

# Free Webinar For Legal Professionals: Advance Care Planning with People with Dementia

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National Elder Rights Training Project for the National Legal Resource Center.  
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# NLRC

Providing Legal Support to the  
Aging Advocacy Network

- <http://www.nlrc.aoa.gov/>
- Collaboration developed by the Administration on Aging between the National Consumer Law Center, National Senior Citizens Law Center, American Bar Association Commission on Law and Aging, Center for Elder Rights Advocacy, and the Center for Social Gerontology
- See upcoming trainings, conferences, and webinars
- Request a training
- Request consulting
- Request technical assistance
- Access articles and resources

# Presenter – Jane Tilly, DrPH

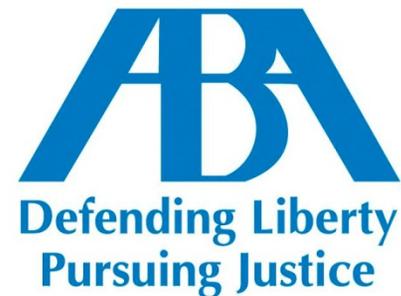
- Joined the Administration on Aging in December 2008 as Team Leader for Dementia and Brain Health Programs.
- She has extensive experience with research and policy analysis on a variety of health, long term services and supports, and public benefit issues at the state, national and international levels stemming from her work at the Urban Institute and AARP's Public Policy Institute.
- Just prior to joining the Administration on Aging she worked on dementia policy and practice issues for the Alzheimer's Association.

# Presenter – Charles Sabatino

- Is a board member of the D.C. based Coalition to Transform Advanced Care and co-chairs their Public Policy Working Group.
- He also serves as the director of the ABA's Commission on Law and Aging, in Washington, D.C., where since 1984, he has been responsible for the ABA Commission's research, project development, consultation, and education in areas of health law, long-term care, guardianship and capacity issues, surrogate decision-making, legal services delivery for the elderly, and professional ethics.
- He has written and spoken extensively on capacity issues, surrogate decision-making, and advance care planning, health care reform, and legal ethics.
- Mr. Sabatino is also a part-time adjunct professor at Georgetown University Law Center where he has taught Law and Aging since 1987.
- He is a Fellow and former president of the National Academy of Elder Law Attorneys.

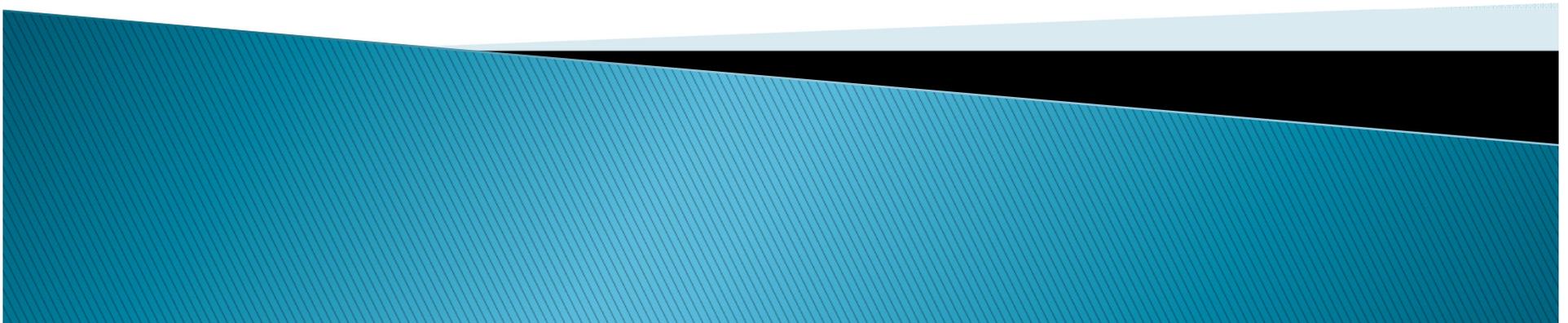
## Presenter – David Godfrey

- Is a senior attorney at the ABA Commission on Law and Aging.
- He is responsible for the ABA's role in the Administration on Aging funded National Legal Resource Center.
- Prior to joining the Commission he was responsible for elder law programming at Access to Justice Foundation in Kentucky.



# Advance Health Care and Financial Planning for Persons with Alzheimer's

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Jane Tilly, DrPH  
Office of Supportive and Caregiver Services, Administration for  
Community Living/Administration on Aging



# Goals for Today

- ▶ Understand the characteristics of a dementia capable legal professional
- ▶ Advise clients on the importance of advance planning and available planning tools for health care and finances
- ▶ Provide keys to reviewing existing advance planning
- ▶ Understand and mitigate risk of abuse, neglect and exploitation
- ▶ Draft accountability into advance planning documents



# Dementia Considerations:

- ▶ Dementia is a fatal illness involving a progressive decline in decision-making and personal independence.
- ▶ Decision-making discussions early in the disease process are crucial for ensuring that the wishes of the person with dementia are honored regarding financial matters and health and long-term care services.
- ▶ Difficulties with financial management and other matters involving “executive function” (the ability to manage one’s life) are often the first signs of dementia.
- ▶ Caregivers, when available, take on more and more decision-making for the person with dementia and need to be involved in discussions as needed/appropriate.



# Dementia Capable Legal Professionals

- ▶ Have skills needed to identify individuals with possible dementia, assess capacity and communicate with them and their families
- ▶ Empower and support persons with dementia and their families
- ▶ Know the legal issues and risks faced by persons with dementia
- ▶ Know the local services available to help people with dementia and their caregivers
- ▶ Provide linkages to other community-based services that are dementia capable



# Assessing Capacity

- ▶ See archive of first Webinar in this series at:
  - [http://www.aoa.gov/AoARoot/AoA\\_Programs/HPW/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx) (*under Resources and Useful Links*)
- ▶ Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers
  - [http://www.americanbar.org/groups/law\\_aging/resources/capacity\\_assessment.html](http://www.americanbar.org/groups/law_aging/resources/capacity_assessment.html)
- ▶ Assessing capacity is an ongoing process with clients with dementia
- ▶ The level of capacity varies with the task at hand

# Empower the Client and Family

- ▶ A diagnosis does not revoke capacity or the individuals' fundamental rights
- ▶ Rule 1.14 duty
  - ...the lawyer shall, “as far as reasonably possible, maintain a normal client–lawyer relationship....”
- ▶ Section (b) provides criteria for a lawyer taking protective action



# Goals of planning

- ▶ Honor the beliefs, values and wishes of the individual with dementia
- ▶ Empower the individual to participate to the extent possible
- ▶ Plan for declining capacity due to dementia
- ▶ Avoid abuse, fraud and undue influence in planning
- ▶ Protect individual from potential abuse, neglect and exploitation



# Why Financial Planning is Critically Important

- ▶ Dementia is progressive and a decline in capacity is expected
- ▶ Risks Without financial planning
  - Expenses will not be paid as needed (self neglect)
  - Resources may be squandered
  - Guardianship filing that may be avoidable
  - Abuse, neglect and exploitation
- ▶ Some research shows that financial management may be the first skill to decline



# Financial Planning

## Direct Deposit of Income

- ▶ Is it set up?
- ▶ Are there trustworthy alternate signers for the account?
- ▶ Is someone watching the account and bills to assure they are being paid?
- ▶ Do the alternate account signers know what they need to do?
- ▶ Have courtesy alerts on bills been set up where possible?



# Automatic Bill Paying

- ▶ Handle recurring costs
  - Utility bills
  - Loan payments
  - Insurance
  - Taxes
- ▶ Bill directly to bank account, debit or credit card (that can be auto paid from the bank account) when possible
- ▶ Understand that not all bills can be paid automatically
- ▶ Have someone monitor activity



# Joint Accounts

- ▶ Signers – More than one authorized signer is common
  - Benefit – any signer can access the account and pay bills
  - Risk – any signer can access the account and withdraw funds
  - Subject to judgments or bankruptcy of joint account holders
  - Risk – frequently creates a “right of survivorship” and may affect estate plans
- ▶ Trust, but verify – allow access to account information by third party (online statements are making this easier)



# Power of Attorney (POA)

- ▶ A Power of Attorney names an agent and grants them authority to act on behalf of the grantor
- ▶ State laws governing POA vary
- ▶ To be durable, POA must satisfy state law
- ▶ Authority is as granted in the document or by state law
- ▶ Duty of agent to carry out wishes of the grantor and not abuse the “fiduciary” duty
- ▶ Selection of agent and back-up is crucial



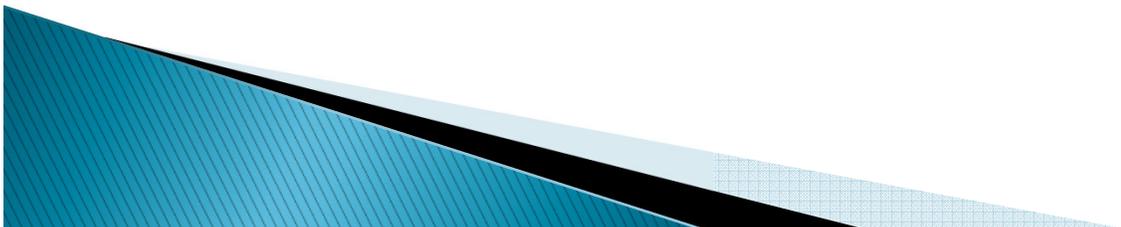
# Reviewing Power of Attorney

- ▶ Review existing POA
- ▶ Determine what powers it grants and to whom
- ▶ Review the agent(s) to ensure they are:
  - Aware
  - Available
  - Trustworthy
- ▶ Provisions for back-up agent
- ▶ Determine what powers are missing and whether gaps can be covered by other tools
- ▶ Determine if no POA or changes are desirable
- ▶ Assess capacity of client and proceed accordingly



# Drafting Protections in POAs

- ▶ Agent Accountability
  - Require agent(s) to keep records
  - Provide accounting to third party
  - Grant access to financial records to third party
- ▶ Maintain and provide an inventory of assets
  - Provide inventory to third parties
  - Allow for verification of inventory by third party
- ▶ Provide back-up agents
- ▶ Make provisions for termination of authority for abuse of authority or failure to act
- ▶ Require 2<sup>nd</sup> approval on large transactions



# Types of POA Abuse

- ▶ Transactions exceeding intended authority
- ▶ Transactions conducted for self-dealing
- ▶ Transactions contravening principal's expectations
- ▶ Use after death of principal
- ▶ Problems with creation of the POA
  - Incapacity at signing
  - Forgery
  - Fraud-Misrepresentation
  - Undue influence



# Impact of POA Abuse

- ▶ Loss of money & property
- ▶ Guardianship may become necessary
- ▶ Inability to obtain Medicaid benefits
- ▶ Need for Medicaid & other public benefits
- ▶ Physical & emotional impact



# Representative Payee (also consider VA Fiduciary)



- ▶ Social Security
- ▶ Due-process protections
- ▶ Application, allegation of incapacity
- ▶ Verification by SSA (form to/from Doctor)
- ▶ Notice to beneficiary – object to need or proposed payee
- ▶ Appointment by SSA
- ▶ Termination by beneficiary with documentation of capacity

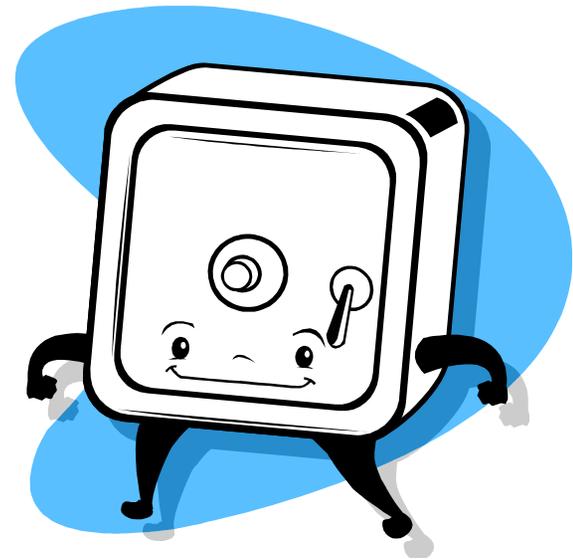


# Representative Payee

- ▶ Annual Reporting, paper or online
- ▶ Guidelines on spending
- ▶ Separate account
- ▶ Titling of account

## Concerns:

- Nominal due process
- Minimal accounting to SSA only
- SSA does not share
- SSA benefits only



# Reviewing Rep-payee

- ▶ Does it exist?
- ▶ Who receives the income
- ▶ Are they spending on needs of the individual with dementia
- ▶ SSA does not recognize guardianship (or POA)
  - Guardians must become representative payees
- ▶ Representative payee can be used as a tool
  - When there is no financial planning
  - or
  - When income is being squandered
- ▶ Report exploitation by Payees to APS and Social Security – request change of payee



# Trusts (Inter vivos/living trusts)

- ▶ A trust is an entity, that can own, buy, sell and manage assets
- ▶ A trust can provide for successor trustees and set conditions for successor trustees taking over
- ▶ Trustee is not likely to be challenged in legal authority; very clear law on what trustee can and can't do
- ▶ Trusts are very helpful with complex assets
  - Rental property
  - Complex investments
- ▶ Harder to challenge than a POA
- ▶ Trustees need legal advice before acting



# Reviewing Existing Trusts

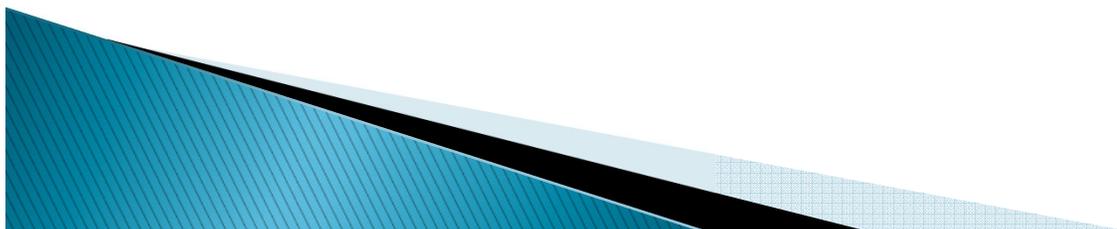
- ▶ Is the trust needed?
- ▶ What are the terms?
- ▶ Who is the successor and what trigger is available? (successor trustee needs legal advice before acting.)
- ▶ Is the successor aware, available and reliable?
- ▶ Are assets in the name of the trust?
- ▶ Are changes desirable? If so,
  - Assess capacity of the grantor with dementia to create or amend trust
- ▶ Complex planning requires higher levels of capacity



# Money Management Services



- ▶ Services include receiving and accounting for income, paying expenses, & providing personal financial management services
- ▶ Authority is as granted by contract
- ▶ Accountability is as required by contract
  - Require accounting and records to third party
- ▶ Regulation, if at all, is by state law
- ▶ Services should be bonded and insured
- ▶ Money managers are not decision-makers



# Guardianship is the Last Resort for a Person with Dementia

1

An adult lacks capacity to make informed decisions;

and

2

Alternatives have been exhausted and either don't work or are being abused;

and

3

Decisions must be made to protect the person or property.



# Advance Health Care Planning



# Dementia Considerations:

- ▶ Dementia is a fatal illness.
- ▶ Decision-making discussions early in the disease process are crucial for ensuring that the wishes of the person with dementia are honored regarding the types of health and long term care they want to have.
- ▶ Caregivers, when available, take on more and more decision-making for the person with dementia when he or she is dying and need to be involved in discussions about care as needed/appropriate.
- ▶ Dying due to dementia in the end stages involves dependence in all daily activities, including an inability to eat, swallow, move about, or use the toilet.



# Landscape of Health Decisions Law Today

1. Default Surrogate Laws
2. Health Care Advance Directives
  - Health Care DPAs
  - Living Wills
  - Special Mental Health Advance Directives
3. Out-of-Hospital DNR Laws
4. Organ Donation Laws
5. Guardianship Laws
6. Physician Orders for Life-Sustaining Treatment (POLST/MOLST/POST)
7. Physician Aid in Dying

# 30+ Years of Research on Advance Directive Documents...

- ▶ Most people don't do them.
- ▶ Forms hard to understand.
- ▶ Standard form not useful guidance.
- ▶ People change.
- ▶ Agent/proxy slightly better than clueless.
- ▶ Health care providers clueless about the directive.
- ▶ Even if providers know directive exists, it's lost in space.
- ▶ Even if in the record, it's still lost in space.

# Communications Approach

## “Advance Care Planning”

- ▶ Less focus on legal formalities
- ▶ Legal focus primarily on naming a proxy decision-maker
- ▶ Discussion focused (with proxy, family, health care providers)
- ▶ More broadly focused on values, spiritual questions, family matters of person with dementia
- ▶ Less treatment focused
- ▶ Developmental and iterative in nature

# Poster Child of ACP: The La Crosse Model – “Respecting Choices”

- ▶ Study examining 2007–08 data, that under Gundersen Health Systems program:
  - 99.4% of patients had an advance directive in the medical record at the time of death,
  - In 99.5% of cases, medical treatment was in accord with patient wishes.
  - *J Am Geriatr Soc.* 2010 Jul;58(7):1249–55
- ▶ Individuals are assisted in advance planning by trained “facilitators” through three stages of health: (1) healthy stage, (2) progressive advanced illness, (3) nearing end of life.

# Self-Help Workbook Examples...

ABA Resource List: <http://bit.ly/QJKw1N>

- ▶ ***Consumer's Tool Kit for Health Care Advance Planning***  
ABA Commission on Law and Aging
- ▶ ***Finding Your Way: A Guide for End-of-Life Medical Decisions***, by the Center for Healthcare Decisions  
Sacramento Healthcare Decisions
- ▶ ***Caring Conversations***, The Center for Practical Bioethics
- ▶ ***Good to Go Toolkit and Resource Guide***, Compassion and Choices
- ▶ ***Thinking Ahead – My Way, My Choice, My Life at the End***, California Dept. of Developmental Services
- ▶ **MyDirectives.com** - Free, interactive web-based program and registry.

# Tools for Proxies

## **Making Medical Decisions for Someone Else: A How-To Guide**



[www.americanbar.org/groups/law\\_aging/resources/health\\_care\\_decision\\_making/Proxyguide.html](http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/Proxyguide.html)

**The American Bar Association  
Commission on Law and Aging**

# Key Questions for Major Treatment Decisions for Someone with Dementia

1. Will treatment make a difference?
2. Do burdens of treatment outweigh benefits?
3. Is there hope for recovery?
  - If so, what will life be like afterward?
4. What does the patient value?
  - What is the goal of care?

Adapted from Pat Bomba, [CompassionAndSupport.org](http://CompassionAndSupport.org)

# The Big Gap in the ACP Process



How to bridge  
the gap ?



**Individual's  
Wishes/  
Goals of  
Care**

**Actual  
Plan of  
Care**

**Solution?** Instead of standardizing patients' directives, standardize what providers have to do to ascertain and implement patients' wishes?

- ▶ Already have some experience with this:  
Out-of-Hospital DNR Orders, but...
  - Limited to CPR
  - Not required to follow patients across care settings
  - No obligation to offer an OOH-DNR order to any patient



# The POLST Paradigm

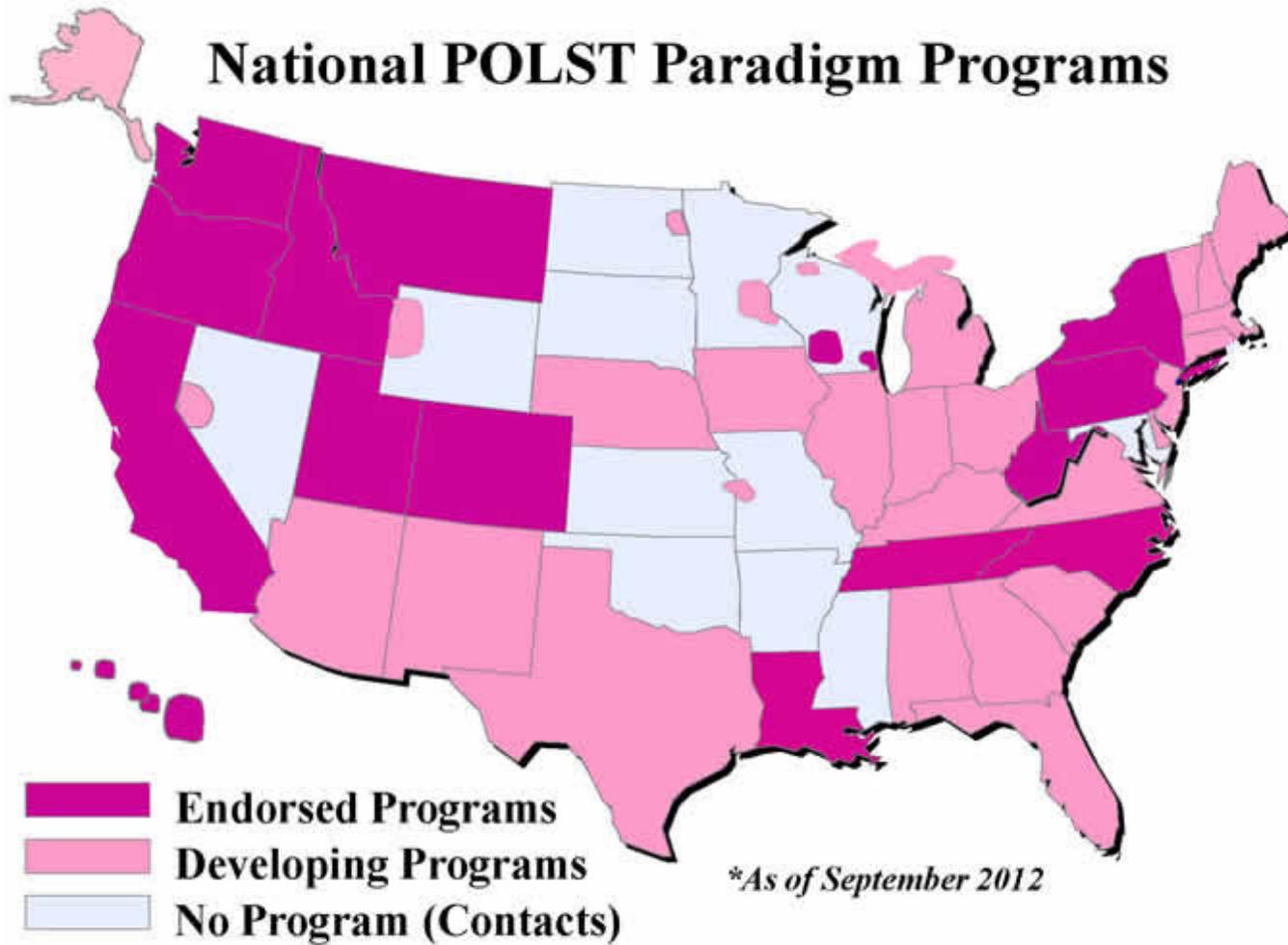
- ▶ Additional, systemic step to bridge gap between patient's goals/preferences and implementation of an actual plan of care.
- ▶ Four actions required:
  1. Discussion: Find out patient's goals/wishes re: CPR, care goals (comfort vs. treatment), N&H, etc.
  2. Translate into doctors orders on visually distinct medical file cover sheet.
  3. Ensure order set follows patient across care settings.
  4. Review

**POLST is not a form, it's a Process.**



# www.POLST.org

## National POLST Paradigm Programs



**FORM SHALL ACCOMPANY PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED**

**Physician Orders  
for Scope of Treatment (POST)**

This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed indicates full treatment for that section. When need occurs, first follow these orders, then contact physician.

Last Name

First Name/Middle Initial

Date of Birth

**Section A**  
*Check One Box Only*

**CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.**  
 **Resuscitate (CPR)**                       **Do Not Attempt Resuscitation (DNR/no CPR)**  
 When not in cardiopulmonary arrest, follow orders in B, C, and D.

**Section B**  
*Check One Box Only*

**MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.**  
 **Comfort Measures** Treat with dignity and respect. Keep clean, warm, and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location.**  
 **Limited Additional Interventions** Includes care described above. Use medical treatment, IV fluids and cardiac monitoring as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. **Transfer to hospital if indicated. Avoid intensive care.**  
 **Full Treatment** Includes care above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer to hospital if indicated. Include intensive care.**  
*Other Instructions:* \_\_\_\_\_

**Section C**  
*Check One Box Only*

**ANTIBIOTICS**  
 **No Antibiotics**  
 **Antibiotics**  
*Other Instructions:* \_\_\_\_\_

**Section D**  
*Check One Box Only*

**Medically Administered Fluids and Nutrition: Oral fluids and nutrition must be offered if medically feasible.**  
 **No IV fluids (provide other measures to assure comfort)**                       **No feeding tube**  
 **IV fluids for a defined trial period**     **Feeding tube for a defined trial period**

# Compare:

## POLST vs. Advance Directives



	<b>POLST Paradigm</b>	<b>Advance Directives</b>
<b>Population:</b>	<b>Advanced progressive illness</b>	<b>All adults</b>
<b>Timeframe:</b>	<b>Current care/ current condition</b>	<b>Future care/ future conditions</b>
<b>Where completed:</b>	<b>In medical setting</b>	<b>In any setting</b>
<b>Resulting product:</b>	<b>Medical orders</b>	<b>Advance directive</b>
<b>Surrogate role:</b>	<b>Can consent if patient lacks capacity</b>	<b>Cannot do</b>
<b>Portability:</b>	<b>Provider responsibility</b>	<b>Patient/family responsibility</b>
<b>Periodic review:</b>	<b>Provider responsibility</b>	<b>Patient/family responsibility</b>

# Challenges for Dementia Capable Professionals

1. Involving person with dementia in decision-making to the extent possible.
2. Involving the caregiver of the person with dementia as appropriate.
3. Ensuring the quality of the conversation among all parties underlying ACP and POLST.
4. Training health care providers (Facilitators).
5. Educating health care agents/ proxies/ guardians.
6. Recognizing the role of default surrogates for those who have no appointed Proxy.
7. Ensuring protections for those with dementia.
8. Decision-making for those who have no appointed proxy (the “unbefriended”).
9. Knowing when judicial involvement is necessary.

# Default Surrogate Laws (Family Consent)

- ▶ Range/Priority of Surrogates
- ▶ Scope of Decision Making Authority
- ▶ Triggers/Pre-conditions
- ▶ How Disagreements are Handled
- ▶ *Close Friend and Unbefriended Patient*
- ▶ ABA Summary chart: <http://bit.ly/TjwOON>



# Reviewing Advance Health Care Planning with Dementia

- ▶ Does individual have current capacity to do or revise an advance directive?
- ▶ Are there written directives?
  - Don't Assume. Read them.
  - Do they reflect the beliefs and values of the individual?
  - Who is named?
  - Does the agent know and understand
  - Is "family" in agreement?
  - Are health care providers aware and un-opposed?



# Questions?



# Thank You

- ▶ Thank you for taking the time to join us today
- ▶ Register for the next webinars in our series:
  - December 12: *For Aging Professionals: Critical Legal Issues in Alzheimer's*  
<https://www1.gotomeeting.com/register/511689240>
  - January 24: Elder abuse, neglect and exploitation and clients with Alzheimer's  
<https://www1.gotomeeting.com/register/954571312>
- ▶ Recordings and materials for this series will be posted at:
  - [http://www.aoa.gov/AoARoot/AoA\\_Programs/HPW/Alz\\_Grants/index.aspx](http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Alz_Grants/index.aspx) (*under Resources and Useful Links*)

# Contact Information

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