RUSH 2023
Palliative Care and Stroke

M. Stanton, FNP-C, ACHPN

Understanding stroke

- Ischemic (80%)
- Hemorrhagic (20%)
- Risk factors: smoking, atrial fibrillation, DM, HTN, family hx

Understanding palliative

SPECIALIZED MEDICAL CARE FOR PATIENTS FACING SERIOUS ILLNESS

SYMPTOM MANAGEMENT

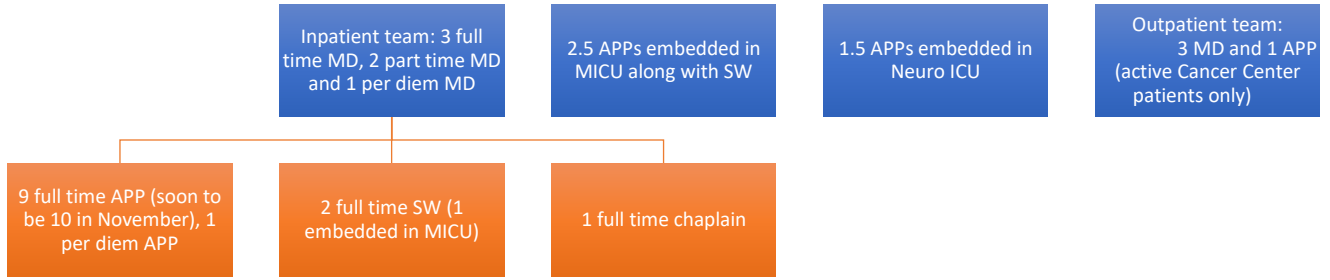
GOAL=IMPROVEMENT IN QOL

COINCIDE WITH CURATIVE TREATMENT

DOCTORS, APPS, NURSES, SW, PHARMACISTS, PSYCHIATRY TO MAKE UP THE TEAM DEPENDING ON FACILITY/INSTITUTION

HOSPICE DIFFERENCES: PROGNOSIS <6MONTHS, WITHDRAWAL OF CURATIVE CARE, EOL CARE

Palliative Care at Upstate



PC involvement in the Neuro ICU

- Embedment began in 8/2020 driven by the needs of the Neuro Critical Care service
- Typical diagnoses: stroke, TBI, tumors, seizures

- Majority of stroke patients are seen to assist with establishing wishes regarding advance directives and goals of care as it relates to QOL

Early involvement

- We urge consultation early to help build rapport throughout hospitalization for aid with difficult discussions
- Studies indicating shorter length of stay as well as patient/family satisfaction
- WHY?
- An ICU stay can be harrowing, induce anxiety, depression and grief due to the difficulty of making reliable prognoses, instability of critical illness and complexity of critical care treatments.
- Research notes deficiencies in ICU with symptom management, inadequate communication, conflicting goals/values amongst interdisciplinary team, moral distress

Communication

- Strive for effective communication amongst patient/family and all members of the interdisciplinary team for better satisfaction
- Aid in facilitating family meetings and guide goals of care conversations surrounding patients wishes/best interest
- Barriers: lack of death experience, unrealistic expectations, changing role of religion, trust, fear, language, bias/judgment/assumption.

Aids for GOC discussion

SPIKES (setting up, perception, invitation, knowledge, emotions/empathy, summary)

REMAP (reframe, expect emotion, map out goals, align with goals, propose plan)

6 step approach communicating bad news

- 1. arrange the physical context and emotional atmosphere
- 2. find out how much patient/family knows
- 3. find out how much they want to know
- 4. share information (educate)
- 5. respond to feelings
- 6. make a plan and follow through

Symptom management

- Dysphagia
- Death rattles
- Dyspnea
- Pain
- Anxiety
- Confusion/delirium
- Agitation
- Constipation
- Dry mouth
- Seizures
- Numbness/tingling
- Sleep disturbance
- Nausea/vomiting
- Bladder/bowel incontinence

- Barriers to effective symptom management- cognitive impairment, aphasia, dysarthria

Case study

- 65 yo male
- Presented to Neuro ICU for TBI with SDH, tSAH following an MVA. While admitted developed acute left gaze preference and RUE/RLE weakness. MRI revealed new left MCA infarct. Significant concern for cerebral edema with impending need for surgical decompression prompted a PC consult. Patient had a prolonged hospital course needing CVVH. He was successfully extubated but the primary team continued to navigate decreased LOC with periods of agitation. Optimizing wakefulness was a priority to best evaluate safe swallowing. A family meeting was held during this course to review diagnosis, complications, prognosis and plan. Ultimate decision for PEG placement and pursuit of rehab. PC was available to patient, wife and daughters to aid in communication, clarification of plan of care, and remained available to the team to assist with agitation/delirium as needed.

DT81048

UPSTATE UNIVERSITY HOSPITAL
HEALTH CARE PROXY

Patient Name: _____ MR#: _____

Account #: _____ DOB: _____ Date: _____

Upstate University Hospital • Health Information Management • 750 East Adams Street • Syracuse, NY 13210

(1) I, Jane Doe

hereby appoint John Doe (333) 333-3333
(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. *(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 Jane Doe

Your Signature Jane Doe Date 9/22/23

Your Address 33 Third St.

(6) Optional: Organ, Eye and/or Tissue Donation

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

☐ Any needed organs, eye and/or tissues

☐ The following organs, eye and/or tissues _____

☐ Limitations _____

If you do not state your wishes or instructions about organ, eye 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.

Witness 1

Date 9/27/23

Name (print) Michael Jackson

Signature Michael Jackson

Address 750 E. Adams St.
Syracuse, NY 13210

Witness 2

Date 9/27/23

Name (print) Justin Timberlake

Signature Justin Timberlake

Address 750 E. Adams St.
Syr. NY 13210

1430 NYS DOH 08/22

F81048–Health Care Proxy (NYS Department of Health Form Revised: Aug. 2022) Rev. 9/2022 Review: 9/2022 MR

UPSTATE UNIVERSITY HOSPITAL
HEALTH CARE PROXY

Patient Name: _____ MR#: _____

Account #: _____ DOB: _____ Date: _____

Upstate University Hospital • Health Information Management • 750 East Adams Street • Syracuse, NY 13210

(1) I, Jane Doe

hereby appoint John Doe (333) 333-3333
(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. *(Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire (specify date or conditions):

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(5) Your Identification *(please print)*

Your Name Jane Doe

Your Signature Verbal Date 9/22/23

Your Address 33 Third St.

(6) Optional: Organ, Eye and/or Tissue Donation

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

☐ Any needed organs, eye and/or tissues

☐ The following organs, eye and/or tissues _____

☐ Limitations _____

If you do not state your wishes or instructions about organ, eye 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.

Witness 1

Date 9/22/23

Name (print) John Doe

Signature John Doe

Address 33 Third St.

Witness 2

Date 9/22/23

Name (print) _____

Signature _____

Address _____

1430 NYS DOH 08/22

NEW YORK STATE DEPARTMENT OF HEALTH

Medical Orders for Life-Sustaining Treatment (MOLST)

This Medical Orders for Life-Sustaining Treatment (MOLST) form is generally for patients with advanced illness who require long-term care services and/or who might die within 1-2 years.* The MOLST may also be used for individuals who wish to avoid and/or receive specific life-sustaining treatments. A physician, nurse practitioner, or physician assistant reviews the patient's current health status, prognosis, goals for care, and the risks and benefits of each life-sustaining treatment with the patient if they have capacity, or the health care agent or surrogate if the patient lacks capacity.

All ethical and legal requirements must be followed, including special procedures when a patient has an intellectual or developmental disability and lacks capacity. 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's assistant) must follow special procedures and attach the completed Office for People with Developmental Disabilities (OPWDD) MOLST Legal Requirements Checklist for Individuals with I/DD before signing the MOLST. (OPWDD checklist available at **https://opwdd.ny.gov/providers/health-care-decisions**). For more information on requirements for completing the MOLST, see page 4.

This MOLST may not be changed without the consent of the patient (or their health care decision-maker if the patient lacks capacity). Completing a MOLST is voluntary and cannot be required. The patient should keep this original MOLST with them at all times, whenever they leave home and during travel to different care settings. The physician, nurse practitioner, or physician assistant keeps a copy. All health care professionals and emergency medical services (EMS) providers are required to follow these medical orders. HIPAA permits disclosure of MOLST to other health care professionals & electronic registry as necessary for treatment. For further information on MOLST, see **https://www.health.ny.gov/professionals/patients/patient_rights/molst/**

SECTION A Patient Information

Doe, Jane
LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

33 Third St.
ADDRESS/CITY/STATE/ZIP

PREFERRED PHONE NUMBER

01/01/1930
DATE OF BIRTH (MM/DD/YYYY)

eMOLST NUMBER (THIS IS NOT AN eMOLST FORM)

Check All Advance Directives Known to be Completed
☑ Health Care Proxy ☑ Living Will ☐ Organ Donation ☐ Documentation of an Oral Advance Directive

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

Check **one:**
☐ **CPR Order: Attempt Cardio-Pulmonary Resuscitation**
☑ **DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**

SECTION C Orders for Life-Sustaining Treatment When the Patient Has a Pulse and is Breathing

Respiratory Support: Non-invasive Ventilation and/or Intubation and Mechanical Ventilation
Check **one:**
☐ Intubation and long-term mechanical ventilation, includes tracheostomy
☐ A trial of non-invasive ventilation and/or intubation and mechanical ventilation*
☐ A trial of non-invasive ventilation only; if fails, Do Not Intubate*
☑ Do Not Intubate (DNI) and Do Not Use Non-invasive Ventilation or Mechanical Ventilation

Future Hospitalization/Transfer
Check **one:**
☐ Send to the hospital, when medically necessary
☐ Send to the hospital only if pain and severe symptoms cannot be controlled
☑ Do not send to the hospital

SECTION D Consent for Sections B and C

SIGNATURE OF INDIVIDUAL MAKING DECISIONS

John Doe
PRINTED NAME OF INDIVIDUAL MAKING DECISIONS

☑ Verbal consent, leave signature line blank

9/22/23 1000
DATE/TIME OF CONSENT

Who is the individual making decisions:
☐ Patient ☑ Health Care Agent ☐ FHCDA Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate for individual with I/DD

Winnie the Pooh
PRINTED NAME OF FIRST WITNESS*

mickey mouse
PRINTED NAME OF SECOND WITNESS

*If this decision relates to an individual with an intellectual or developmental disability, refer to the instructions on page 4 before proceeding.

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

If Section D is completed by a §1750-b Surrogate, a physician must sign this Section E. Prior to the physician signing this Section E when Section D is completed by a §1750-b Surrogate, the physician must complete and attach the OPWDD Checklist.

Maura Stanton, NP
SIGNATURE

Maura Stanton, NP
PRINT NAME

343687
LICENSE NUMBER

9/22/23 1000
DATE/TIME

Doe, Jane
LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

01/01/1930
DATE OF BIRTH (MM/DD/YYYY)

SECTION F Additional Orders for Life-Sustaining Treatment

TREATMENT GUIDELINES
Check **one:**
☐ No limitation on medical interventions
☐ Limited medical interventions, only as described below
☑ Comfort measures only. Provide medical care and treatment with the primary goal of relieving pain and other symptoms

ARTIFICIALLY ADMINISTERED FLUID AND NUTRITION

FEEDING TUBE
Check **one:**
☐ Long term feeding tube
☐ Determine use or limitation if need arises*
☑ No feeding tube

IV FLUIDS
Check **one:**
☐ IV fluids
☐ Determine use or limitation as need arises*
☑ No IV fluids

ANTIBIOTICS
Check **one:**
☐ Use antibiotics to treat infections
☐ Determine use or limitation of antibiotics when infection occurs*
☑ Do not use antibiotics

DIALYSIS
Check **one:**
☐ Use dialysis to treat renal failure
☐ Determine use or limitation if renal failure occurs*
☑ Do not use dialysis

OTHER MEDICAL ORDERS AND INSTRUCTIONS (only as discussed with the physician, NP, or PA. May include instructions and goals for trials*. If nothing else is discussed, write NONE.)

SECTION G Consent for Section F

SIGNATURE OF INDIVIDUAL MAKING DECISIONS

John Doe
PRINTED NAME OF INDIVIDUAL MAKING DECISIONS

☑ Verbal consent, leave signature line blank

9/22/23 1000
DATE/TIME OF CONSENT

Who is the individual making decisions:
☐ Patient ☑ Health Care Agent ☐ FHCDA Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate for individual with I/DD

Winnie the Pooh
PRINTED NAME OF FIRST WITNESS*

mickey mouse
PRINTED NAME OF SECOND WITNESS

*If this decision relates to an individual with an intellectual or developmental disability, refer to the instructions on page 4 before proceeding.

SECTION H Physician/Nurse Practitioner/Physician Assistant Signature for Section F

If consent for this order was provided by a §1750-b Surrogate for an individual with an intellectual or developmental disability, only a physician may sign this section, and only after the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD has been completed and attached.t.

Maura Stanton, NP
SIGNATURE

Maura Stanton, NP
PRINT NAME

343687
LICENSE NUMBER

9/22/23 1000
DATE/TIME

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

Doe, Jane | 01/01/1930
LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT | DATE OF BIRTH (MM/DD/YYYY)

SECTION I Review and Renewal

A physician, nurse practitioner, or physician assistant should review this form at least every 90 days and whenever the patient or other decisionmaker changes their mind about treatment. The MOLST should also be reviewed if the patient moves from one location to another to receive care, or if the patient has a major change in health status (for better or worse).

This MOLST remains valid and must be followed even if it has not been reviewed in the 90-day period.

Date/Time	Reviewer's Printed Name and Signature	Location of Review	Outcome of Review
			☐ No change ☐ Form changed, new form completed ☐ Form voided, no new form
			☐ No change ☐ Form changed, new form completed ☐ Form voided, no new form
			☐ No change ☐ Form changed, new form completed ☐ Form voided, no new form
			☐ No change ☐ Form changed, new form completed ☐ Form voided, no new form
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			☐ No change ☐ Form changed, new form completed ☐ Form voided, no new form

Doe, Jane | 01/01/1930
LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT | DATE OF BIRTH (MM/DD/YYYY)

In addition to the MOLST form, the New York State Department of Health and OPWDD have developed legal requirements checklists and instructions to assist in the proper completion of the MOLST. The checklists are intended to assist providers in satisfying the ethical and legal requirements associated with decisions concerning life-sustaining treatment for all patients.

Adult Patients

The instructions and legal requirements checklists for **adult patients** can be found at **www.health.ny.gov/professionals/patients/patient_rights/molst/**. For adult patients, there are five different checklists. The correct checklist should be chosen based on the patient's decision-making capacity and the setting.

- **Checklist #1** Adult patients with medical decision-making capacity - any setting
- **Checklist #2** Adult patients without medical decision-making capacity who have a health care proxy - any setting
- **Checklist #3** Adult hospital, hospice or nursing home patients without medical decision-making capacity who do not have a health care proxy, decision-maker is Public Health Law Surrogate
- **Checklist #4** Adult hospital, hospice or nursing home patients without medical decision-making capacity who do not have a health care proxy and for whom no surrogate from the list is available
- **Checklist #5** Adult patients without medical decision-making capacity who do not have a health care proxy, and the MOLST form is being completed in the community

A Public Health Law Surrogate (aka a FHCDA Surrogate) means a surrogate under Public Health Law Article 29-CC (the Family Health Care Decisions Act).

Minor Patients

The instructions and legal requirements checklists for **minor patients** can be found at: www.health.ny.gov/professionals/patients/patient_rights/molst/

Individuals with Intellectual or Developmental Disabilities (I/DD)

The law governing the decision-making process differs for individuals with I/DD. Surrogate's Court Procedure Act Section 1750-b (SCPA 1750-b) must be followed when making a decision for an individual with I/DD who is determined to lack capacity and who does not have a health care proxy.

- **Sections E and H of this form may only be signed by a physician,** not a nurse practitioner or physician's assistant.
- In sections D and G of this form, **one witness must be the individual's treating physician.**
- Completion of the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD, including notification of certain parties and resolution of any objections, is **mandatory prior to completion of a MOLST.**
- Both the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD and SCPA 1750-b process apply to individuals with I/DD, **regardless of their age or residential setting.**
- **Decisions to withhold or withdraw life sustaining treatment (LST) for an individual with I/DD** must be specifically listed and described in step 2 of the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD and only after the surrogate has had a discussion with the individual's treating physician regarding their medical condition, possible treatment options and goals for care. SCPA 1750-b also requires that two physicians determine that the individual's condition meets specific medical criteria **at the time the request to withhold or withdraw treatment is being made,** including that the provision of the life sustaining treatment would impose an extraordinary burden on the individual. These requirements are included in step 4 of the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD. The individual's medical condition for the purposes of a request to withhold or withdraw LST **must never include consideration of their intellectual or developmental disability.**
- Trials for an individual with I/DD: Whether or not a new checklist is required following an unsuccessful trial of LST depends on the parameters of the trial, as specified in step 2 of the OPWDD MOLST Legal Requirements Checklist for individuals with I/DD. **If a trial period is open ended, and the authorized surrogate subsequently decides to request withdrawal of the LST, a new checklist is required.**

The complete instructions and legal requirements checklists for **people with intellectual or developmental disabilities** can be found at: **www.opwdd.ny.gov/providers/health-care-decisions** or at **www.health.ny.gov/professionals/patients/patient_rights/molst/**.

Resources

- https://www.health.ny.gov/professionals/patients/patient_rights/molst/
- https://www.health.ny.gov/professionals/patients/health_care_proxy/
- https://www.stroke.org/en/

References

- *American Stroke Association: A division of the American Heart Association*. www.stroke.org. (n.d.). https://www.stroke.org/en/
- Cowey, E., Schichtel, M., Cheyne, J. D., Tweedie, L., Lehman, R., Melifonwu, R., & Mead, G. E. (2021). Palliative care after stroke: A Review. *International Journal of Stroke*, *16*(6), 632–639. https://doi.org/10.1177/17474930211016603
- *Department of Health*. Choosing Your Health Care Agent. (n.d.). https://www.health.ny.gov/professionals/patients/health_care_proxy/
- *Department of Health*. Medical Orders for Life-Sustaining Treatment (MOLST). (n.d.). https://www.health.ny.gov/professionals/patients/patient_rights/molst/
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- Steigleder, T., Kollmar, R., & Ostgathe, C. (2019). Palliative care for stroke patients and their families: Barriers for implementation. *Frontiers in Neurology*, *10*. https://doi.org/10.3389/fneur.2019.00164