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4 Bioethics Tools for Shared Decision Making, Evaluating Danger, and Creating a Good Care Plan

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5 Core Questions Flowchart

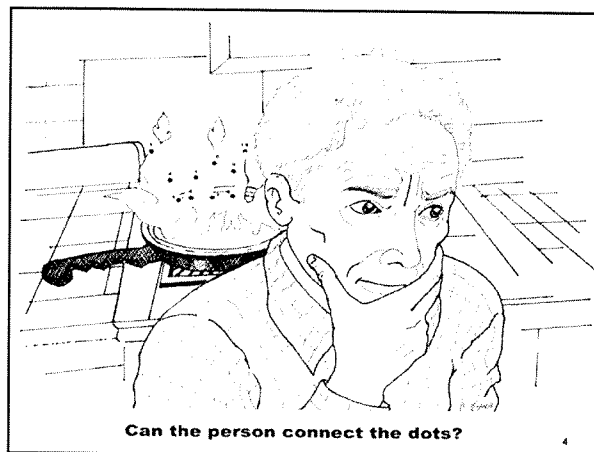
4 Bioethics Tools are
Embedded in the Process

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Capacity vs. No Capacity

- Capacity for what?
 - To express preferences?
 - To see the dangers?
 - To understand the consequences?
- A person can be very verbal and charming but not be able to understand the dangers
- Can the person connect the dots?

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A More Positive Approach When Evaluating the Situation, Person and Needs

The Cards I've Been Dealt

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Risky Decisions of the Person With Capacity

- Autonomy – People, with full capacity, have the right to determine the course of their lives
- People have the right to make a wrong decision
- There is a limit to this right – When our actions harm others: “The Harm Principle”
- (People are allowed to harm themselves)
- Is the help/advice you are offering wanted?

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Our Obligations Change When the Person Lacks Capacity

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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?

Best Interest Standard

- “What would a reasonable person want in this situation?” Or, “What would a generic person want?”
- This is the worst option as someone must guess what is in the best interest of the patient
- 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. *Advocacy Team Policy*

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Using the Best Interest Standard

- **Talk to the hands-on caregiver about basic preferences, signs of comfort or discomfort, and how to best communicate**
- 1. Ask all the necessary factual 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?
- 3. Reevaluate and adjust the plan based on person's condition

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What Makes A Life Worth Living?

- This is not a generic person but a unique individual
- **Step inside their existence to feel what brings him/her happiness, comfort, meaningful life**
- Value in being able to return to same familiar environment with familiar smells, familiar noises, familiar caregivers and a familiar schedule.
- **Evaluate the quality of life by this person's standards**
- **Help to humanize your person to those who will be caring for him/her**

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Better Information = Better Decisions

- When asked what patients might want if they were in advanced dementia state in a skilled nursing facility:
 - 50% comfort care
 - 21% everything done
 - 18% some interventions
 - 11% unsure
- After being shown a 2-minute video of a patient with advanced dementia being cared for in a SNF:
 - 89% comfort care
 - 0% everything done
 - 11% some interventions or unsure
 - Differences regarding race, ethnicity and education level disappeared

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But She is Okay Some of the Time!

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I Don't Want to Accept That Mom Needs Help!

- Do you know which days or times of day she will be fine?
- If there is a fire, will she be able to get out of the house and call for help, even on the days when she isn't doing well?
- I had the sisters repeat to themselves: *"We can't take a chance that the danger will happen on one of her bad days."*
- What really helped were the next two tools

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Empower and Enable the Person Based on His/Her Mental Age

- Whether you estimate 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?

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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.

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The Sliding Scale for Decision Making

*How serious is this situation?
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

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Watching Out For Red Flags

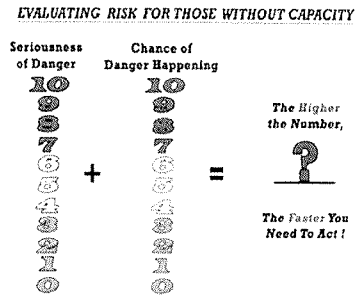


Has the Person Changed?

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What is *this person's* score when he or she is *not thinking* clearly?

- Showering
- Turning on the stove
- Wandering
- Taking medications incorrectly



Short-Term Plan vs. Long-Term Plan

- **Lower Score:** Take some time to develop a good long-term plan which both protects the person and provides a good quality of life
- **Higher Score:** Take action quickly and put a short-term plan in place. Then take some time to create a better long-term plan
- Knew my dad was in danger, so I moved him immediately into a skilled nursing facility
- They placed in restraints to keep him “safe”

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Physical/Chemical Restraints Risks

- | | |
|---|--|
| <ul style="list-style-type: none"> ■ Falls ■ Strangulation ■ Pressure Sores ■ Decreased Mobility ■ Loss of muscle tone and stiffness ■ Reduced Bone Mass/Fractures ■ Increasing weakness ■ Incontinence ■ Constipation/Impaction ■ Infection ■ Restricted breathing and aspiration | <ul style="list-style-type: none"> ■ Sleep disturbances ■ Fear, agitation, frustration ■ Loss of hope and internal motivation ■ Loss of dignity and humiliation ■ Increased boredom, loneliness and helplessness ■ Feelings of being punished ■ Depression, isolation, withdrawal ■ Thoughts of suicide ■ Learned dependence ■ Diminished staff opinion of resident ■ Death |
|---|--|

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Solutions for A Restraint-Free Life

- There is no *one-size-fits-all* solution
- Personalize the solution to fit the individual
- If one solution doesn't work, try another
- Here is a partial list of solutions: (email me for 80 more options at kindethics@gmail.com)
 - Fall reduction class
 - Medication evaluation
 - Frequent family visitors
 - Removal of obstacles that impede movement

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Balance Reducing the Risk While Improving Person's Quality of Life

- A life without danger may mean a life without meaning
- What are the **burdens** of the solution?
 - Emotional, physical, loss of control and dignity?
- **What will it feel like and be like for the person to experience this decision?**
- **If the person loses a part of their quality of life, what can we add to put more quality back into their life?**

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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 said. Don't get frustrated as the person is doing the best he/she can.
3. Using developmentally appropriate language (language the patient can understand), to give the person the necessary information about his or her illness.

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- 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.

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Emotional Memory

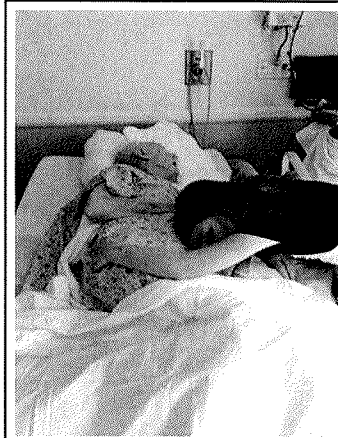
- If individuals with Alzheimer's have a happy experience, or someone treats them gently and with compassion, then that positive feeling can last anywhere from 6-24 hours
 - If the person has an unhappy or unkind experience, the negative feeling can last even longer
 - It is up to us to make sure that we are treating those with cognitive impairments as kindly and gently as possible because what we do has a lasting effect
- Dr. Annette Swain

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Using the Tools Together

- 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 or higher, and it is safe for the person to participate in the decision-making process

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End-of-Life Decision Making

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Discrimination At the End of Life For Our Most Vulnerable

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When Should You Begin Talking About End-of-Life Options?

- Is he able to do what he used to do? Is he in bed more? Sleeping more? Eating less? More frequent hospitalizations?
- Ask the doctor the "Surprise Question"
 - *Would you be surprised if he didn't make it back for his next appointment/in the next 6 months?*
 - *Would you be surprised if you got a call from the nurse that he had died?*

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The “Mixed Message” Problem

- “The kidneys are doing fine, the heart is worsening, the liver is failing, and the lungs are improving.”
- Tendency to focus on the most optimistic piece of information
- Solutions:
 - Go see patient with your own eyes or skype
 - Ask for a daily update regarding patient’s *overall* condition

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Is There a Medical Benefit or Is the Treatment Futile?

- **Physiological** –The treatment will or will not provide the desired medical outcome. Determined by the physician.
 - Medically Inappropriate, Medically Non-beneficial, Medically Ineffective
- **Qualitative** –The recommended treatment will or will not create the quality-of-life outcome desired by the patient. Determined by the patient or decision maker using the patient’s values.

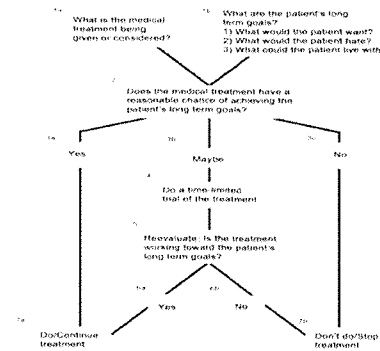
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The Two-Hand Test for Medical Decisions

- Before medical decisions can be made, both questions must be answered with a “yes,” or both hands have to be “up” to move forward. This answers the Substituted Judgment question (What would the patient want?) and Medical Futility question.
- **One hand:** “Is the treatment good for the patient?” (Physiologically beneficial?)
- **Other hand:** “Is the treatment wanted by the patient?” (Meets the patient’s personal goals?)

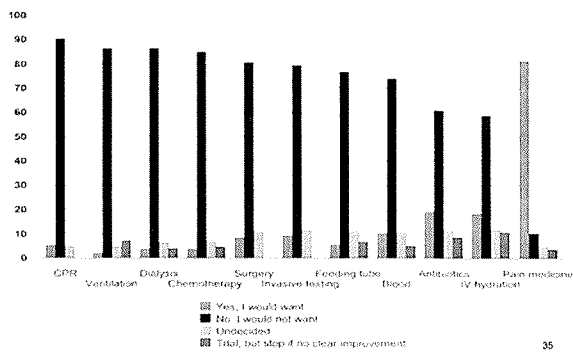
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EVALUATING TREATMENT OPTIONS WHEN YOU KNOW THE PATIENT’S LONG TERM GOALS



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How Doctor’s Die, Dr. Ken Murray



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DNR or AND (Allow Natural Death)

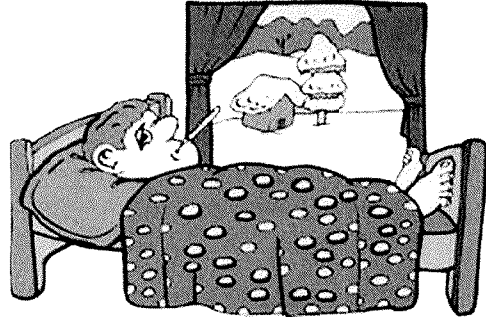
1. What do you know about CPR?
 - Chest compressions, mouth to mouth resuscitation, paddles to shock the heart, intubation, ventilation and medications
2. What really happens during CPR
 - On TV, it works 75% of the time
 - Overall hospital CPR survival – 15-17%
 - Frail SNF resident – 0-5%
 - Metastatic cancer/multi-organ system failure 0-1%

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- 4. You may come back to life in a worse condition than before, both mentally and physically. Ask for specifics regarding this patient's condition
 - Leaving the hospital with your brain back to where it was before CPR – 7%
 - Rib fractures – up to 97% of the time
 - Breastbone fractures – up to 43% of the time
 - Bruising of chest – 59%, Defibrillator burns – 30%
 - Bleeding in chest. Damage to trachea, esophagus, abdominal organs, lungs, teeth and/or lips
- 5. The type of death you are choosing is probably not what you would choose if you understood

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When You are Home Sick in Bed, Do You Want Your Feet Tucked In?



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You Are Responsible For More

- How can I increase this person's ...?
 - Comfort
 - Joy
 - Peace
 - Dignity
 - Relief from suffering
 - Opportunities to complete unfinished business
 - Access to grief support

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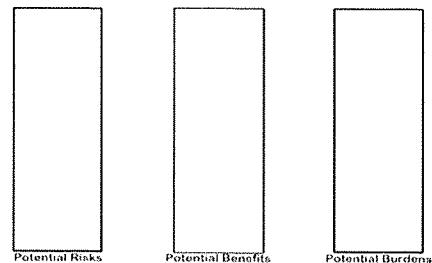
Virtual Dementia Kit

Balancing Benefits, Risks and Burdens

- “What will it “feel like and be like” for the person to experience this choice?”
 - What does it feel like to be on dialysis? Die from kidney failure? Have a feeding tube? Be on hospice?
- “What will the treatment do “to” the patient?”
“What will the treatment do “for” the patient?”
- “...And then what?”

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Weighing the Options Risks, Benefits and Burdens



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WebMD.com – Short Term View

- **What Happens During the Feeding Tube Placement?**
- **What Happens After Getting a Feeding Tube?**
- For a couple of days, you may have minor soreness in your abdomen where the PEG tube was inserted. This will feel like a pulled muscle. You will receive medication to help relieve pain the first day after the procedure.
- The amount of care needed for the PEG tube varies among patients. Generally, PEG tubes do not need to be replaced for several months, and may even function well for two or three years.

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Richard Taylor, PhD - Deceased

Alzheimer's and Throat Cancer

Richard's Thoughts...

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"When I have completed whatever course of therapies they offer me and when I recover from surgery, would I be better off then – than now? Would the deteriorated quality of life I knew was going to occur while I was experiencing these therapies buy/extend my life and if so, by how long? And more importantly, would I be able to enjoy an acceptable quality of life during this extended period?"

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Chanel White – Diagnosed Age 18

Raynauds, Systemic Lupus, and Polymyosist

Severe esophageal dysmotility, constricted esophagus, GERD, gastroperisis, malabsorption, and bowl dysmotility

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Daily Responsibility

"Much work must be done as upkeep for these small devices to work properly. Feeding tube care is essential to a healthy patient. They must be flushed, cleaned, and cared for multiple times a day. The stoma, which is the medical hole the tube is inserted through, in itself demands proper care as it can easily become infected."

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"Though feeding through a tube itself is not painful, having a tube can be. The stoma becomes aggravated often as the body is unused to a foreign object protruding through it. Granulated tissue forms around the tube causing intense pain upon movement or use of the abdominal muscles. This GT is difficult to get rid of and is something tubies must deal with for the duration of their tube feeding expectancy."

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Many people ask how I cope with this situation and to be honest, since I don't have another option, I just do. I see no reason to resent the apparatus that keeps me alive. On days when I feel lost and depressed about what has become of my life; being kept alive through tubes, ports, and drugs, I must remember that those things actually *gave me my life back*. The girl pre feeding tube was not living, she was surviving. For months she didn't sleep, she didn't leave her house, she didn't enjoy her life, she didn't like what she saw in the mirror. Now when I look in the mirror I see a strong women who is empowered by her disabilities and proud of the apparatuses that keep her alive. (updated April 2015)

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Katie Lunsford Age 25

Endometriosis, fibromyalgia, and now chronic pancreatitis

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"I completely underestimated how difficult it would be to adjust with getting all my nutrition through a tube. I struggled with the reality that there was a tube sticking out of me. I felt deformed, I felt weird, I felt like something other than myself. I struggled daily with getting enough calories into my body. It hurt at first and it was uncomfortable to pump formula into my intestines. I would wake up sick in the middle of the night because I wasn't on the right formula. I dealt with clogs, pain and some infections from the new hole in my body. At times, I didn't know how I could get through the week. What was I doing? How did I get to this point? My body was failing me and I had no control over it. I felt lost, but luckily I made it through the rough patches."

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"I'm slowly starting to be able to participate in life again. I will start grad school in the fall and hopefully pick up a part time job. I'm still me. I'm not broken, I am just different. I'm not going to lie, it is difficult to try to get back in the dating world. If I try to tell a potential date about it, things get awkward. I just like to consider myself as a cheap date because I don't eat at restaurants

I still struggle at times being self-conscious about my tube, getting all my calories, or even struggle at times with avoiding food. But, my tube is beginning to be a new normal for me. I'm a tubie and my tube is letting me get back to life. I feel like myself -- tube and all!"

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End-of-Life Videos

- Link to research article:
<https://dash.harvard.edu/handle/1/4662006>
- Link to videos:
<https://www.acpdecisions.org/products/videos/>
- Article about videos being used in Hawaii:
- <http://www.npr.org/sections/health-shots/2015/03/29/394087394/videos-on-end-of-life-choices-ease-tough-conversation>

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Contextualizing the Feeding Tube Decision into this Person's Life

- Loss of ability to enjoy food
- Risks involved in procedure
- Risks involved with having a feeding tube
- What is it like to live with a feeding tube and to be fed through a feeding tube?
- Are we improving quantity and/or quality of life?
- If actively dying, should he be fed?
- What is our obligation to feed the disabled?
- Move to higher level of care in a different care facility?

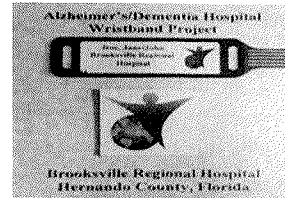
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Other Questions to Answer

- Who decides?
- Will it be medically beneficial/effective?
- Is it wanted by the patient? What is the patient's goal?
- What are the benefits, risks and burdens of the treatment?
- What will it get him? What will it cost him?
- Should it be a time-limited trial? And then what?
- What about the other influences? Culture, religion, patient preferences?

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Dementia Wristband Project



- Patients with a prior diagnosis will have a Purple Angel affixed to their hospital wristband
- A Purple Angel is placed on the door so that anyone entering knows they should approach with the patient's special needs in mind

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- A dementia screening will be added to the admission process in hopes of identifying cognitive impairment
- Use of "sitters" will become standard practice, allowing families to take much needed breaks without worrying that their loved one will be left alone.

Hospital staff, volunteers, and first responders receive training developed by Gary Joseph LeBlanc with the Alzheimer's Association-Florida Gulf Coast Chapter www.commonseccaregiving.com

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Decision Making Tools

- **Go Wish Cards** www.gowish.org (English/Spanish)
- **The Cards I've Been Dealt** – *Needs Assessment* cards and *Values and Wishes* cards to help the patient and/or family review the patient's abilities, needs and preferences www.thecardsivebeendealt.com
- **Thinking Ahead Project** <http://www.coalitionccc.org> (English, Spanish, Korean, Chinese)
- **Consider the Conversation** part 1 and part 2 – Documentary about making the decisions meaningful www.considertheconversation.org
- **Great end-of-life website** www.CAPOLST.org

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Some of Viki's Favorite Resources

- **They're My Parents Too** by Francine Russo
- **The Lost Art of Listening – How learning to listen can improve relationships** by Michael P. Nichols Ph.D
- **How to Say it to Seniors – Closing the communication gap with our elders** by David Solie, MS, PA
- **To Weep For A Stranger – Compassion Fatigue in Caregiving** By Patricia Smith
- **My Stroke of Insight: A Brain Scientist's Personal Journey** by Dr. Jill Bolte Taylor

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Additional Resources

- www.MedicalFutility.Blogspot.com – Thaddeus Pope JD
- <https://secondchancetolive.wordpress.com/> Inspiring articles about living well after a life changing event
- **Virtual Dementia Kit** https://www.youtube.com/watch?v=LJL_Gq7Shc-Y
- **Well Spouse Association:** A wonderful website, chat room, and support system for spouses, partners and significant others. www.wellspouse.org
- **Kindness Reminders:** Free weekly ideas to help people show love and support to a loved one. (Especially helpful for those doing long distance caregiving) and sign up in the box in the upper right hand corner of KindEthics.com

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