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## Advance Decision-Making Planning Sheet

Take the time to develop a care plan for current and possible future challenges. The purpose of planning is to help guide your decisions in the event of an acute situation in a stressful time when emotions, fears, doubts, and guilt can take over and cloud your judgement. NO decision is permanent, if you choose to change your decision at any given time along any healthcare journey all prior decisions can be revoked if you are the legal caregiver or guardian. Those who have legal medical power of attorney or conservatorship/guardianship would be the legal representative to make end-of-life decisions and carry out wishes that have already been discussed can offer comfort to those responsible during these times.

This plan helps identify the decision-making process for the entire caregiver team. It is important to understand the development of the plan is a process, not all situations are relevant and can be addressed over time. The plan is unique to the caregiver personality and the patient's condition. There is no right or wrong decisions. It is never too early to discuss these difficult situations. The younger your loved one is you should consider only discussing 1 – 2 topics at a time. Things to consider to be a part of a legal documents or discussed with the caregiver team (family):

### 1. Nutrition, food, and hydration.

- Situations where alternative routes would be considered, such a nasogastric tube or more permanently PEG-tube. These are both invasive, yet minor procedures. Both are performed at the bedside. Once your loved one has recovered these can both be removed and typical nutrition feeding routes can be resumed.
- Situations where decisions of withholding certain nutrition interventions. This is more common during irreversible situations when end of life is being discussed. During the dying transition, the desire or metabolic needs for food or water change. It is important not to force food or water during this time. Allow the person to decide the timing and amount of food consumed. It is about comfort not nutrition. Forcing food can have unfortunate consequences such as aspiration (food accidentally goes down airway).

### 2. Symptom Control and Management

- Physical areas to navigate:

- Pain regimen: How to identify pain – is it verbalized or through facial or body cues? What is acceptable and safe. When is comfort your main priority over treatment? Under some situations pain medication will be withheld to maintain basic life function. There is never a “giving up” period. Care goals change, based on all the information in specific unique situation.
  - Infection treatment & management: Are there situations during care where you would not want antibiotics, wound therapy, surgical debridement, wound vacs etc.
  - Acute issues such as breathing, neurological function. Are there situations where you would not want advanced life support?
  - Blood Transfusions: Is this acceptable treatment or are there religious or personal beliefs that restrict this option?
- Psychological: How to provide comfort and support especially if your loved one is nonverbal during difficult times? What is a source of comfort for your loved one? Such as a special blanket, pillow, stuffed animal, or book.
  - Spiritual support: Are there spiritual needs during necessary during difficult times?

### 3. Resuscitation “Life Support” Interventions

- Do not resuscitate/do not intubate (DNR / DNI): This means there will be no medical interventions by medical personal if core basic functions have stopped. Such as, no longer having a heartbeat, absences of breathing.
- Full code: This is where all life-saving interventions would be completed by medical personal in the event the heart or breathing stopped. These interventions include, chest compressions (pumping on the chest wall), intubation (a breathing tube), defibrillation (shocking with electric pads), and medications (given in efforts to reverse fatal arrhythmias, causes or in hope to regain a heartbeat).
- These interventions can be unique and specific to your loved one. These interventions can be all the above, none or certain in between varieties based upon your wishes. These can look like anything from a full code to chemical code only chest compressions in chemical code only notification or intubation.
- It is important to understand that these decisions can be reversed at any time. Having a plan in place or having the discussions with another caregiver regarding these difficult conversations can change throughout your journey. Adapt accordingly. Empowered decisions are those who are knowledgeable about all the options so you can make the best choices for your loved on.

### 4. Acute dialysis: This is intervention can be done due to an acute illness in someone who is susceptible to kidney failure. However, this can also occur in situations where the body has started to shut down and the kidneys are no longer processing in a way to sustain life. It would be important to understand the situation to be able to navigate if this intervention should occur. Regardless, there

are some who might feel that this option would not be in the best interest of their loved one regardless of the etiology. All decisions are unique and should never be compared to others even with the same rare disease or other diagnosis.

5. Other medical interventions and procedures. It is impossible to cover all options, but the main objectives will always remain the same. The type of questions you would want to ask yourself would be:

- What is the purpose of this intervention or procedure?
- Will this fix the current issue or relieve stress.
- What is the benefit of this procedure?
- Is this a temporary fix or will this procedure or intervention need to be repeated and if so, what does that look like.
- What is the risk of these procedures?
- Will this intervention be long term?
- Does this intervention change our quality of life?
- What are the added barriers if we carry out this intervention?
- Is this a sustainable option? How long could this be feasible for the family dynamic?

Difficult situations can provoke emotions due to different point of views in families. Be open and compassionate to each other during these discussions and keep the overall goal as the loved one you all care about centered. Transition phases in caregiver roles, such as an aging parent to an adult sibling should consider having this discussion with the adult sibling as an equal part of the process. If these conversations need to be addressed but feel it will cause issues within a family dynamic consider reaching out to a local counselor, clergy, or palliative care service to help moderate these difficult talks. Remember, you are not alone during these times.