UPSTATE
UNIVERSITY HOSPITAL

Palliative Care and Large Vessel Occlusion

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Benefits of Palliative Collaboration

- The palliative APRN can play an important collaborative role in caring for patients with neurological conditions
- Management of symptoms
- Education and supportive counseling for the emotional and physical demands

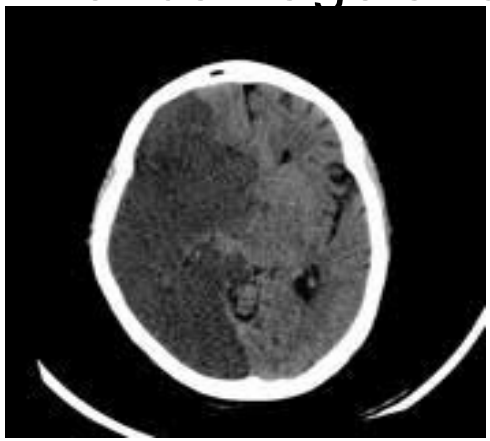
Palliative care involvement early (at diagnosis) is beneficial to lower symptom burden and assist with decision making

Common Palliative care concerns with this population

- Prognosis- as with chronic illnesses, this can wax and wane throughout progression
- Functional decline
- Psychosocial concerns- financial, physical and emotional burden of care giving

Stroke -5th leading cause of death in the US

- Location determines deficit
- Impacts can be consciousness, motor function
- Effects extending beyond initial injury can be caused by swelling
- Care is focused on prevention of further damage and meeting physical needs



Symptom management

- No strong evidence on management of syndromes. However, current practice suggests following headache and central pain management guidelines
- Headache, central poststroke pain, spasticity, hemiplegic shoulder pain, dysphagia, depression and anxiety
- End-of-life post stroke- many unable to self report, use of pain scales to conclude effective symptom management
  - Management of common sources of distress such as labored breathing, dry mouth, upper airway secretions

Timing of Consults and Role

For patients with stroke, palliative care can begin at presentation and be offered concurrently with acute treatment. The degree of integration depends on patient and hospital factors. The role may be more significant for patients with marked functional or cognitive challenges or those confronting dependency on life-prolonging measures (mechanical ventilation and enteral feeding)

Advance Care Planning

- Ongoing process in which patients, their families/caregivers, and health care providers reflect on the patient's goals, values, beliefs; discuss how they should inform current and future medical care; and, ultimately, use this information to accurately document the patient's future health care choices.
- Goals of Care
    - Clarifying goals in the acute setting
    - Re-addressing goals in the post-acute setting

Team support

- Caregiver support
  - Physical, emotional, psychological
  - Information and decision support
  - Instrumental (home care, respite care)
- Staff support

Optimizing communication

- Improving communication skills
- Facilitating discussion
- Key steps to holding family meetings and discussing/delivering serious news

Decision making

- Principles of shared decision making
- Acuity of decisions
- Role of surrogate decision makers/health care proxy

End-of-life care

Hospice eligibility: Karnofsky Performance Scale or Palliative Performance Scale

Palliative Performance Scale (PPSv2) version 2[2]

	PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
Stable	100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
	90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
	80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
Transitional	70%	Reduced	Unable to do normal job/work Significant disease	Full	Normal or reduced	Full
	60%	Reduced	Unable to do hobby/housework Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
	50%	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
	40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
End-of-Life	30%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy +/- confusion
	20%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy +/- confusion
	10%	Totally bed bound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma +/- confusion
	0%	Death	-	-	-	-

KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disable; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

Ethical Dilemmas

- Nondecisions:
  - Disagreement between team members about life supporting treatments for patients
  - Physicians bias that patients need more time to determine direction of care (progress or regress)
  - For nursing staff nondecisions or clear care plans bringing on sense of insecurity
  - Lack of symptom management, specifically pain relief unless a patient is on full comfort measures
  - Easier to treat than not to treat

  Communication barriers leading to nondecisions

  Difficulty in identifying next-of-kin

Ethical Dilemmas Continued

- Results show:
  - Having a relationship with the patient/family is essential
  - Understanding wishes previously expressed and preferences of care
  - Each reduce emotional barriers for the care team

4 principles

- 1. autonomy
- 2. beneficence
- 3. non-maleficence
- 4. justice
- Medical indications: beneficence and non-maleficence
- Patient preferences: respect for autonomy
- Quality of life: beneficence, non-maleficence and respect for autonomy
- Contextual features: principles of loyalty and fairness

Case study

- 32-year-old male presented s/p high speed MCA into guardrail. He suffered severe TBI with IPH, tSAH, DAI, diffuse cerebral edema, brain compression and midline shift. An emergent decompressive hemicraniectomy was performed. He was discovered to have suffered a right carotid and vertebral dissection leading to right MCA infarct also. He happened to also suffer fractures of left ulna, ribs, and orbit.
- Medical team felt there was lack of sufficient evidence to definitely say catastrophic brain injury would preclude favorable neurological recovery
- Family expressed that patient would never want to continue living with compromised quality of life
- Family meeting was held to discuss goals of care. Ultimate plan was to aggressively wean sedation to better assess clinical status and prognosis requiring follow-up with another meeting in 48 hours.
- The bioethical dilemma in this situation was to determine whether stopping treatment was the right thing to do. Patients' family wanted to stop aggressive treatment however the medical team was in disagreement. The family's rights to self determination based on the ethical principle of respecf tor autonomy. The HCP or SDM are expected to make decisions baed on what the patient would have wanted. In these situations, consider a palliative care and/or ethics consult. Consider a family meeting and pre-conference with interdisciplinary team prior to meeting with family.

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/NURSE PRACTITIONER/PHYSICIAN ASSISTANT 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/nurse practitioner/physician assistant 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/nurse practitioner/physician assistant 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/nurse practitioner/physician assistant and consider asking the physician/nurse practitioner/physician assistant 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 an intellectual or developmental disability (I/DD) and lacks the capacity to decide, the physician (not a nurse practitioner or physician assistant) must follow special procedures and attach the completed Office for People with Developmental Disabilities (OPWDD) legal requirements checklist before signing the MOLST. See page 4.

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.

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. Individuals with I/DD who do not have capacity and do not have a health care proxy must follow SCPA 1750-b.

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 decisions? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate*

SECTION C Physician/Nurse Practitioner/Physician Assistant Signature for Sections A and B

PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT SIGNATURE* PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT NAME DATE/TIME

PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT LICENSE NUMBER PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT 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

***If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.**

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

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT DATE OF BIRTH (MM/DD/YYYY)

SECTION E Orders For Other Life-Sustaining Treatment and Future Hospitalization When the Patient has a Pulse and the Patient is Breathing

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. **If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped. Before stopping treatment, additional procedures may be needed as indicated on page 4.**

Treatment Guidelines No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

☐ **Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.

☐ **Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.

☐ **No limitations on medical interventions** The patient will receive all needed treatments.

Instructions for Intubation and Mechanical Ventilation *Check one:*

☐ **Do not intubate (DNI)** Do not place a tube down the patient's throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should not be checked if full CPR is checked in Section A.)

☐ **A trial period** *Check one or both:*
- ☐ **Intubation and mechanical ventilation**
- ☐ **Noninvasive ventilation (e.g. BIPAP), if the health care professional agrees that it is appropriate**

☐ **Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient's throat and connect to a breathing machine as long as it is medically needed.

Future Hospitalization/Transfer *Check one:*

☐ **Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**

☐ **Send to the hospital, if necessary, based on MOLST orders.**

Artificially Administered Fluids and Nutrition When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. **Additional procedures may be needed as indicated on page 4.**
Check one each for feeding tube and IV fluids:

☐ **No feeding tube** ☐ **No IV fluids**
☐ **A trial period of feeding tube** ☐ **A trial period of IV fluids**
☐ **Long-term feeding tube, if needed**

Antibiotics *Check one:*

☐ **Do not use antibiotics.** Use other comfort measures to relieve symptoms.
☐ **Determine use or limitation of antibiotics when infection occurs.**
☐ **Use antibiotics** to treat infections, if medically indicated.

Other Instructions about starting or stopping treatments discussed with the physician/nurse practitioner/physician assistant or about other treatments not listed above (dialysis, transfusions, etc.).

Consent for Life-Sustaining Treatment Orders (Section E) (Same as Section B, which is the consent for Section A)

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 decisions? ☐ Patient ☐ Health Care Agent ☐ Based on clear and convincing evidence of patient's wishes ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate*

Physician/Nurse Practitioner/Physician Assistant Signature for Section E

PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT SIGNATURE* PRINT PHYSICIAN/NURSE PRACTITIONER/PHYSICIAN ASSISTANT NAME DATE/TIME

***If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.**

 This MOLST form has been approved by the NYSDOH for use in all settings.

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 d*ecisions 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. *(Optional: 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

References

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