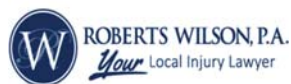


North Mississippi Rural Rural Legal Services 2018 Elder Law Conference



Friday, August 10, 2018

Oxford Conference Center
102 Ed Perry Boulevard
Oxford, MS 38655



INCORPORATING SUPPORTED DECISION-MAKING INTO ADVANCE CARE PLANNING

North Mississippi Rural Legal Services
2018 Elder Law Conference

**Morgan K.
Whitlatch**

*Legal Director,
Quality Trust*

*Project Director,
National
Resource
Center for
Supported
Decision-Making*

WHAT IF....

- Your **life decisions** were called into question by people close to you or by third parties, such as health care facilities, banks, and government agencies?
- Your **personal choices** were used as “evidence” that your decision-making capacity was not adequate or in decline?
- Concerns about your **health or safety** were determined to be **more important** than your personal history, beliefs, heritage and **preferences**?
- You were **not included** in discussions about where you live, what medical treatment you receive, and how your money is spent?

DINO AND LILLIAN - 2015



<https://www.nytimes.com/2015/01/26/nyregion/to-collect-debts-nursing-home-seizing-control-over-patients.html>

QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES

- Independent advocacy and monitoring
- Support people with disabilities in DC and beyond
- Dignity, respect. and autonomy
- Rights protection and decision-making supports
- Jenny Hatch Justice Project (2013 to present)
(www.JennyHatchJusticeProject.org)
- Lead National Resource Center for Supported Decision-Making (2014 to present)
- www.DCQualityTrust.org

NATIONAL RESOURCE CENTER ON SUPPORTED DECISION MAKING

- Funded in 2014 by the Administration on Community Living
- Focused on Research, Training and Information Sharing about Supported Decision Making (SDM)
- Addressing the issues of older people and people with disabilities
- Linking development efforts throughout the country
- www.SupportedDecisionMaking.org

GOALS FOR THE PROJECT

- Build **national consensus** on SDM
- **Change attitudes** regarding decision making and capacity
- Identify and develop **principles and tools for interdisciplinary support** across the lifespan for with people of varying abilities, challenges and life situations.
- **Increase collaboration** and information sharing for implementing of SDM principles.
- Bring together **training and technical assistance network** promoting practices consistent with SDM

SUPPORTED DECISION-MAKING: WHAT?

- A way for an adult with a disability (including changes in memory and cognition) to **make his or her own decisions**, by using friends, family members, professionals, and other people he or she trusts to:
 - **Help understand** the issues and choices;
 - **Ask questions**;
 - **Receive explanations** in language he or she understands; and
 - **Communicate** his or her to others.
- (See, e.g., Blanck & Martinis 2015; Dinerstein 2012; Salzman 2011)

GENERAL CONTINUUM OF DECISION-MAKING SUPPORTS

➔ **Supported Decision-Making**

- Advance Directive &/ or Power of Attorney
- Representative payee
- Other Substitute or Surrogate Health Care Decision-Maker, depending on state law
- Court-appointed Guardian
 - Temporary or Permanent
 - General/Plenary or Limited

These are examples of alternatives to guardianship.

There are many more – e.g., POLST forms, joint accounts, trusts, technology, etc.



- ▶ “Supported Decision-Making has the **potential to increase the self-determination** of older adults and people with disabilities, encouraging and empowering them to reap the benefits from increased life control, independence, employment and community integration.”
(Blank & Martinis 2015)

SELF-DETERMINATION

- ▶ **Self-Determination**
 - ▶ Life control — People’s ability and opportunity to be “causal agents . . . Actors in their lives instead of being acted upon”
(Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000, p. 440)
- ▶ **People with greater self-determination are:**
 - ▶ More **independent**
 - ▶ More **integrated** into their communities
 - ▶ **Healthier**
 - ▶ Better able to **recognize and resist abuse**
(Powers *et al.*, 2012; Shogren, Wehmeyer, Palmer, Rifenbark, & Little 2014; Wehmeyer & Schwartz, 1997 & 1998; Wehmeyer & Palmer, 2003; Khemka, Hickson & Reynolds 2005; Wehmeyer, Kelchner, & Reynolds 1996)

MORE EVIDENCE

- **When denied self-determination**, people can:
 - “[F]eel **helpless, hopeless, and self-critical**” (Deci, 1975, p. 208).
 - Experience “**low self-esteem**, passivity, and feelings of inadequacy and incompetency,” decreasing their ability to function (Winick, 1995, p. 21).
- **Decreased Life Outcomes**
 - Overbroad or undue guardianship can cause a “significant negative impact on . . . physical and mental health, longevity, ability to function, and reports of subjective well-being” (Wright, 2010, p. 354)

MORE EVIDENCE

- Students with disabilities who have self-determination skills are **more likely to successfully make the transition to adulthood**, including improved education, employment, and independent living outcomes (Wehmeyer & Schwartz, 1997)
- **Older adults with more self-determination** have improved psychological health, including better adjustment to increased care needs (O'Connor & Vallerand, 1994)

MORE EVIDENCE

- ▶ **People with intellectual and developmental disabilities** who do not have a guardian are more likely to:
 - Have a paid **job**
 - **Live independently**
 - Have **friends** other than staff or family
 - Go on dates and **socialize** in the community
 - Practice the **religion of their choice**

(National Core Indicators, 2013-2014)

13

OR, AS THE NATIONAL GUARDIANSHIP ASSOCIATION SAYS:

“Alternatives to guardianship, **including supported decision making**, should always be identified and considered whenever possible **prior to the commencement of guardianship proceedings.**”

- National Guardianship Association, “Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making” (2015)

EXPLORE ALTERNATIVES FIRST

■ Finding the Right Support:

- What **kind of decision** needs to be made?
- How much **risk** is involved?
- How hard would it be to **undo** the decision?
- Has the person made a **decision like this** before?
- Is the decision likely to be **challenged**?



■ **Ask:** What is the **least restrictive** support that might work?

■ **Right Tool**, at and for the **Right Time**

ABA PRACTICAL TOOL FOR LAWYERS: STEPS IN SUPPORTING DECISION-MAKING

- ▶ **Presume** guardianship is not needed.
- ▶ **Reason.** Clearly identify the reasons for concern.
- ▶ **Ask** if a triggering concern may be caused by temporary or reversible conditions
- ▶ **Community.** Determine if concerns can be addressed by connecting the individual to family or community resources and making accommodations
- ▶ **Team.** Ask the person whether he or she already has developed a team to make decisions

https://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

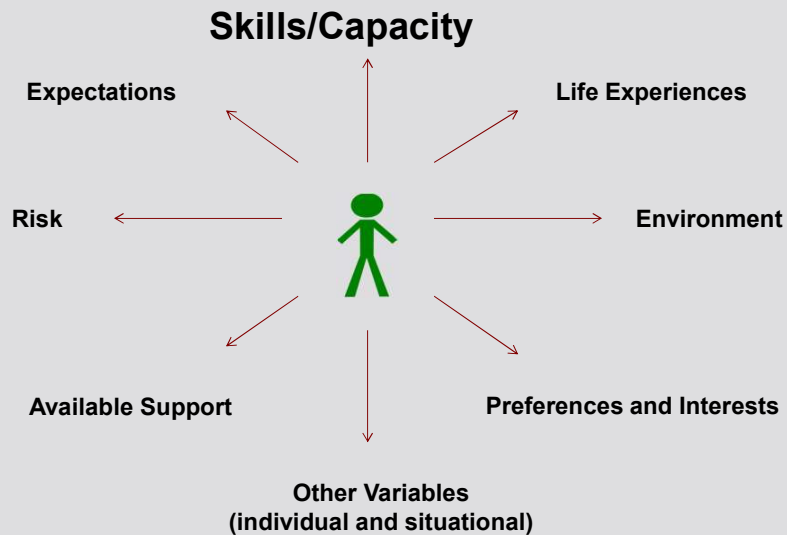
ABA PRACTICAL TOOL (CONT.)

- ▶ **Identify abilities.** Identify areas of strengths and limitations in decision-making if the person does not have an existing team and has difficulty with specific types of decisions.
- ▶ **Challenges.** Screen for and address any potential challenges presented by the identified supports and supporters.
- ▶ **Appoint** legal supporter or surrogate consistent with person's values and preferences.
- ▶ **Limit** any necessary guardianship petition and order.

RETHINK "CAPACITY"

- Capacity is **not**
 - **"all or nothing"**
 - Based solely on **IQ or diagnosis.**
- People **may have "capacity" to:**
 - Make **some decisions** but not others.
 - Make **decisions some times** but not others.
 - **Make decisions if they get help understanding** the decision to be made.
- A **lack of opportunity** to make decisions can prevent people from developing capacity or **further decrease capacity** (Salzman, 2010)

RETHINK “ASSESSMENTS”



RETHINK “HUMAN DECISION-MAKING”

- **Many decisions** are made every day
 - Some are big, and some are small.
- Typical decision-making is **flawed**
- **No standard way to measure “goodness”**
- **Culture and personal values** are important
 - **Most** life decisions are **personal**
- **History, experience, and relationships** often reflect personal preference and identity
- **Brain and decision making science** are deepening our understanding of ways to help

RETHINK “SUPPORTED DECISION-MAKING”

- An approach to assisting people with making life decisions that **mirrors how everyone makes decisions**.
- Gives people the **help they need and want** to understand the situations and choices they face, so they can **make their own decisions**
- Promotes **human dignity**, by recognizing the **inherent value and worth** of a person, honoring the person's **unique identity**, **preserving and/or building** the person's **capacity**, and ensuring **access to accommodations** as needed.
- **Supported** Decision-Making **≠** **Substitute** Decision-Making

SUPPORTED DECISION-MAKING: WHY? Dolores' Story



“It makes you feel powerful to be in charge of your own life. You can have a lot of help everywhere, but you are your own boss”

– “Dolores”

For more on this story, visit
<http://www.supporteddecisionmaking.org/slate-review/district-columbia>

SUPPORTED DECISION-MAKING: WHY?

- The **shift from “surrogacy” to support** is consistent with:
 - the **Older Americans Act**
 - the **Americans with Disabilities Act**, and
 - **Medicaid Home and Community Based Services** regulations.

USING THE LAW TO SUPPORT DECISION-MAKING

U.S. Americans with Disabilities Act

- ▶ Provides comprehensive **civil rights protections** for people with disabilities.
- ▶ Title II covers **state and local governments**
- ▶ Title III covers “**public accommodations**.”
 - ▶ Requires “**reasonable modifications** to policies, practices and procedures”
- ▶ Link to ***Olmstead v. L.C.***
 - ▶ Greater Self-Determination = Greater Community Integration



Lawyer's Responsibility to Accommodate

- **The ADA applies to you!**
- Reasonable modifications/accommodations may include:
 - **Plain language**
 - **More time** for information to be fully understood
 - **Multiple meetings** at different times
 - **Repeating information in different ways** as necessary
 - **Breaking down information** or activities into small steps
 - **Using pictures** or simple photographs
- See Trevor Finneman and Michelle Uzeta, "**Serving Clients with Disabilities: An Accessibility Guide for Law Firms**," ABA Law Practice Today (July 2013), available at: https://www.americanbar.org/content/newsletter/publications/law_practice_today_home/lpt-archives/july13/serving-clients-with-disabilities.html

SUPPORTED DECISION-MAKING: HOW?

- There is **no "one size fits all" method** of Supported Decision-Making
- **It is a paradigm**, not a process or program
 - It means **working with the person** to identify where help is needed and finding a way to provide any help that's needed.
 - **Solutions are different** for each person.
 - The key question is **"what will it take?"**

COMMON CONSIDERATIONS

- All forms of SDM recognize:
 - The person's autonomy, presumption of capacity, and **right to make decisions** on an equal basis with others;
 - That **a person can take part in a decision-making process** that does not remove his or her decision-making rights; and
 - **People will often need assistance in decision-making** through such means as interpreter assistance, facilitated communication, assistive technologies, and plain language.
- (Dinerstein, 2012)

SDM TOOLS

- **Effective Communication**
 - ASAN with the UCF Office of Developmental Primary Care, "Everybody Communicates: Toolkit for Accessing Communication Assessments, Funding, and Accommodations"
 - <http://odpc.ucsf.edu/communications-paper>
- **Informal or Formal Supports**
- **Peer Support**
- **Practical Experiences**
- **Role Play and Practice**
- **Life Coaching**
- **Mediation**



SDM TOOLS

■ Written Documents


- Release of Information forms – “HIPAA” or “FERPA”
- Other Written Plans

■ Written Agreements

- Model Forms: <http://supporteddecisionmaking.org/node/390>

■ Supported Decision-Making Guides

- <http://supporteddecisionmaking.org/legal-resource/supported-decision-making-brainstorming-guide>
- <http://www.supporteddecisionmaking.org/sites/default/files/Supported-Decision-Making-Teams-Setting-the-Wheels-in-Motion.pdf>



Supported Decision Making Form

Adult Student: _____

Address: _____

City: Washington, DC

I understand that I may create a network of individuals to help me inform my educational decisions related to my Individualized Education Program (IEP) once I reach the age of majority. I would like the following individual(s) to assist me with making educational decisions. I understand that my parent or other individuals may support me in the decision making process and may have access to the documents listed below.

NAME	RELATIONSHIP	HOME ADDRESS	EMAIL ADDRESS	PHONE NUMBER
1. _____	_____	_____	_____	_____
2. _____	_____	_____	_____	_____

Members in my network may have access to the following educational documents if I have checked the box next to it:

DOCUMENT	ACCESS
IEP meeting invitations, and agendas	<input type="checkbox"/>
Requests for assessments	<input type="checkbox"/>
Requests for changes in placement	<input type="checkbox"/>
Requests for changes in services	<input type="checkbox"/>
Exit requests	<input type="checkbox"/>
Progress reports	<input type="checkbox"/>
Report cards	<input type="checkbox"/>
Attendance information	<input type="checkbox"/>
Assessment results	<input type="checkbox"/>
Other	<input type="checkbox"/>

It is my understanding that I make the final decisions about my educational future after communicating with members in my network, and can remove a member from my network, or their access to my educational documents at any time.

Adult Student Signature: _____ Date: _____

Network Member Signature: _____ Date: _____

Network Member Signature: _____ Date: _____

Revised 2/2015

■ Q: What does this DCPS SDM Form look like?

■ A: A modified FERPA Form!

Supported Decision-Making in Health Care

Like “Capacity” is to guardianship, **informed consent** is the lynchpin of self-determination in medical care

Three Key Parts:

- **Information** to the person
- **Understanding** by the person
- **Choice** by the person

Supported Decision-Making in Health Care

- ▶ **Remember the Americans with Disabilities Act!**
 - ▶ Doctor must **reasonably accommodate** the person’s disability when obtaining his or her **informed consent**.
 - ▶ **Assistance** can be provided to help the person make and participate in medical decisions:
 - ▶ **“Explain that to me in English**
- ▶ **Remember not all medical decisions are the same!**
 - ▶ Flu Shot vs. Surgery
- ▶ **Remember “HIPAA” Release Forms!**
 - ▶ The person can sign a release form to authorize the doctor to share confidential information with the person’s supporters, so they can provide support to the person in making his or her own decisions.
- ▶ **Model D.C. Durable Power of Attorney for Health Care** with Special Provisions for Supported Decision-Making
 - ▶ <http://www.supporteddecisionmaking.org/node/390> (info purposes only)

SDM in Special Instructions of Advance Directive

- ▶ This power is subject to the following **conditions or limitations**:

1. My agent will have the authority to **act for me** with respect to health care **only in the event I am certified to be incapacitated** to make my own decisions, even with support, either temporarily or permanently. Such mental incapacity must be certified, in writing, by my primary physician.
2. **Until such time** as the certifications in Section 1 are made, **my agent will give me the support I need and want to make my own decisions**. This means my agent will help me understand the situations I face and the decisions I have to make. Therefore, at times when my agent does not have full power to make any decision(s) for me, s/he will **provide support to make sure I am able to make decisions** to the maximum of my ability, with me being the final decision-maker.

SDM in Special Instructions of Advance Directive

- ▶ This power is subject to the following conditions or limitations: . . .

3. **In the event the certifications in Section 1 are made**, my health care agent will follow my **expressed or known wishes** regarding health care services, service providers, and activities that I want or need. My agent will **explain** to me the treatment options available, the prognosis, the risks and benefits of various treatment options, and the recommendations from my doctors, and then **ask for my choice or preference**. I ask that my agent continue to do this, even if it appears that I may not be able to understand what is being explained. I ask that any decisions that are made by my agent be **based on what my agent thinks I would do** if I were able to make the choice. When in doubt, please consult the remainder of this Advance Directive for guidance. This document reflect my instructions, my health care goals, and my personal values in making health care decisions.

SDM in a Durable Power of Attorney

- ▶ I ask that my agent, **before taking any actions** using this document, **always discuss with me** what is being considered, what the options are, what his/her recommendations, and what my input is. Even it appears that I am unable to understand, I ask that my agent continue to explain to me what is happening and the choice he or she is making and why. Third parties may rely on my agent's representation that they have followed this request. A failure to follow this request shall not invalidate any transaction entered into by my agent using this document.

Draft In Limits — Examples

- ▶ Financial transactions in excess of \$_____ require the signature of my agent and either myself or _____.
- ▶ My agent shall not have authority to sell, gift, or otherwise transfer any interest in any real estate that I own.
- ▶ My agent shall only sell, transfer or gift my home, after consultation with and agreement by _____.

Growth Clause

- ▶ “My agent and I will review this [Power of Attorney/Advanced Directive/Plan] to see if it should be changed or cancelled at least every _____. However, unless my agent and I change the power of attorney, I cancel it, my agent resigns, or either I or my agent dies, the [Power of Attorney/Advanced Directive/Plan] will remain in effect.”

WHAT CONCERNS DO WE HEAR ABOUT OLDER ADULTS USING SDM?



SDM AND DEMENTIA

- **Declines** in Memory and Cognition
 - Not all dementia affects each person the same way
- **Early Diagnosis:**
 - Improved treatment options (no “cure”)
 - Improved opportunities for **PLANNING** and building a support network
- As dementia progresses:
 - Look at **history of decisions and preferences**
 - A **history of practicing SDM will prepare** supporters

SUPPORTED DECISION-MAKING: OPPORTUNITIES ABOUND!

- **Informed Consent** in Medical Care
- **Person Centered Planning** in the Medicaid World
- **Student Led IEP** in Special Education
- **Informed Choice** in Vocational Rehabilitation
- **Within the Guardian/Person Relationship**

For Archived Webinars on the above, visit:

[http://www.supporteddecisionmaking.org/
education](http://www.supporteddecisionmaking.org/education)

NRC-SDM State Grantees

2015 - 2016	2016 - 2017
<p>DE – Led by Delaware Developmental Disabilities Council</p> <p>IN -- Led by The Arc of Indiana</p> <p>ME -- Led by Disability Rights Maine</p> <p>NC -- Led by First In Families of North Carolina</p> <p>WI – Led by Wisconsin Board for People with Developmental Disabilities</p> <p>For final reports and links to related SDM resources, visit: http://www.supporteddecisionmaking.org/node/425</p>	<p>FL – Led by the Northern Florida Office of Public Guardian</p> <p>GA – Led by the University of Georgia</p> <p>ME – Led by Disability Rights Maine</p> <p>NV – Led by the Second Judicial District Court, State of Nevada, Washoe County</p> <p>NY – Led by Brookdale Center for Healthy Aging of Hunter College (Research Foundation SUNY)</p> <p>TN – Led by The Arc Tennessee</p>

Trends: SDM in U.S. State Courts

- **Pennsylvania** – In re Peery, 727 A.2d 539 (Pa. 1999)
- **New York** – In re Dameris L., 956 N.Y.S.2d 848 (N.Y. Sur. Ct., New York County, 2012); Guardian for A. E. 2015-XXXX, 2015 NYLJ LEXIS 4377 (N.Y. Sur. Ct., Kings County, 2015); Matter of D.D., 50 N.Y. Misc. 3d 666 (N.Y. Sur. Ct., Kings County, 2015); Matter of Hytham M. G., 2016 N.Y. Misc LEXIS 2722 (N.Y. Sur. Ct., Kings County, 2016); Matter of Michelle M., 2016 N.Y. Misc LEXIS 2719 (N.Y. Sur. Ct., Kings County, 2016 7/22/16); Estate of Hilton, 2017 NYLJ LEXIS 284 (N.Y. Sur. Ct., Kings County, 2017); Estate of Albert J., 2017 NYLJ LEXIS 475 (N.Y. Sur. Ct., Kings County, 2017)
- **Virginia** -- Ross v. Hatch, No. CWF120000426P-03 (Va. Cir. Ct. 2013) (see <http://www.supporteddecisionmaking.org/impact-stories/jenny-hatch>)

SDM in U.S. State Courts (cont.)

- **Massachusetts** – Cory’s Story, Berkshire County Probate Court; Pittsfield, MA (11/17/15) (see <http://supporteddecisions.org/cory/>)
- **District of Columbia** – In re Ryan King, 2003 INT 247, D.C. Sup. Court Probate Div., 10/11/16) (see <http://www.supporteddecisionmaking.org/impact-stories/freedom-ryan-king>); “Dolores’ Story” (D.C. Sup. Court Probate Div., 6/2018), (see www.supporteddecisionmaking.org/state-review/district-columbia)
- **Florida** – Consent Order for M.M. (10/13/16) (see http://www.disabilityrightsflorida.org/podcast/story/episode_5_supported_decision_making)

SDM in U.S. State Courts (cont.)

- **Vermont** – In re C.B., Stipulation to Dismiss Guardianship In re C.B. (Superior Court, Orleans Unit 4/11/2017)
- **Kentucky** – Suzie’s Story (2017) (see <http://www.supporteddecisionmaking.org/impact-stories/freed-guardianship-kentucky-first-suzie-wins-her-rights-court-using-sdm>)
- **Nevada** – In the Matter of the Guardianship of the Person and Estate of KH, Case No PR03-00264 (2nd Judicial District Court, County of Washoe, NV, 9/11/2017)
- **Maine** – In re Joshua Strong, Order of Termination of Guardianship (State of Maine, Knox County Probate Court, Docket No. 2002-0082 (6/6/2018)
- **Indiana** -In re the Guardianship of Jamie Beck, Order to Terminate Guardianship (State of Indiana, County of Wayne, Superior Court No. 2, Cause No. 89D02-1804-GU-000044 (June 13, 2018)

Trends in State Legislation (Part 1)

■ SDM Agreements

- ✓ **Texas:** H.B. 39, 84th Leg., Reg. Sess. (enacted 5/29/15 with form); S. 1881, 84th Leg., Reg. Sess. (enacted 6/9/15 with form); S. 39, 85th Leg., Reg. Sess. (enacted 6/9/17 to define fiduciary duties of supporter and prevent conflict of interests)
- ✓ **Delaware:** S.B. 230, 148th Gen. Assem, 2nd Year (enacted 9/15/16; form issued by state agency in 1/2018)
- ✓ **Wisconsin:** Assem. B. 655, 103rd Leg., Reg. Sess. (enacted 4/16/18 with form)
- ✓ **District of Columbia:** B. 22-154, 22nd Council Period, Reg. Sess. (official law in 5/5/18 with form)
- ✓ **Missouri:** S.B. 806, 99th Gen. Assem., 2nd Reg. Sess. (Governor signed 6/1/2018, effective 8/28/18, no form)

Trends in State Legislation (Part 2)

■ SDM Agreements

- **Alaska:** H.R. 336, 30th Leg., 2nd Reg. Sess. (Passed House and Senate; awaiting transmittal to Governor as of 6/1/2018; would include form)
- **Rhode Island:** H.B. 7992, 2017 Leg., Reg. Session (passed House 5/28/18, referred to Senate Committee on Judiciary 5/31/18, would include form); S. 2753, 2017 Leg. Reg. Sess. (intro 3/27/18, hearing/ consideration 4/12/18, held for further study)

Trends in State Legislation (Part 3)

■ **SDM as Less-Restrictive Alternative Only**

- ✓ **New Mexico:** S.B. 19, 53rd Leg., 2nd Reg. Sess. (enacted 2/28/18) - Enacted UGCOPAA, which formally recognizes SDM and requires court consideration of it before ordering guardianship, conservatorship, or other protective arrangements)
- ✓ **Maine:** H.R. 91, 128th Leg., 1st Reg. Sess. (enacted 4/20/18) – Completely repealed and replaced Maine's Probate Code and recognized and required consideration of less restrictive alternatives to guardianship, including SDM.

Trends in State Legislation (Part 4)

■ **Supported Decision-Making & Health Care**

- ✓ **Maryland:** S.B. 792, 435th Gen. Assem., Reg. Sess. (enacted 5/12/15) - Incorporated "SDM services" into law concerning non-discrimination in access to organ transplantation.
- ✓ **Delaware:** H.B. 21, 149th Gen. Assem., 1st Year (enacted 9/13/17) - Similar in effect to above DE law
- ✓ **Kansas:** H.B. 2343, 87th Leg., Reg. Sess. (enacted 2/12/18) - Similar in effect to above DE law

Trends in State Legislation (Part 6)

■ **SDM in Education**

- ✓ **District of Columbia:** D.C. Act 20-486 (eff. 3/2015) -States that “student[s] who ha[ve] reached 18 years of age may receive support... to aid them in their decision-making”
 - Law reform preceded by D.C. Public Schools, Transfer of Rights Guidelines (Aug. 2013), recognizing SDM and advancing use of SDM Form.
 - Law reform resulted in District-wide Office of State Superintendent of Education Regulations recognizing supported decision-making (July 2016).
- ✓ **Texas:** S. 748, 85th Leg. Reg. Sess. (enacted 6/9/2017); H.B. 1886, 85th Leg., Reg. Sess. (enacted 6/15/2017) – Incorporates SDM and SDMA into special education transition planning requirements

Trends in State Legislative Resolutions

■ **Studies of Supported Decision-Making**

- **Virginia** – H.J. Res. 190, 2014 Leg., Reg. Sess. (adopted 3/4/14)
- **Maine** – H.R. 900, 127th Leg., 1st Reg. Sess (resolved 3/29/16)
- **Indiana** – S. Res. 44, 120th Gen. Assemb., 1st Reg. Sess (adopted 4/18/17)

U.S. Trends: Examples of SDM Pilots

- **California:** Saks Institute Project
- **Georgia:** Collaboration with CPR, Georgia Advocacy Office, and Citizens Advocacy Program
- **Indiana:** Disability Rights Indiana project in the court
- **Kentucky:** My Choice Kentucky
- **Maine:** NRC-SDM State Grantee SDM Pilot (2016-2017)
- **Massachusetts:** CPR and Nanotuck Resource Associates SDM Pilot (2014-2016) and New State-Wide CPR Pilots
- **New York:** SDM Pilot (2016-2021)
- **Texas:** Volunteer SDMA Advocate Pilot (2012); SDM Law Clinic Pilot (Univ of TX at Austin) (2014-2015, continuing)
- **Vermont:** SDM Pilot (underway, state taskforce)

More SDM Policy & Practice Initiatives

Entity	Resource
Social Security Advisory Board (2016)	Representative Payees: A Call to Action <ul style="list-style-type: none">• States SSA should consider SDM as an alternative to appointing a representative payee• http://ssab.gov/Portals/0/OUR_WORK/REPORTS/Rep_Payees_Call_to_Action_Brief_2016.pdf
American Bar Association (2016)	PRACTICAL Tool and Resource Guide <ul style="list-style-type: none">• Helps lawyers identify and implement decision-making options for people with disabilities that are less restrictive than guardianship, including SDM.• Being used by social workers at the Center for Excellence in Supported Decision-Making, led by Volunteers of America of Minnesota• http://www.americanbar.org/groups/law_aging/resources/guardianship_law_practice/practical_tool.html

More SDM Policy & Practice Initiatives

Entity	Resource
Uniform Law Commission (2017)	Uniform Guardianship, Conservatorship, and Other Protective Arrangements Acts (UGCOPAA) <ul style="list-style-type: none"> Model law that, among other things, formally recognizes SDM and requires its consideration as a less-restrictive alternative to guardianship. http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act
American Bar Association (2017)	ABA Resolution 113 <ul style="list-style-type: none"> Urges legislatures to amend their guardianship statutes to require SDM "be identified and fully considered as a less restrictive alternative before guardianship is imposed" and a grounds for termination of guardianship. https://www.americanbar.org/content/dam/aba/administrative/crsj/supported_decision_making_newspiece.authcheckdam.pdf

More SDM Policy & Practice Initiatives

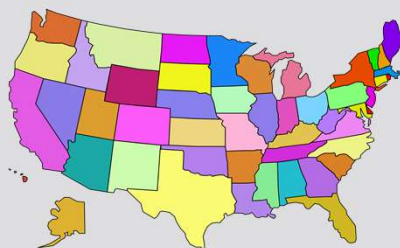
Entity	Resource
AAIDD & Arc (2016)	Joint Position Statement on Autonomy, Decision-Making Supports, and Guardianship <ul style="list-style-type: none"> Promotes less restrictive means of decision-making support, including SDM. http://uniformlaws.org/Committee.aspx?title=Guardianship, Conservatorship, and Other Protective Arrangements Act
U.S. Department of Education, OSERS (2017)	A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities <ul style="list-style-type: none"> Recognized SDM and other less-restrictive decision-making support for adult students in special education. https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf

More SDM Policy & Practice Initiatives

Entity	Resource
National Council on Disability (2018)	<p>Beyond Guardianship: Towards Alternatives that Promote Greater Self-Determination for People with Disabilities</p> <ul style="list-style-type: none">• Report designed to foster a greater understanding of guardianship and alternatives, including SDM, within the context of disability law and policy;• Made federal-level recommendations to help align the use of guardianship and decision-making alternatives with the Americans with Disabilities Act.• https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives

For More State SDM Updates

- Please visit NRC-SDM's "In Your State" at: <http://www.supporteddecisionmaking.org/states>



Join the Conversation

National Resource Center for Supported Decision-Making:

SupportedDecisionMaking.Org

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About this Project

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ADVANCED PLANNING

Advanced Planning can be Voluntary or Involuntary.

Voluntary - With Capacity

- Power of Attorney
- Advance Health-Care Directive

Involuntary - Without Capacity

- Default Health Care Surrogate
- Guardianship or Conservatorship

CAPACITY

- The ability to make an informed decision or choice. The person must understand what he or she is doing.
- Voluntary advanced planning requires capacity at the time the planning is done.
- There is no single standard for capacity. It is task specific and can be transient.

POWER OF ATTORNEY

- Power of Attorney is a document, not a person, and covers decisions over financial matters.
- The person you choose is your agent or Attorney in Fact.
- Requires capacity to create – must understand what financial matters you have and what you are asking your agent to do on your behalf.
- Must be in writing, but there is no statutory form.
- Can be revoked or modified with capacity.
- You have the ability to grant the amount of power you wish – the terms of the document, and state law, define the scope of authority.

MISSISSIPPI'S DURABLE POWER OF ATTORNEY ACT

- Governed by Miss. Code Ann. §§ 87-3-101 through 113
- § 105: To be durable, the document must show the principal's intent for agent to have authority notwithstanding the subsequent disability or incapacity of the principal or a lapse of time.
- The statute recommends the following phrases, or words of similar substance:
 - "This power of attorney shall not be affected by subsequent disability or incapacity of the principal or lapse of time"; or
 - "This power of attorney shall become effective upon the disability or incapacity of the principal."

ISSUES TO CONSIDER

- Non-springing vs Springing? Does the agent have the authority immediately or only upon your incapacity? The *appointment* is effective immediately; the document defines when the *power* becomes effective.
- If Springing, how will your incapacity be certified? And how will regaining capacity be certified?
- Name of agent and alternate agent? Choose people you trust to handle your financial matters.
- What power(s) do you want your agent to have? General? Or limited?
- The document should have a clause stating that the power can only be used on the principal's behalf, not on the agent's behalf.

POWERS OF ATTORNEY AND GUARDIANS/CONSERVATORS

Miss Code Ann. § 87-3-109

- If a court appoints a guardian or conservator over the principal, the attorney in fact will be accountable to that fiduciary as well as to the principal.
- The guardian/conservator can revoke or amend the power of attorney.

The principal can avoid this controversy by nominating, in the power of attorney, the person he or she would want to be the guardian/conservator should the need arise. Per the statute, “[t]he court shall make its appointment in accordance with the principal’s nomination in a durable power of attorney except for good cause or disqualification.”

REVOCAATION OR TERMINATION

- The principal can revoke or terminate a power of attorney at any time (with capacity), but this should be done in writing. The principal should also make sure to notify any businesses that may have worked with the agent that the agent no longer has that power.
- The power of attorney ceases upon the principal's death. However, any actions committed by the agent in good faith and before learning of the death are valid and enforceable.

UNIFORM HEALTH-CARE DECISIONS ACT

Governed by Miss. Code Ann. §§ 41-41-201 through 229

- §203 definitions
 - **Advance health-care directive** – an individual instruction or a power of attorney for health care
 - **Agent** – the individual granted the power to make decisions
 - **Capacity** – an individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health-care decision
 - **Health care** – any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect an individual's physical or mental condition
 - **Health-care decision** – includes selection (and discharge) of providers and institutions; approval/disapproval of tests, procedures, programs, orders not to resuscitate; and directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care

ADVANCE HEALTH-CARE DIRECTIVE

- You can name the person you want to make your health-care decisions when you are unable
 - The agent cannot be an owner, operator, or employee of a residential long-term health-care institution where you receive care unless related by blood, marriage, or adoption
- Choose someone who understands you and your values – make sure you have conveyed your wishes clearly, both in person and in the document
- Requires capacity to create
- Gives the agent broad authority, unless you limit it in the document

QUESTIONS TO CONSIDER

- What present or future experiences are most important for you to live well?
- What fears or worries do you have about your illness or medical care?
- Who or what sustains you when you face serious challenges in life?

EXECUTION OF AHCD

Miss. Code Ann. § 41-41-205

- Must be in writing, dated, and signed by principal and must include either:
 - Signatures of two witnesses with following declaration in substance: "I declare under penalty of perjury pursuant to Section 97-9-61, Mississippi Code of 1972, that the principal is personally known to me, that the principal signed or acknowledged this power of attorney in my presence, that the principal appears to be of sound mind and under no duress, fraud or undue influence, that I am not the person appointed as agent by this document, and that I am not a health-care provider, nor an employee of a health-care provider or facility."

EXECUTION OF AHCD (CONT'D)

- Further, *at least one* of the witnesses must attest that he/she is not related to the principal by blood, marriage, or adoption and that the witness is not entitled to any part of the principal's estate upon the principal's death.
- **OR** the document can be acknowledged before a notary, with the notary certifying, under penalty of perjury, that the individual appears to be of sound mind and under no duress, fraud or undue influence

Executing an AHCD does not require an attorney, and there is no statutorily mandated form. There is, however, a sample form in the statute (Miss. Code Ann. § 41-41-209).

AGENT'S AUTHORITY

Miss. Code Ann. § 41-41-205

- The agent has no decision-making authority until the primary physician determines that the principal does not have the capacity to make the decision. The agent's authority ends when/if the principal recovers capacity.
- The agent's decision must align with the instructions in the document. If no instructions, the decision should follow any other wishes known or be made in accordance with the agent's determination of the principal's best interest.

REVOCAION OR TERMINATION

Miss. Code Ann. § 41-41-207

- You can revoke the agent only in writing (preferred method) or by personally informing the supervising health care provider.
- You can revoke anything else at any time and in any manner that communicates an intent to revoke.
- If you name your spouse as agent, a divorce or legal separation will automatically revoke that designation unless otherwise specified in the court order or AHCD.
- A more recent AHCD will revoke an older AHCD (or at least any clauses in conflict).

AHCDs AND GUARDIANS/CONSERVATORS

Miss. Code Ann. § 41-41-213

- A court-appointed guardian or conservator must comply with the AHCD and cannot revoke the document unless the court expressly authorizes that authority.
- The guardian/conservator cannot overrule the AHCD agent's decisions unless authorized by court order.
- If there is no AHCD, a guardian/conservator can make the health care decisions without court approval.

DEFAULT HEALTH CARE SURROGATE

Miss. Code Ann. § 41-41-211

- If the agent is not available or the patient lacks capacity and does not have an AHCD
- Mississippi has a descending order of preference: spouse, adult child, parent, adult sibling
- Otherwise, an adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, and who is reasonably available
- Basically, the surrogate has the same authority as an agent and makes decisions by taking into account the patient's wishes, values, best interest

HEALTH CARE SURROGATE (CONT'D)

- The surrogate's decision is effective without judicial approval.
- The surrogate cannot be involved in the institution where the patient is receiving care, unless related, or if the patient is in a state-operated facility and there is no other surrogate reasonably available to act.
- There can be multiple surrogates. If so, majority decisions will prevail. If the group is evenly divided on a decision, those with lower priority will be disqualified.

PROVIDERS AND INSTITUTIONS MAY REFUSE TO COMPLY WITH AHCD

Miss. Code Ann. § 41-41-205

- Providers and Institutions are allowed to decline to comply with a health care decision for reasons of conscience or if the decision is contrary to the institution's policy.
- However, they must then: promptly inform the patient, if possible, and the agent/surrogate; provide continuing care until a transfer can be arranged (to a provider or facility willing to comply); and make all reasonable efforts to assist in the transfer.

GUARDIANSHIP / CONSERVATORSHIP

- Often the avenue of last resort that is pursued when someone has lost capacity but has not executed the appropriate advanced planning documents.
- A guardian or conservator can be appointed AFTER the court has determined that the person is in need of protection. The fiduciary is then accountable to the court for all actions taken on behalf of the incapacitated adult (ward).
- Even when the ward has advanced planning documents, a court might still appoint a guardian or conservator, who can then override the power of attorney but not the advanced health-care directive.
- Governed by Miss. Code Ann. §§ 93-13-13 through 265.

GUARDIAN / CONSERVATOR

- Mississippi does not have a uniform definition for these roles. The two terms appear to be used interchangeably by courts, even though the process to appoint each one differs.
- Traditionally, guardian was of the person and conservator was of the estate.
- The modern trend is to appoint a fiduciary to be over both the person and the estate. Mississippi courts tend to follow the modern trend.

GUARDIANSHIP PROCESS

Miss. Code Ann. § 93-13-111

- The Court may appoint a guardian for persons in need of mental treatment and incapable of taking care of their person and/or estate.
- Petition can be filed by a relative, a friend, or *any other interested party*.
- The proposed ward must receive 5 days' notice of the hearing.
- A guardianship requires a judicial determination of incompetence after evidence has been presented.
- If a guardian is appointed, the costs and expenses of the proceeding are paid out of the ward's estate. If not, paid by petitioner.

CONSERVATORSHIP PROCESS

Miss. Code Ann. § 93-13-251

- Petition can be filed by a relative or friend.
- Petitioner must show that the proposed ward is “incapable of managing his own estate by reason of advanced age, physical incapacity or mental weakness.”
- Court can appoint conservator over estate, and, if deemed advisable, over the person.

Miss. Code Ann. § 93-13-257

- If conservator is appointed, costs are paid out of ward's estate. Otherwise, paid by petitioner.

NOTICE OF CONSERVATORSHIP HEARING

Miss. Code Ann. § 93-13-253

- The proposed ward must be given 5 days' notice, unless the Court determines it should be shorter, after good cause shown.
- If the proposed ward did not join in the petition, then notice must also be provided to a relative, within at least third degree of kinship and a resident of Mississippi.
- If there is no such relative, the Court must designate some other appropriate person to receive notice or appoint a guardian ad litem.

CONSERVATORSHIP HEARING

Miss. Code Ann. § 93-13-255

- The Court must conduct a hearing in which the chancellor determines “the number and character of the witnesses and proof to be presented.”
- However, the proof must include at least two physicians’ certificates stating the result of the physician’s examination of the proposed ward.
- Prior to the hearing, the Court can appoint a guardian ad litem to protect the ward’s interest.

SCOPE OF AUTHORITY

Miss. Code Ann. § 93-13-15

- Every guardian appointed is a general guardian, even if “general” is not specified in the decree. Miss. law does not mandate consideration of limited powers or least restrictive alternatives.

Miss. Code Ann. § 93-13-259

- Every conservator has the same duties and powers as a guardian of a minor (general guardian).

Miss. Code Ann. § 93-13-17

- Guardians (and thus conservators) are required to subscribe to an oath and to post a bond.

REPORTING

Miss. Code Ann. § 93-13-33

- Guardian/conservator is required to deliver an inventory of the ward's assets to the court within three months of appointment and annually.

Miss. Code Ann. § 93-13-67

- Guardian/conservator is required to make an annual accounting of the ward's estates, including vouchers and receipts of all monies. Court can authorize guardian to receive \$100 annual fee. Some exceptions may apply if the estate is less than \$3,000 and is not likely to grow.

RESTORATION TO REASON

Miss. Code Ann. § 93-13-151

- Must file a petition to dismiss guardian. All interested parties have a right to appear and testify. Chancellor determines sufficiency of proof. The statute does not define what would be considered “competent proof.”

Miss. Code Ann. § 93-13-265

- For a person under conservatorship, the procedure for restoration is merely stated as “on petition for appropriate hearing by the court and decree thereof.” The statute does not mention what testimony or proof would be necessary.

MODIFYING OR TERMINATING A GUARDIANSHIP/CONSERVATORSHIP

Miss. Code Ann. § 93-13-75

- The Court can discharge the guardian when the estate is worth less than \$2,000 and there is no prospect of it growing. The guardian must make a final accounting and deliver the estate to the court to be delivered to the ward or an appropriate person or bank for safekeeping.
- Otherwise, the statute does not provide guidance for termination or modification, and many courts are reluctant to do so once the person has been brought under the Court's protection.

RESTORATION OF RIGHTS

Restoration of rights might occur in three circumstances:

- The ward is now capable of making decisions and managing his estate.
- The ward has developed decision-making supports.
- New evidence has arisen concerning capacity.

*Erica Wood, *Guardianship and Supported Decision-Making*, Bifocal, Volume 38, Issue 2 (Dec. 2016),
https://www.americanbar.org/publications/bifocal/vol_38/issue_2_december2015/guardianship-supported-decision-making.html

MINNESOTA

Minn. Stat. § 524.5-317

- The Court may terminate a guardianship upon petition and showing that the ward no longer needs the guardian's assistance or protection; or
- The Court may modify the guardian's powers upon a finding that the current power is excessive or insufficient.
- The petitioner's case for termination can be rebutted with proof that the guardianship is in the best interest of the ward.

ILLINOIS

755 ILCS 5/11a-20

- Upon petition, the Court may terminate the adjudication of disability of the ward, revoke the letters of guardianship, or modify the guardianship if the ward's capacity to manage his person and estate has been demonstrated by clear and convincing evidence.

WASHINGTON

Rev. Code Wash. § 11.88.120

- Termination or modification proceeding can be brought by motion of Court, an attorney, or the ward, or by written complaint. The Court may grant relief as it deems just and in the vest interest of the ward.
- The Court must modify or terminate a guardianship when shown that a less restrictive alternative is available and will adequately provide for the ward's needs.

SUMMARY

- Read all of the documents and know the limits of the law – one tool does not cover everything.
- Know the voluntary and involuntary tools.
- Capacity is required for voluntary planning and to revoke or modify a voluntary plan.
- A judicial determination of incompetence is required for a guardianship.
- The standard is low for a conservatorship – “advanced age, physical disability or mental weakness.”
- Health care is the only place where default agents occur.

ACKNOWLEDGEMENT

- Some of the materials in this presentation came from an NCLER presentation given by David Godfrey of the American Bar Association.
- NCLER is the National Center on Law and Elder Rights, which is a “national resource center for the legal services and aging and disability networks, focused on the legal rights of older adults.” Their website is ncler.acl.gov.

Ethics for Professionals Serving the Aged and Disabled Population

Catherine V. “Ginny” Kilgore, J.D.

Elgalene Close, MSW

Attorneys and Social workers collaborate to
help elders achieve their goals

Elder Law attorneys can provide
higher quality of service to their
clients if they receive cross-
disciplinary training.

Charles Sabatino, J.D., ABA Commission on Law and Aging,

Remarks at the 2016 National Aging and Law Conference in Washington, D.C.

Attorneys and Social workers collaborate to help elders with their goals

Social Workers also benefit from cross-discipline training individual, family, group, inpatient or outpatient therapeutic approaches and collaborating with other agencies to best meet the needs of our clients.

Attorneys and Social workers collaborate focusing on helping elders with similar approaches

- Lawyers often have a narrow approach as problem solvers. Social workers are trained to look at the whole environment.
- Assess personality, and mental status and competency status to establish services to the client.
- Social workers communicate with and about the client. Communicate about colleagues and supervisors.
- Social workers manage confidential information and case records; store and access information about the clients using technology.

Attorneys and Social workers collaborate focusing on helping elders with similar approaches

- Perform crisis management and prioritize the most immediate needs.
- Apply counseling techniques, family history, and current issues along with evaluating client's needs.
- Work out solutions through mediation and collaboration
- Bring about a more holistic solution.

Attorneys and Social Workers have differences in ethical rules that are not insurmountable

- Social workers must have a bachelor or higher level of education to provide services to clients along specific license requirements such as: LSW, LMSW, LCSW provided by MS Board of Examiners for Social Workers and Marriage and Family Therapist to provide high levels of care for clients in most hospital and agency settings.
- Social workers must have 40 hours of continuing education with 4 continuing education hours in ethics and 2 hours of continuing education in culture and diversity training every two years.
- Social workers are governed by the Code of Ethics of National Association of Social Workers(NASW).

Elder Law is a growing area of practice

- 1993, over 1/5 of population was age 55 or over, 12% were 65 or over.
- The 65-plus population is growing twice as fast as the rest of the population over the last two decades.
- It is projected that in 2030, the 65-plus population will be 20% of the population (69 million).

AGING POPULATION IS BOOMING

- There are about 77 million **baby boomers** in the U.S. **Baby boomers** are defined as people born between 1946 and 1964 in the post-World War II era. ...
- 10,000 **baby boomers** are reaching retirement age every day. ...
- 59% of baby boomers who are parents are financially supporting their children ages 18-39.
- **Baby boomers are *not* well-prepared for retirement..**
- Even when combined with Social Security income, this isn't nearly enough for most retirees to sustain their quality of life. Worse yet, 45% of baby boomers report having no retirement savings whatsoever

Five recurring ethical challenges in elder law

- Competence as an elder law attorney
- Client identification
- Confidentiality
- Conflicts of Interest and
- A Normal Client Relationship

SOCIAL WORK KEY ETHICAL STANDARDS

- PRACTITIONER COMPETENCE
- CLIENT PRIVACY AND CONFIDENTIAL
- INFORMED CONSENT
- CONFLICTS OF INTEREST
- BOUNDARIES AND DUAL RELATIONSHIPS
- DOCUMENTATION

Competence as an elder law attorney

- Rule 1.1 Competence of attorney to represent the client.
- A lawyer shall provide competent representation to a client. Competent representation requires the legal knowledge, skill, thoroughness and preparation reasonably necessary for the representation.

Social Work 1.04 Competence

- (A) Social workers should provide services and represent themselves as competent only within the boundaries of their education, training, license, certificates, consultation received, supervised experience, or other relevant professional experience.
- B ...
- C...
- D..
- E. Social workers who use technology in providing social work services should comply with laws governing technology and social work practice in the jurisdiction in which they are regulated and located and, as applicable, in the jurisdiction in which client is located.

Elders have legal problems in the most important areas of life

Accessing or maintaining:

- Income.
- Housing: single dwelling maintenance, financing and transfers; planning techniques; aging in place vs. assisted living or nursing home.
- Health Care: Medicaid, Medicare, veteran's benefits, private insurance, affordable care act
- Other public benefits

Elders have legal problems in the most important areas of life

- Incapacity Planning: powers of attorney, advance health care directives, and issues related to maintaining autonomy and freedom from abuse, neglect and exploitation
- Situations in which incapacity occurs, but was not planned for, including guardianship, conservatorship and/or supported decision-making.
- Estate planning and tax issues: wills, living trusts, and tax issues

Competence as an elder law attorney

- The attorney must possess, acquire or obtain by association with another attorney, the knowledge necessary to do the job.
- “a newly admitted lawyer can be as competent as a practitioner with long experience.” The most fundamental skill that any attorney can possess is the ability to determine what legal problem a situation may involve. Comments to Rule 1.1
- “In an emergency a lawyer may give advice or assistance in a matter in which the lawyer does not have the skill ordinarily required, where referral to or consultation with another lawyer is impractical... Assistance should be as limited to that reasonably necessary in the circumstances” Comments to rule 1.1.

Competence across the disciplines

- Attorney Rules of Professional Conduct and Social Work ethical requirements do not conflict in the area of professional competence.

Who is the Client? Make it clear to all

- Attorneys must identify at the onset who is the client.
- Lawyers who represent elders often find that others want to be involved-spouses, family friends or other professionals. The husband and wife may seek representation. The bottom line is that an attorney should take all possible steps to identify the client at the earliest stage and explain it to everyone.
- The Elder Law attorney should have an established procedure for handling the presence of third parties.

Social Work Commitment to Clients 1.01

- Social worker primary responsibility is to promote well being of clients. HOWEVER, social workers' responsibility to the larger society or specific legal obligations may, on limited occasions, supersede the loyalty owed clients and clients should be advised..
- **SOCIAL WORKERS ARE MANDATED REPORTERS AND REQUIRE BY LAW TO REPORT THAT A CLIENT HAS ABUSED A CHILD OR HAS THREATENED TO HARM SELF OR OTHERS.**
- **Attorneys are also mandatory reporters of child abuse and abuse, neglect and exploitation of vulnerable persons.**

Who is the client?

- The Rules of Professional Conduct do not define “client” although many references are made to the “client” throughout the Rules.
- the “Scope” section of the Rules in paragraph 3 provides:
“Furthermore, for purposes of determining the lawyer’s authority and responsibility, principles of substantive law external to these Rules determine whether a client-lawyer relationship exists. Most of the duties flowing from the client-attorney relationship attach only after the client has requested the lawyer to render legal services and the lawyer has agreed to do so.”

SOCIAL WORK SELF DETERMINATION 1.02

- SOCIAL WORKER RESPECT AND PROMOTE THE RIGHT OF CLIENTS TO SELF-DETERMINATION AND ASSIST CLIENTS IN THEIR EFFORTS TO IDENTIFY AND CLARIFY **THEIR GOALS**. SOCIAL WORKERS MIGHT LIMIT CLIENTS RIGHT TO DETERMINATION **WHEN**, IN THE SOCIAL WORKERS' PROFESSIONAL JUDGEMENT, CLIENTS' ACTION OR POTENTIAL ACTIONS POSE A SERIOUS, FORESEEABLE, AND IMMINENT RISK TO THEMSELVES OR OTHERS.
- **Example: Client want to go home but he is threatening to burn down the house because he is mad.. ????**

Who is the client - Scope of the Rules continued

- “But there are some duties, such as that of confidentiality under Rule 1.6, that may attach when the lawyer agrees to consider whether a client-lawyer relationship shall be established. Whether a client-lawyer relationship exists for any specific purpose can depend on the circumstances and may be a question of fact.” Scope of the Rules of Professional Conduct, paragraph 3.

Suggested procedure for attorneys handling the presence of third parties

1. As soon as the elder is identified as the client, the attorney should ask for the opportunity to talk with the elder alone to ascertain whether the client desires the presence of the family member for their interview.
2. The attorney should ask questions that would reveal whether or not the client may be subject to undue influence by the accompanying family member or anyone else and whether the client has capacity to understand the subject matter to be discussed and make independent decisions. A recommended resource: the ABA pamphlet “why am I in the Waiting Room” download for free from the ABA website.

Social Work Privacy and confidential

- Social workers should respect clients' right to privacy. Social workers should not solicit private information from or about clients except for their compelling reasons.
- (b) Social worker may disclose confidential information when appropriate with valid consent from the client or a person legally authorized to consent on behalf of the client.
- Social workers should not discuss confidential information in public. Electronically or in person in any setting unless privacy can be ensured.
- **Q Social workers should avoid searching or gathering client information electronically unless there is informed consent.**

Social work ethical rules to the client and
third parties

The 2018 NASW Code of Ethics contain
the social worker's ethical duties to the
client and to third parties.

Attorney's duty to keep information Confidential

Rule 1.6 requires that absent informed consent, an attorney must keep information secret, unless one of the narrow exceptions set out in Rule 1.6 applies or unless disclosure is impliedly authorized in order to carry out representation. Even if the client has a third party in the interview room, the information is still a confidence that the attorney can't reveal, except as required by the Rules. Keeping the information confidential is a duty owed by the attorney to the client, governed by the Rules of Professional Conduct.

Social work conflict of interest: 1.06

- Social worker should be alert to and avoid conflicts of interest that interfere with the exercise of professional, discretion and impartial judgement. Social workers should inform clients, when a real or potential conflict of interest arises and take responsible steps to resolve the conflict.
- Social workers should not take unfair advantage of any professional relationship or former clients in which there is a risk of exploitation or potential harm to the client.

Social Worker Boundaries

Dual Relationships

- Social workers should avoid communications with clients using technology (such as: social networking sites, online chat, email, text messages, telephone and video's) for personal or non-work-related purposes.
- Social workers should be aware that posting personal information on professional webs or social media might cause boundary, confusion, inappropriate dual relationships or harm to clients.
- Social workers should avoid accepting requests from or engaging in personal relationships with client on social networking or other electronic media to prevent boundary confusion, inappropriate dual relationships or harm to client.
- **Social workers should avoid posting any identifying information or confidential information on professional web pages or any form of**

Exceptions to Rule 1.6 permit disclosure

- Rule 1.6(b) “A lawyer may reveal such information to the extent the lawyer reasonably believes necessary:
 - “(1) to prevent reasonably certain death or substantial bodily harm;
 - (2) to prevent the client from committing a crime or fraud that is reasonably certain to result in substantial injury to the financial interest or property of another and in furtherance of which the client has used or is using the lawyer’s services;
 - (3) to prevent, mitigate or rectify substantial injury to the financial interests or property of another that is reasonably certain to result or has resulted from the client’s commission of a crime or fraud in furtherance of which the client has used the lawyer’s services.”

Exceptions to Rule 1.6 continued

- “(4) to secure legal advice about the lawyer’s compliance with these rules;
- (5) to establish a claim or defense on behalf of the lawyer in a controversy between the lawyer and the client, to establish a defense to a criminal charge or civil claim against the lawyer based upon conduct in which the client was involved, or to respond to allegations in any proceeding concerning the lawyer’s representation of the client.
- (6) to comply with other law or court order.”

Attorney-Client Privilege

- The **privilege**, on the other hand, is the client's and is governed by the rules of evidence. The presence of the third party may cause the attorney-client privilege to be waived. The attorney may be required to testify regarding the information, in subsequent litigation. The client should be so advised

The family is not the “client” under the Rules

- Attorneys may engage in joint representation in some circumstances.
- Often the husband and wife both want representation on estate matters. Clients, properly informed, may consent to waive confidentiality, since the attorney owes the duty to the client.
- Although the rules do not recognize “family representation,” it is not unusual when the children of a current or former client want to hire an attorney to take action, such as protective action, for their elderly parent. Other family members may want to be involved. Elder law attorneys face many ethical challenges.

Conflicts of interest

- Conflicts of interest may occur in joint representation.
- Attorneys should consult Rule 1.7. Not all conflicts can be waived.
- Even if waivable, should the client waive the conflict?
- Avoid conflicts by clearly identifying the client.

Client under a disability; A normal client relationship

- Rule 1.14 Client Under a Disability
- (a) When a client's ability to make adequately considered decisions in connection with the representation is impaired, whether because of minority, mental disability or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.
- (b) A lawyer may seek the appointment of a guardian or take other protective action with respect to a client, only when the lawyer reasonably believes that the client cannot adequately act in the client's own interest.

Client under a disability continued – Rule 1.14

- (c) Information relating to the representation of a client who may be impaired is protected by Rule 1.6. When taking protective action pursuant to paragraph (b), the lawyer is impliedly authorized under Rule 1.6(a) to reveal information about the client, but only to the extent necessary to protect the client's interest.

The Mississippi Rules of Professional Conduct, Rule 1.14.

Client under a disability; the attorney's duty

- The Rule does not define capacity.
- State law defines the level of capacity necessary for specific transactions.
- Modern movements in the law, both on the national scene and in many states, recognize varying degrees of capacity exist and that an individual may have lucid moments, even if they experience periods of incapacity. Some jurisdictions have gone further than others to require that to the extent possible the law must preserve autonomy through mechanisms such as supported decision-making. The modern view is not always addressed by existing Mississippi statutes and legal precedent

Client under a disability; two issues to decide

- Two initial issues must be addressed by attorneys:
- Does the individual have capacity to contract with an attorney for services (do you have a client?).
- Does the client have the capacity to complete the legal transaction?
- Attorneys usually are not trained in evaluating diminished capacity. However, failure to assess capacity can be grounds for malpractice. The attorney must decide 1. Can representation go forward, and 2. Should the attorney take protective action to protect the client's interests.

Client under a disability; resource for assessing capacity

The Assessment of Older Adults with Diminished Capacity: A Handbook for Lawyers (2005) (Handbook), by the American Bar Association and the American Psychological Association seeks to provide tools for assessing capacity. The Handbook also outlines steps for a lawyer to take in assessing capacity. It is recommended that the attorney establish an initial screening procedure to determine the client's level of incapacity

Client under a disability; the attorney's duty

- No or very minimal evidence of diminished capacity : (representation can proceed).
- Mild problems - some evidence of diminished capacity, but insufficient to preclude representation or proposed transaction: (representation can proceed).
- More than mild problems: substantial evidence of diminished capacity. Warrants consultation with or referral to mental health professional. (proceed with great caution or seek evaluation or consultation).
- Severe problems: client lacks capacity to proceed with the transaction and the representation. (representation cannot proceed)(secure client's interests as best you can).
- Handbook, pp. 3, 26.

Scenarios:

- Case Study: Mrs. Gray, a resident in a nursing facility wants to return home. her condition has improved, and she has asked the social worker to help her in her efforts to go back home. The social worker has contacted the local services that can assist with the transition, but Mrs. Gray's family opposes the move and won't cooperate. Mrs. Gray needs the keys to her house so that it can be inspected as a preliminary to getting it ready for her return, her health care cards, credit cards, Social Security Card, checkbook and other bank records, to make applications. her credit card company informing her that her credit card charges of \$15,000, that she doesn't remember making, are past due.

Mrs. Gray, continued

- The social worker referred Mrs. Gray to legal services after she failed in her attempt to mediate the situation. The legal services attorney and law students met with Mrs. Gray and developed a plan for the lawyer to request the items from her daughter. When the lawyer got back to the office, he had a call from the social worker. Mrs. Gray's daughter Jane had filed a petition for a protective order, a guardian and a conservator, alleging that Mrs. Gray is incapable of managing her finances or her person. She has attached statements from two physicians who treated Mrs. Gray in the recent past.

Mrs. Gray, Continued

- daughter refuses to bring the keys to the house or her cards so that the agency can assess the premises and set up services, alleging that it is in Mrs. Gray's best interests to remain in the nursing home. Mrs. Gray has received a collection letter from her credit card company saying she is behind on her payments on the \$15,000 she charged to the card while she was in the nursing home. She doesn't remember making any charges.

Mrs. Gray, Continued

- What are the areas of law that the attorney needs to know for purposes of competent representation of Mrs. Gray?
- What skills and areas of knowledge does the social worker need in order to assist Mrs. Gray?
- What are some of the ethical issues that may apply to social workers and attorneys in this case?

Elgalene Close, MSW
District Ombudsman
North Delta Planning & Development District
220 Power Drive
Batesville MS 38606
662-561-4100 Ext: 4133
662-360-7333 Direct Line
662-561-4112 Fax Line

Catherine V. “Ginny” Kilgore, J.D.
Adjunct Professor of Elder Law
University of Mississippi School of Law

SELF-DETERMINATION

Definition of self-determination

1. Free choice of one's own acts or states without external compulsion.
2. Determination by oneself, without outside influence.
3. Freedom to live as one chooses, or to act or decide without consulting another or others.

Aging in Place

Aging in place helps fulfil the self-determination in the elderly by preserving dignity in the face of competing interest and grim alternatives.

So what exactly is aging in place?

Aging in place is a term used to describe a person living in the **residence of their own choice**, for as long as they are able, as they age.

The most popular choice of aging in place is a person's home. This is the place you have raised your children and visited with your grandchildren. You have been neighbors to Mr. and Mrs. Jones for 50 years, and this is the place you are most familiar with. This is the place you call home.

Along with all of those good memories come a lot of aging changes. We are now having problems with our **vision, muscle strength, altered mental status, risk of illness, reduced hearing, decreased mobility, missing medications, lack of social and spiritual involvement**.

So, does this mean it's time to pack up and move with family or a facility? Absolutely not! All that this means is that it's time to start planning.

So the planning process has started and everyone involved agrees for mom or dad to continue to live at home for as long as possible. This decision has become a very easy decision to accommodate.

According to the Census Bureau, and help from the baby boomers, senior citizens are the fastest growing age group in the United States.

With this being true, we need resources to help keep seniors at home as long as they can. You have choices such as **Companion Care, Home Health, and Hospice**, just to name a few. Some people do not quite understand the difference of these selections and what they may provide.

Companion care offers a variety of services in your home. Unlike home health and hospice, a referral from the doctor is not needed for this type of service, but they do work with physicians, hospitals, and family members to develop and individualized plan of care for your loved one's daily needs.

Home Health care is also a variety of services that can be given in your home for an illness or injury. Home health care is comparable to the care received in a skilled nursing facility and a hospital. Some of the services they provide are wound care services, Intravenous (IV) therapy, injections, monitoring of serious illnesses, physical, occupational and speech therapy, just to name a few services. This is a service that a health care provider must refer you to have.

SELF-DETERMINATION

Hospice care is another service a person can receive in their home or a home like setting. This type of service concentrates on the patient's physical, emotional, and spiritual needs. Hospice also concentrates on pain management, and other symptoms to make the patient as comfortable as possible to allow them to make the most of the time they have left. This service also requires a referral from a health care provider.

There is a time when living at home is not a choice anymore. Whether the reason is medical, physical, mental or a person just decides they do not wish to live alone anymore. The next question is, "Where do I go from here?"

The choices will be either assisted living or nursing home, and this is also depending on the type of care you will need and financial status.

Assisted Living verses Nursing home

What is Assisted Living?

An assisted living community is a community for older adults that cannot or choose not to live at home any longer. The community is a place that provides a group living environment with associates dedicated to enhancing health, wellness and lifestyle through programs and services tailored to residents in every level of accommodations and care.

Services normally provided are:

- Assistance with personal needs including dressing, bathing and dining
- Licensed nurse on-site 24 hours a day
- Personal service plan
- Medication management(if needed)
- Ongoing monitoring of resident's health status
- Weekly housekeeping services
- Three freshly prepared meals
- Daily programs, events or outings
- Scheduled transportation services available
- Incontinence care/ management
- Diabetic care
- Respite care available
- Personal check-ins throughout the day
- Ambulation and escort services
- Ongoing dementia training and support for staff

Assisted living communities also have different accommodation styles such as studio, one-bedroom and two-bedroom apartments depending on the community of choice. Most are handicap accessible with emergency response systems.

SELF-DETERMINATION

There are steps to take in order to move into an assisted living community. So, you have decided that assisted living is where you want to be. Your first step will be meeting move in criteria.

Every state has different criteria one has to meet before they can be approved to move into assisted living. The state of Mississippi requires that you are:

- Ambulatory whether with a walker , cane ,or self propelling a wheel chair
- Able to transfer yourself
- No feeding tubes
- No foley Catheters
- No open sores

The next step will be discussing your finances and budget. Unlike a nursing home, most assisted living communities only accept private pay. Private pay can also mean long term care insurance or VA aid and attendance. Medicare and Medicaid does not provide payment for this type of home, but Medicare will pay for any therapy you receive while living in assisted living. Most assisted living communities offer in house therapy.

Now we're moving right along. We have met requirements both physically and financially. The next step is deciding which community is right for you.

Timing is very important. Assisted living communities are designed for you to age in place. So, what does that mean? We know that with time your health will decline and sometimes accidents may happen that will prevent you from meeting move in requirements. As long as you were already a resident under certain circumstances you will be allowed to stay in the community. That is why if you know this is the move you want to make, it's important to make it while you are still able to meet requirements.

Just say one of the things mentioned earlier happens, such as a decline in health or an accident. Depending on the problem, we may have to bring in a third party provider, such as home health or hospice to assist in care. There is normally no reason you will be asked to leave your home.

In rare cases, you or your family may decide that you need skilled nursing. If at any time you feel the care for your loved one is too much for assisted living, the nursing home would be your next choice.

Another service offered in assisted living is respite stay. Respite stay is a service offered to a person that may need a short term stay. It may be that a person needs care for an elderly person they care for while they are out of town, or for a person that has been hospitalized for some reason and needs a little help before they return home. Respite care will allow you to enjoy all the services that a permanent resident receives for a limited time while you receive therapy or just stay for the company. A person would have to meet the same requirements as one moving in. The pay is usually by the day and is all inclusive. In some communities you are allowed to stay from two weeks to three months under the respite lease. These services are also private pay with Medicare paying for any therapy you may receive during your stay.

SELF-DETERMINATION

What is a nursing home or skilled nursing home?

Most nursing homes are very similar to assisted living. They offer a lot of the same services and is more geared towards skilled nursing.

Nursing homes, like assisted living, provides around -the- clock care for elderly people. Unlike assisted living, nursing homes can accept Medicare and Medicaid.

Most nursing homes also offer acute rehab for patients that may need therapy in a facility before returning to their home after certain illnesses or accidents. This is a very good service to rehabilitate a patient to the health and ability to return to their home. Acute rehab can last from a couple of weeks or several months depending on the needs of the patient. This service is also normally covered by Medicare.

There are so many resources around to assist the elderly population to age with dignity and respect at different levels of the aging process. There are so many resources that all were not mentioned. In order to meet the demands of the fast growing elderly population, I'm sure there is a lot more to come.



CARE

Changing Aging Through Research and Education®

Best Approaches to End-Of-Life Care

Learning Objectives

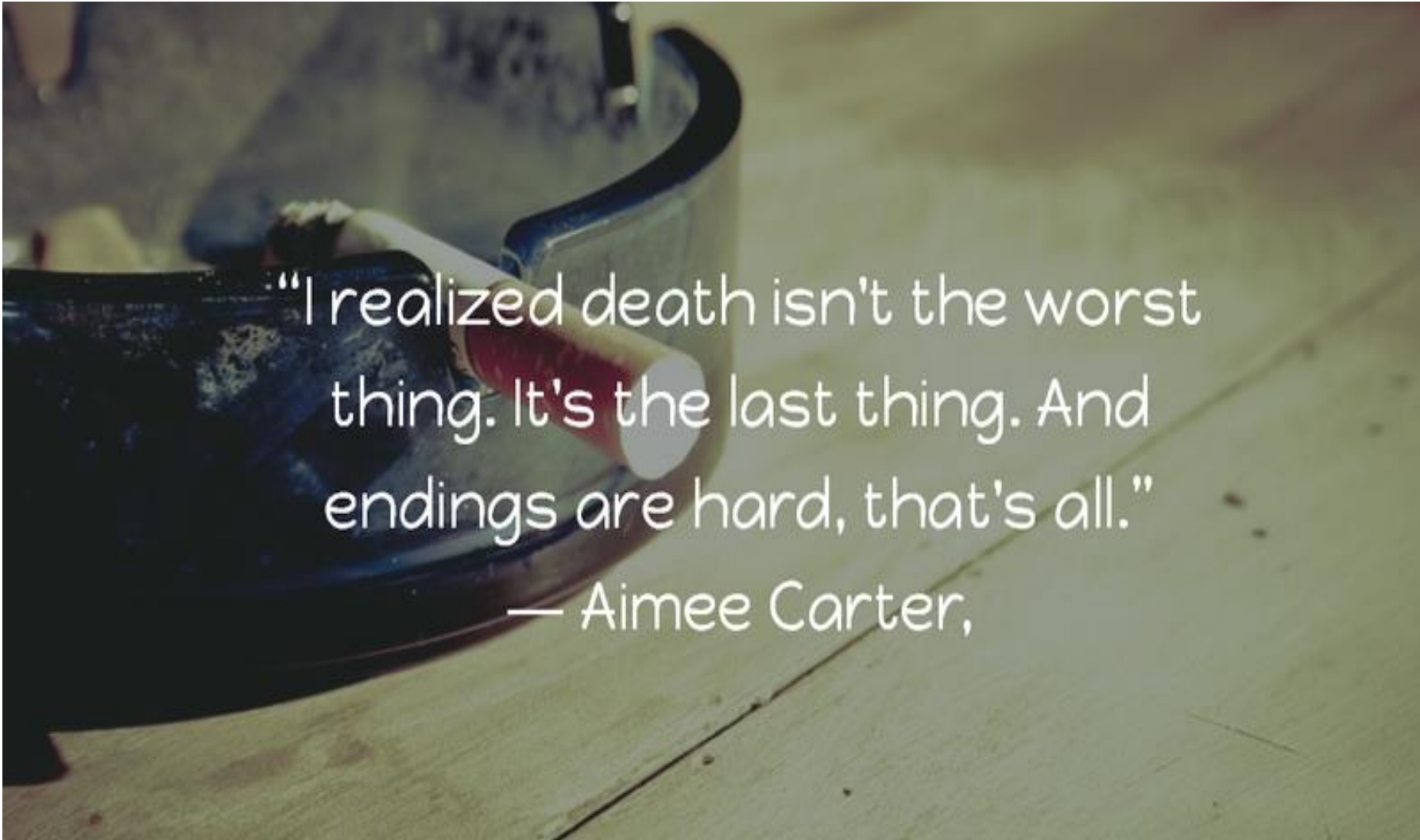
At the end of this presentation, you will be able to:

1. Gain a clear understanding of some of the primary fears associated with end-of-life care.
2. Be equipped with an understanding of some of the tips for physical and emotional support during end-of-life care.
3. Differentiate hospice and its purposes in comparison to other types of care in the home or clinical setting.

HOW OLD IS OLD?

World's oldest person dies in Japan at age 117

TOKYO -- The world's oldest person, a 117-year-old Japanese woman, has died. Nabi Tajima, born on Aug. 4, 1900, was the last known person born in the 19th century. She reportedly had more than 160 descendants, including great-great-great grandchildren.



“I realized death isn't the worst thing. It's the last thing. And endings are hard, that's all.”
— Aimee Carter,

Fears Associated With End-Of-Life Care



To us, it's personal.

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Fear #1: The Process Of Dying

“Will it hurt?”

“Will feeding tubes and ventilators be keeping me alive?”

Living Wills

Five Wishes – www.agingwithdignity.org

Fear #2: “I don’t want to live in a nursing home, and I don’t want to die in a hospital.”

- Options for end-of-life care:
 - Stay at home or Live with family?
 - Living community?
 - Nursing Home?
 - Hospice Residence?

Fear #3 : “What if I get dementia and can no longer make my own decisions?”

Who will act on my behalf?

POA

Fear #4 : “I don’ want to lose my independence”

- Look for help to stay at home
- Discuss with family
4070talk.com

Hospice and Palliative Care

When you support a loved one who is in hospice, you are accompanying them on a very intimate journey filled with unique challenges and experiences.



True or False?

- Hospice is where you go when “nothing else can be done.”

FALSE

True or False?

- Hospice is a place.

FALSE

True or False?

- Hospice is just for the patient.

FALSE

True or False?

- Most people in hospice pass away at a hospital or in a hospice facility.

FALSE

Hospice

- Hospice is not always the last resort for the dying. Hospice not only provides an individual with medical care, pain management, and emotional and spiritual support, but also offers support for the family caregiver, who is the primary caregiver.
- Statistics show that 80% of care is provided in the home.

Hospice Care

- Palliative Care
- Comfort, pain relief and dignity
- No longer receiving curative treatment
- Focuses on improving the quality of life for patients facing death
- Supports the family members



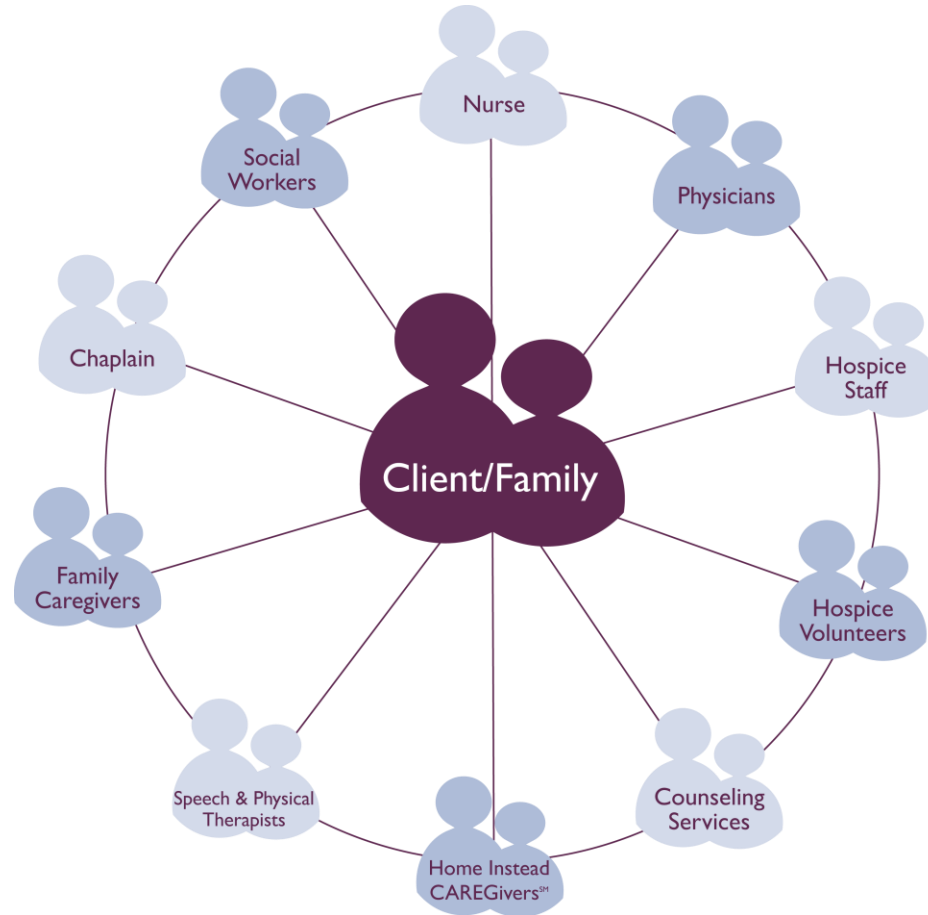
Palliative Care

- Focuses on relieving pain and providing comfort
- Provided to people:
 - Undergoing treatment for curable illnesses
 - Living with chronic diseases
 - Nearing death

Common Medical Conditions of Those on Hospice

- Lung disease (COPD, chronic pulmonary obstructive disease)
- Heart disease (congestive heart failure)
- Stroke
- Coma
- Advanced liver disease (cirrhosis)
- End-stage kidney disease
- Dementia
- Advanced neurological diseases (Parkinson's disease, ALS),
- Human immunodeficiency virus (HIV/AIDS)

The Hospice Team



Role of Home Care

- Medical Home Health
- Non-Medical Home Care



Medical Home Health

- Temporary and rehabilitative
- Prescribed by a doctor
- Must be “Home-Bound”
- RN, PT, OT, ST, CAN
- Paid for by Medicare & Most Private Insurance

Non-Medical Home Health

- Assist with ADLs
- Remain independent at home
- Not paid for by Medicare & Most private insurance
- Private pay, some Medicaid, some VA, LTC insurance

Tips For Physical and Emotional Support at End of Life

Responding to Questions About Death

- “Am I dying?”
- “Why me?”
- “I’m not ready to die?”
- What if the individual is crying?
- What if you are dealing with challenging relatives?

Stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Responding to Grief

- “I’m sorry.”
- “I’m sad for you.”
- “How are you doing with all of this?”
- “I don’t know why it happened.”
- “What can I do for you?”
- “I’m here and I want to listen.”
- “Please tell me what you are feeling.”
- “This must be hard for you.”

How to Support Emotional Needs

- Be honest
- Be non-judgmental
- Allow silence
- Respect your loved one's space

Spiritual Experience

- “What did my life mean?”
- “Where will I go when I die?”
- “Will my family be OK after I die?”
- “Is there any unfinished business I need to complete?”

Spirituality, Religion and Faith

- Spirituality helps people deal with the unknown elements of life and gives purpose.
- Religion is often used to describe an organized collection of beliefs.
- Faith is confidence or trust in a person, thing or deity.

Spiritual Distress

Each person has different spiritual needs:

- For involvement and companionship
- To resolve unfinished business
- For a positive outlook
- To love others
- To feel love from others
- To review spiritual beliefs and seek reaffirmation
- To resolve distress or conflict

Life Legacy Tool

- The Life Legacy aid is a tool you can use to help gather information that is important to your loved one.

A white rectangular form titled "Life Legacy" with a tree icon. It features three large, light-yellow rectangular boxes for writing. The Home Instead logo is in the top right corner. The text on the form is as follows:

Life Legacy

Home Instead
SENIOR CARE
To us, it's personal.

What is your most cherished family tradition? Why is it important?

Do you have any unfinished business that needs completed?

What would you especially like your family to know and remember about you? What would you like to be remembered for and who would you like to be remembered by?

Relationship Completion

- “I love you.”
- “Thank you.”
- “Forgive me.”
- “I forgive you.”
- “Goodbye.”

Participant Guide – Pages 22 & 23

Questions



To us, it's personal.

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Other Resources

- Caregiverstress.com
- Letstalkaboutdriving.com
- Protectseniorsonline.com
- Keepinghomesafeforseniors.com
- Daughtersintheworkplace.com
- Helpforalzheimersfamilies.com

PHYSICIAN AID IN DYING: WHAT WE HAVE LEARNED IN THE LAST 20 YEARS

Lindsey S. Hinton, MD

OBJECTIVES

- Define terms related to the Death with Dignity Law
 - Discuss historical framework for thinking about physician assisted death
 - Explore the arguments of opponents and proponents of these laws
 - Examine the data out of Oregon and think about potential application to the practice of medicine and the care for patients with serious illness
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PALLIATIVE CARE

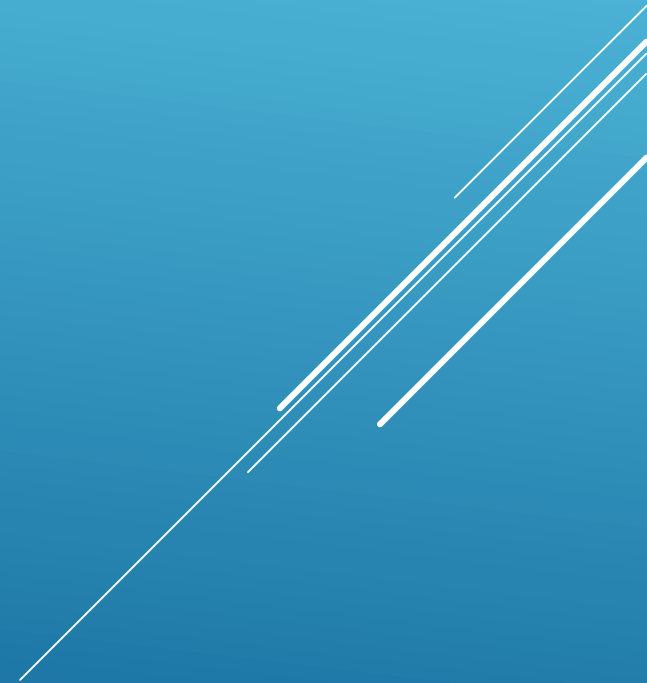


PAL-EE-UH-TIV

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain and stress of a serious illness- whatever the diagnosis.

The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists who work with a patient's other doctors to provide an **extra layer of support**. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

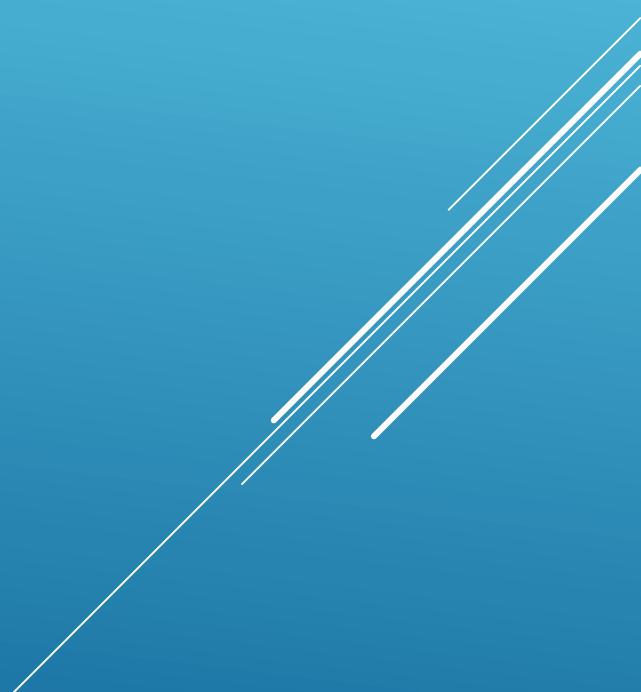
¹Center to Advance Palliative Care (CAPC)



UNDERSTANDING TERMINOLOGY

- ▶ Physician-assisted dying (PAD): practice where a physician provides a terminally ill patient, at his or her explicit request, with a prescription for a lethal medication that they can take on their own
 - ▶ Also Medical aid in dying (MAiD)
 - ▶ Death with dignity
 - ▶ Physician assisted suicide
- ▶ Voluntary active euthanasia (VAE): the physician administers the lethal medication at the patient's request , usually by injection (NOT LEGAL IN THE US)

OREGON'S DEATH WITH DIGNITY ACT 1997



- ▶ What?
- ▶ Who?
- ▶ When?
- ▶ Where?
- ▶ How?



PROCESS

- ▶ Patient must make 2 oral requests separated by at least 15 days
- ▶ Patient must provide a written request to the physician, signed in the presence of 2 witnesses, at least 1 is not related to the patient
- ▶ The attending physician and consulting physician must confirm the patient's diagnosis and prognosis

Both physicians must determine whether patient has decision making capacity

Oregon Public Health Division

<http://public.health.oregon.gov>

Process Continued....

- ▶ If either physician believes judgement is impaired by a psychiatric or psychological disorder (such as depression), they must be referred for psychological evaluation
- ▶ Physician must inform the patient of feasible alternatives
- ▶ Physician must request, but not require, that the patient notify their next-of-kin

Oregon Public Health Division

<http://public.health.oregon.gov>

HISTORICAL PERSPECTIVE

1970s: *Quinlan:* A young woman has brain injury and is in a PVS. She is on a ventilator and family asked for this to be removed. Her doctors are concerned that this would be active killing. Case goes to court which finds her family can make decisions for her and that with autonomy she could refuse to continue the mechanical ventilation.

HISTORICAL PERSPECTIVE

1980s: Cruzan: Right to refuse or discontinue life sustaining treatment

Young woman has a brain injury and is in a PVS. She has a feeding tube and her family asked for it to be removed. Missouri AG objects. The case goes to the US Supreme Court which finds that any life sustaining treatment may be declined or discontinued, including artificial nutrition and hydration.

HISTORICAL PERSPECTIVE

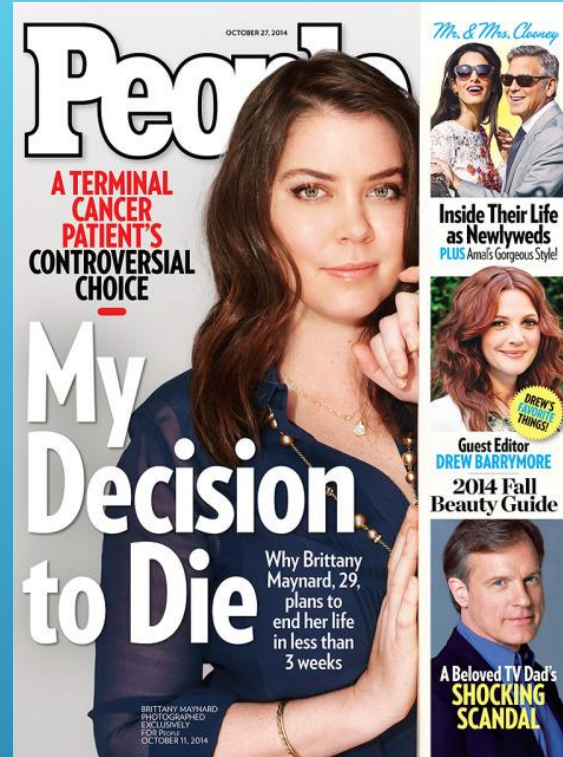
1990s: *Oregon Death with Dignity Law*: Oregon passes a physician-assisted death law. Federal government attempts to block the law. US Supreme Court find that there is no US constitutional right to PAD but states can make their own laws.

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IN THE NEWS:

2014: Brittany Maynard


"I do not want to die. But I am dying. And I want to die on my own terms."




THE DEBATE



PROPONENTS

- Autonomy (self-determination)
 - Mercy
 - Nonmaleficence
 - Beneficence
 - “Psychological Insurance”
 - Different from terminating life-sustaining treatments?
- 
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OPPONENTS

- ▶ Wrongness of taking innocent life
 - ▶ Threaten the integrity of medicine
 - ▶ Invite abuse
 - ▶ Adequate palliative care and hospice would relieve most pain and suffering
- 
- A series of white diagonal lines of varying lengths and thicknesses, located in the bottom right corner of the slide.

QUICK FIX FOR MORE COMPLICATED PROBLEMS...

- Financial burdens
 - Inequitable access to palliative medicine
 - Lack of knowledge about effective management of symptoms
 - Medical reimbursement
 - Societal values
 - Lack of resources
- 
- A series of three parallel white diagonal lines on a blue background, located in the bottom right corner of the slide.

AAHPM STATEMENT ON PAD

June 24, 2016

“Studied neutrality”

A series of three parallel white lines of varying lengths, slanted diagonally upwards from left to right, located in the bottom right corner of the slide.

DATA OUT OF OREGON

- ▶ 1857 people had prescriptions written under the DWD Act
- ▶ 1179 people died from ingesting the medications
 - ▶ Approximately 1/3 of those who obtain the medications do not use them
- ▶ 96% white
- ▶ 92% insured
- ▶ 72% some college
- ▶ Median age 72
 - ▶ Median age at death of 76 for Oregonians who died of the same underlying illnesses without DWDA prescription

MAJOR CONCLUSIONS:

- ▶ **It is primarily oncology patients who utilize PAD:**
 - ▶ 77.1% Cancer
 - ▶ 8% ALS
 - ▶ 4.5% COPD
 - ▶ 1.9% Heart disease
 - ▶ 0.8 HIV/AIDS
 - ▶ 7.3% other illnesses
- 
- A series of three parallel white diagonal lines extending from the bottom right towards the top right of the slide.

- **In most reports, uncontrolled pain is NOT a major determinant of interest in or use of PAD**

- 91.6% Loss of autonomy

- 89.7% “less able to engage in activities making life enjoyable”



- 24.7% Inadequate pain control in the future

- 4% Finances

INITIAL RESPONSE TO REQUESTS FOR HASTENED DEATH

- ▶ Respond empathically to the patient's emotions
- ▶ Intensify treatment of pain and any other physical symptoms
- ▶ Consult with specialists in palliative care and/or hospice
- ▶ Consult with experts in spiritual or psychological suffering
- ▶ Encourage dialogue and trust
- ▶ Discontinuation of potentially life prolonging treatments such as steroids, insulin, dialysis, oxygen or tube feeding
- ▶ Voluntary cessation of eating and drinking

UNIPAC 6

Ryan Nash, MD and Leonard Nelson, JD

START A CONVERSATION

“What scares you?”

“What do you worry about?”

“What defines your quality of life?”





OP ED FROM THE LA TIMES 8/1/2017

"One doctor said we should be able to order the
End of Life Option Act without the drugs."

- Dr. Neil Wenger

Director of the UCLA Health Ethics Center

“Medicine has forgotten how vital such matters are to people as they approach life’s end. People want to share memories, pass on wisdoms and keepsakes, connect with loved ones, and to make some last contributions to the world.”

- Atul Gawande, MD
“The Best Possible Day” NY Times 2014

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RESOURCES

Compassion & Choices, Death with Dignity

Oregon Health Authority

AAHPM

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