



Opportunity's Knocking:


How Advance Care Planning Improves Residents' Quality of Life and Your Survey

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*“It sounds paradoxical: by excluding death from our life
we cannot live a full life, and by admitting death into
our life we enlarge and enrich it.”*

Interrupted Life: The Diaries of Etty Hillesum 1941-43

*“I have always found that plans are useless, but planning is
indispensible.”*

Dwight D. Eisenhower



Objectives

- Cultivate an understanding of advance care planning and its importance
- Identify different limitations and potential barriers to effective advance care planning
- Understand various components of advance care planning
- Identify different advance care planning documents and benefits and limitations of each
- Understand CMS's new guidance on advance directives and how it will impact you
- Tips on integrating advance care planning part of person-centered care at facility



Ombudsman & Advance Care Planning

NJ Supreme Court in In re Conroy ruled that the Ombudsman should be involved in withholding/ withdrawing of life-sustaining treatments of residents of nursing homes.

Office provides support for RECs and where no REC available works with resident, family and friends, and facility staff to identify the resident's wishes and gathers clinical information regarding the resident's cognition, condition, and prognosis, to ensure that legal standards for withholding/withdrawing treatment are met

Provide trainings to various disciplines on advance care planning to decrease number of individuals in end-of-life situations where their wishes are unknown.

Provide technical support to facilities with regard to advance care planning

Primary focus: resident's wishes are respected.



Regional Ethics Committees (RECs)

- Multi-disciplinary teams, including social workers, nurses, clergy, and hospice workers
- Established to serve as resources to residents and health care professionals of LTCFs who face ethical dilemmas:
 - Treatment decisions
 - Health care conflicts
 - Withholding/withdrawing LST
 - Quality of life issues
- Consultation not required and recommendations not legally binding but can often de-escalate and resolve ethical dilemmas as close to the bedside as possible.



Why Do We Need Advance Care Planning

- Virtually all of us will have a period of serious illness/disability before we die

BUT IT'S NOT JUST ABOUT END OF LIFE

- We should all understand our health condition so we can advocate on behalf of ourselves
- If face a critical decision, more prepared/less stress if given thought before to what might want
- Likely there will be points before “end-of-life” where we may be unable to speak for ourselves
- Gives us the opportunity to build relationships



Why Now Is the Time

- NJ's rollout of POLST
- CMS Surveyors and Advance Directives
- Reduction of Hospital Readmissions (INTERACT II)



ACP = Good Care

- Person-centered care
 - “Person before the task”
 - Resident choice
 - Empowering caregivers to honor resident choice
- Resident-directed care
 - Promotes resident choice in all aspects of life
- Tool for enacting person-centered care.
 - CMS: “The advance care planning process is an integral aspect of the facility’s comprehensive care planning process and assures re-evaluation of the resident’s desires on a routine basis and when there is a significant change in the resident’s condition.”



Advance Care Planning

An ongoing process of communication and negotiation that focuses on goals of care and likely outcomes

Touches on multiple domains of care:

- Medical
- Physical
- Psychological
- Social
- Spiritual
- Financial



Advance Care Planning

ACP Is Not:

A legal process

A one-time thing

A checklist of various medical interventions

About how a person wants to die

ACP Is:

Communicating, reflecting, documenting, and revisiting

A process

A reflection of an individuals' goals and values and how that connects to their health

About how a person wants to live



Outcomes

Benefits of ACP

- Improved quality of life
- Increased satisfaction with care
- Opportunity to regain sense of control
- Reinforces health care needs will be met
- If critical event happens, won't be first time thinking about issues
- Reduced stress and anxiety for proxies and staff
- Avoid conflict among family
- Strengthen relationships

Consequences of No ACP

- More aggressive intervention or insufficient intervention
- No matter what decision made, family/HCP live with uncertainty, resulting in lasting distress
- Imposes stress on staff b/c of inability to constructively deal with grief/loss and added time to sort through ethical complexities



Barriers

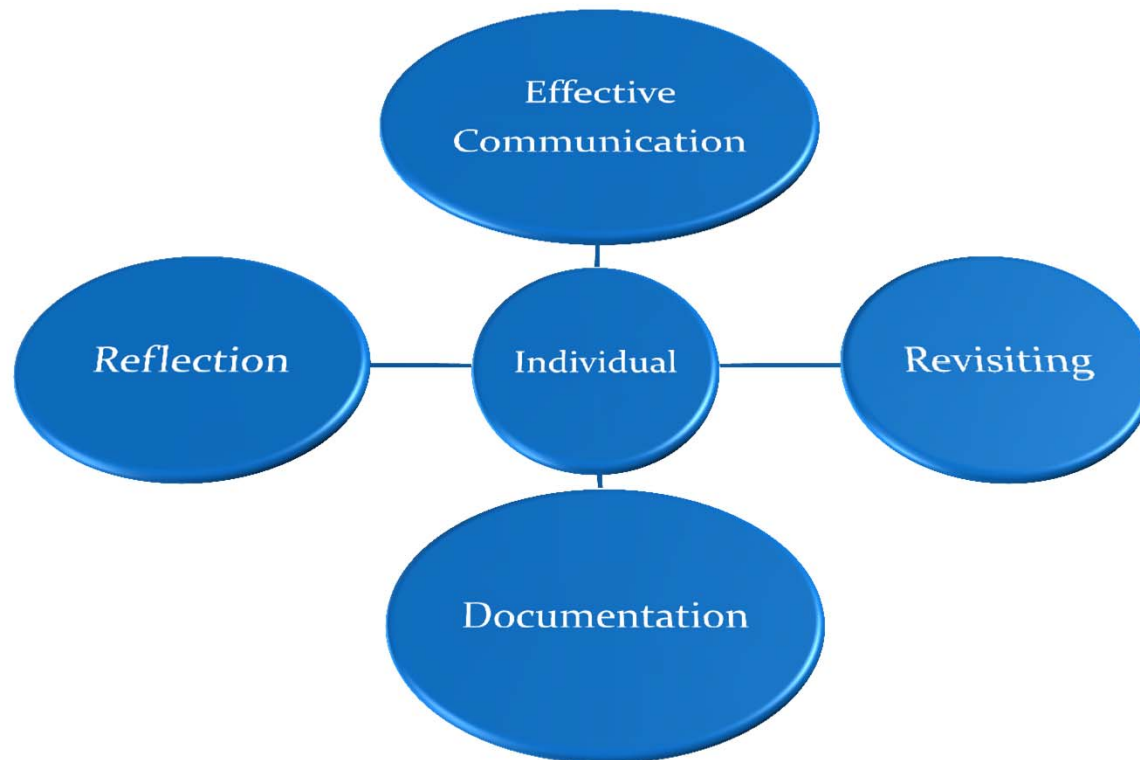
- Denial (society and individuals)
- Health care system
- Lack of awareness
 - How it can help
 - How to express wishes/ACP
 - HCP's awareness of individuals' expression
 - What medical all means (CPR, AHN, Palliative Care)
- ACP not for me (not until sick or did one already)
- Confusion (concerns emphasizing palliative care and end-of-life care impact aggressive treatment)
- Cultural Differences (cultural humility/cultural competency)



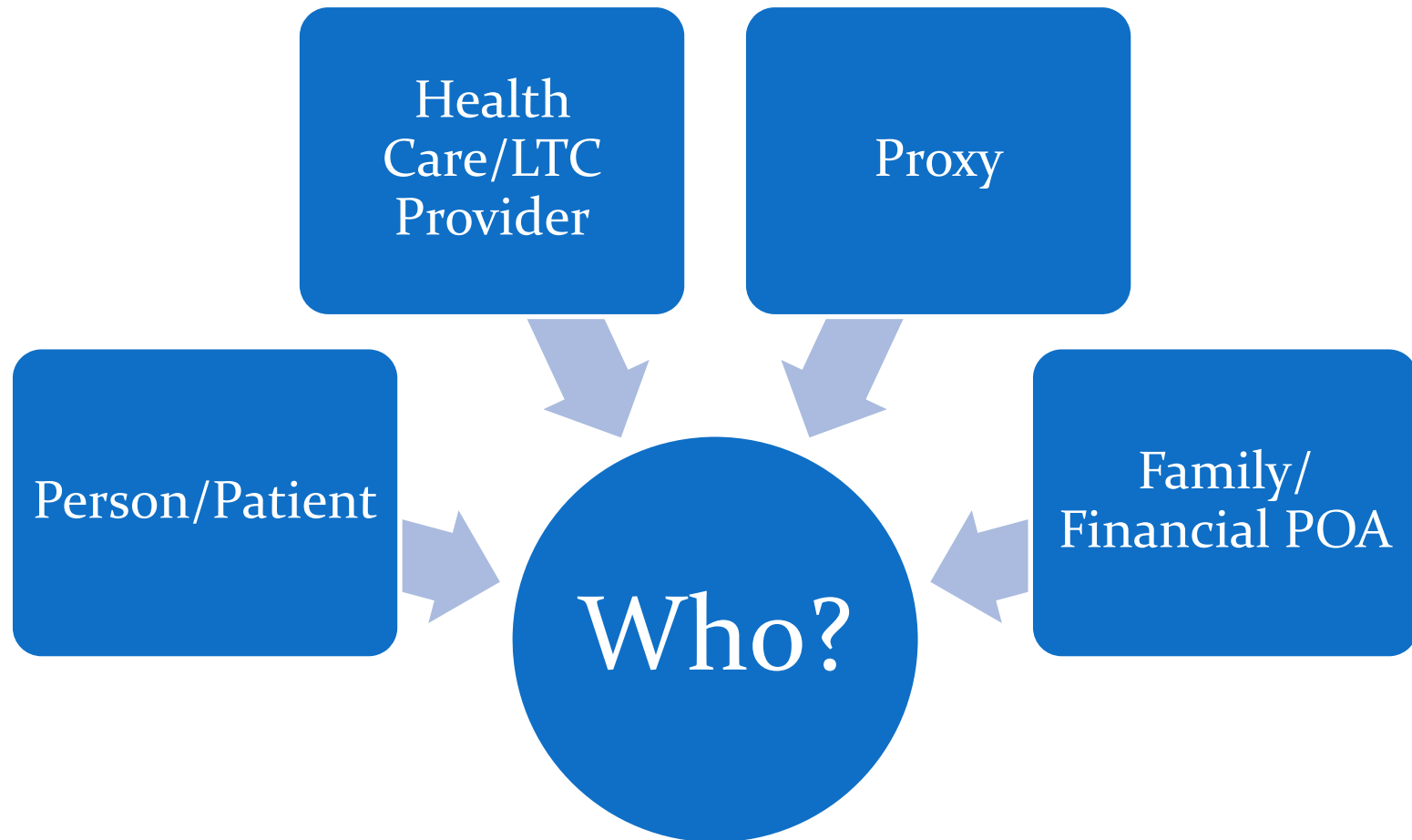
ACP in Today's World

- Many people think it's important
- Few have done it
 - NJ (2001– 16% have AD, 65+ ~40%)
 - Nat'l (2004 – 65% - 56% DNR/18% AD)
- Surrogates are poorly prepared to act
- Forms can be vague/difficult to understand when filling out
- Forms are not written in a way that is useful to HCP
- People change but ADs don't
- Forms aren't accessible

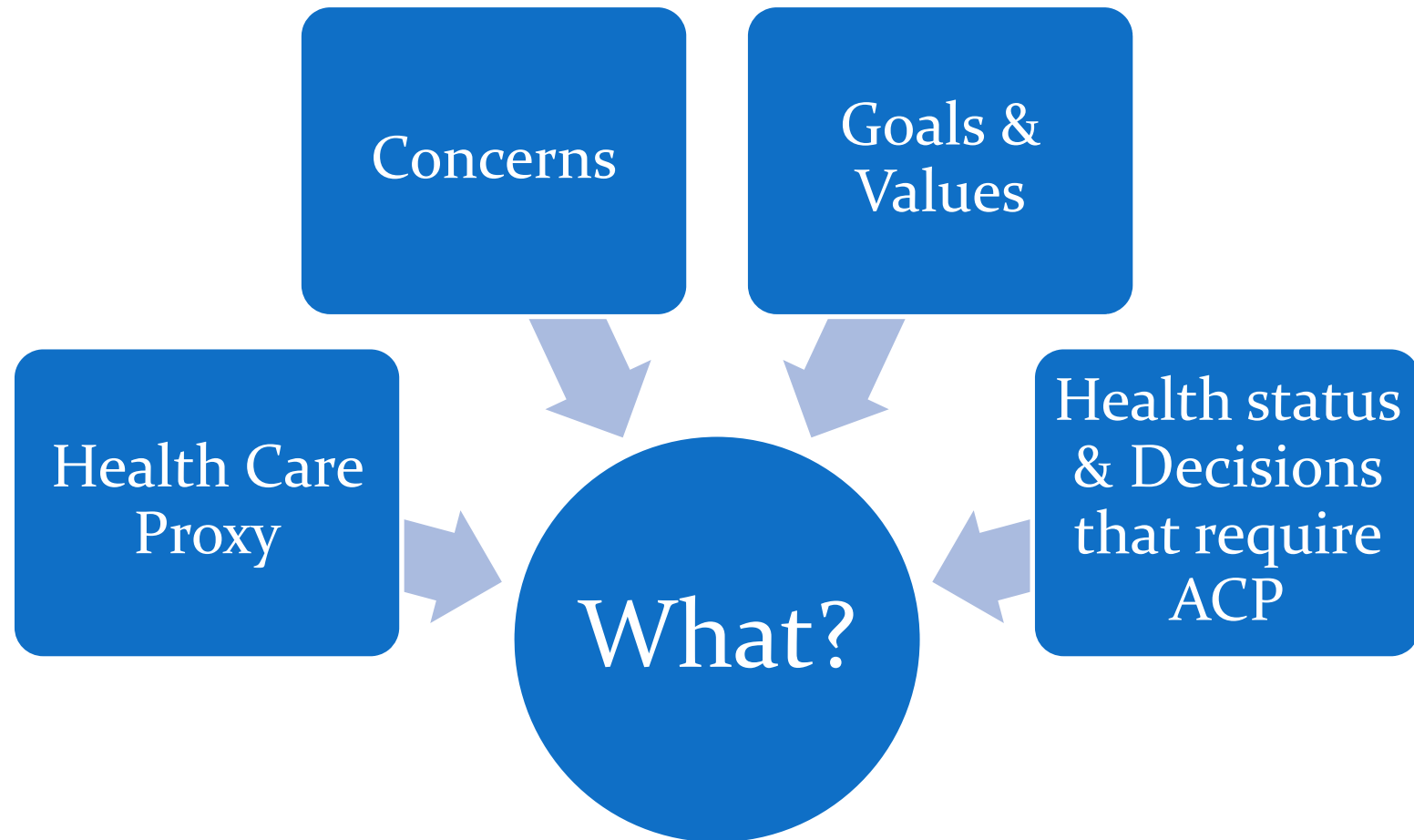
Components of Successful ACP



Effective Communication



Effective Communication





Health Condition

- Health care provider
 - Diagnosis
 - Prognosis
 - All possible treatment options
 - Benefits/burdens of various treatments
 - Role of palliative care and hospice
- Individual/resident
 - What a person understands/experiences about their disease



Goals & Values

- What an individual hopes for, what he or she fears, what makes life worth living
 - Activities
 - Fears/concerns (breathing, pain, family strife)
 - Where individuals want to be
- Focus: Longevity, maintenance, comfort
- Every person is different and that must be valued
 - Aggressive treatment until death
 - Endure side effects for certain period of time
 - Focus on closure, comfort care
- Goals and values change



Health Care Proxy

- How to Pick a Proxy
 - Is the person willing to take on the role?
 - Is the person willing to listen to and understand individuals' goals, values, and beliefs for future health care decisions?
 - Can the person make decisions under difficult and stressful situations?
 - Can the person follow your wishes even if they are different than their own?
 - Will the person be available?
- Covenant v. Contract
 - Flexibility?



Things to Keep in Mind

- Listening is key – empathetic and reflective
- No one communication strategy
 - Tailor to the disease trajectory
 - Tailor to needs/communication style of individual and family
- Must work from where person is & where willing to go
 - A lot of education will likely be needed
- Process that happens over time
- **MUST COMMIT** to ensure preferences are honored

Reflection





Documentation

- Advance Directives
 - “Living Will”
 - “Health Care Proxy”
- DNRs/DNHs/DNIs
 - Do Not Hospitalize
 - Do Not Resuscitate
 - Do Not Intubate
- POLST: Practitioner Orders for Life-Sustaining Treatment

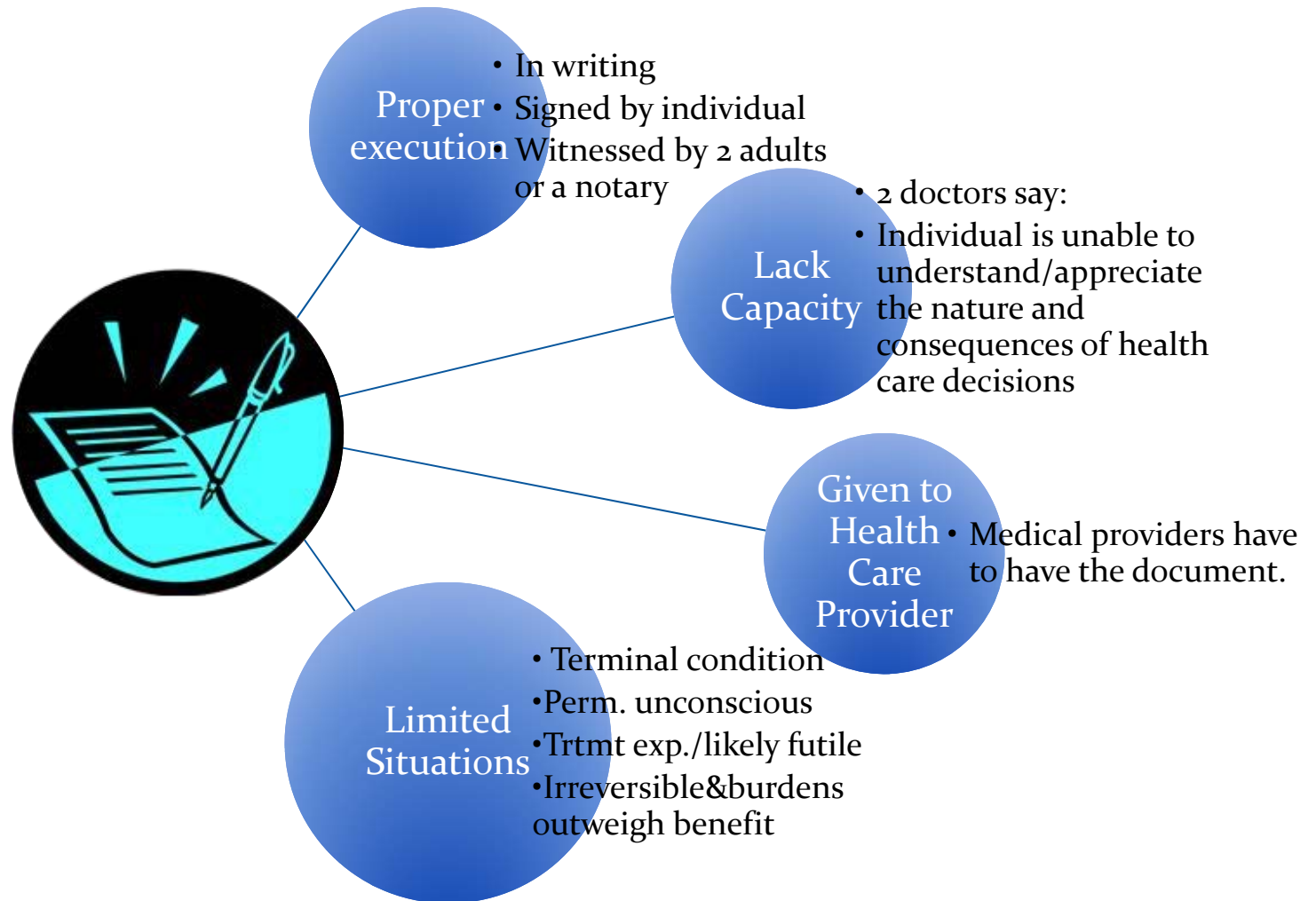


Myths & Misconceptions

THESE ARE NOT TRUE

- Financial power = health care proxy
- DNR = Living will
- Advance directive (DNR, DNH) = don't treat
- Once an individual names a proxy they lose control
- Only older people need ADs

Advance Directives





DNRs/DNHs/DNIs

- DNRs/DNHs/DNIs are orders written by doctors or advanced practice nurses (in collaboration with doctors) that are made part of a resident's medical record
- Do not travel across medical settings

POLST

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY

NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)

Follow these orders, then contact physician/APN. This Medical Order Sheet is based on the current medical condition of the person referenced below and their wishes stated verbally or in a written advance directive. Any section not completed implies full treatment for that section. Everyone will be treated with dignity and respect.

Person Name (last, first, middle)		Date of Birth
A	GOALS OF CARE (See reverse for instructions. This section does not constitute a medical order)	
B	<p>MEDICAL INTERVENTIONS: Person is breathing and/or has a pulse</p> <p><input type="checkbox"/> Full Treatment. Use all appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section D for resuscitation status.</p> <p><input type="checkbox"/> Limited Treatment. Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use non-invasive positive airway pressure. Generally avoid intensive care.</p> <p><input type="checkbox"/> Transfer to hospital for medical interventions.</p> <p><input type="checkbox"/> Transfer to hospital only if comfort needs cannot be met in current location.</p> <p><input type="checkbox"/> Symptom Treatment Only. Use aggressive comfort treatment to relieve pain and suffering by using any medication by any route, positioning, wound care and other measures. Use oxygen, suctioning and manual treatment of airway obstruction as needed for comfort. Use Antibiotics only to promote comfort. Transfer only if comfort needs cannot be met in current location.</p> <p>Additional Orders: _____</p>	
C	<p>ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION:</p> <p>Always offer food/fluids by mouth if feasible and desired.</p> <p><input type="checkbox"/> No artificial nutrition.</p> <p><input type="checkbox"/> Defined trial period of artificial nutrition.</p> <p><input type="checkbox"/> Long-term artificial nutrition.</p>	
D	<p>CARDIOPULMONARY RESUSCITATION (CPR)</p> <p>Person has no pulse and/or is not breathing</p> <p><input type="checkbox"/> Attempt resuscitation/CPR</p> <p><input type="checkbox"/> Do not attempt resuscitation/DNAR</p> <p>Allow Natural Death</p>	<p>AIRWAY MANAGEMENT</p> <p>Person is in respiratory distress with a pulse</p> <p><input type="checkbox"/> Intubate/use artificial ventilation as needed</p> <p><input type="checkbox"/> Do not intubate - Use O₂, manual treatment to relieve airway obstruction, medications for comfort.</p>
E	<p>If I lose my decision-making capacity, I authorize my surrogate decision maker, listed below, to modify or revoke the NJ POLST orders in consultation with my treating physician/APN. <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Print Name of Surrogate (address on reverse) _____ Phone Number _____</p>	
F	<p>SIGNATURES:</p> <p>I have discussed this information with my physician/APN.</p> <p>Signature _____</p> <p><input type="checkbox"/> Person Named Above</p> <p><input type="checkbox"/> Health Care Representative/Legal Guardian</p> <p><input type="checkbox"/> Spouse/Civil Union Partner</p> <p><input type="checkbox"/> Parent of Minor</p> <p><input type="checkbox"/> Other Surrogate _____</p> <p>Has the person named above made an anatomical gift:</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>These orders are consistent with the person's medical condition, known preferences and best known information.</p> <p>PRINT - Physician/APN Name _____ Phone Number _____</p> <p>Physician/APN Signature (Mandatory) _____ Date/Time _____</p>	



POLST

Initial POLST

- Seriously ill with life-threatening illness
- Advanced frailty with significant weakness & difficulty with ADLs
- May lose capacity to make their own health care decisions within the year
- Strong preferences for EOL care
- Chronically ill individuals who have frequent health care system contact
- Individuals who reside in LTCF

Revisiting POLST

- Transferred to a different care setting
- Experiences a significant change in health status
- Changes his or her treatment preferences
- Changes his or her primary care provider



POLST

- Voluntary
- Modification/Revocation
 - Individual with DMC can change/revoke POLST at any time or request alternative treatment to what is on POLST
- Surrogates
 - Can sign based on known preferences or, if none, best interest
 - May modify/revoke if patient authorized
- Most recent verbal or written directive of patient governs

Differences Between Documents

Advance Directive	DNR/DNH/DNI	POLST
All Adults	People w/Advanced Illness	People w/Advanced Illness
Any Setting	Medical Setting	Medical Setting
Legal Document	Medical Order	Medical Order
Indiv./Med. Records	Medical Records	Medical Records
Transportable	Not transportable	Transportable
Future Care/Condition	Current care/condition	Current care/condition
No surrogate	Surrogate	Surrogate
Limited to certain situations	Limited to where drafted	Not limited by situation or place
Not operational in field	Not operational in field	Operational in field
Loss of capacity	No loss of capacity	No loss of capacity



Effectiveness of Documents

- Individual understands document
- Surrogate understands wishes
- HCP knows documents exist/has a copy
- HCP understands documents and complies with them
- Documents are relevant, i.e., revised as condition and goals change



Revisiting

- First, if you don't have one – NOW or when you turn 18
- The 5 Ds:
 - Decade
 - Death of a loved one
 - Divorce
 - Diagnosis
 - Decline/Improvement



Considerations

Ability to return to certain activities

Sense of independence

Financial consideration/Insurance

Family/Social relationships

Capacity/availability of formal and informal supports

Religious/Spiritual beliefs/Cultural Background (eg, locus of decision-making, socio-political & historical factors)*

Previous experiences with advance care planning and health care system



Considerations

Individual autonomy

Full disclosure for
informed decision-making

Control over dying process

No one should suffer

Written and formal

Future

Relationships/Docs decide

Truth is harmful/burden

It's God's will

Life involves suffering

A person's word is sufficient/
Indirect conversations

Present



Common Pitfalls

- Failing to plan
- Failing to include the proxy in discussions
- Failing to clarify preferences
- Focusing discussion too narrowly
- Ignoring individuals
- Failing to read/revisit previous planning

Components





Surveys

- Ref: S&C 12-47-NH “F tag 155--Advance Directives” related to
<http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-12-47.pdf>
- 42 USC 483.10(b)(4) and (8) requires that the facility:
 - Promote and protect the resident’s right to formulate, modify or rescind an advance directive, refuse treatment, and to refuse to participate in experimental research, and to;
 - Maintain written policy and procedures regarding these rights.



What Surveyors Are Looking For

Whether facility has promoted the residents' rights to accept or refuse treatment and to formulate ADs* by:

- Establishing & maintaining policies/procedures re: rights
- Informing & educating resident about these rights and facility policy/procedure re: these rights
- Helping residents exercise these rights
- Incorporating residents' choices into treatment, care, and services

* ADs include living will, health care proxy/power of attorney, directives to doc, medical orders (DNR, POLST)



CMS & Advance Care Planning

- “In order for a resident to exercise his or her right to make knowledgeable choices about care and treatment or to decline treatment, the primary care provider and facility staff should provide information (in a language and terminology that the resident understands) to the resident and/or his/her legal representative regarding the resident’s health status, treatment options, and expected outcomes.
- “Whether or not the resident chooses to execute an advance directive, discussion and documentation of the resident's choices regarding future health care should take place during the development of the initial comprehensive assessment and care plan and periodically thereafter. The process of having such discussions, regardless of when they occur, is sometimes referred to as “advance care planning.”



Surveyor Protocol

- Use: (1) has an advance directive or a condition where advance care planning is particularly relevant; (2) has any orders related to provision of LST; or (3) has refused medical or surgical treatment
- Observations: consistent with care plan, progress notes, resident choices



Surveyor Protocol-Interviews

- Resident/Rep: What has the facility/staff/practitioner done to:
 - Determine resident's choices regarding care and treatment?
 - Inform resident about medical condition and relevant health care issues?
 - Inform resident/legal rep about treatment options and relevance of those options to the resident's goals, wishes, medical condition and prognosis?
 - Help resident or resident's legal rep document treatment choices (e.g., in the form of advance directives or another format consistent with state and federal law and regulation)?



Surveyor Protocol-Interviews

- Staff:
 - How facility determines if resident has AD or other relevant doc?
 - How practitioner/facility informs/educates resident/legal rep re: formulate an advance directive?
 - What training staff receives re: ADs and how to initiate conversation?
 - How practitioner/facility inform/educate resident/legal rep re: medical condition/ health care issues, treatment options and right to accept/refuse medical treatment?
 - How staff help resident/legal rep document treatment choices/formulate AD?
 - How assess health care decision-making capacity?
 - How documented choices and treatment decisions are communicated to IDT?
 - How staff knows how to access the documented information on the resident's treatment choices during both routine care and in urgent situation?
 - How facility ensures that practitioner orders and treatment decisions are consistent with the resident's documented choices and goals?



Surveyor Protocol-Interviews

- Health Care Practitioner
 - How facility seeks, identifies, and documents the resident's wishes regarding ACP and life-sustaining treatments?
 - How the facility ensures that medical orders and treatments reflect the resident's choices and goals?
 - Process by which the staff and practitioners are involved in advising the resident/legal rep re: right to accept or refuse treatment (including LST)?
 - How documented choices and treatment decisions are communicated to IDT?
 - How staff know where to access the documented information on the resident's treatment choices and Ads in the medical record, during both routine care and in an urgent or emergent situation?
 - How the staff and practitioner periodically reassess the resident's condition and prognosis to identify whether existing advance directives remain pertinent and/or whether there is a need to review or possibly modify them?



Survey Protocol

Residents' Record Review

- Whether the facility determined at admission if the resident had AD/offered the resident the option to formulate AD
- Whether info re: rights provided in writing
- Evidence of whether/how facility determines the resident's capacity to understand/make decisions re: right to accept/refuse treatment and formulate AD
- Note whether the care plan considers the resident's choices.
- Whether documentation of rationale for recommendations and treatment decisions related to LST options;
- Whether the practitioner's orders consistent w/documented choices and goals;
- Whether any treatments or interventions ordered (e.g., unplanned hospitalizations or placement of a feeding tube) are inconsistent with the documented acceptance or refusal of treatment or with any existing AD
- Whether AD is incorporated into his or her active record, including in medical orders, progress notes, the resident care plan or other relevant means of communication to the interdisciplinary team.



Surveyor Protocol- Review of Facility Practices

Facility's policies, procedures, records related to determining and documenting resident wishes regarding advance care planning and implementing medical orders that reflect a resident's wishes. Review of other documents may be necessary, including policies, staffing, staff training and/or functional responsibilities.



What Compliance Looks Like

- Established & implemented policies/procedures regarding the right to formulate advance directives, to decline treatment /interventions
- Informed & educated resident about rights and facility's policies
- Determined whether resident had AD or has offered the resident the opportunity to develop an advance directive
- Helped resident exercise these rights
- Incorporated the resident's choices into the medical record and orders related to treatment, care and services
- Monitored the care and services given the resident to ensure that they were consistent with the resident's documented choices and goals.



Examples of Deficiencies

Level 4 (Immediate Jeopardy)

- As a result of the facility's failure to obtain and implement physician orders for two weeks after the resident had documented choices related to life-sustaining treatments, the resident was transferred to the hospital for an acute change of condition, where a feeding tube was placed against the resident's wishes and the resident returned to the facility where the tube feeding was continued for three months despite the facility's knowledge that the intervention was against the resident's wishes.



Examples of Deficiencies

Level 3 (Actual Harm, Not Immediate Jeopardy)

- A facility allowed family members, who did not have legal standing under state law, to make such decisions on behalf of the resident and to override the resident's expressly documented choices to decline life-sustaining treatments. As a result, the resident received treatments that were contrary to his/her documented choices.
- As a result of the facility's failure to identify physician orders that were in conflict with the resident's advance directive and plan of care, the facility performed CPR on the resident and then had the resident transported to the hospital for additional treatment that was also contrary to the resident's documented wishes.



Examples of Deficiencies

Level 2 (No Actual Harm, with Potential for More than Minimal Harm that is not Immediate Jeopardy)

- As a result of the facility's failure to obtain physician orders that were consistent with the resident's documented wishes, the direct care staff was unaware of the resident's wishes, although a situation involving life-sustaining treatment options had not yet arisen in the resident's care.
- As a result of the facility's failure to take action when the resident requested assistance to develop an advance directive, the resident had not formulated an advance directive, despite the resident's desire to do so.



Examples of Deficiencies

Level 1 (No Actual Harm with Potential for Minimal Harm)

- The failure of the facility to recognize and facilitate the exercising of the resident's right to refuse treatment, to refuse to participate in experimental research and to formulate an advance directive; and to maintain written policies and procedures regarding these rights, places the resident at risk for more than minimal harm. Therefore, Severity Level 1 does not apply for this regulatory requirement.



Positive Facility ACP Process

- Staff are trained and supported about ACP, and how to deal w/ethics dilemmas, with death/dying of residents
- Ensure resident and family are fully informed of (1) resident's medical condition, (2) prognosis and range of possible outcomes (hope for best, prepare for rest) and (3) common medical interventions (CPR, ANH)
- Residents have the opportunity to express wishes about goals of care and medical interventions clearly.
- Facility has policies and procedures in place to document, communicate, and honor wishes of residents.



Opportunities for ACP

- Admission (and within a couple of weeks)
- Care conferences
- When there is a change in resident's condition
- When a resident or family member raises it (“I’ve lived my life”; “I’m ready to go”; “I hate to see my mother like this”)



The Conversation

- Prepare
 - Review resident's goals & values, medical condition & prognosis, any ACP docs, resident's capacity, identify key family members and/or health care proxy if necessary
 - Create the space: private, enough time, turn off cell – give full attention
 - Be mindful to use simple language and respond empathetically
 - Have tissues



The Conversation

- Discussion
 - Describe purpose of meeting
 - Identify spokesman if not resident and there is one
 - Assess resident's current state of mind, comfort level
 - Ask what resident/family understand of condition and prognosis
 - Talk about ACP – what resident has, what ACP is
 - Ask about resident's goals of care, values, wishes
 - Go more in-depth about condition and prognosis and clarify any areas of confusion



The Conversation

- Discuss possible interventions (use of antibiotics, CPR, ANH) and palliative care or hospice
- Discuss/fill-out any medical orders; encourage filling out advance directive
- Ending the Discussion
 - Ask: What do you understand about what we've talked about? (Not do you have any questions.)
 - Explain will always have provide comfort
 - Offer to have a follow-up meeting if necessary and explain will revisit whenever needed



What You Can Do

- Do It Yourself
- Get Comfortable with Dying as a Part of Life
- Get Your Family and Friends To Do It
- Assess What Your Facility Is Doing
- Talk to the Ombudsman for Assistance
- Talk with Residents & Family
- Engage with Regional Ethics Committee
- Attend to Yourself



Resources

Tools for Developing a Facility Plan

- Coalition for Compassionate Care of California
 - <http://coalitionccc.org/nursing-homes.php>
- Advancing Excellence in America's Nursing Homes
 - Goal 6 – Advance Care Planning
http://www.nhqualitycampaign.org/star_index.aspx?controls=resByGoal



Resources

Tools that May Help Have the Conversation


- INTERACT II
 - <http://www.interact2.net/tools.html>
- Hospice & Palliative Nurses Association TIPS Sheets
 - <http://www.hpna.org/DisplayPage.aspx?Title=TIPS>
- American Hospice Foundation: Medical Issues to be Considered in Advance Care Planning
 - <http://www.americanhospice.org/articles-mainmenu-8/advance-care-planning-mainmenu-9/46-medical-issues-to-be-considered-in-advance-care-planning>



Resources

Advance Care Planning Tools

- The Conversation Project
 - <http://theconversationproject.org/>
- Engage with Grace
 - <http://www.engagewithgrace.org/>
- 5 Wishes
 - <http://www.agingwithdignity.org/five-wishes.php>
- Caring Conversations
 - <http://practicalbioethics.org/resources/caring-conversations.html>
- American Bar Association
 - http://www.americanbar.org/groups/law_aging/publications.html
- Your Life Your Choices
 - http://www.rihlp.org/pubs/Your_life_your_choices.pdf



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