

Meeting the needs of patients with complex communication needs in end-of-life (EOL) situations.

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Life isn't fair. It doesn't follow a Fixed script!

33 Variations by Moises Kaufman, Dramatist Play Service, Inc., 2011

Context: Clara's mother has ALS and Mike is her mother's nurse and is Clara's boyfriend.

Mike: Or is it about the fact that she's dying. Because she is dying.

Clara: I know that. I'm so stupid. I thought if I came here, somehow, she and I would be able to figure things out.

Mike: Well what if that doesn't happen?

Clara: What?

Mike: I see people go through this all the time. Everybody wants some kind of closure before the end. But it doesn't work that way. It never happens the way people want it to happen.

Clara: Then what am I doing here?

Mike: You're spending time with your mother. You're taking care of her, feeding her, bathing her. And that might be what you get. I'm sorry you found out like that. But these moments with your mom, that might be what you get.

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Conversations about dying are not easy!

- As a society we are uncomfortable with death and dying.
- We avoid talking about dying.
- We try to avoid talking about any "Bad News."
 - "Don't shoot the messenger"
 - "Provide hope"
 - "Not admit we can do no more"
 - "Scared of the emotional response"







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Visiting a dying friend or relative

- You approach the visit with trepidation
- You are uncertain how to initiate the conversation?
 - Conventional conversation starters feel awkward.
 - "How are you doing?"
- Typically easy discourse content feels uncomfortable.
 - Talk about treatment and outcomes.
 - Talking about the future
 - Talk about feelings re: illness

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Provider Communication with Patients

- Patient Rights versus perceived Best Interests
 - Autonomy
 - Paternalism of Healthcare Providers
 - Cultural Differences
- Telling/providing information
 - Technical Accuracy
 - Impact of Health Literacy
 - Impact of the Patient's Limited Proficiency in the Provider's Language
- Insuring understanding information.
 - "Teach Back" technique / AskMe3

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Patient Communication with Providers, Family and Friends

- Wanting Information but scared of what the information might be.
 - Internet: Friend or Foe
- Wanting Autonomy versus Relegating Decision Making
- · Fear, Denial, Anger
- · Concern for Others- Putting up a Front
- Maintaining Face
 - Not admitting ignorance
 - Coming off as irrational





The Problem

- It is hard for all parties to talk about
 - Death & Dying
 - End-of-Life choices/decision making
- How can we be sure the patient is competent and can participate in decision making
- We want to be sure that everyone understands
 - The situation
 - The consequences of choices/decisions

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The Complications of CCN

- Patients with complex communication needs may also lack:
 - Expository skills to partake in EOL conversations
 - Ability to comprehend provider or family communication
 - Sensory Deficits
 - · Cognitive/Language Deficits
 - Language competency (LEP)
 - Ability to demonstrate that they
 - Are cognitively competent to participate in conversations
 - · Understand what they are being told

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Health Literacy & Understanding

- Not all patients have a sufficiently high level of health literacy.
 - No Experiential Knowledge to apply to the situation
 - Understanding Technical Terms
 - Understanding Disease Processes
 - Understanding Treatment/Procedures
- The problem with using a yes/no question to assess comprehension
- The value of the "teach back" method of assessing comprehension.



AAC Challenge

- How does one program an AAC system to allow for EOL conversations?
 - How does one tell the patient the gravity of their condition and be sure they understand?
 - How does one structure the AAC strategies to allow the patient to play an active and interactive role in subsequent conversations?
 - There is no "perfect" way to deliver bad news.
 - There may be no unique set of response options to include in all AAC systems.

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Building AAC systems

- Selecting content needs to be based on
 - Understanding what the user wants to know and talk about
 - Providing the user with the ability to express his/her personal Voice
 - -Ethical & Legal Issues

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Communicative Needs in EOL Scenarios

- Expressions of Comprehension
 - Allow patient to affirm that they have understood what they have been told and to allow them to ask follow-up questions to further understanding
- Expressions of Reactions
 - Allow patients to let others know how they feel about what they have been told
- · Expressions of Desires
 - Allow patients to become active participant in critical decision making about treatment goals

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Health Literacy and Understanding in Patients with CCN

- Establishing a reliable response to demonstrate competency.
- · Need for more than a binary Yes/No response
 - Need to distinguish "no I don't want X" from
 - "no, I don't understand what X is"
 - "no, I don't want to decide about X now"
 - "no, I don't want to talk about X now"
 - "no, I don't want to talk about this until Y is here to hear it too"
- · Need for ways to request more information
- Need for ways to demonstrate comprehension using "teach back."

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Withdrawal of Life Support Scenario

- One can't assume that the patient understands,
 - The gravity of the situation
 - The consequences of maintaining or withdrawing ventilatory support
- When everyone genuinely accept the patient's right to participate in the decision, then posing the question of withdrawal of life support requires,
 - Directly posing the question
 - Verifying that the patient understands the consequences

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Withdrawal of Life Support Scenario

- When anybody questions the patient's ability to decide, the form and content of the alternatives presented to the patient become controversial.
- Some argue that no matter how alert and competent the patient may appear, there is now way that they can give truly informed consent to withdraw life support.
- However, it is unclear that family members under stress are in any better position to do so.

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Selecting Content for EOL Scenario

- Selecting content may be no different from selection of content for other scenarios like;
 - Doctor's office visit
 - Restaurant encounters
 - Classroom activities
- Everything needs to be contextualized for the patient.
 - Hospital menus are tailored to the dietary needs/restrictions of patient
 - Communication boards need to be tailored to the patient's medical status

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A Pragmatic Approach

- One would not want a patient to first encounter the possibility that they are dying by reading a DNR order consent form or seeing the phrase "Am I going to die?" on a communication board.
- On the other hand, "Am I dying?" is a legitimate question that many patients want to ask even if they are scared of what the answer might be.

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Impact of Health Literacy

- Patients who are unfamiliar with physiological systems may respond differently to questions like:
 - Do you want to come off the ventilator?
 - Do you want to live?
 - Do you want the machine to stop breathing for you?
- Patients who are unfamiliar with side effects of medications?
 - Do you want us to give you something for pain?

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Guiding Strategy on Content

- Determine that patient understands how an AAC system works.
- Let the patient know that the selection options are there to give the patient the widest range of options, given our knowledge of what other patients in comparable situations have asked and wanted to talk about.

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The case for multiple options

- If the patient can't construct questions, it is essential that the AAC system provide them with a range of responses and follow-up questions.
- As painful as it might be for some family members to see those phrases on the communication boards, patients with CCN should have the same opportunities that a patient who can speak would normally have.

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Take Home Lesson

- It is unwise and insensitive to generate a onesize-fits-all template for patients facing and EOL decision.
- How options are phrased and organized need to be informed by the physical and cognitive state of the patient and family members
- Options must take into consideration legal obligations as well as the patient's cultural background and its views on death and dying.

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The Obligation of Healthcare Providers

- Patients and their families may not be prepared for the "bad news" conversation.
 - Never give it to the patient alone if the patient has designated a "support person" to be present when critical information is being exchanged (JC, 2012)
- · Healthcare providers can't afford not to be prepared.
 - Better training on patient-provider communication
 - Availability of AAC tools to meet the needs of patients with CCN
 - N.B. New Joint Commission standards on communication (2012)

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Hypothetical Case

Constructed from a real case

Background: Mr. Smith is an eighty-three year old who prior to his falling off a ladder led a very active vigorous life and from all reports was cognitively intact. The fall resulted in his sustaining a C3 lesion that has left him unable to move anything below his neck and he is intubated and ventilator dependent. His children are at the hospital and they are divided as to what his wishes about treatment options. None of them have power of attorney for health

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Hypothetical Case Issues

How do we (the care team),

- Determine that the patient is competent to make decisions about his care.
- 2. Inform the patient of his condition and prognosis.
 - a. Allow the patient to ask questions and demonstrate an understanding of his condition.
- 3. Inform the patient of what his options might be.
 - Allow the patient to demonstrate an understanding of the consequences of each of the options.
 - b. Allow the patient to ask follow-up questions about each of the
- Allow the patient and family members to participate in the decisions about which care option should be implemented.

Determining that the patient is competent	
to make decisions about his care.	
 Determine if the patient is alert and can orient to an interlocutor (staff or family member). 	
 Identify a voluntary gesture that the patient can produce and which can be reliably identified by everyone. 	
- ID the gesture(s)	
– Map the gesture on to responses (yes/no/other)	
 Use the voluntary gesture to ascertain that the patient can respond to questions about identity, time and place and demonstrate that he is cognitively 	
intact	
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Voluntary Gestures	
Gesture options to assess Fig. Blink Fig. 18 Fig.	
Eye BlinkEye Gaze	
– Minimal Head Nod	
N.B. patient has not under gone spinal fusion	
- Brow Movement	
- Tongue Movement	
 Lip Pursing 	
Gesture detection	
 Perception of the gesture(s) by interlocutors 	
 Transduction by switch or sensor 	
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Information of the property of the state of	
Inform the patient of his condition and	
prognosis.	-
 Provide accurate information in both oral and written form to patient and family. 	

- Structure the form and content to take into account the Health Literacy of all participants
- Adjust the form and content to accommodate for the cultural and/or religious beliefs of the patient and family, to the extent possible
- Structure the form and content to take into account the level of English language competence of all participants
- Provide a mechanism to allow the patient to ask questions and verify comprehension



Response Menus

- Include list of possible clarification questions that the patient can select for each "point" that is part of the information provided about his condition and prognosis.
- Include a multiple choice set of responses for the patient so that the care providers can use the teach back technique to verify the patient's comprehension of the information provided

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Inform the patient of what his options might be.

- · What choices does the patient have?
- What are the consequences of each choice?
 - Issues related to life support (e.g. mechanical ventilation)
 - Issues related to nutrition and hydration (e.g. Swallowing problems and PEG)
 - Issues related to needs for Nursing, RT, OT and PT

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Choice Option Menus

- · List choices
 - Stay on Vent or come off Vent
 - · Oral intubation versus Tracheostomy
 - Have surgery to fuse cervical spine or not
 - Have Feeding Tube (PEG) or not
 - Sedation Level
 - Pain Management
- List of follow-up questions about the consequences of choices
 to
 - To allow patient to be fully informed
 - To allow use of teach back to confirm patient understands

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Patient and family participation in decisions about the implementation of care options

- Insure that patient and family members are informed of the general prognosis and the care/treatment options that are available including Palliative Care.
- Insure that everyone understands the consequences of selecting or not selecting a particular care options.
- Allow for the patient and family to have conversations both prior to and after the patient has decided on care options.
- Build in a mechanism that allows the patient to change his mind about treatment options.

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Many EOL care decisions can have irreversible consequences

- A DNR order precludes resuscitation (CPR)
- Taking a vent dependent patient off of the ventilator will in all likelihood lead to death
- Not providing nutrition and hydration will also lead to death
- Withholding analgesic drugs (narcotics) to allow the patient to be more conscious can lead to debilitating pain
- Withholding antibiotics can lead to serious infections and sepsis

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Be careful and certain!

- Insure knowledge of the consequences of a care option choice by building a teach back option into the communication templates
- Insure that all parties witness the entire set of exchanges on care options and their consequences
- Follow-up if there is any chance of ambiguity in the manner in which the patient makes his intentions known
- Allow for an appropriate window of time to pass prior to implementing a particular decision about a treatment option and verify that the patient has not changed his mind

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Implementing an AAC program for EOL

- Plan ahead- there isn't enough time to start from scratch when you encounter a patient with CCN who needs help with EOL issues
- Have both low and high tech options available for the likely scenarios
 - Have general templates that can be quickly tailored to the needs of a specific patient
 - Have AAC devices and switches that can be easily setup
 - WARNING there is no "one size fits all" solution
- Provide training for staff on EOL decision making as well as using AAC strategies with CCN patients
 - This should spill over to helping all patients improve their EOL interactions and facilitate decision making

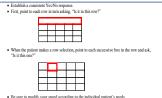
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RESPONSE SELCTION OPTIONS

- COMMUNICATION BOARD-PATIENT POINTS
- COMMUNICATION BOARD- PARTNER AIDED SCANNING WITH PATIENT USING A SINGLE GESTURTE TO INDICATE SELECTION
- EYE GAZE ETRAN BOARD
- EYE GAZE EYE TRACKING AAC
- AAC SWITCH SCANNING WITH PATIENT USING SINGLE GESTURE TO INDICATE SELECTION

	UNCERTAIN			
YES		NO		
LATER				
Establish a consistent Yes/No response.				



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COMPONENTS OF A GOOD TEMPLATE

- Expressions of Comprehension
 - Allow patient to affirm that they have understood what they have been told and to allow them to ask follow-up questions to further understanding
- Expressions of Reactions
 - Allow patients to let others know how they feel about what they have been told
- · Expressions of Desires
 - Allow patients to become active participant in critical decision making about treatment goals
- · Expressions of Personality
 - Allow the patients' personal "voice" to preserved in the form of the messages



COMMUNICATION ABOUT PATIENT'S CONDITION

•	PROVIDE THE PATIENT WITH THE
	ABIITYY TO ASK QUESTIONS AT THE
	MACRO LEVEL
٠	PROVIDE THE PATIENT WITH THE
	OPPORTUNITY TO EXPRESS LEVEL
	OF UNDERSTANDING
٠	PROVIDE THE PATIENT THE
	OPPORTLINITY TO SOLICIT

ADDITIONAL INFORMATION PROVIDE THE PATIENT WITH THE OPPORTUNITY TO INDICATE THE ABILITY/WILLINGNESS TO TALK ABOUT THE SUBJECT

PROVIDE THE PATIENT CONTROL
OF WHEN AND WITH WHOM THE CONVERSATION SHOULD OCCUR
ALLOW THE PATIENT TO UNDERSTAND THE DECISION OPTIONS AND WHETHER THE

DECISIONS ARE REVERSABLE

WHAT IS MY DIAGNOSIS	WHAT IS MY PROGNOSIS	WHAT ARE MY OPTIONS	I AM CONFUSED
TELL ME MORE	WHAT DOES THAT MEAN	WHAT HAPPENS IF WE DO NOTHING	I CAN'T DEAL WITH THIS NOW
LET'S TALK ABOUT THIS LATER	WHY CAN'T I GET BETTER	WHAT HAPPENS IF WE DO THAT	I WANT TO THINK ABOUT THAT
LET'S TALK ABOUT THIS WITH MY FAMILY	CAN I HAVE AN ADVOCATE PRESENT	WILL I BE ABLE TO CHANGE MY MIND	LET'S CHANGE THE SUBJECT

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Follow-up Conversations about **Ventilatory Status**

ALLOW THE PATIENT TO UNDESRTAND WHY SHE IS ON A VENTILATOR ALLOW THE PATIENT TO

UNDERSTAND WHAT MIGHT HAPPEN IF SHE IS TAKEN OFF THE VENTILATOR ALLOW THE PATIENT TO

INDICATE HER DECISION
ABOUT CONTINUING ON THE VENTILATOR

 ALLOW THE PATIENT TO DEMONSTRATE AN UNDERSTANDING OF THE CONSEQUENCES OF HER DECISION ALLOW THE PATIENT TO

INDICATE WHETHER SHE IS PREPARED TO MAKE ANY DECISIONS AT THIS TIME

WHY AM I ON A VENTILATOR	WHEN WILL I COME OFF THE VENTILATOR	CAN I COME OFF THE VENTILATOR	I WANT TO COME OF THE VENTILATOR
WHAT HAPPENS IF I AM TAKEN OFF THE VENTILATOR	I UNDERSTAND WHAT CAN HAPPEN IF I AM TAKEN OFF THE VENTILATOR	I UNDERSTAND THAT IF I WISH TO LIVE I MUST STAY ON THE VENTILATOR	I UNDERSTAND THAT WITHOUT THE VENTILATOR I WOULD DIE
I WANT TO BE TAKEN OFF THE VENTILATOR	DON'T TAKE ME OFF THE VENTILATOR	CAN I HAVE A VENTILATOR AT HOME	CAN I HAVE A VENTILATOR IN A NURSING HOME
I UNDERSTAND	I DON'T WANT TO TALK ABOUT THIS NOW	WHEN DO I HAVE TO DECIDE WHAT SHOULD BE DONE	I DON'T UNDERSTAND

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Follow-up Conversations about Dialysis

	DIALYSIS
•	ALLOW THE PATIENT TO
	UNDERSTAND WHAT MIGHT

HAPPEN IF SHE IS TAKEN OFF THE DIALYSIS
ALLOW THE PATIENT TO INDICATE
THAT SHE DOES NOT WANT TO BE
PUT ON DIALYSIS

PUT ON DIALYSIS
ALLOW THE PATIENT TO INDICATE
HER DECISION ABOUT
CONTINUING ON THE DIALYSIS
ALLOW THE PATIENT TO
DEMONSTRATE AN
UNDERSTANDING OF THE
CONSEQUENCES OF HER DECISION

ALLOW THE PATIENT TO INDICATE
WHETHER SHE IS PREPARED TO
MAKE ANY DECISIONS AT THIS
TIME

WHY AM I ON A DIALYSIS	N A WHEN WILL I CAN I COME OFF THE DIALYSIS DIALYSIS		I DO NOT WANT TO BE PUT ON DIALYSIS IF MY KIDNEYS FAIL
WHAT HAPPENS IF I AM TAKEN OFF THE DIALYSIS	I UNDERSTAND WHAT CAN HAPPEN IF I AM TAKEN OFF THE DIALYSIS	I UNDERSTAND THAT IF I WISH TO LIVE I MUST STAY ON THE DIALYSIS	I UNDERSTAND THAT WITHOUT THE DIALYSIS I WOULD DIE
I WANT TO BE TAKEN OFF THE DIALYSIS	DON'T TAKE ME OFF THE DIALYSIS	I DO NOT WANT TO BE PUT ON DIALYSIS IF MY KIDNEYS FAIL	
I UNDERSTAND	I DON'T WANT TO TALK ABOUT THIS NOW	WHEN DO I HAVE TO DECIDE WHAT SHOULD BE DONE	I DON'T UNDERSTAND



DNR AND RELATED DECISIONS

•	PROVIDE THE PATIENT THE MEANS TO UNDERSTAND WHAT MIGHT BE ENTAILED IN RESCUCITATION PROVIDE THE PATIENT WITH	WHAT WILL YOU DO IF MY HEART STOPS	WHAT WILL YOU DO IF I STOP BREATHING	WHAT IS CPR	WHAT CAN HAPPEN IF YOU DO CPR
•	THE MEANS TO SOLICIT FURTHER INFORMATION PROVIDE THE PATIENT THE MEANS TO DEMONSTRATE AN UNDERSTANDIING OF THE	I WANT YOU DO EVERYTHING POSSIBLE TO REVIVE ME	I DO NOT WANT YOU TO DO ANYTHING TO REVIVE ME	I DO NOT WANT TO BE MECHANICALLY VENTILATED	I UNDERSTAND THAT WITHOUT THE VENTILATOR I WOULD DIE
	CONSEQUENCES OF ANY FROM OF DNR ORDER PROVIDE THE PATIENT WITH THE ABILITY TO PUT OF DISCUSSION AND DECISIONS	I WOULD LIKE ANY PROCEDURE OR DEVCICE THAT WILL KEEP MY HEART GOING	I DO NOT WANT ANY INVASIVE PROCEDURES DONE	I DO NOT WANT YOU TO DO CHEST COMPRESSIONS	I DO NOT WANT YOU TO USE A DEFIBRILATOR ON ME
	ABOUT DNR ORDER PROVIDE THE PATIENT THE ABILITY TO INQUIRE ABOUT PERMAMNCE OF ANY DNR ORDER	IF I CHANGE MY MIND HOW WILL I BE ABLE TO LET YOU KNOW	I DON'T WANT TO TALK ABOUT THIS NOW	WHEN DO I HAVE TO DECIDE WHAT SHOULD BE DONE	I DON'T UNDERSTAND

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DEATH AND DYING: FIRST ENCOUNTER

- PROVIDE A MEANS FOR THE PATIENT TO FIND OUT IF SHE IS GOING TO LIVE OR DIE .
- ALLOW THE PATIENT TO ASK ABOUT TIME COURSE.
- ALLOW THE PATIENT TO ASK ABOUT WHAT WILL HAPPEN ALLOW THE PATIENT TO ASK ABOUT WHO KNOWS ABOUT HER IMPENDING DEATH
- ALLOW THE PATIENT TO INDICATE WHO SHOULD BE INFROMED
- ALLOW THE PATIENT TO CHOOSE HOW SHE WANTS TO BE INVOLVED WITH THE "MESSENGER"

AM I GOING TO LIVE	AM I GOING TO DIE	WILL I HAVE PAIN	HOW LONG DO I HAVE TO LIVE
WHAT WILL HAPPEN	I WANT TO TALK ABOUT IT	I DON'T WANT TO TALK ABOUT IT	WHOM HAVE YOU TOLD
I WANT MY FAMILY TO KNOW	I DON'T WANT MY FAMILY TO KNOW	I WANT MY FRIENDS TO KNOW	I DON'T WANT MY FRIENDS TO KNOW
I NEED TO BE ALONE	DON'T LEAVE ME ALONE	PRAY WITH ME	PRAY FOR ME

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EXPRESSION OF EMOTIONS

- PROVIDE A MEANS FOR THE PATIENT TO EXPRESS HER EMOTIONS
- PROVIDE A MEANS FOR THE PATIENT TO SET THE DEGREE OF ENGAGEMENT
- ALLOW THE PATIENT TO INQUIRE ABOUT HOW HER INTERLOCUTORS ARE
- ALLOW EMOTIONS TO BE CHARACTERIZED IN THE PATIENT'S "VOICE"

FEELING.

"ANGRY" VERSUS
 "PISSED"

I AM	I AM SAD	I AM	I AM	
ANGRY		CONFUSED	ANXOUS	
I AM FEELING ALONE	THIS IS TAXING ME	I NEED SOME TIME TO BE ALONE	HOW ARE YOU	
I WANT TO TALK ABOUT IT	LET'S NOT TALK ABOUT IT	LET'S TALK ABOUT OTHER THINGS	LET'S JUST SIT QUIETLY	
I AM	I AM	I AM	I AM AT	
CONFUSED	SCARED	WORRIED	PEACE	



GENERAL TIPS FOR CONVERSATION TEMPLATES

•	ALLOW PATIENT TO SELECT APPROPRIATE REGISTER AND ADJUST REGISTER TO FIT TO THE CONVERSATION AND ITS PARTICIPANTS	I AM DOING OK	I AM NOT DOING SO WELL	THEY SAY I AM DYING	HEY! I AM FINALLY GOING O KICK THE BUCKET
	FORMAL/DISTANT FAMILIAR/OPEN FAMILIAR/"GALLOWS HUMOR"	WE CAN TALK ABOUT IT	LET'S NOT TALK ABOUT IT	WHAT DID YOU THINK ABOUT THE DEBATES	ARE THINGS OK ON THE FARM
	ALLOW PATIENT TO BE RESPONSIVE ALLOW THE PATIENT TO INITIATE AND TO DIRECT	THAT'S GOOD	THAT'S TOO BAD	TELL ME MORE	I LOVE YOU
	THE TOPICS OF CONVERSATION ENABLE THE PATIENT TO TERMINATE INTERACTIONS	THANKS FOR COMING	I AM PRETTY TIRED NOW	COME BACK LATER	BEAT IT

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OTHER POSSIBLE DECISION TEMPLATES

- BLOOD
- TRANSFUSIONS
- CHEMOTHERAPY
- RADIATION THERAPY
- FEEDING TUBES
- SEDATIVES
- PALIATIVE SURGERY
- ONGOING PHYSICAL AND OCCUPATIONAL THERAPY
- BUSINESS ISSUES
- LEGAL ISSUES
- RELIGIOUS WISHES









• LAST WISHES Assistive Devices Lab at The University of Iowa



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UV WX YZ

M N O P

Q R S T

- Provide keyboard option to allow patient to create novel-unscripted utterances
- Select keyboard to suit patient's background (QWERTY versus ALPHABETICAL).
- Low Tech- ETRAN, pointing or partner aided scanning
- High-Tech SGD-
 - Direct select via touch or eye gaze
 - Scanning via switch Rate enhancement
 - · Word prediction
 - Abbreviation
 - Expansion

QWERTYUIOP ASDFGHJKL ZXCVBNMPAIN ERROR SPACE
A B C D Error E F G H STARE I J K L M N O P Qu R S T U V W X Y Z
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Not So Hypothetical Case Outcome

- The siblings were arguing about whether their father would want to be kept on life support. They were doing at his bedside unaware that he was listening. A nurse noticed that he was listening and upset.
- The AAC team established his competency and provided an AAC system. The patient indicated his desire to come off life support.
- The patient was able to explain his decision to his children. He had a "good death" and his children were spared having a family feud.
- "all is well that ends well"

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Contact Information and Access to Templates



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