include a physician, nurse practitioner, nurse, and a social worker.
    - Remember, not all palliative care is hospice, but all hospice is palliative.
    - If you're faced in a situation involving difficult scenarios and difficult life choices, always consult the attending medical doctor or team – you are not alone in this journey.
- The COVID-19 pandemic has created many challenges in medical facilities.
    - Due to the complex changes, many institutions have been inconsistent and unpredictable with visitation polices.
    - The most common question is "how will I know if my loved one's needs are being met with compassion and quality" imposed by COVID-19 restrictions?
        - Ask up front about visitation policies. Depending on the state, Title III of the ADA does require hospitals to provide accommodations.
        - Most facilities do make accommodations to allow one support person to always remain at the bedside.
        - This does change depending on the higher level of care needed such as an intensive care unit, and this can change and influence the accommodation that you might've had in a different setting of the same hospital.
        - If you are found in this situation it is best to speak with the intensive care nurse manager, palliative care nurse, social worker, or case manager to discuss a family intervention plan.

Despite clear and direct communication, you might still find yourself in a situation where you do not feel like your voice is being heard or the needs of your loved one are being met. If that is the situation, the following steps may help expedite your concerns and increase resolution.

- Communicate directly with the bedside nurse.
- Discuss care expectations with the nurse manager.
- Repeat these steps as necessary during a hospitalization. If you still do not feel you are being heard or interventions are not being carried out at any point in this process, you can reach out to the hospital patient advocate or liaison. This can occur at any step of the hospitalization including the emergency department. If things continue to not go well and you are needed to expedite care, you can always reach out to the chief medical officer or depending on the issue request an ethics committee consult. It is best to try to resolve any conflict prior to those steps, but all situations are unique and understanding your options will help empower you to have a sense of direction during the most difficult circumstances.

If you decide to have a family meeting it's always best to have a written agenda with your concerns and questions you want addressed. Don't be afraid to speak up. Don't be afraid to have an advocate who is slightly removed emotionally from the situation to make sure that your objectives are being carried out, so you also have a clear picture of what is going on given the current barriers and restrictions.

If you are alone but would like to express your wishes in writing, ask the unit security or bedside nurse to make a copy of your agenda so each person attending the meeting can

read it themselves, thus putting less pressure on you. Another key person to consider having present is a chaplain, clergy or religious leader (the hospital can help you connect if you don't have one in mind) for moral support for you and who can moderate discussion if it becomes intense between you and the healthcare team.