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
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
  o Financial
  o Legal
  o Health
  o 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
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.”

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
I have Alzheimer’s Disease

- [http://www.alz.org/i-have-alz/plan-for-your-future.asp](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](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
Planning for Your Future: A Toolkit for Long-term Services and Supports

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

<table>
<thead>
<tr>
<th>Type of service</th>
<th>Cost of service (state average)</th>
<th>Anticipated amount of time</th>
<th>Estimated yearly cost of services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing facility</td>
<td>$7,057 per month X [ ] months</td>
<td>= $__________</td>
<td></td>
</tr>
<tr>
<td>Assisted living</td>
<td>$4,023 per month X [ ] months</td>
<td>= $__________</td>
<td></td>
</tr>
<tr>
<td>In-home care worker</td>
<td>$20 per hour X [ ] = $ [ ] hours per week X 52 weeks = $__________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult day services</td>
<td>$94 per day X [ ] = $ [ ] X 52 weeks = $__________</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult foster/care home</td>
<td>$2,043 per month X [ ] months = $__________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.
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_careDecision_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


- **Advance Directive: Your Life, Your Decisions,**
  A planning guide for key conversations and advance planning forms
  
  Oregon Health Decisions
  ([www.oregonhealthdecisions.org](http://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
Making Medical Decisions for Someone Else: A How-To Guide

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?
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%)
### Types of Elder Abuse in the Community

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td>44%</td>
</tr>
<tr>
<td>Neglect</td>
<td>22%</td>
</tr>
<tr>
<td>Verbal</td>
<td>21%</td>
</tr>
<tr>
<td>Physical</td>
<td>10%</td>
</tr>
<tr>
<td>Abandonment</td>
<td>1%</td>
</tr>
<tr>
<td>Sexual</td>
<td>1%</td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
</tr>
</tbody>
</table>
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

Sally
At Risk

- Self neglect
- Financial exploitation

Martha
Guardianship

- 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

Martha
Conservatorship

- Court appointed position for a protected person (evidence of inability to manage 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

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

Martha
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


- [http://www.or.polst.org/](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

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