ADRC Dementia Care Training

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

Module 7: Decision Support in Care Transitions
Aging Services and Supports for People Living with Dementia

Tier 1:
1. Understanding Person-Centered Care
2. Communication and Behavioral Expressions
3. Medical and Clinical Aspects of Dementia
4. Complex Information and Referral Issues

Tier 2:
5. Honoring Personhood through Person-Centered Decision Support (orientation and building trust)
6. Honoring Decision Support through Person-Centered Planning
7. **Decision Support in Care Transitions**
8. Decision Support for Advanced Care and End-of-Life Planning
Options Counseling Competency Areas

- Understand needs, values and preferences from the point of view of the person (Module 5)
- Support self-determination (Modules 5 and 6)
- Encourage a future orientation (Module 8)
- Knowledge of private and public resources (Modules 6, 7, 8)
- Follow-up (Modules 7 and 8)
Review of Modules 5 and 6

Module 5
- Team Performance Model
- Tools supporting person-centered planning
- Introducing the cast of characters!

Module 6
- Setting goals
- Developing and implementing plans
- More tools to support person-centered planning
Module 7 Objectives

Participants will

- Understand the differences between dementia, depression, and delirium
- Be able to describe common care transitions experienced by persons living with dementia.
- Understand the risks to the person living with dementia associated with various care transitions.
- Be able to support families and others to reduce adverse effects of transitions for people living with dementia and their families.
Team Performance Model

- Team Performance Model
  - Orientation
  - Build trust
  - Identify goals and roles
  - Commitment
  - Implementation
  - Performance
  - Renewal
Performance and Renewal

- **Performance**
  - Participants feel it is working well
  - Routine communication rather than formal planning
  - Can change goals and responses as needed

- **Renewal**
  - Dementia progresses, plans no longer work
  - People get tired
  - New planning and action needed
Transitions with Dementia

- Psychological
  - Changes for the person with dementia and family
  - Depression
  - Caregiving

- Changes in physical settings
  - Home and driving
  - Transitions to and from the hospital
  - Transitions to residential care setting
Psychological Transitions

- Becoming a person with dementia
- Becoming a person with dementia who needs more support and supervision

Sarah and her children years ago

Sarah and Bill sharing memories
Family Transitions

- What have we learned about dementia?
- What supports are available to people with dementia?
- What supports are available to families?

Sarah’s husband, Bill
Psychological Transitions

Becoming a family member of someone with dementia

- What is dementia?
- What will happen to Dad?
- What will happen to the Family?
- What are my new roles?

Dennis’ daughter, Sally
30% of people with dementia meet diagnostic criteria for depression (Segal, Qualls, and Smyer, 2011)

Onset of depression occurs over weeks and months

Depression often masks dementia

Dementia often masks depression
Depression  (adapted from C. Van Son, 3 D’s of Confusion)

- Some Causes
  - Heredity
  - Biochemical changes
  - Drugs (prescription, over the counter)
  - Illness
  - Sensory deficits
  - Stress
  - Seasons
  - Prior history of depression → elevated risk

Sarah
Depression: Common Symptoms
(adapted from C. Van Son, 3 D’s of Confusion)

- Loss of interest/pleasure in activities
- Depressed mood, sadness, emptiness
- Feeling slowed down or restless
- Self-neglect
- Impaired attention
- Impaired information processing
- Feeling worthless or guilty
- Thoughts of death or suicide
- Increase or decrease in appetite
- Trouble sleeping, sleeping too much
- Loss of energy, fatigue
- Problems thinking, making decisions concentrating
Depression and Dementia

- Common Symptoms of both:
  - Loss of interest/pleasure in activities
  - Self-neglect
  - Impaired attention
  - Impaired information processing
  - Problems thinking, concentrating, making decisions

- Get a thorough physical, cognitive, and psychological exam!
Family Caregivers and Depression

- 26% of family caregivers suffer from depression
- Majority of family caregivers of those with young onset dementia experience mild to severe depression
- Spouse caregivers at increased risk of loneliness

Sarah’s husband, Bill
Additional Issues with Younger Onset

- Difficulties getting a diagnosis
- High levels of family conflict
- Lack of services for those <60
- Impact on work life and finances

Van Vliet et al, 2010
How Options Counselors Can Help

- Help keep the person in the forefront
- Explore values, needs, and preferences from the person’s perspective early and often
- Identify what is “important to” and “important for” the person
- Include family members perspectives in “what is working” and “what is not working”
- Help plan and prepare for future transitions
Caregiver Support Services

- ADRC
  - [www.adrcforegon.com](http://www.adrcforegon.com)
    - Family caregiver support program
    - Family caregiving training
    - Caregiving guides
    - Self-assessments
  - [www.HelpforAlz.org](http://www.HelpforAlz.org)

- Family Caregiver Alliance
  - [www.caregiver.org](http://www.caregiver.org)

- Alzheimer’s Association
  - [www.alz.org](http://www.alz.org)
    - 24/7 telephone support
    - Younger onset dementia
    - Exploring support groups
    - Education programs (face-to-face, online)

- Alzheimer’s Network
  - [http://alznet.org/](http://alznet.org/)
Transitions in Physical Settings

- Transitioning at home
- Transitioning to and from the hospital
- Transitioning to a residential care setting
Transitioning at Home: Focus on Safety

Common Safety Concerns

- Driving
- Medication Management
- Falls
- Cooking
- Getting adequate nutrition
- Getting lost

www.HelpforAlz.org
www.alz.org
Giving Up the Car Keys

- **Some signs**
  - Forgetting how to locate familiar places
  - Failing to observe traffic signals
  - Making slow or poor decisions
  - Driving at inappropriate speeds
  - Returning from a routine drive later than usual

- **Families, care partners may need to:**
  - Talk to the person about stopping to drive
  - Ask a doctor to write a “do-not-drive” prescription
  - Control access to the car keys
  - Disable the car or keep it out of site
  - Have the person evaluated by a driving rehabilitation specialist

Transitioning to and from the Hospital

- People with dementia are at greater risk of hospitalization

- Common causes:
  - Infection
  - Breathing difficulties
  - Delirium
  - Falls

- Common outcomes
  - Decline in mobility
  - Decline in activities of daily living
  - Delirium

- https://www.youtube.com/watch?v=xZPR4ulloLM

- What families can do:
  - Talk with health providers
  - Learn when to avoid hospitalization
ADRC Care Transition Programs*

- Schedule and complete follow-up visits with personal physician
- Ensure medications are correct
- Learn to recognize warning signs that condition is worsening
- Have updated personal health record to facilitate communication

*Not in all locations
Delirium: A Medical Emergency

Delirium is a serious disturbance in a person's mental abilities that results in a decreased awareness of one's environment and confused thinking. The onset of delirium is usually sudden, often within hours or a few days.

Mayo Clinic

http://www.mayoclinic.org/diseases-conditions/delirium/basics/symptoms/con-20033982

- Primary Causes
  - Medications/interactions
  - Anesthesia
  - Infections

- Risk factors
  - Age
  - Dementia
  - Frailty
Symptoms

- Rapid onset
- Inattention
- Perseveration
- Disorganized thinking
- Reduced level of consciousness
- Perceptual disturbances
- Sleep-wake disturbance or psychomotor activity
- Disoriented to time, place, person
- Memory impairment
- Easily distracted
- Fluctuating symptoms
Some More Facts About Delirium

- 50% of hospitalized older adults experience delirium
- Occurs 4-5 times more often in people with dementia
- 70% of individuals with hospital acquired delirium are not identified or treated
- It can take weeks or months to treat
- Consequences:
  - Deconditioning, falls, malnutrition, incontinence
  - Poorly managed pain
  - As many as 1/3 of those with delirium will die
Dennis’ Daughter on Delirium
How the Options Counselor can Help

- Help make families aware of delirium
- Provide tools for preparing for hospital admissions if possible
- Help families advocate: e.g., asking about delirium, efforts to prevent delirium, knowing signs to watch for.
- Connect families to transition care services

http://consultgerirn.org/resources

Information and Assessment tools including:

- Assessing pain in persons with dementia
- Wandering in hospitalized older adults
- Assessing and managing delirium in persons with dementia
Transitioning into a Residential Care Setting

Sample Tools

  - MOVE Consumer Guide to Person Centered Long Term Care
  - National Consumer Voice for Quality Long Term Care Resources

ADRC staff and partners:

- Inform person and family members about options
- Stress person-centered care approaches, finding the best matches available.
- Review ADRC resources
- Help families plan the transition
- Let families know how to stay involved following the transition.
Sarah and Bill
Sarah and Bill

Sarah
Sarah and Bill
Recap, Module 7

- Team Performance Model:
  - Plan is no longer performing well
  - New plan, action needed

- Psychological Transitions
  - Depression
  - Caregiving

- Transitions in Physical Settings
  - Safety at home
  - Risk for delirium in hospitalization
  - Residential care settings
Module 8 – Advance Planning and End-of-Life

- Early planning
  - Legal
  - Financial
  - Health care
  - Long-term Services and Supports
  - End-of-life

- Care at end-of-life
Thank You!

www.HelpforAlz.org
Thank you for your participation!

Please give us your feedback on this training module.

https://www.surveymonkey.com/s/Dementiamodule7

This training was developed by Portland State University on behalf of Oregon Department of Human Services – Aging and 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.