

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

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Contributors

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www.VirginiaAdvanceDirectives.org

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

Abbreviation	Detail
AD	Advance Directive
DBHDS	Virginia Department of Behavioral Health and Developmental Services
HCDA	Health Care Decisions Act
POST	Physician Order for Scope of Treatment
SMI	Serious mental illness

Advance Directive	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... "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".
Agent	an adult appointed by the declarant under an advance directive,..., to make health care decisions for him.
Durable Do Not Resuscitate Order	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.
Guardian	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.
Incapable of making an informed (health care) decision	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.
Physician Order for Scope of Treatment (POST)	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.

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.

WHY ADVANCE CARE PLANNING IS SO IMPORTANT

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.



The goal of advance care planning:

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

OVERVIEW OF ADVANCE DIRECTIVES (AD)

WHAT IS AN ADVANCE DIRECTIVE?



POLL

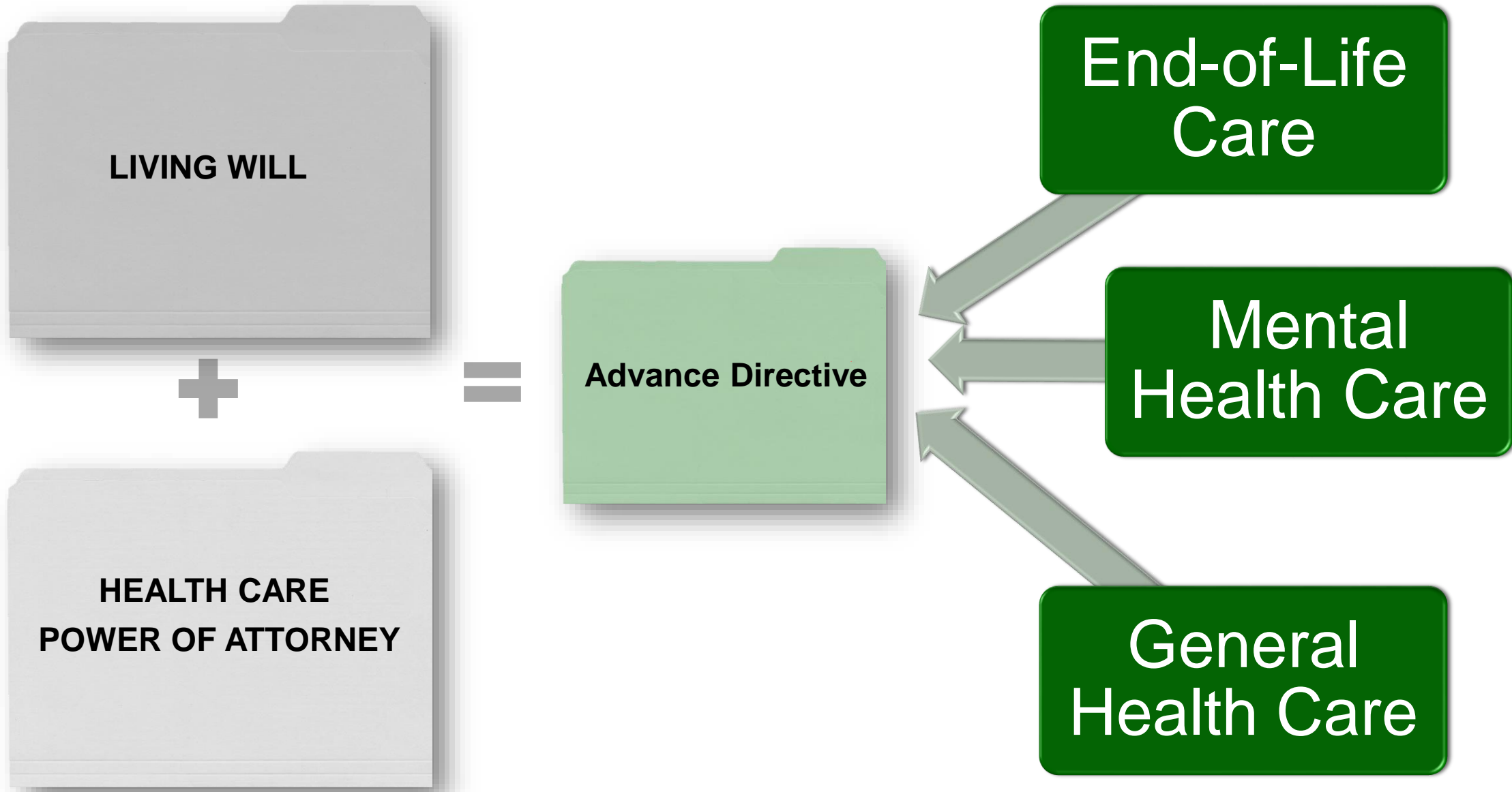
Do you have an Advance Directive?

- ☐ **Yes**
- ☐ **No**

ADVANCE CARE PLANNING: AN ASSORTMENT OF TOOLS



ADVANCE DIRECTIVES IN VIRGINIA



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.

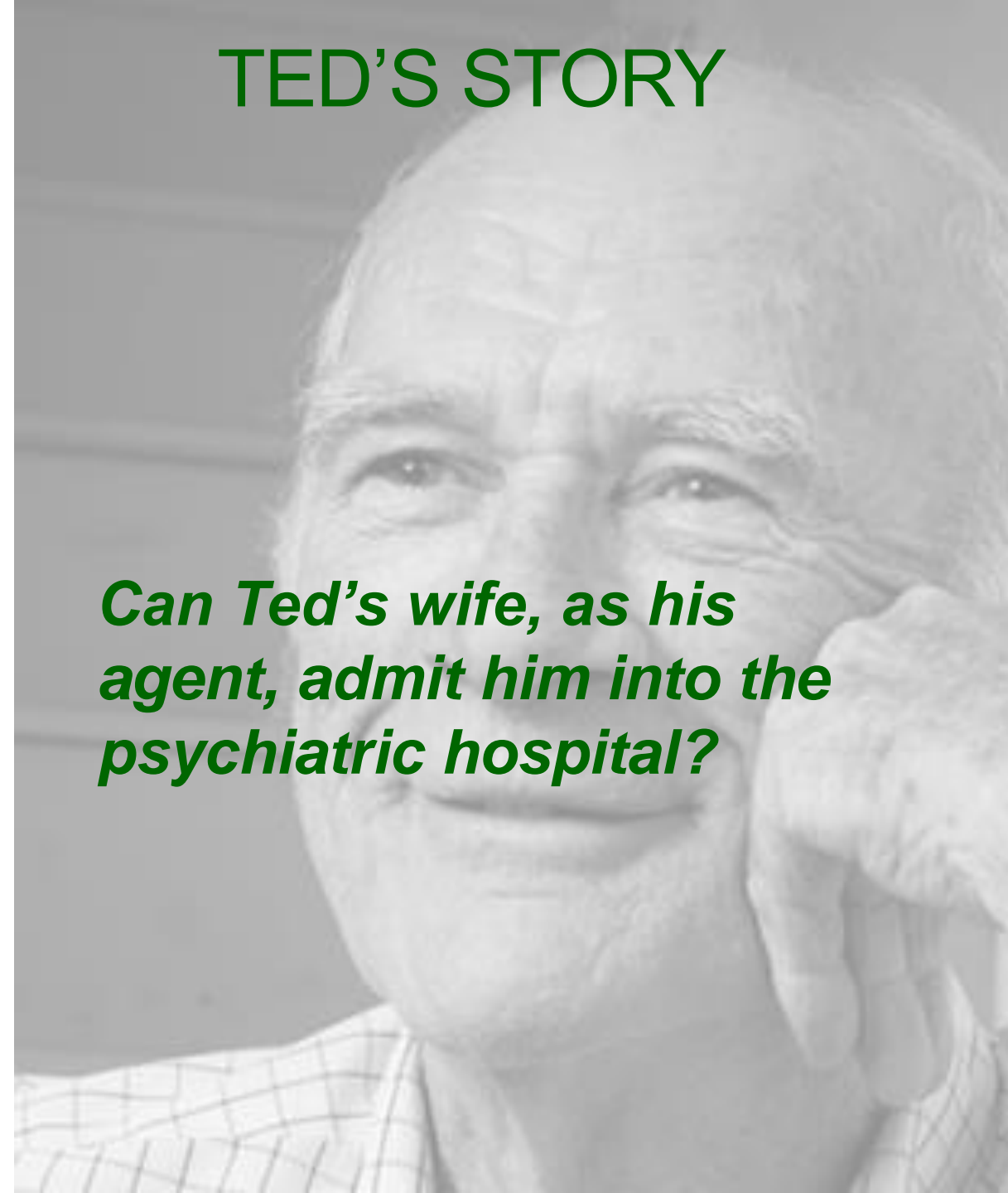
Ted's Advance Directive does not specifically give his wife the power to make decisions about his mental health care.

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.

TED'S STORY

Can Ted's wife, as his agent, admit him into the psychiatric hospital?



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

LAWS & STANDARDS SUPPORTING USE OF ADs

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.

STANDARDS SUPPORTING USE OF 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

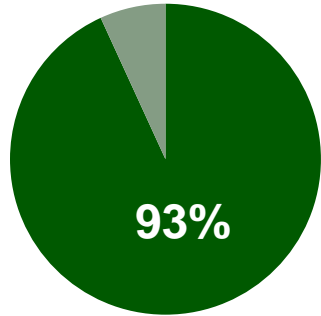
Knowledge
of and
attitudes
about ADs
from:

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

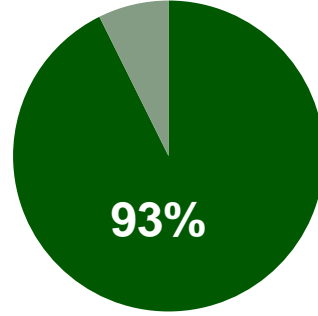
Everyone had favorable views of ADs with instructions for mental health care

(Wilder, Swanson et al., 2013)

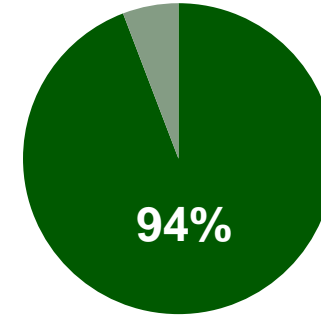
ARE WE INTERESTED IN ADs IN VIRGINIA?



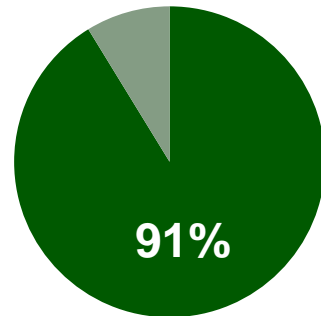
ADs will give people with SMI more control over their lives



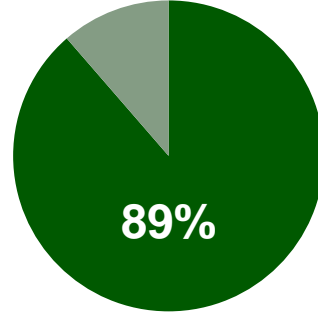
ADs will lead to better understanding of treatment desires in crisis



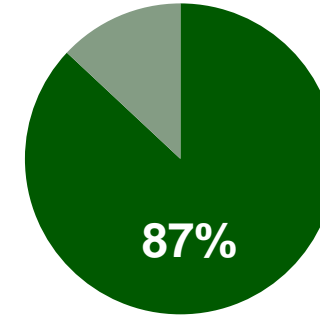
ADs will lead to better understanding of treatment desires in outpatient settings



ADs will lead to improved quality of life for individuals



ADs will improve relationships between providers & consumers



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

EVIDENCE OF THE CLINICAL UTILITY OF ADs

All ADs were rated as including useful instructions

In agreement with
clinical practice
standards

No one used an AD
to reject all
treatment

Everyone authorized
hospitalization or
feasible alternative

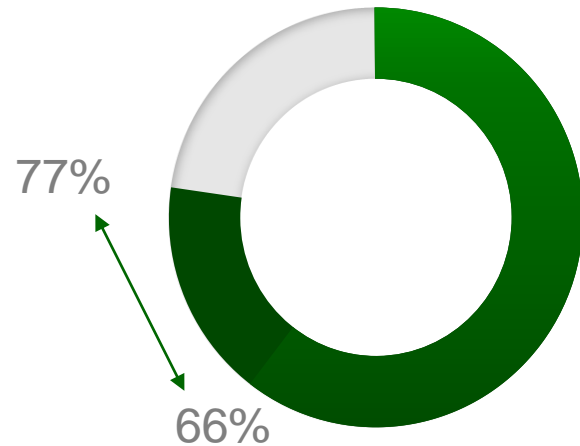
When reasons for
medication refusal
given, doctors more
likely to honor that
choice

(Srebnik et al., 2005; Swanson et al., 2006; Wilder et al., 2007)

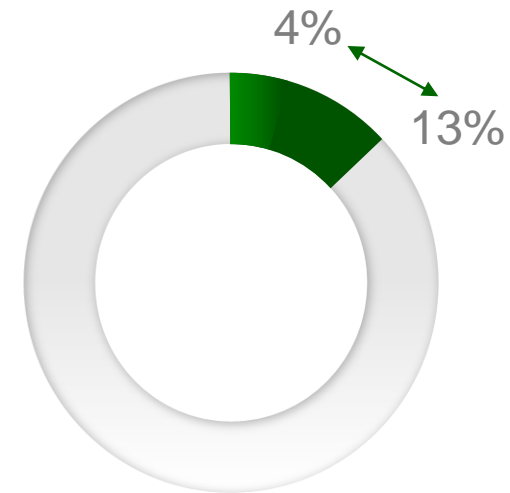
A PERVASIVE PROBLEM FOR ADs

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

Demand



Actual Usage



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...

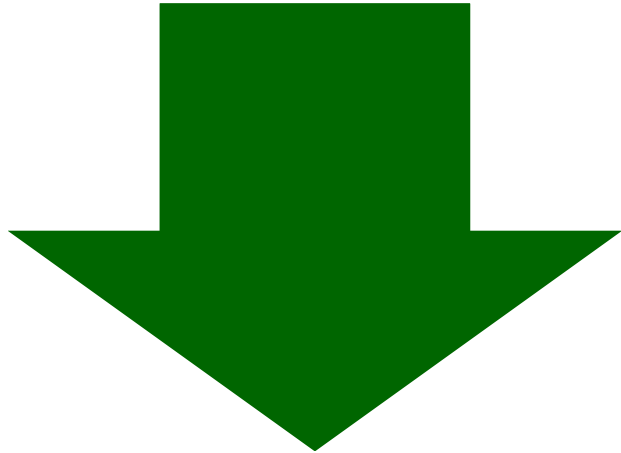
VIRGINIA **LAWS AND REGULATIONS**

VIRGINIA HEALTH CARE DECISIONS ACT (HCDA)

[VA. CODE §§ 54.1-2981 THROUGH 2993](#)

([HTTP://LAW.LIS.VIRGINIA.GOV/VACODEFULL/TITLE54.1/CHAPTER29/ARTICLE8/](http://law.lis.virginia.gov/vacodefull/title54.1/chapter29/article8/))

VIRGINIA'S REQUIREMENTS FOR LEGAL VALIDITY OF EVERY ADVANCE DIRECTIVE



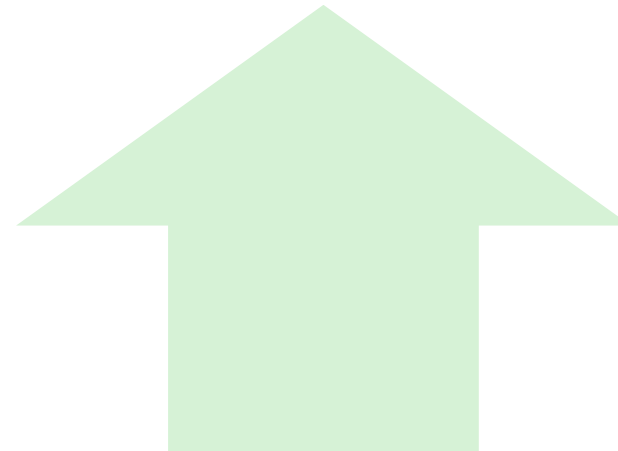
An AD needs only:

- 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

CAPACITY



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.

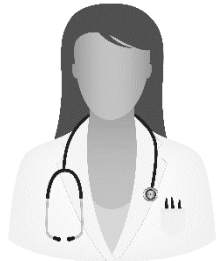
Any person can challenge the validity of another person's AD in the local circuit court. (Va. Code § 54.1-2985.1)

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

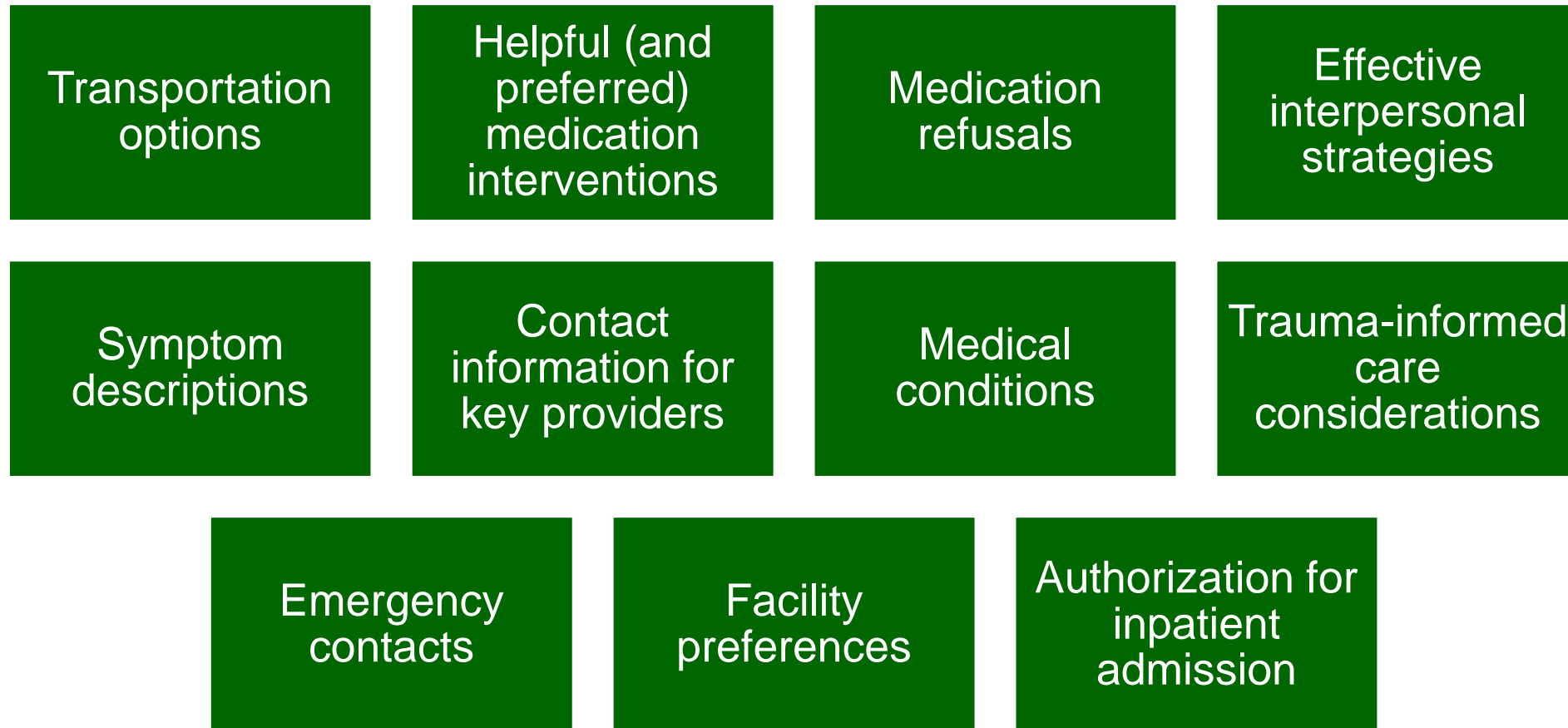
- The agent must act in line with the individual's instructions

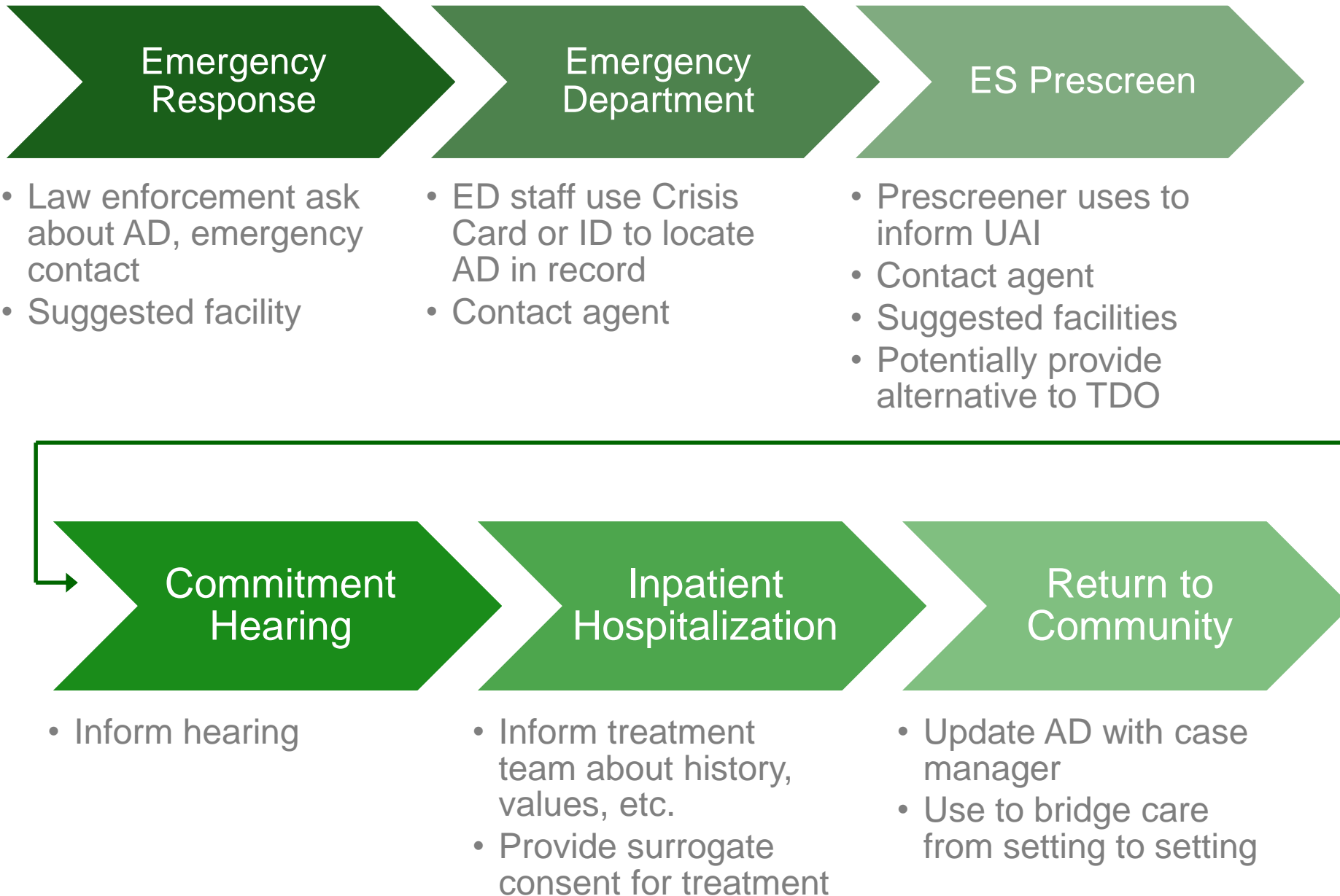
Effect on the doctor

- 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





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 [HCDCA]) authorizes your doctor to seek consent for your treatment from the following (if “available, willing and capable”):

1st

- Your Court-appointed guardian (*if you have one, and the guardian is authorized by the Court to make these healthcare decisions for you*).

2nd

- 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

3rd

- 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

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”

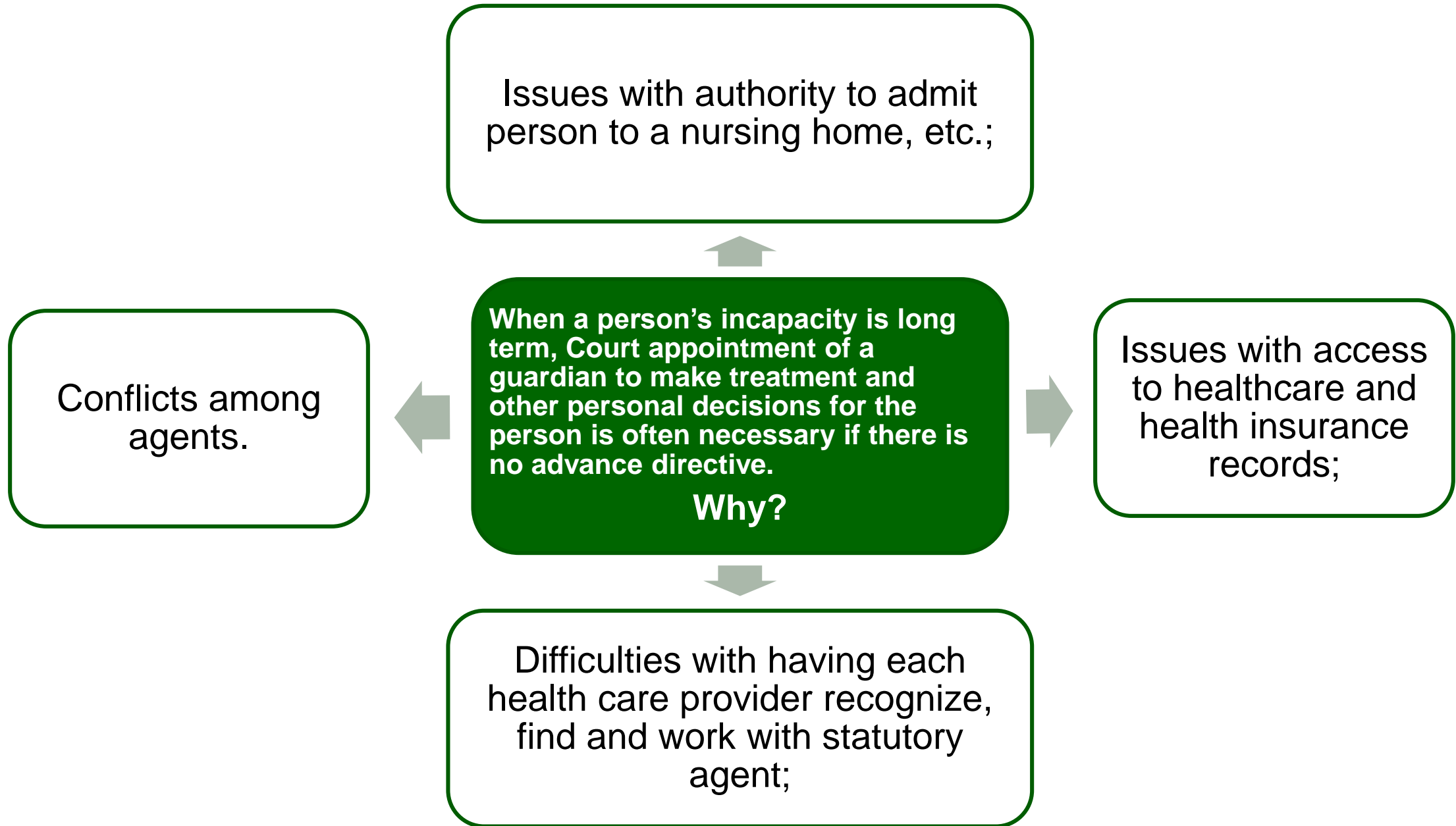
JUDICIAL AUTHORIZATION FOR TREATMENT

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.

GUARDIANSHIP

THE **NEED** FOR GUARDIANSHIP



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

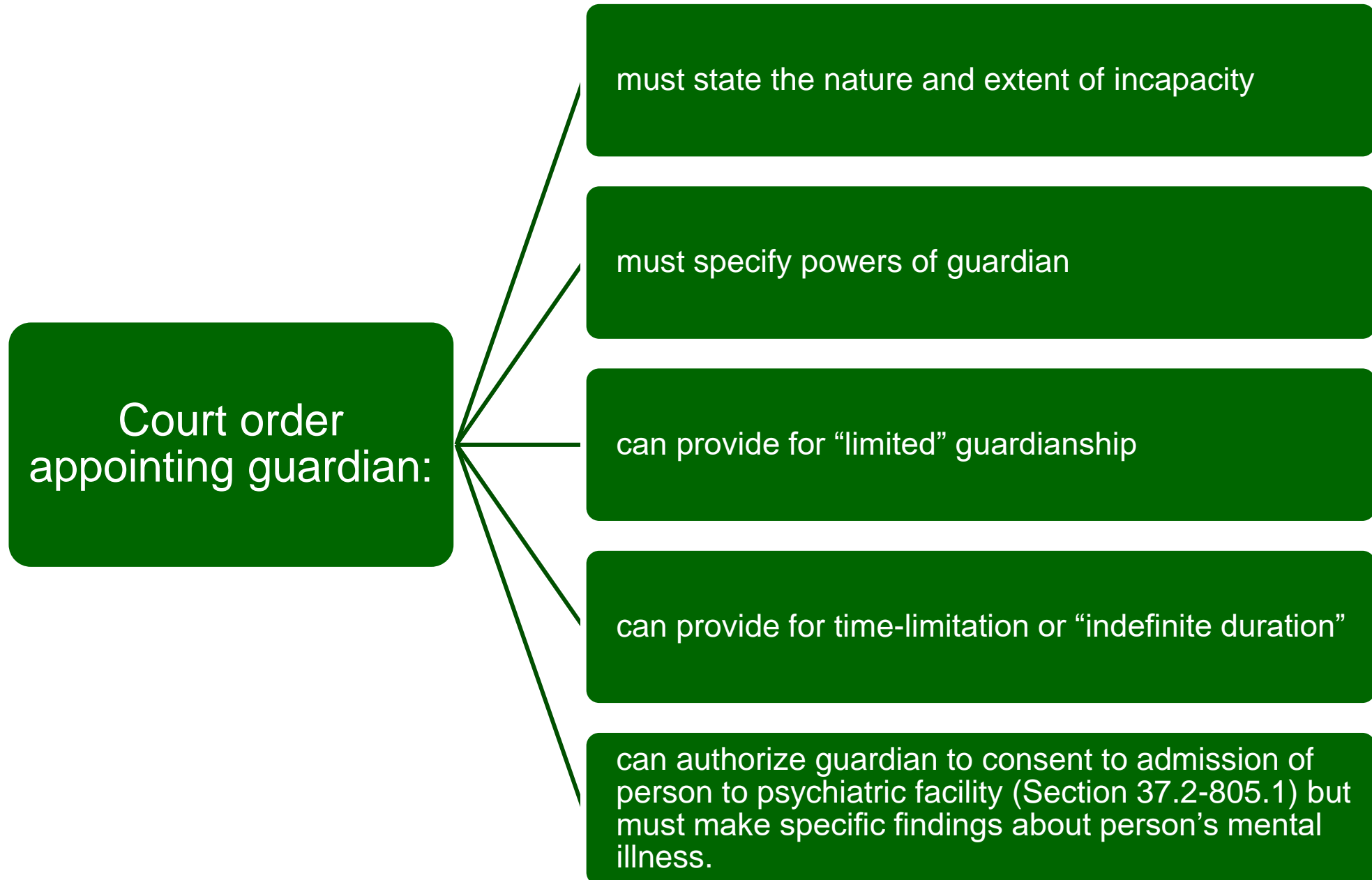
THE PROCESS FOR APPOINTING A GUARDIAN

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

INCAPACITY DETERMINATION BY THE COURT



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

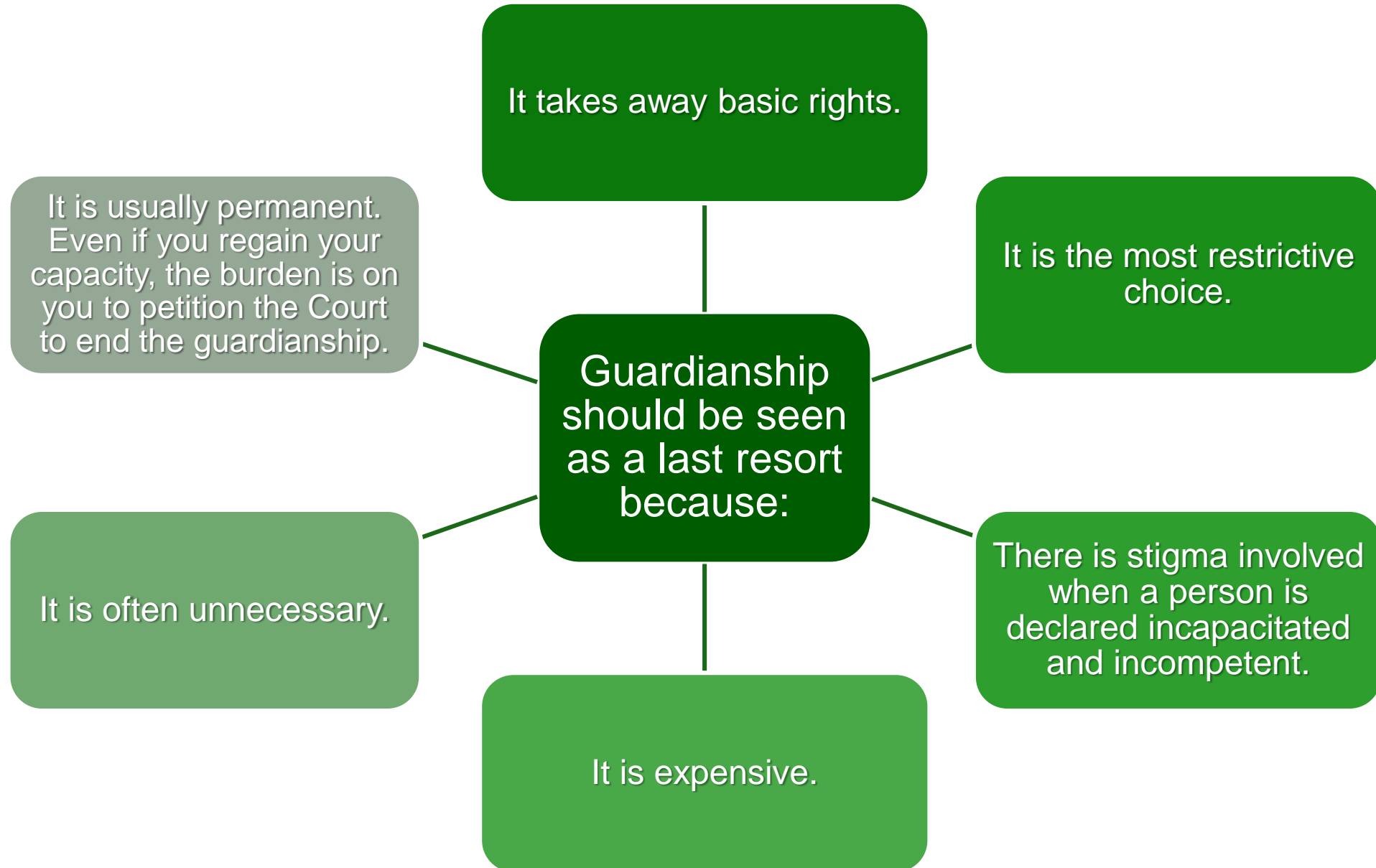
Make or revoke a
Will or
Advance Directive

Drive

Possess a firearm

Buy, sell or rent
property

THE BURDENS OF GUARDIANSHIP



OTHER **TOOLS** TO KEEP IN MIND

AUTHORIZATION FOR INFORMATION DISCLOSURE

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.

FINANCIAL POWER OF ATTORNEY

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.

PHYSICIAN'S ORDER FOR SCOPE OF TREATMENT (POST)

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 HCDA - <http://law.lis.virginia.gov/vacodefull/title54.1/chapter29/article8/>

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/>

Virginia Judicial Authorization of Treatment - <http://law.lis.virginia.gov/vacode/title37.2/chapter11/>

Virginia Financial Power of Attorney - <http://law.lis.virginia.gov/vacode/title64.2/chapter16/>

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