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Helping Families/Caregivers Make the Difficult Decisions for Those Without Capacity

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Case Studies

- Maria: 75 y/o with devastating stroke – family wanting to do everything even though Maria would say she wouldn't want to live like this
- Taye: 88 y/o with end-stage renal disease and dementia – lives in skilled nursing facility, no family, staff has only known him with dementia
- Bob: 67 y/o with an early stage Alzheimer's diagnosis – he has a supportive wife – She is beginning to worry about his ability to drive

5 Core Questions Along the Path

- 1. Does the individual have the ability to make his or her own decisions? Does he or she have decisional capacity?
- 2. If the person is not able to speak for him- or herself, how long will it last?
- 3. Was the individual able to speak for him- or herself in the past?
- 4. Who should make the decisions when this person can't?
- 5. About how old is the person developmentally? What is his or her mental age?

The Framework and Tools

- The Decision Making Framework
- The Shared Decision Making Model
- The Sliding Scale for Decision Making
- The Assent Tool
- “The 5 Core Questions Flowchart” is your unofficial 5th tool which will guide you through the decision-making process.

Core Question #1: Does the individual have the ability to make his or her own decisions?

- 1. Does the patient realize there is a decision that needs to be made?
- 2. Can the patient understand what is being said about the disease and the treatment options?
- 3. Can the patient understand the consequences of each of the different options, including the option to do nothing?
- 4. Can the patient think about what he or she wants to do based on his or her own values/beliefs and how the choices would affect his or her life?
- 5. Can the patient communicate his or her decision to the doctor and explain why he or she has made this decision? (Even if an alternate means of communication needs to be used.)

Core Question #2: If the person is not able to speak for him- or herself, how long will it last?

- 1. Permanent—the person will never regain the ability to make his or her own decisions
 - 2. Temporary—the person may get better
 - 3. Fluctuating Capacity—sometimes the person has capacity, and sometimes he or she does not
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- If it is fluctuating, you will need to use the right tools based on the person's condition that day
 - Based on the doctor's evaluation, the family can begin planning for the short or long term

Core Question #4: Who should make the decisions when the patient/person can't?

- The person specified on the Advance Directive
- Conservator or Guardian
- Spouse
- Significant Other
- Partner
- Adult Child
- Parent
- Adult Sibling
- A relative
- Friend
- The family
- The healthcare team
- The administrator of the nursing home (in some states)
- Other

Capacity? How long? Who?

- Maria: 75 y/o with devastating stroke – family wanting to do everything even though Maria would say she wouldn't want to live like this
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The Decision-Making Framework

Framework	Ranking	Definition
Autonomy	Best option	Autonomy means a person with decisional capacity is allowed to make decisions about what will happen to his or her own body.
Substituted Judgment	2 nd best option	Substituted Judgment is used when the person has lost decisional capacity. Someone else will make the decisions based on the <u>patient's values and wishes</u> .
Best Interest Standard	3 rd best option	A decision maker and/or the healthcare team, who may or may not know the patient, will make the decision without the benefit of knowing what the patient would want. What would a generic or reasonable person want in this situation?

Substituted Judgment

- The decision maker is supposed to step into the patient's life and speak with the patient's voice—not their own voice
- *“What would the person be telling us if he or she were able to speak right now?”*
- Consider all that is known about the person, what she has said in the past, what her values are, and what would be important to her
- Using this information, make the decision you think the person would make

- Maria: 75 y/o with devastating stroke – family wanting to do everything even though Maria would say she wouldn't want to live like this
- How are we going to help this family to understand their role in this decision?

Substituted Judgment Questions

- What would the patient say if he or she could talk right now?
- Would the patient want to live like this? If not, what condition would the patient be willing to live with?
- Did the patient say anything to you or others in the past that indicates what he or she might want?
- What would the patient say is important to consider when making this decision? What personal, religious, or cultural beliefs would be important to the patient in this situation?
- If the patient would say, “I want my family involved in making these decisions” or “I would want to do what my family wants me to do,” then you can add the family’s opinions to the decision-making process. If not, you should focus on what the patient would tell you.
- If I don’t know what the patient would say, whom should I ask?
- What do I *not* want to admit to myself or to the doctors about what the patient would say about this situation? What am I afraid to say aloud?
- What would I want and how is that different from what the patient would want?

Best Interest Standard

- Used when we don't know what a patient would want or we can't find someone to speak for the person – Like Taye
- This is the worst option as someone must guess what is in the best interest of the patient
- “What would a reasonable person want in this situation?” Or, “What would a generic person want?”
- Better to **make these decisions as a group** in order to have a variety of people express their opinions about what a reasonable person would want. It is also best if someone who knows even a little bit about an individual is involved in the process.

Who Will Need The Best Interest Standard?

- 1. A person whose mental age never progressed to a point at which he would be able to provide us with important information about his preferences
- 2. Individuals who have been found unconscious or those who have been living in a care facility and the healthcare team can't find any friends or family members who can speak for them
- 3. Or perhaps the family has been found but they have been out of contact with the patient for many years and don't really know this person or are unwilling to make the decisions

Using the Best Interest Standard

- Talk to the caregiver about basic preferences, signs of comfort or discomfort, and how to communicate
- 1. Ask all the necessary medical questions in order to make an informed decision.
- 2. Ask quality-of-life questions. How has the patient's quality of life changed because of the current medical situation. Will the treatment being considered improve the person's quality of life? Is the patient suffering? What will the decision mean to the patient's future living situation?
- 3. Once a decision is made, have the physician document the decision.
- 4. After making the decision, continually reevaluate and adjust the plan depending on the patient's condition. Stay in communication with the healthcare team.

Determining What Is In The Patient's Best Interest

- Severity of the patient's medical condition
- Availability of curative or corrective treatments
- Achievability of important medical goals
- Presence of serious neurological impairments
- Extent of the patient's suffering
- Multiplicity of other serious medical problems
- Life expectancy of the patient
- Proportionality of treatment-related benefits and burdens to the patient

Weir and Bale, 1989

The Medical Goal vs. The Quality-of-Life Goal

- Figure out the quality of life goal first
- Then, once you know the quality of life goal, can it be achieved medically?
- What medical options are available and could they improve or maintain the person's quality of life?
- Is a time-limited trial appropriate to see if the quality of life goal and medical goal can be reached?
- If the quality-of-life goal is not achievable, what level of recovery is possible?
- What would be an acceptable level better?

Quality-of-Life Questions

- Evaluate the quality of life by the patient's standards
- Based on the patient's quality of life before this hospitalization or treatment, how has the patient's quality of life changed?
- If I don't know, can I find out more about the patient?
- Is this change in quality of life something that the patient would be willing to live with?
- Will the patient be able to return to the same caregivers, friends and family? Will the patient be able to return to the same environment? If not, how can we help the patient adjust to a new environment?
- Will the patient be able to enjoy his or her meals as before?
- Will the patient be able to enjoy the same activities as before?
- Is the patient suffering?
- Will the treatment being considered improve the person's quality of life or just the quantity of life?

Medical Treatment Questions

- **Would the treatment be both wanted by the person and good for the person?**
- What is the proposed treatment?
- What procedures will be followed?
- Who will perform the treatment or action?
- What are the possible risks, side effects or discomforts?
- What steps will be taken to minimize the risks?
- What alternatives are available?
- What will happen if nothing is done?
- Why now and not later?
- *(For a more extensive list of questions to ask, go to the resource page on TheCaregiversPath.com)*

Is The Plan Working?

- After the treatment begins, check in to see how the patient is reacting to the treatment.
 - Is the patient doing better?
 - Did the treatment help?
 - Is it making the patient worse?
 - If the patient is not receiving the treatment, how is she doing without the proposed treatment?
 - If the treatment is not going as it should, the decision maker can change your mind, withdraw the consent, and create a new treatment plan
 - Keep in mind that the decisions are based on what the individual would want
- Too often, doctors, patients or caregivers get going in one direction and forget to change course when the plan stops working. Be willing to say, “We need to stop and make a new decision.”

Core Question #5: About how old is the person developmentally? What is his or her mental age?

- Whether you estimated the person's mental age or the patient has been given a formal evaluation, the answer will fit into one of these categories
- These age ranges will help guide you as you begin to use the Shared Decision Making Model
- 0-6 years old?
- 7-13 years old?
- 14-17 years old?

The Shared Decision Making Model

- Determines how much the individual should participate and how big of a voice he or she should have in important life and health decisions
- For a person with very minimal capacity, she might be able to make decisions about what to wear or what to watch on TV, but it would be dangerous to let her make important medical decisions
- **A less risky decision requires less capacity while a more risky decision requires more capacity**
- Use this tool to adjust this process to fit the individual's mental abilities as it changes over time
- For those with fluctuating capacity, you will need to adjust the age range as the person's condition changes each day

The Shared Decision Making Model

Approximate Developmental Age	Decision Making Tool	With adults, who participates?
Age 0–6	Decision Maker's Consent	The patient's decision maker uses Substituted Judgment or the Best Interest Standard.
Age 7-13	Assent	The decision maker, with the help of the doctor if needed, talks to the patient about the medical decisions and gets the patient's assent/dissent. The decision maker gives the final consent.
Age 14-17	Consent	If the patient has enough capacity, the patient uses autonomy and makes the decisions. If not, you move back up one level and use Assent.

Using The Shared Decision Making Model

- 0-6 age range: You will need to make the decisions for him or her because it wouldn't be safe for the individual to participate in important decisions.
- 7-13 age range: The person will be able to have a voice in most decisions but will not make the final decision.
- 14-17 age range: The person may have enough capacity to make his or her own decisions. If not, you will want to use the 7-13 year old guidelines.
- The ages on the chart are a guideline, not a rule. You can adjust the ages up or down a little bit, but be careful about moving the developmental age too far out of the decision making guidelines that are shown here: you might end up using the tool in the wrong way.

The Sliding Scale for Decision Making

How serious is this situation and is it safe for the person to participate?

No capacity	A little bit of capacity	Some capacity	Almost full capacity	Full capacity
No decision making	Some small decisions	Daily decisions and some voice in medical decisions, but not life-and-death decisions	Larger voice in important decisions	Full voice in his or her own decisions, including life-and-death decisions

A Non-Life-Threatening Decision

Age 0-6		Age 7-13		Age 14-17
No capacity	A little bit of capacity	Some capacity	Almost full capacity	Full capacity
No participation	No participation	Will ask for the patient's assent or dissent	Will ask for the patient's assent or dissent	Patient can make his or her own decisions

The Assent Tool

- The Assent Tool shows you *how* to give the person a voice in the decision making process
- When you ask for the person's assent, you are asking for permission
- The person is given a voice or a vote in the decision
- This is only one vote, not the final vote
- As you begin to see how it changes your interactions with the individual, if it isn't working, don't be afraid to try another category

Steps to Asking for Assent/Dissent

- 1. Evaluate the person's mental age, maturity level, psychological condition and ability to give assent/dissent.
- 2. Allow enough time to use an alternate method of communication. You may need to slow down and repeat yourself a number of times. The person may need multiple meetings with the doctor before he or she can understand what is being discussed. Don't get frustrated as the person is doing the best he or she can.
- 3. Using developmentally appropriate language (language the patient can understand), give the person the necessary information about his or her illness. Don't use complicated medical terms or tell the individual too much all at once. You may want to use pictures, a video or a simply written handout.

Continued...

- 4. Give the person the details of the proposed treatment, test or surgery. Explain what the experience will be like *from the patient's perspective*.
 - What will it be like for the patient to experience the proposed treatment, test or surgery? Where will the test take place?
 - Will the test hurt? Will the patient be left alone or can you stay with your loved one during the procedure?
 - Even if the patient can't give assent, the person should be informed about what will be happening at the hospital or the doctor's office
- 5. If the person says yes, be careful that the person isn't just saying that to make you happy. Make sure that the person really understands what is being discussed.
- 6. If the patient doesn't understand what you are talking about, then try again. If the person still can't understand, then you shouldn't use assent. You will need to make the decision as if this individual is developmentally 0-6.

Does No Mean No? For Now, Yes!

- Don't ask the question if you can't respect the answer. Instead just inform the person about what will be happening and give the necessary information to reassure and comfort this person.
- You can:
 - Try asking again at a later time, but be careful you aren't bullying the person into agreeing with you
 - Don't nag the person to change his or her mind just because you want to do things your way
 - Your goal is for the person to retain as much power in her life as possible for as long as possible
 - You are in a long-term relationship with this person, if you decide to ask for a yes or no, then the person's decision should be honored

A Life-or-Death Decision

Age 0-6		Age 7-13		Age 14-17
No capacity	A little bit of capacity	Some capacity	Almost full capacity	Full capacity
No participation	No participation	Patient will not be allowed to make life-and-death decisions. Will <i>not</i> ask for assent as this is life and death.	Patient can probably make less risky decisions, but will not ask for assent as this is life and death	Patient can make life-and death-decisions

Using the Tools Together

- 5 Core Questions Flowchart:
- 1. Think back to the Decision Making Framework and determine if you will be using Substituted Judgment or the Best Interest Standard
- 2. Look at the Shared Decision Making Model to determine how much the person should be involved in the decision making process
- 3. Check with the Sliding Scale of Decision Making to decide how serious the decision is that you need to make and how you should proceed
- 4. Use Assent if the person's mental age is in the range of 7-13 and it is safe for the person to participate in the decision-making process

When The Process Isn't Working

- You may be using the wrong tool or using it the wrong way
- Perhaps you are letting the person have a voice in too important of a decision
- Or perhaps the individual's mental condition is changing and you need to reevaluate whether or not the person should still participate in the process. It may be time to shift to the zero to six developmental age category.
- Or you may be the problem if you don't like what the person is choosing
- You may find yourself in a power struggle as the person is fighting to keep some control over his or her life
- It might be some or all of these, but the main issue I see when assent fails is a problem with communication.
- We have to begin by asking ourselves, "Why isn't the person cooperating?"

Putting The Tools Into Action

- Use the 5 Core Questions Flowchart
- Decide how you will use the 4 Tools in each situation
- What insights can you give this family so they can become better decision makers?
- What questions will you want to ask?
- How would you approach this family?
- What else do you think might be going on?
- Don't make assumptions - Be prepared for surprises
- **Make sure you keep the patient/person at the center of the conversation – Frame the information based on how the decisions will be experienced by the patient/person**

Practice Case #1

- A thirty-five-year-old man was in a terrible car accident and now has a developmental age of nine. The patient used to be able to think for himself and his family knows him well. His doctor says he needs to have a colonoscopy because of his rectal bleeding. His family history includes a brother with colon cancer at a young age. The patient has an Advance Directive that indicates he wants his wife to make his decisions for him.
- How important is this decision? (Life-or-death, important but not life-or-death, or not important)
- Which framework should I use? (Autonomy, Substituted Judgment or Best Interest Standard)
- What is the person's mental age? Should the person participate in the decision based on the age ranges in the Shared Decision Making Model? (0–6 years old, 7–13 years old or 14–17 years old)
- Who should be the decision maker?

Practice Case #2

- A woman, age fifty-five, is developmentally disabled with a developmental age of one. She has never been able to express any preferences. A public conservator has been appointed by the county to make medical decisions for her. The decision to be made is about an elective surgery; the doctors indicated that they could wait to see if she can get better without it. What do you think should be done?
- How important is this decision?
- Which framework should I use?
- What is the person's mental age? Should the person participate in the decision?
- Who should be the decision maker?

Practice Case #3

- A sixty-three-year-old man with advancing Alzheimer's has a developmental age of eight. This patient used to be able to think for himself, but has now lost most of his ability to communicate. He can still communicate his basic preferences about what to eat or if he is in pain. He lives in a nursing facility and there is nobody to speak for him. The test the doctor wants him to have is important, but not life-or-death.
- How important is this decision?
- Which framework should I use?
- Should the person participate in the decision? What is the person's mental age?
- Who should be the decision maker?

Three Additional Resources

- Personalizing the decisions:
- Questions to Ask When Making Decisions
 - Medical
 - Cultural
 - Religion
 - Financial
 - Quality of life
- Decision Making Worksheet
- Action Questions

Life-or-Death Case

- Teye: 88 y/o with end stage renal disease and dementia – lives in skilled nursing facility, no family, staff has only known him with dementia
- The team determined that he is end-stage and in the process of dying
- He has a mental age of 3, so he hasn't been able to express any values beyond his favorite food. (He loves to eat)
- His quality of life has changed dramatically over the last month and now he can no longer eat
- Should a feeding tube be placed? Should he be placed on hospice? Should he be a DNR?

Be Careful...

- A life-and-death situation doesn't mean that all treatments are worth the chance
- Balance the risks versus the benefits
- Some treatments have no chance of working or the suffering will be so severe from the treatment that it isn't worth it
- When decisions are made for children, the treatment has to have a great enough chance of success to justify putting the child through the toxic side effects
- And, remember to use Substituted Judgment if appropriate. Would the patient would want to take the chance and endure the suffering?

Cultural differences in attitudes regarding end-of-life care

- Trust in the medical system
- Communication styles
- How decisions should be made
- Religious beliefs
- Language interpretation
- Use of hospice as of 2003: 82% White, 8% African American, 3% Hispanic/Latino (1)
- Societal issues such as access to care
- Pain description and the ability to pay for meds

Discrimination At The End of Life

- The laws that protected the patient may end up causing harm or preventing a peaceful, dignified death
- The patient cannot say, “Enough already, I am ready to die,” so the dying/suffering may be prolonged
- Doctors hesitate to do what they would do for a “regular” patient because they don’t want to get in trouble
- Without a strong advocate, the healthcare professional will feel obligated to continue
- We treat the dying disabled patient different than a regular dying patient. And this can significantly change the dying experience.
- At the end of life, we shouldn’t treat mentally disabled people as “special” but instead we should treat them as “normal.”
- They are entitled to all of the normal good care and support we give to other patients during the process of dying.
- Help your patient get a referral to hospice, appropriate pain management, grief support, comfort for their suffering and anything else we can do to make the journey more peaceful.

Recognizing Death Approaching

- Doctors are not very good at recognizing approaching death
- *Would you be surprised if he didn't make it back for his next appointment? Would you be surprised if you got a call that he died?*
- *Is he or she sick enough to die?*
- People haven't seen a death at home so they don't know what to expect
- Is he able to do what he used to do? Is he in bed more? Sleeping more? Eating less?
- As times goes on: Withdrawal, disorientation, processing one's life, confusion, etc...

A Hospital vs. Hospice death

- Making the difficult choices:
 - About a DNR
 - To send the person to the hospital
 - To put the person on hospice
 - Putting in the feeding tube
 - Withdrawing the ventilator

10 Pitfalls in DNR Decision Making

- 1. Patients don't understand what really happens during CPR.
- 2. Patients think it works just like on television.
- 3. Patients don't understand that they may come back to life in a worse condition than they were in before, both mentally and physically.
- 4. Patients don't understand that the type of death they are choosing is probably not what they would want if they understood.
- 5. The decision maker won't sign the DNR because of his or her own guilt, grief, desperation etc.
- 6. Pushing our agenda.
- 7. Physician discomfort when talking about end-of-life issues.
- 8. Doctors weren't trained to have a great CPR/DNR conversation.
- 9. MD's thinking the DNR decision tells them everything they need to know about a patient's end-of-life wishes.
- 10. The doctor won't respect the Advance Directive that says, "No CPR."

Other Issues That Need To Be Addressed

- Prolonging life vs. prolonging dying
 - Is he suffering?
 - Can we change is quality or only his quantity of life?
 - Hospice referral?
- Return home vs. go to a skilled nursing facility vs. stay in hospital
 - What is possible?
 - What would be in his best interest?
 - What are the benefits and burdens?
- Placement of feeding tube vs. no feeding tube
 - Risks involved in procedure
 - Loss of ability to enjoy food
 - Improving quantity and/or quality of life
 - If actively dying, should he be fed?
 - Obligation to feed the disabled
 - Couldn't go back to group home with the feeding tube as he would need a higher level of care
 - Could go back to group home on hospice

What Makes A Life Worth Living?

- We need to adjust our view of what constitutes a good life
- Just because we might not want to live like they do, doesn't mean that they are not experiencing a good life
- Step inside their existence to feel what brings this individual happiness, comfort and a meaningful life.
- The disabled need continuity throughout their lives and especially when dying
- Value in being able to return to same familiar environment with familiar smells, familiar noises, familiar caregivers and a familiar schedule.
- They are unique individuals. They are not just some generic incapacitated person
- We need to be careful as their bodies will experience the consequences of our decisions. We need to protect them as they are not be able to speak for themselves.
- **Evaluate the quality of life by the patient's standards**