ADVANCE CARE PLANNING FOR DEMENTIA AND SERIOUS MENTAL ILLNESS
A PRIMER FOR PROVIDERS

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This presentation is for general education purposes and is not intended to provide legal advice or to create an attorney-client relationship with any participants. Participants are advised and encouraged to contact legal counsel to address any specific legal questions or concerns they may have.
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Session Overview

OVERVIEW OF ADVANCE DIRECTIVES

STANDARDS AND EVIDENCE SUPPORTING USE OF ADVANCE DIRECTIVES

VIRGINIA LAWS AND REGULATIONS

ALTERNATIVES IN THE ABSENCE OF AN ADVANCE DIRECTIVE
- STATUTORY AGENTS
- JUDICIAL AUTHORIZATION FOR TREATMENT
- GUARDIANSHIP
- OTHER TOOLS TO KEEP IN MIND
### Abbreviations used in this material

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Detail</th>
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<tr>
<td>AD</td>
<td>Advance Directive</td>
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<tr>
<td>DBHDS</td>
<td>Virginia Department of Behavioral Health and Developmental Services</td>
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<tr>
<td>HCDA</td>
<td>Health Care Decisions Act</td>
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<tr>
<td>POST</td>
<td>Physician Order for Scope of Treatment</td>
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<td>SMI</td>
<td>Serious mental illness</td>
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<td><strong>Advance Directive</strong></td>
<td>a witnessed written document, voluntarily executed by the declarant ... or a witnessed oral statement, made by the declarant subsequent to the time he is diagnosed as suffering from a terminal condition... &quot;to address any or all forms of health care in the event the declarant is later determined to be incapable of making an informed decision&quot;.</td>
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<td><strong>Agent</strong></td>
<td>an adult appointed by the declarant under an advance directive,..., to make health care decisions for him.</td>
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<td><strong>Durable Do Not Resuscitate Order</strong></td>
<td>a written physician's order...to withhold cardiopulmonary resuscitation from a particular patient in the event of cardiac or respiratory arrest. ...[A] Durable Do Not Resuscitate Order is not and shall not be construed as an advance directive.</td>
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<td><strong>Guardian</strong></td>
<td>a person appointed by the court who is responsible for the personal affairs of an incapacitated person, including responsibility for making decisions regarding the person's support, care, health, safety, habilitation, education, therapeutic treatment, and...residence.</td>
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<tr>
<td><strong>Incapable of making an informed (health care) decision</strong></td>
<td>the inability of an adult patient, because of mental illness, intellectual disability, or any other mental or physical disorder that precludes communication or impairs judgment, to make an informed decision about providing, continuing, withholding or withdrawing a specific health care treatment or course of treatment because he is unable to understand the nature, extent or probable consequences of the proposed health care decision, or to make a rational evaluation of the risks and benefits of alternatives to that decision.</td>
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<tr>
<td><strong>Physician Order for Scope of Treatment (POST)</strong></td>
<td>a physician's order communicating treatment preferences of a patient who is nearing the end of life and instructing health care provider to follow such preferences.</td>
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There is no one form that must be used in Virginia, so ADs can be tailored to each person’s needs.

By way of example we have provided two forms that demonstrate the range of detail that can be included in an AD. (both forms are also available at the event website – www.worldeventsforum.net/mhati/advance-care-planning-for-dementia-and-serious-mental-illness/)

**The short AD form**

- provides sections for:
  - appointing an agent,
  - providing end-of-life care instructions,
  - a brief “other instructions concerning health care” section, and
  - anatomical gift instructions.

**The long AD form**

- also includes sections for
  - appointing an agent,
  - health care instructions, and anatomical gift instructions;
- however, it provides much more space for greater details, and prompts individuals about many specifics that can be included in an AD.
The goal of advance care planning:

We control who will make decisions for us and what those decisions will be.

It could happen to any of us!

We need health care (including mental health care)… But, because of illness, age, accident, we are not able to make informed decisions about our care.

What happens then?

Someone must make decisions for us when we can’t make them for ourselves.
OVERVIEW OF ADVANCE DIRECTIVES (AD)
WHAT IS AN ADVANCE DIRECTIVE?

A legal document to direct future health care if a person becomes incapable of making an informed decision about health care.
POLL

Do you have an Advance Directive?

- Yes
- No
ADVANCE CARE PLANNING: AN ASSORTMENT OF TOOLS

- Health Care Power of Attorney
- Living Will
- Physician Order for Scope of Treatment
- Crisis Plan
- Do Not Resuscitate
ADVANCE DIRECTIVES IN VIRGINIA

- Living Will
- Health Care Power of Attorney
- Advance Directive

- End-of-Life Care
- Mental Health Care
- General Health Care
JILL’S STORY

Jill is a widow who just retired, and she is re-writing her will and getting her affairs in order.

As part of that process, she wants to plan for her end-of-life health care.

Jill meets with her four adult children to show them what she has done. She shares with them that she does not want life-prolonging treatments at the end of her life. Two of Jill’s children agree with what Jill wants regarding end-of-life care, but the other two strongly disagree. While Jill tells them what she wants, she never executes an advance directive.

A few years later, Jill suffers sudden cardiac arrest and is rushed to the hospital. Her four children arrive and hear the attending doctor tell them that Jill is unconscious and is alive only because she is connected to machines. The prognosis is that she will never regain consciousness.

What happens now? How could it have been different?
POLL

How will decisions be made about Jill’s end-of-life care?

- The oldest adult child will have the authority to make decisions.
- The two who agreed with Jill will make decisions because they agreed with Jill.
- The dissenting adult children will make decisions because they support treatment instead of termination of treatment.
- No substitute decisions will be made and Jill will remain on life support by default.
Ted made a general medical Advance Directive and named his wife as his agent.

Ted’s Advance Directive does not specifically give his wife the power to make decisions about his mental health care.

Ted develops dementia and loses the ability to make informed decisions about his treatment.

He later becomes confused, agitated and aggressive toward others, and his psychiatrist recommends a short psychiatric hospitalization to adjust his medications and stabilize his condition.
POLL

Can Ted’s wife, as his agent, consent to Ted’s admission to the psychiatric hospital?

- Yes
- No
- Yes, if an independent mental health evaluator confirms that admission is appropriate
STANDARDS AND EVIDENCE SUPPORTING USE OF ADVANCE DIRECTIVES
Patient Self-Determination Act
42 CFR § 489.102

Maintain written policies and follow certain procedures;
Document whether patient has an AD;
Comply with all State laws regards ADs;
Not condition health care on whether or not patient has an AD;
Inform patients how complaints re ADs may be filed;
Provide staff and community education on ADs.
The Joint Commission

Requires that organizations have an AD protocol in place.

Just providing information about ADs is not enough.

Facilities must follow ADs as closely as possible.

Access to care cannot be predicated upon whether a person has an AD.
STANDARDS SUPPORTING USE OF ADs

DBHDS’s *Creating Opportunities Plan*

• Advance planning should be widely and routinely used

• ADs should be a routine practice in behavioral health care

• ADs are a tool for preventative care and crisis management

**DBHDS regulations**

• An agent named in an AD should be sought out before appointing an authorized representative

(12VAC35-115-146)
Are we interested in ADs in Virginia?

Stakeholder survey in 2010 in anticipation of legislative changes

Knowledge of and attitudes about ADs from:

- Mental health service users,
- Family members,
- Administrators of hospitals,
- CSBs, and
- Advocates.

Everyone had favorable views of ADs with instructions for mental health care

(Wilder, Swanson et al., 2013)
ARE WE INTERESTED IN ADs IN VIRGINIA?

93%: ADs will give people with SMI more control over their lives
93%: ADs will lead to better understanding of treatment desires in crisis
94%: ADs will lead to better understanding of treatment desires in outpatient settings
91%: ADs will lead to improved quality of life for individuals
89%: ADs will improve relationships between providers & consumers
87%: ADs will increase providers listening to consumers
## BENEFITS FOR CONSUMERS

| Increased sense of control → increased sense of well-being | Improved working alliance with providers | Improved feeling of having treatment needs met | Increased likelihood of receiving medication requested → increased likelihood of staying on medication, reducing symptoms | Half as likely to experience coercive interventions |

(Srebnik & LaFond, 1999; Swanson et al., 2006, 2008)
EVIDENCE OF THE CLINICAL UTILITY OF ADs

All ADs were rated as including useful instructions

- In agreement with clinical practice standards
- Everyone authorized hospitalization or feasible alternative
- No one used an AD to reject all treatment
- When reasons for medication refusal given, doctors more likely to honor that choice

(Srebnik et al., 2005; Swanson et al., 2006; Wilder et al., 2007)
A PERVASIVE PROBLEM FOR ADs

Survey in five cities indicated a demand for ADs ranged between 66-77% while the actual usage of ADs was only between 4-13%
A PILLAR OF AD IMPLEMENTATION

Facilitation overcomes barriers to AD completion

People who completed an AD on their own…

People who completed an AD with help from a facilitator…
VIRGINIA HEALTH CARE DECISIONS ACT (HCDA)

VA. CODE §§ 54.1-2981 THROUGH 2993

(HTTP://LAW.LIS.VIRGINIA.GOV/VACODEFULL/TITLE54.1/CHAPTER29/ARTICLE8/)
VIRGINIA’S REQUIREMENTS FOR LEGAL VALIDITY OF EVERY ADVANCE DIRECTIVE

An AD needs **only**:
- Signature of the person making it
- Signatures of two adult witnesses to signature

An AD does *not* need:
- To be on a particular form
- To be notarized
- To be written by an attorney

Photocopies of the original are valid for use by health care providers
For the Advance Directive to be valid, the person making the AD must have capacity.

Under Virginia law, every adult is presumed to have capacity.

A person for whom a guardian has been appointed by a court cannot make an AD about those matters that the guardian controls.

- If the person made an AD before the guardian was appointed, the AD remains in effect (unless the court rules otherwise), and the guardian must follow it.

Any person can challenge the validity of another person’s AD in the local circuit court. (Va. Code § 54.1-2985.1)
WHEN IS AN AD ACTIVATED & DE-ACTIVATED?

A physician conducts an in-person evaluation and finds incapable of making informed decisions about health care.

A second physician or licensed clinical psychologist conducts an in-person evaluation and also finds incapable of making informed decisions about health care.

As soon as any doctor examines person and finds he is able to make informed decisions again.
APPOINTING A HEALTH CARE AGENT

An agent is a person the individual trusts who will advocate on her behalf and carry out her wishes.

Any competent adult can be an agent.

• But best to pick someone who knows values and preferences, and is willing.

An agent has the duty to follow the individual’s instructions and preferences.
SPECIAL POWERS TO ACT OVER OBJECTION – PROTEST PROVISION

An individual may give her agent the power to authorize treatment **over her objection**.*

Authority for her agent to make decisions and doctor to act, even if she objects, regarding:

- Admission to mental health care facilities, and/or
- Health care treatment choices

Objections to the withholding or withdrawal of life-prolonging procedures are always honored.

* Physician or licensed clinical psychologist certification required
GIVING INSTRUCTIONS

In an AD, an individual can give instructions about the health care she agrees to and the health care she refuses.

Effect on the agent

• The agent must act in line with the individual’s instructions

Effect on the doctor

• In most cases, providers must honor the instructions, but there are exceptions
  • Provider *not* required to provide treatment that the provider finds illegal, unethical, or medically inappropriate;
  • Provider must honor individual’s *refusals* of treatment, unless there is separate legal authority to treat despite refusal:
    • Emergency treatment to prevent serious harm or death;
    • Court ordered treatment
Q: WHAT CRISIS-RELEVANT INFORMATION CAN AN AD CONTAIN?

A: Quite a lot

- Transportation options
- Helpful (and preferred) medication interventions
- Medication refusals
- Effective interpersonal strategies
- Symptom descriptions
- Contact information for key providers
- Medical conditions
- Trauma-informed care considerations
- Emergency contacts
- Facility preferences
- Authorization for inpatient admission
**Emergency Response**
- Law enforcement ask about AD, emergency contact
- Suggested facility

**Emergency Department**
- ED staff use Crisis Card or ID to locate AD in record
- Contact agent

**ES Prescreen**
- Prescreener uses to inform UAI
- Contact agent
- Suggested facilities
- Potentially provide alternative to TDO

**Commitment Hearing**
- Inform hearing

**Inpatient Hospitalization**
- Inform treatment team about history, values, etc.
- Provide surrogate consent for treatment

**Return to Community**
- Update AD with case manager
- Use to bridge care from setting to setting
ALTERNATIVES IN THE ABSENCE OF AN ADVANCE DIRECTIVE

In other words, what if you don’t have an Advance Directive?
STATUTORY AGENTS
WHO MAKES DECISIONS FOR YOU

Va. Code § 54.1-2986 (in the Virginia Health Care Decisions Act [HCDA]) authorizes your doctor to seek consent for your treatment from the following (if “available, willing and capable”):

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<th>2nd</th>
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<tr>
<td>• Your Court-appointed guardian <em>(if you have one, and the guardian is authorized by the Court to make these healthcare decisions for you)</em>.</td>
<td></td>
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</tbody>
</table>
| • Your relatives, in the following order of priority:  
  • your spouse (except where a divorce action has been filed and the divorce is not final)  
  • your adult child or children*  
  • your parent or parents*  
  • your adult sibling or siblings*  
  • any other relatives* in the descending order of blood relationship |
| • An “interested adult”: a person familiar with you and your beliefs and values, who is approved by (1) the “patient care consulting committee” in the facility where you are being treated, or (2) by 2 physicians not involved in your care.  
  NOTE: This person does not have the authority to make decisions regarding the withholding or withdrawal of life-prolonging treatment |

*If they disagree, majority rules. (If they tie, it’s a mess.)
POTENTIAL PROBLEMS WITH STATUTORY AGENTS

• These people may not be the people you want.

• These agents will not have any instructions from you about what care you want and don’t want. (HCDA states they have a duty to act according to your “known values and preferences”, and, if those are unknown, in your “best interests”).

• You could have multiple agents (adult children; parents; siblings) who can’t agree on your treatment.

• These agents have no authority to consent to your admission into a psychiatric hospital when you’re in crisis, or to consent to your mental health care over your objection.
JUDICIAL AUTHORIZATION FOR TREATMENT
If no one is available with authority to make treatment decisions:

Virginia Code § 37.2-1100, et seq allows “any person” to file a petition for court authorization for treatment.

Court must find:

- person incapable of consenting to treatment;
- there is no one available with authority to consent;
- the proposed treatment is in the person’s “best interests”
Limits on Court order:

- Court cannot authorize treatment it finds is contrary to the person’s religious beliefs, values or stated preferences, “unless the treatment is necessary to prevent death or a serious irreversible condition”.

- Psychotropic medications can be authorized for max of 180 days, and cannot be authorized over person’s objection unless the person has been/is being involuntarily committed.
THE NEED FOR GUARDIANSHIP

When a person’s incapacity is long term, Court appointment of a guardian to make treatment and other personal decisions for the person is often necessary if there is no advance directive.

Why?

Issues with authority to admit person to a nursing home, etc.;

Issues with access to healthcare and health insurance records;

Conflicts among agents.

Difficulties with having each health care provider recognize, find and work with statutory agent;
THE STANDARD FOR APPOINTMENT OF A GUARDIAN

Virginia guardianship statutes (Va. Code Sections 64.2-2000-64.2-2029)

To appoint a guardian for a person, a local circuit court must find that the person is “incapacitated”:

1. “incapable of receiving and evaluating information effectively or responding to people, events, or environments to such an extent that

2. the person “lacks the capacity to…meet the essential requirements for his health, care, safety, or therapeutic needs without the assistance or protection of a guardian”

The fact that a person “displays poor judgment” is not enough to find the person incapacitated
THE PROCESS FOR APPOINTING A GUARDIAN

Requires a petition, appointment of guardian *ad litem* for the person, notice to the person and family, and hearing in Court.

An “evaluation report” by a doctor or mental health professional is normally required.

Burden of proof: clear and convincing evidence.
Court order appointing guardian:

- must state the nature and extent of incapacity
- must specify powers of guardian
- can provide for “limited” guardianship
- can provide for time-limitation or “indefinite duration”
- can authorize guardian to consent to admission of person to psychiatric facility (Section 37.2-805.1) but must make specific findings about person’s mental illness.
THE BURDENS OF GUARDIANSHIP

Time, expense and possible turmoil:

Requires petition and hearing before a Circuit Court, with notice to the person and family members, appointment of a “guardian ad litem” for the person.

Court must find by “clear and convincing evidence” that person is “incapacitated”, and must specify the extent and duration of the guardian’s authority.

Guardian’s authority can be plenary” (complete) or “limited” as specified by the Court.

(Note: in Virginia, a “conservator” is appointed by court to make financial decisions.)
(see Va. Code §§ 64.2-2000 et seq)
THE BURDENS OF GUARDIANSHIP

If the Court finds you’re incapacitated, you’re also declared legally incompetent, unless the Court order specifically states otherwise.

Once declared incompetent, you lose the right to:

- Marry and divorce
- Vote
- Enter contracts
- Make or revoke a Will or Advance Directive
- Drive
- Possess a firearm
- Buy, sell or rent property
Guardianship should be seen as a last resort because:

- It takes away basic rights.
- It is the most restrictive choice.
- There is stigma involved when a person is declared incapacitated and incompetent.
- It is expensive.
- It is often unnecessary.
- It is usually permanent. Even if you regain your capacity, the burden is on you to petition the Court to end the guardianship.
OTHER TOOLS TO KEEP IN MIND
Written authorization for disclosure of medical information:

- An agent has authority (including right of access to medical information) only when the Advance Directive is activated (person found incapable).

- The agent may be able to help before things get so bad that Advance Directive is activated.

→ Authorization allows proactive sharing of important information in order to help the person.
A person who cannot make treatment decisions almost certainly cannot make financial decisions.

If there is no one with the authority to arrange payment for treatment, needed care can be delayed or denied.

Conservatorship proceedings, like those for guardianship, take time and cost money.

→ A financial POA should be part of any conversation about future loss of capacity. Finding a trusted and trustworthy person is key.
The POST is now used by many physicians and hospitals in Virginia.

It developed in the context of care for chronic illnesses and end-of-life situations. (Patient wishes often overlooked.)

Greater compliance with a POST by providers, since it is a doctor’s order.

→ POST is patient-centered, based on an ongoing dialogue with the patient and the patient’s agents/family/etc. through the course of care.
WEBSITES ON ADVANCE DIRECTIVES IN VIRGINIA

www.virginiaadvancedirectives.org

www.vhha.com
(or www.vhha.com/healthcaredecisionmaking)

www.vsb.org/site/public/healthcare-decisions-day

www.virginiapost.org
LINKS TO RELEVANT VIRGINIA LAWS


Virginia Statutory Decision Makers (found within the HCDA) - http://law.lis.virginia.gov/vacode/title54.1/chapter29/section54.1-2986/

Virginia Guardianship and Conservatorship - http://law.lis.virginia.gov/vacode/title64.2/chapter20/


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