MJHS
INSTITUTE FOR INNOVATION IN PALLIATIVE CARE

Case Conference: Goals, Advance Care Planning, and Class IV Congestive Heart Failure

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Case Conference: Goals and ACP in Class IV CHF

- A 71-year-old man with advanced heart failure returns to primary care clinic for a follow-up visit following a recent hospitalization
- A quick review of his chart prior to the visit reveals a recent evaluation by his cardiologist, which includes a summary of his hospital course
  - The summary: ***"Hospitalized from ED after period of gradually worsening dyspnea. Clinical response to diuresis. Episode of syncope in the hospital related to orthostasis—no injury."***

Case Conference: Goals and ACP in Class IV CHF

- The quick review of the chart also reveals recent labs ordered by the cardiologist
  - Recent Echo reveals EF of 25%
  - eGFR is 60 ml/min/1.73m^2
  - Hemoglobin A1c is 7%

Case Conference: Goals and ACP in Class IV CHF

- The patient starts the visit by stating that he is feeling better since the hospitalization
- He indicates that he had begun sleeping in a chair because of breathlessness, but that he has been able to return to bed since his discharge
  - He brings a list of his medications and indicates that he is now taking them exactly as they are prescribed

Case Conference: Goals and ACP in Class IV CHF

- Medications
  - Lasix 80 mg po bid
  - Metoprolol succinate 100 mg po qdaily
  - Spironolactone 50 mg po qdaily
  - Digoxin 0.125 mg po qdaily
  - Lisinopril 20 mg po qdaily
  - Metformin 500 mg po q12h
  - Simvastatin 40 mg po qevening
  - ASA 81 mg po qdaily

Background to the Case

- Medical History
  - Type II diabetes and hypertension for more than 30 years, and hyperlipidemia diagnosed 15 years ago
  - First episode of angina 6 years ago led to diagnosis of coronary artery disease, both large and small vessel
  - S/P MI and CABG 4 years ago
  - AICD placement 2 years ago
  - Two CHF exacerbations in past year, both requiring hospitalization
  - Other major problem has been chronic knee pain due to osteoarthritis

Case Conference: Goals and ACP in Class IV CHF

- Current status
  - Dyspnea with very minimal exertion
  - Ability to walk improved by supplemental oxygen at 2L/min NC, but also limited by knee pain
  - Able to perform ADLs but unable to participate in usual activities
  - Mostly housebound
  - Also reports chronic fatigue and insomnia

Case Conference: Goals and ACP in Class IV CHF

- Social history
  - Tobacco: Previously smoked 1 PPD, quit 20 years ago
  - Occasional beer, no other alcohol
  - No other drug use
  - Retired mechanic
  - Divorced and remarried, with adult stepson
  - Sister lives in apartment above him
  - Supportive relationship with his wife and sister
  - Receiving social security disability

Case Conference: Goals and ACP in Class IV CHF

- Advance care planning
  - Health care proxy form is in the chart, and names the patient's first wife as agent

Case Conference: Goals and ACP in Class IV CHF

- Family history
  - Mother died of ovarian cancer at age 72
  - Father died of myocardial infarction at age 61
  - Wife and sister are healthy

Back to the Visit

- The patient is a 71-year-old man with Class IV CHF, multimorbidity, and progressive decline
  - On presentation, no urgent medical concerns are noted
- The PCP decides that the visit would be a good opportunity to address goals of care
- Noting that the Health Care Proxy is outdated, he elects to make the objective advance care planning

What Does the Case Reveal About Goals Discussions in Primary Care?

- Goals discussions should unfold over time
- The objectives of each discussion vary
- Advance care planning is a type of goal discussion
- There is a need for a framework and a guideline for best practices appropriate to the primary care setting

Goals Discussions: Practical Considerations

- Introducing the…

"When, What, How (OPUS) Model" for Goals Discussions in Primary Care

  - For patients with any type of serious chronic illness
  - To support best practices to communication, particularly ***when signs indicate advanced disease or prognosis is 1-2 years***

"When, What, How (OPUS)" Model

- **WHEN** to have a goals discussion?
  - At least once during a ***stable*** period
  - Repeatedly after '***triggers***'
    - Hospitalization for CHF exacerbation may be a trigger

"When, What, How (OPUS)" Model

- **WHAT** should be discussed?
  - Key point
    - Plan for ***each*** discussion by having ***specific objectives*** in mind

What Are the Objectives of Goals Discussions?

- Objectives may be general or specific
  - General
    - Impediments to communication
    - Patient's or family's values and preferences
  - Specific
    - Prognostic awareness
    - Specific treatment decisions
    - Advance care planning

Objectives of Goals Discussions

- Values and preferences
  - Examples: 'Decisional control preferences', desire for information, quality vs. quantity of life, views about specific interventions, e.g., hospitalization
- Prognostic awareness
  - Examples: Life expectancy or expected course of illness
- Specific treatment decisions
  - Examples: Inotropic therapy, stopping an AICD
- Advance care planning

"When, What, How (OPUS)" Model

- **HOW** to meet these objectives?
  - A structured approach with the mnemonic ***OPUS***

O = *"**O**pener"*

P = *"**P**ermission"*

U = *"**U**nderstanding"*

S = *"**S**upport"*

"When, What, How (OPUS)" Model

***O* = "Opener"**

- **Setting the stage**
- **Neutral opening statement**
- **Main objective, in general terms**

- ***O*** = *"Opener"*
  - Setting the stage
    - » Time, adequate space, privacy, seating
  - Neutral opening statement
    - » Example: "I would like to talk to you about your illness, make sure that your questions are answered and that I understand a few things."

"When, What, How (OPUS)" Model

O = "Opener"

- **Setting the stage**
- **Neutral opening statement**
- **Main objective, in general terms**

- ***O*** *= "Opener"*
  - Main objective, in general terms
    - Example: "I want to talk about how decisions regarding your treatment would be made if it ever happened that you became very ill and couldn't speak for yourself."

"When, What, How (OPUS)" Model

P = "Permission"

- **Is it OK to proceed?**
- **Should others be present for this discussion?**

- ***P*** *= "Permission"*
  - Decision-making and information preferences (should others be present?)
    - Example: "Is it OK to have this discussion now, or should we schedule an appointment when someone in your family can come in?

"When, What, How (OPUS)" Model

U = "Understanding"

- **What does the patient or family <u>know</u>?**
- **What does the patient or family <u>want to know</u>?**
- **What information <u>should be elicited</u>?**
- **What information <u>should be provided</u>?**

- ***U*** *= "Understanding"*
  - What does the patient or family know, or want to know? What information should be elicited?
    - Example: "What is your understanding about where you are with this illness?"
    - Example: "Do you have questions about the treatment for heart failure—what do you expect in the future?"
    - Example: "If you heart gets worse, you might be less able to care for yourself or function. If all of the treatments available could not give you a good quality of life, would you want these treatments in the hope of living longer?"

"When, What, How (OPUS)" Model

U = "Understanding"

- **What does the patient or family <u>know</u>?**
- **What does the patient or family <u>want to know</u>?**
- **What information <u>should be elicited</u>?**
- **What information <u>should be provided</u>?**

- ***U*** *= "Understanding"*
  - What information should be provided?
    - Example: "Who would you want to make health care decisions for you if you became unable to speak for yourself?"

"When, What, How (OPUS)" Model

***S* = "Support""**

- **Allow emotion**
- **Empathize**
- **Offer a plan**

- ***S*** = *"Support"*
  - Offer a plan
    - » Example: "Let me schedule another visit with you and your family, so we can go over your health care proxy one more time."

Advance Care Planning

- Information provided by a patient to determine or inform future medical decisions, in the event that the patient loses the ability to speak for him/herself
- Key objective: legal, actionable advance directives
- Includes different types of 'advance directives'
  - **Health Care Proxy form** to designate another person to make decisions (the 'agent')
  - **Instructional directives**
    - Oral or written living will
    - Nonhospital (home) DNR
    - MOLST/POLST

Advance Care Planning: Usefulness

- 2014 systematic review of 45 observational studies
  - Decreased hospitalization (or dying in hospital) 2/5 studies
  - Decreased inappropriate life-sustaining therapies 10/22 studies
  - Increased referral to hospice or palliative care in 5/7 studies

Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. Palliat Med 2014;28:1000

Health Care Proxy

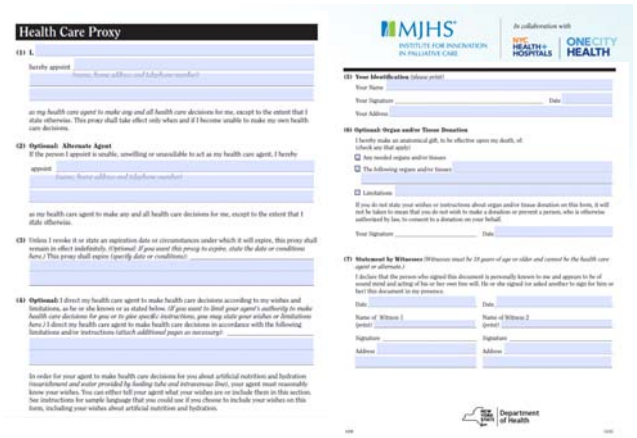
- A ***document*** that is used by a patient to designate one or more 'agents' with authority to make health care decisions in the event that the patient cannot
  - NOTE: An '***agent***' is selected by the patient and documented on a HCP; a '***surrogate***' is selected by the health professional
  - NOTE: In NYS, agency is governed by the NYS Health Care Proxy law, and surrogacy is governed by the Family Health Care Decisions Act
  - Ideally, agents and surrogates make decisions based on specific knowledge of patient's preferences—***substituted judgment***
  - If preferences are unknown, agents or surrogates make decisions based on the ***best interests*** of the patient

Health Care Proxy

- Requirements
  - Name of patient
  - Statement that the agent has authority to make health care decisions on patient's behalf
    - A physician can be an agent, but if so, should not be the attending
  - Must be signed and dated by patient
  - Must be signed and dated by two witnesses
  - Alternate agent can be designated
  - May or may not include other advance directives (living will statements)

Health Care Proxy

- Requirements
  - Agent can make any decision including termination of life support
    - » But the agent cannot require decisions that are contrary to the medical standard of care
  - Agents cannot terminate artificial nutrition or hydration unless there is some evidence of such decision
    - » Best to include a statement about artificial nutrition or hydration, e.g.: "My health care agent knows my wishes concerning the termination of artificial nutrition and artificial hydration."


Health Care Proxy

(1) I,

hereby appoint

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint

(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. If you want this proxy to expire, state the date or conditions here.) This proxy shall expire (specify date or conditions):

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.) I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (attach additional pages as necessary):

In order for your agent to make health care decisions for you about artificial nutrition and hydration (nourishment and water provided by feeding tube and intravenous line), your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification (please print)

Your Name

Your Signature Date

Your Address

(6) Optional: Organ and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of: (check any that apply)

☐ Any needed organs and/or tissues

☐ The following organs and/or tissues:

☐ Limitations:

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature Date

(7) Statement by Witnesses (Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Date Date

Name of Witness 1 (print) Name of Witness 2 (print)

Signature Signature

Address Address

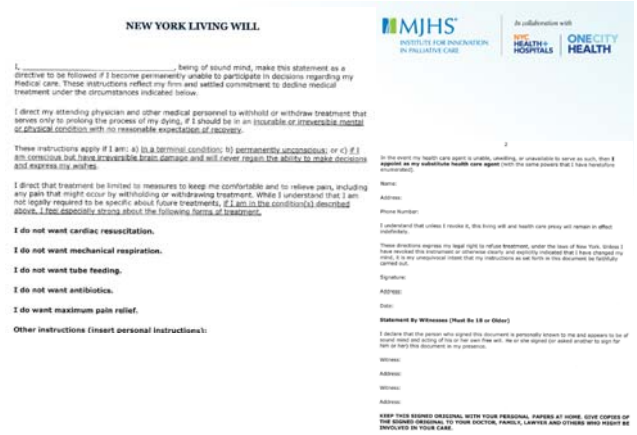
New York State Department of Health

Agent's Perspective

- Agent should know and agree with this role
- Ideally, patient and agent should discuss patient preferences
  - Uninformed agent can be distressed by the need to make decisions based on best interests
  - Health professionals are challenged if the actions of the agent appear to be at odds with patient's best interest

Oral or Written Living Will

- Specific instructions about care—orally or in writing—that apply in the setting of serious chronic illness in the event that the patient's decisional capacity is lost
- No governing law in NYS, but courts have ruled that wishes must be followed if there is clear and convincing evidence of the patient's wishes
- Can be added to a Health Care Proxy or be a separate document



NEW YORK LIVING WILL

I, _____, being of sound mind, make this statement as a directive to be followed if I become permanently unable to participate in decisions regarding my Medical care. These instructions reflect my firm and settled commitment to decline medical treatment under the circumstances indicated below.

I direct my attending physician and other medical personnel to withhold or withdraw treatment that serves only to prolong the process of my dying, if I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery.

These instructions apply if I am: a) in a terminal condition; b) permanently unconscious; or c) if I am conscious but have irreversible brain damage and will never regain the ability to make decisions and express my wishes.

I direct that treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment. While I understand that I am not legally required to be specific about future treatments, if I am in the condition(s) described above, I feel especially strong about the following forms of treatment.

I do not want cardiac resuscitation.

I do not want mechanical respiration.

I do not want tube feeding.

I do not want antibiotics.

I do want maximum pain relief.

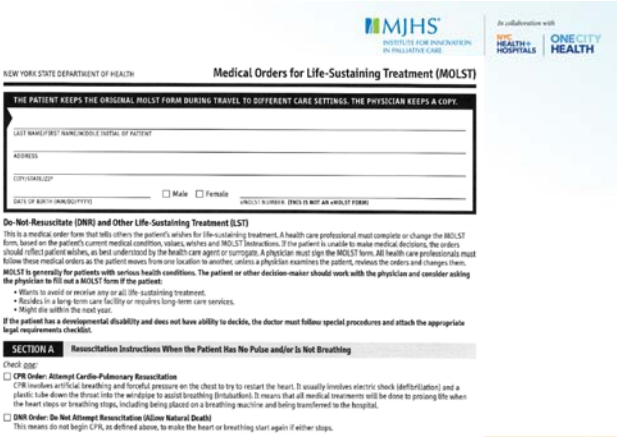
Other instructions (insert personal instructions):

Nonhospital (Home) DNR

- Legal document, signed by the physician, that indicates patients desire to not undergo CPR
- The physician must determine at least every 90 days, whether this order continues to be appropriate and indicate this by a note in the person's medical chart

Medical Orders for Life-Sustaining Treatment (MOLST)

- Physician's order signed after consulting with the patient/surrogate
- Concise form containing specific medical instructions that can be carried out by health care staff
- It may include directives on:
  - DNR
  - Antibiotics
  - IV fluids
  - Hospitalization
  - Artificial hydration/nutrition
  - Mechanical ventilation
  - Any other medical interventions
- MOLST is legal in New York



NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female

eMOLST NUMBER (THIS IS NOT AN eMOLST FORM)

Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form, based on the patient's current medical condition, values, wishes and MOLST instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician examines the patient, reviews the orders and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician and consider asking the physician to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

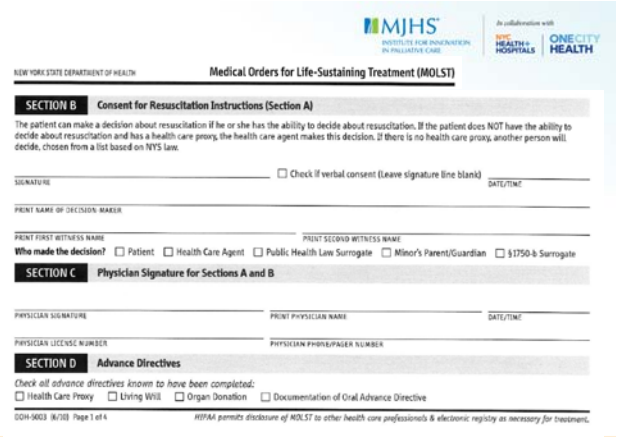
If the patient has a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

SECTION A **Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing**

Check one:

☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.

☐ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.



NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

SECTION B **Consent for Resuscitation Instructions (Section A)**

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law.

SIGNATURE ☐ Check if verbal consent (Leave signature line blank) DATE/TIME

PRINT NAME OF DECISION MAKER

PRINT FIRST WITNESS NAME PRINT SECOND WITNESS NAME

Who made the decision? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate

SECTION C **Physician Signature for Sections A and B**

PHYSICIAN SIGNATURE PRINT PHYSICIAN NAME DATE/TIME

PHYSICIAN LICENSE NUMBER PHYSICIAN PHONE/PAGER NUMBER

SECTION D **Advance Directives**

Check all advance directives known to have been completed:

☐ Health Care Proxy ☐ Living Will ☐ Organ Donation ☐ Documentation of Oral Advance Directive

DOH-5003 (8/10) Page 1 of 4 *HIPAA permits disclosure of MOLST to other health care professionals & electronic registry as necessary for treatment.*

Back to the Visit

- The PCP uses the "When, What, How (OPUS) framework to initiate an advance care planning discussion
  - The objective is a legally executed, accessible Health Care Proxy, which names the patient's wife as primary agent and includes instructional directives if possible
- The completion of the form will be followed by a visit to inform the patient's wife of the patient's stated preferences
- The discussion also is a chance to obtain more information about the patient's values, preferences, fears and goals—all helpful in managing the case going forward

"When, What, How (OPUS)"

- The PCP's "Opener" and "Permission" statements set the stage
  - The PCP asks the patient whether a discussion about the patient's preferences concerning how health care decisions would be made if he became unconscious or unable to speak for himself would be acceptable and asks whether a family member should be present for all discussions or later, after he and the PCP talk
- The patient states that he and the physician can talk today and that he will bring his wife to the next visit

"When, What, How (OPUS)"

- "Understanding" sets the stage for questions and responses
  - The PCP explains that the specific objective is to complete a Health Care Proxy, which would designate his wife or anyone else to make health care decisions for him if he were unconscious or unable
  - The PCP also explains that the Health Care Proxy form includes a space to write in information about specific preferences for care
  - He also states that there is another form for home that may need to be completed, depending on the patient's preferences about cardiopulmonary resuscitation

"When, What, How (OPUS)"

- "Understanding" sets the stage for questions and responses
  - The PCP asks, "What is your understanding of your illness?" What do you expect from your treatments?"
  - "Do you think that your disease is worsening? Do you have concerns or fears about becoming sicker or more short of breath?"
  - "Can you imagine your disease worsening? If it did, you might be less able to care for yourself or function. Time may be limited. If at that time, all of the treatments available could not give you a good quality of life, would you want these treatments in the hope of living longer?"

"When, What, How (OPUS)"

- The PCP shows the patient the Health Care Proxy form and asks the patient to respond to several scenarios, so that the section for instructional directives can be completed
  - "Suppose you were unconscious, and your breathing problems became severe. Doctors may want to have a breathing tube inserted and put you on a ventilator. If you knew that this would be temporary, would you accept it?
  - But what if the doctors believed that it would be very likely that you would be on a ventilator for the rest of your life? If you were unconscious, would you want the ventilator in order to live longer, or would you want to be kept comfortable and not have the ventilator, even if you were to die sooner?
  - Is this something that you would if you became conscious but it was very likely that you would never be able to have the breathing tube and ventilator removed?

"When, What, How (OPUS)"

- The PCP shows the patient the Health Care Proxy form and asks the patient to respond to several scenarios
  - "Suppose you were unconscious and your heart stopped. A doctor may want to insert a breathing tube and start compressing your chest to try to restart your heart. This is called cardiopulmonary resuscitation. If you knew that this procedure could work, allowing you to live longer and function, would you accept it?
  - But what if there was virtually no chance of functioning normally after this procedure, even if your heart was re-started. Would you still want the procedure to try to live longer, or would you want to be allowed to die naturally without the procedure?

"When, What, How (OPUS)"

- "Understanding" sets the stage for questions and responses
  - "Suppose something happened and you were unconscious, and the doctors believed that you would never be fully conscious again. Would you want treatments given to you that would prolong your life in this condition, like a feeding tube or fluids through an IV, or would you rather be kept comfortable and allow nature to take its course?
  - "What about antibiotics should you get an infection?"

"When, What, How (OPUS)"

- From the discussion, the PCP helps guide the patient to add several instructional directives to the Health Care Proxy
- The patient designates his wife as his agent
- The form is witnessed by the PCP and a nurse
- The PCP does not pursue completion of a nonhospital DNR form based on the discussion with the patient
- The PCP asks the patient to talk to his wife about this conversation and to schedule an appointment during the next month or two for he and his wife to return in order to confirm the patient's preferences and ensure that the patient's wife is informed

Case Conference: Goals and ACP in Class IV CHF

- Conclusion
  - Goals discussions (or serious illness discussions) are multifaceted, should be iterative, and should be guided by clear objectives
  - The "When, What, How (OPUS) Model" is an approach to timely and structured communication
  - When the objective is advance care planning, completion of a Health Care Proxy containing additional instructional directives can be accomplished in 1-2 visits

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Q&A