ADRC Dementia Care Training

Aging Services and Supports for People Living with Dementia: Tier 2

Module 8: Decision Support for Advanced Care and End-of-Life Planning

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DHS

Aging Services and Supports for People Living with Dementia

- Tier 1:
  - Understanding Person-Centered Care
  - Communication and Behavioral Expressions
  - Medical and Clinical Aspects of Dementia
  - Complex Information and Referral Issues
- Tier 2:
  - Honoring Personhood through Person-Centered Decision Support (orientation and building trust)
  - Decision Support through Person-Centered Planning
  - Decision Support in Care Transitions
  - **Decision Support for Advanced Care and End-of-Life Planning**
    - Feedback survey, knowledge assessment

Review

- Module 5
  - Person-centered decision support: Building trust, knowing the person
- Module 6
  - Person-centered decision support: Implementing and evaluating plans
- Module 7
  - Transitions in care

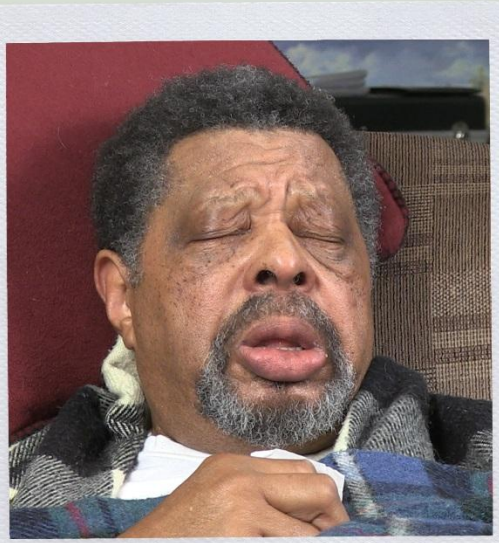
Module 8: Objectives

- Participants will:
  - Understand the importance of advance planning
    - Financial
    - Legal
    - Health
    - End-of-life
  - Identify resources to support people with dementia and their families.
  - Be knowledgeable about end-of-life supports and services

Importance and Challenges of Advance Planning

Sarah and Bill

Martha



Dennis

Capacity

- Legal Capacity: The ability to understand and appreciate the consequences of one's actions and to make rational decisions.

- Incapacitated: “A condition in which a person’s ability to receive and evaluate information effectively or to communicate decisions is impaired to such an extent that the person presently lacks the capacity to meet the essential requirements for the person’s physical health or safety” (DHS 0756, April 2014)

Capacity

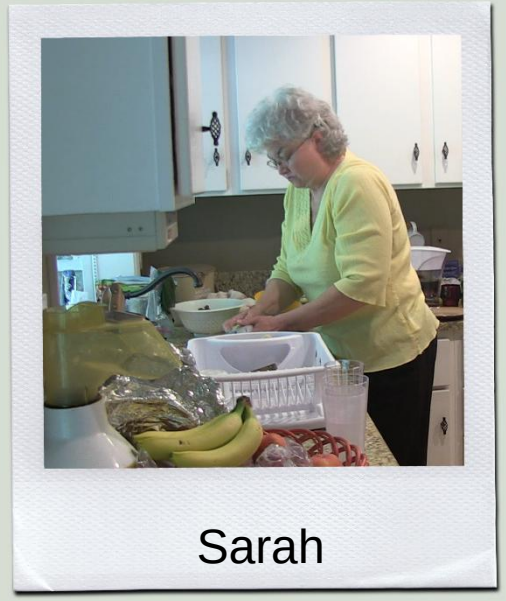
- Ability to make decisions varies from one situation to another. Examples:
  - Medical/health decision making (e.g., advance directives, treatment choices)
  - Financial capacity (e.g., basic monetary skills, bill payment, investment decisions)
  - Driving (e.g., risk assessment)
  - Living arrangements (e.g., living independently, home maintenance living with others)
  - Everyday decision making (e.g., daily routines, meals, activities)

- A person can be legally incapacitated in some areas and not others.

- Legal capacity requirements can vary from one legal document to another.

Having Difficult Conversations with Your Family

- Planning for a future when you don't have capacity
  - Who do you want to talk to?
  - When is a good time to talk?
  - Where would you feel most comfortable?
  - What do you want to be sure to say?
- Conversation starters:
  - "I need your help with something."
  - "I need to think about the future. Will you help me?"
  - "I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."


Sarah

http://theconversationproject.org/starter-kit/intro/

Having Difficult Conversations with Family Members

- Don't wait for a crisis
- Do some research first
- Talk with other family members–
  - Seek agreement on general issues to address
  - How to maintain communication
- Plan ahead:
  - When, where
  - Practice conversations
  - Anticipate multiple discussions
- During the conversation:
  - Make it YOUR problem
  - Emphasize support for self-determination
  - Make it a team effort

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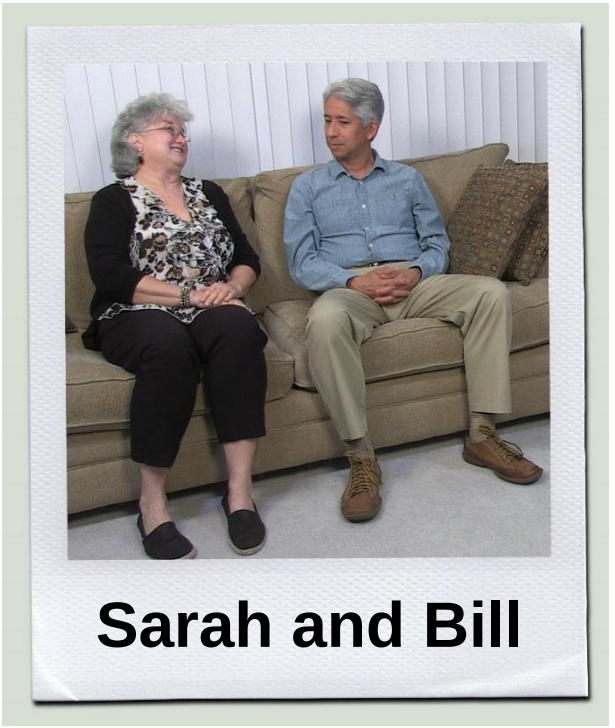
I have Alzheimer's Disease

- http://www.alz.org/i-have-alz/plan-for-your-future.asp
  - Legal
  - Financial
  - Building a care team
  - End-of-life care

http://www.youtube.com/watch?v=YQtDyi865AE



Legal Planning

- Take inventory of existing legal documents, review and make necessary updates
- Make legal plans for finances and property
- Put plans in place for enacting your future health care and long-term care preferences
- Name another person to make decisions on your behalf when you no longer can
  - Health Care Representative (Note: also called “durable power of attorney for health care”)
  - Power of attorney for finances and property

From the “I have Alzheimer’s” website

ADRC Planning Documents

- Planning for Your Future: A Toolkit for Long-term Services and Supports
  - https://adrcof**oregon**.org/consite/forms/ADRC-toolkit-web3.pdf

Financial Planning

- Costs of care
- Navigating Medicare
- Insurance coverage

www.oregon.gov/DCBS/SHIBA/

- Housing, reverse mortgages
- Annuities and trusts
- Public funding eligibility
- Senior Medicare Patrol

ADRC service planning worksheet

Type of service	Cost of service (state average)	Anticipated amount of time	Estimated yearly cost of services
Nursing facility	**$7,057** per month X	____ months	= $ _____
Assisted living	**$4,023** per month X	____ months	= $ _____
In-home care worker	**$20** per hour X	____ = $ ____ X **52** weeks (hours per week)	= $ _____
Adult day services	**$94** per day X	____ = $ ____ X **52** weeks (days per week)	= $ _____
Adult foster/care home	**$2,043** per month X	____ months	= $ _____
		Total estimated yearly cost =	$ _____

Note: The above costs are averages and may be different in your area. Source: Genworth 2013 Cost of Care Survey, 2013 Oregon Medicaid Base Rate + for Adult Foster Homes.

We do not guarantee this worksheet's results or their application to your financial situation. You should seek a qualified professional's advice on financial decisions.

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Advance Directives

https://adrcoforegon.org/consite/plan-legal-and-care-planning-develop-documents.php

- Purpose
  - Identify the choice of a health care representative
  - May provide details about the health care you want if incapacitated (e.g., artificial life support and artificial food/water)
  - Can also direct the health care representative to make these decisions
- Advance Directives
  - Are completed by the person, the health care representative, and two witnesses
  - Must be signed when the person is still able to make decisions
  - All persons will get care for comfort and cleanliness regardless of choices

Health Care Advance Planning

- Consumer's Tool Kit for Health Care Advance Planning (2nd Ed)

  http://www.americanbar.org/groups/law_aging/resources/health_care_decision_making/consumer_s_toolkit_for_health_care_advance_planning.html

Sarah, Bill, and Options Counselor Ashley

Consumer's Tool Kit for Health Care Advance Planning

- How to select your health care agent/proxy [that is, ***health care representative***]
- Are some conditions worse than death?
- How do you weigh odds of survival?
- Personal priorities and spiritual values important to you medical decisions
- After death decisions to think about now
- The proxy quiz for family and physician
- Conversation scripts: Getting past the resistance
- What to do after signing your health care advance directive
- Guide for health care proxies
- Resources: Advance planning for health care

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Health Care Advance Planning

- https://adrcoforegon.org/consite/plan-legal-and-care-planning.php

- *Advance Directive: Your Life, Your Decisions,* A planning guide for key conversations and advance planning forms

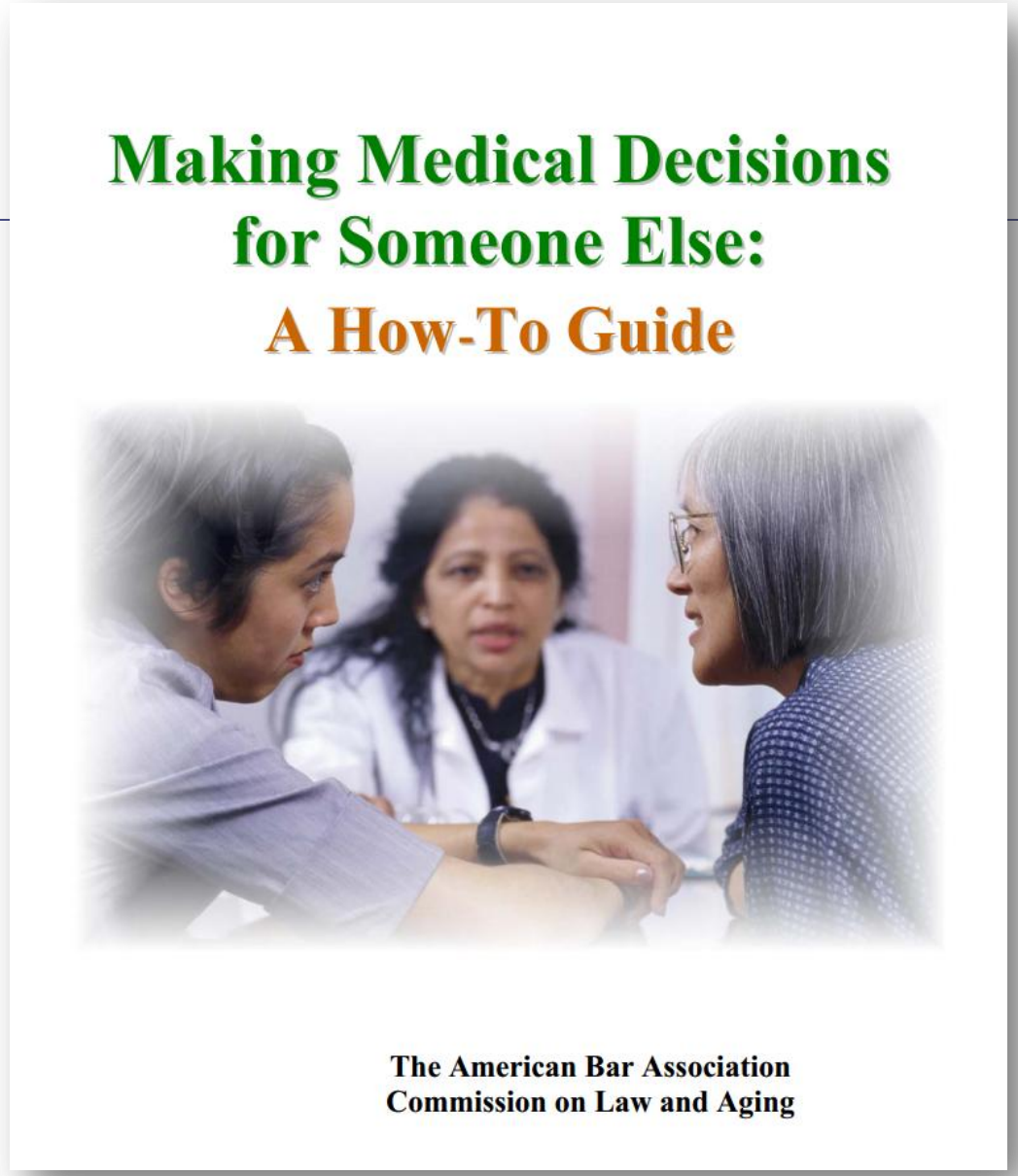
  Oregon Health Decisions (www.oregonhealthdecisions.org)

Sarah, Bill, and Options Counselor Ashley

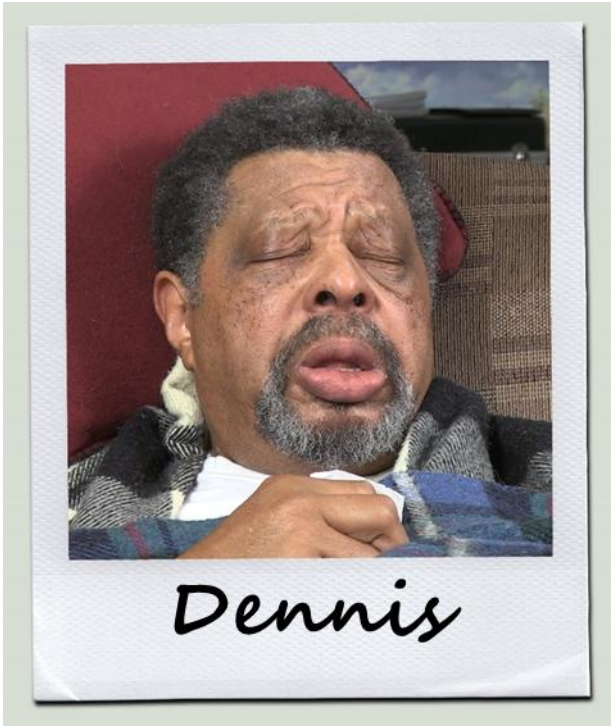
Person-Centered Advance Care Planning

https://www.youtube.com/watch?v=OOH5hVQRxD4

Joanne Lynn, Director, Altarum's Center for Elder Care and Advanced Illness - See more at: http://altarum.org/staff/joanne-lynn#sthash.TBqV1OOS.dpuf



http://www.americanbar.org/content/dam/aba/uncategorized/2011/2011_aging_bk_proxy_guide_gen.authcheckdam.pdf



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Making Decisions for Someone Else

- What is important to Dennis?
- How does he want to live when he can't play cards or read the paper?
- How did he experience his wife's death?
- What does he think about having his daughters helping him with decisions?

Dennis and home care worker

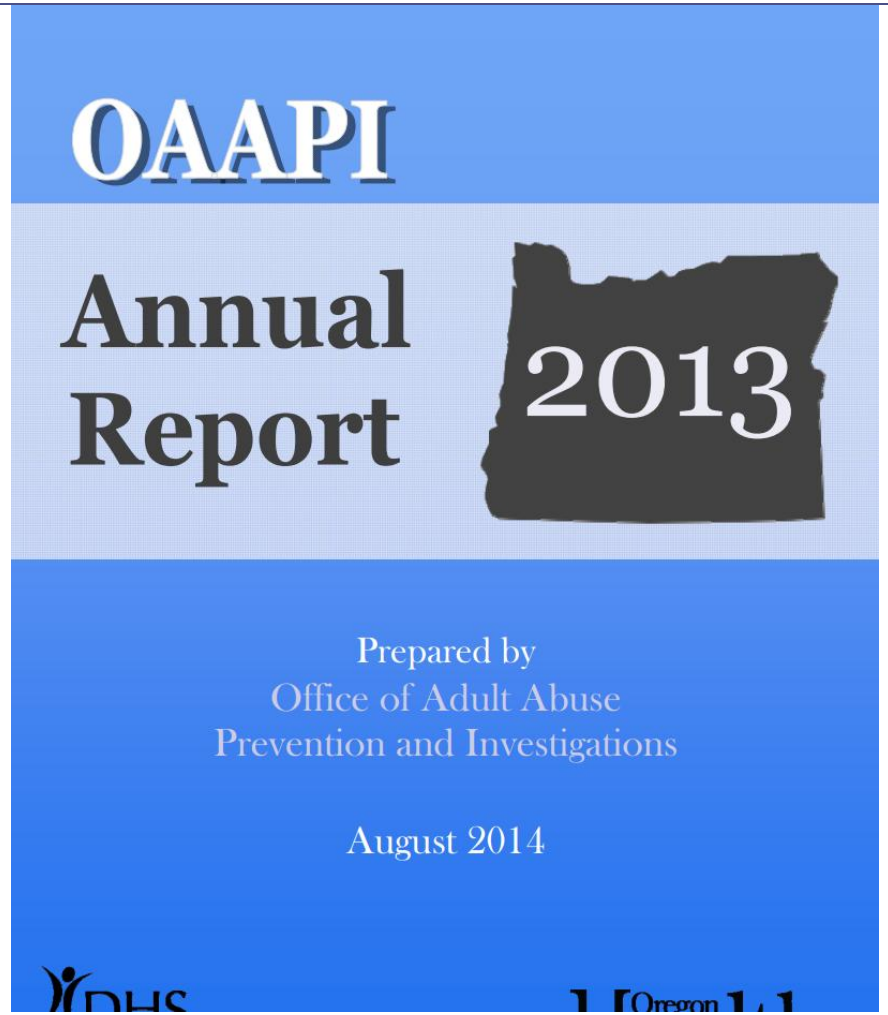
What if . . . ? Risks for Abuse and Neglect

4,211 cases of substantiated abuse

- 57% community
- 25% facility
- 18% self neglect

Prevalence (National estimates)

- Emotional (28-62%)
- Physical (4-23%)
- Neglect (20%)
- Financial (15%)



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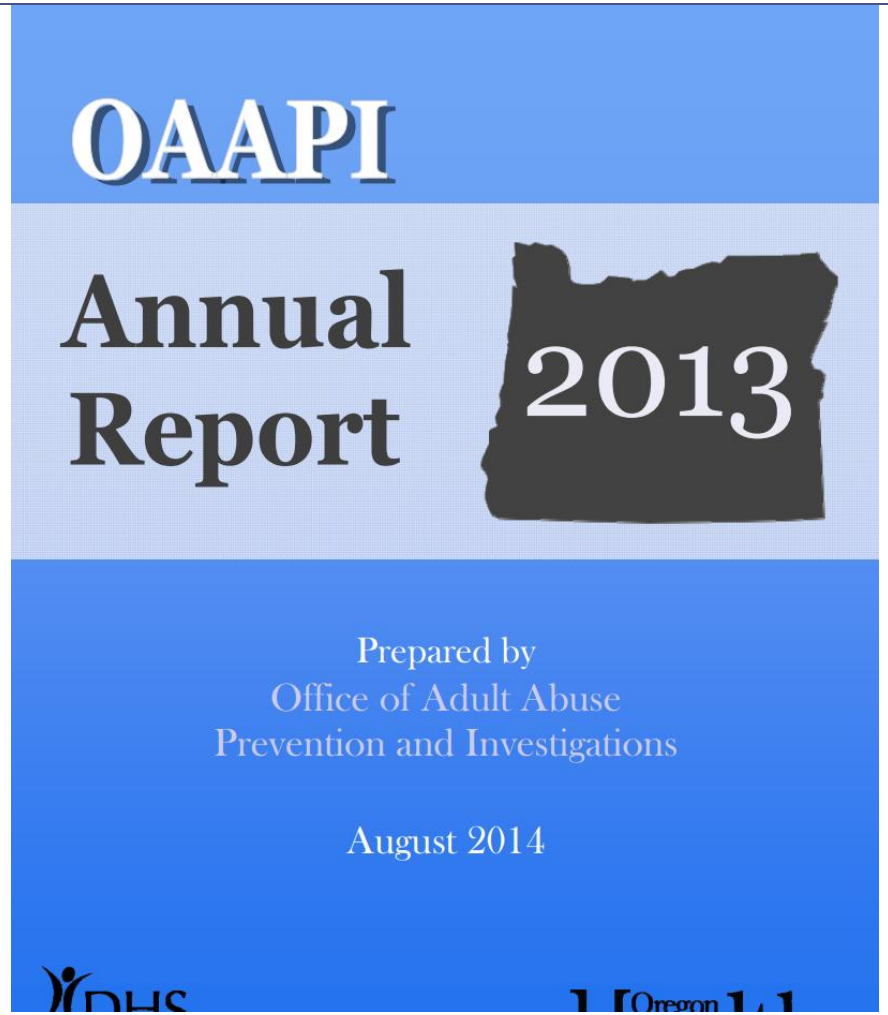
Types of Elder Abuse in the Community

Financial	44%
Neglect	22%
Verbal	21%
Physical	10%
Abandonment	1%
Sexual	1%
Other	3%



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Some More Facts About Abuse

- Many caregivers worry about becoming violent
- Abuse or neglect has been detected in nearly half of surveyed caregivers
- Possible factors:
  - History of conflict
  - Disruptive and aggressive behavior by the person with dementia
- 15% of people with dementia have been victims of financial abuse; 70% of caregivers reported callers routinely target person

Assessing and Preventing Abuse

Assessing

- Routine screening
  - Behavioral signs of distress
- Interdisciplinary focus
- Multiagency collaboration

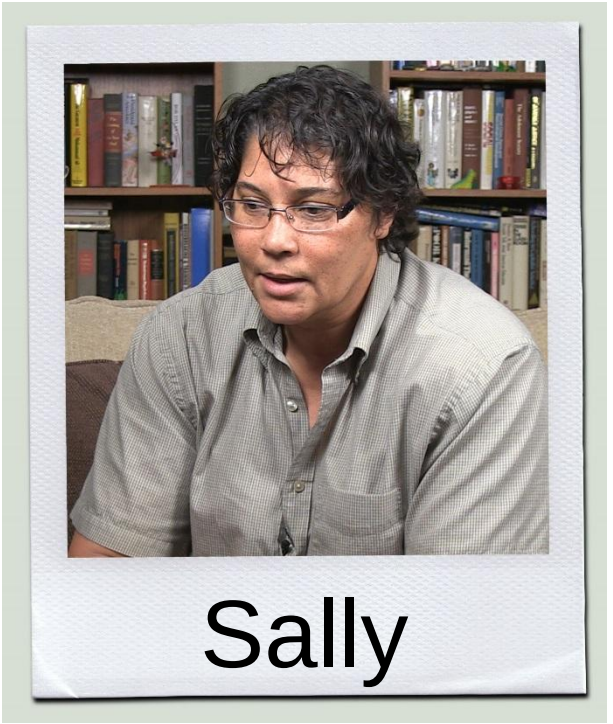
Prevention

- Targeting caregivers (limited evidence)
  - Support for caregiving role
  - Information about dementia care
  - Respite care
  - Reducing isolation

Documenting Consent

https://www.youtube.com/watch?v=2a-Qm2c5VBU

Dennis and his daughter, Sally



At Risk

- Self neglect
- Financial exploitation

Martha

Guardianship

Martha

- Alternative of last resort
- Requires a court proceeding; person may contest
- Person is incapacitated, unable to make decisions for well-being and safety
- Limited number of guardians
- Limited to areas that a person cannot remain independent
- Can manage up to $10,000

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Conservatorship

- Court appointed position for a protected person (evidence of inability to mange financial affairs)
- Manages protected person's money to the benefit of the person
- Annually reports to court on how managed money and property
- Makes financial decisions only; Does not have power to make personal decisions

Martha

Possible Alternatives to Guardianship/Conservatorships

Martha

- Work with bank (e.g., direct bill payment, direct deposit)
- Trusted relationship with case manager (e.g., private, OPI, Medicaid)

End-of-Life Care

- Loss of function
  - Verbal abilities have been lost
  - Full assistance is needed for all personal care
  - Muscles may become contracted
  - May lose ability to swallow
  - Pneumonia is common
- Palliative and Hospice care can reduce distressing symptoms
- Without advance planning:
  - What would the person want?
  - If unknown, what would be in the person's best interests?

End-of-Life Planning

https://adrcoforegon.org/consite/plan-legal-and-care-planning-develop-documents.php

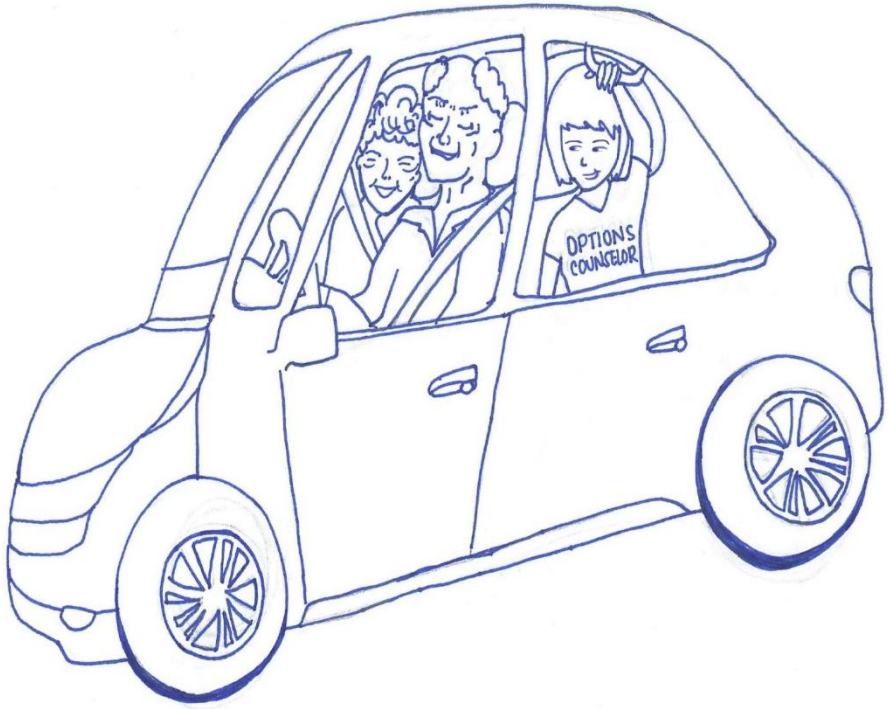
- http://www.or.polst.org/
- POLST (Physician Orders for Life Sustaining Treatment)
  - Completed by a physician or nurse practitioner
  - For use by people with a serious health condition
  - Follows patient wishes and treatment intentions regarding:
    - Resuscitation
    - Medical conditions
    - Use of antibiotics
    - Artificially administered fluids, nutrition

What Sarah may experience

Dementia: End-of-life care

Final Reflections: Supporting People with Dementia

- Person-centered thinking and planning
- Advance planning
- Capacity for decision making
- Resources
  - Guides, planning materials
  - Legal and financial advice
  - Conservatorship/guardianship



Thank You!

www.HelpforAlz.org

Feedback survey and knowledge assessment

Please give us your feedback on this training module and complete the knowledge assessment

https://www.surveymonkey.com/s/Dementiamodule8-Tier2quiz

This training was developed by Portland State University on behalf of Oregon Department of Human Services – Aging & People with Disabilities. Funding for this project was provided by an Administration for Community Living grant (#90DS2001) and funding provided by the Oregon Legislature for mental health training.