

# Pioneer Network Standards for Person-Centered Dementia Care

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# Presentation Objectives

Discover the practices addressed in the dementia care standards and how they can be implemented in your organization

Examine the approaches for dementia care used by an organization to implement a person-centered program

Consider the challenges and learnings to offering person-centered care as more individuals are living with dementia can various co-occurring conditions.

# Review of What We Know About Dementia

- Dementia is not a specific disease
- It is a descriptive term for a collection of symptoms that can be caused by a number of disorders affecting the brain
- People with dementia have significantly impaired intellectual functioning:
  - Interferes with normal activities and relationships
  - Loss of ability to solve problems and maintain emotional control
  - May experience personality changes and behavioral problems - agitation, delusions, hallucinations
- While memory loss is a common symptom of dementia, memory loss by itself does not mean that a person has dementia
- Although it is common in very elderly individuals, dementia is not a normal part of the aging process

# Review of What We Know About Dementia

Doctors diagnose dementia only if 2 or more brain functions - such as memory and language - are significantly impaired without loss of consciousness

- Some diseases that can cause symptoms of dementia:
  - Alzheimer's disease
  - vascular dementia
  - Lewy body dementia
  - Frontotemporal dementia
  - Huntington's disease
  - Creutzfeldt-Jakob disease
- Doctors have identified other conditions that can cause dementia or dementia-like symptoms, including:
  - Reactions to medications
  - Metabolic problems and endocrine abnormalities
  - Nutritional deficiencies
  - Infections
  - Poisoning
  - Brain tumors
  - Anoxia or hypoxia (conditions in which the brain's oxygen supply is either reduced or cut off entirely)
  - Heart and lung problems

# The Stats are Staggering

One in three people over 65 will develop dementia

Two-thirds of people with dementia are women

The number of people with dementia is increasing because people are living longer

The number of people living with dementia worldwide is currently estimated at 47.5 million and is projected to increase to 75.6 million by 2030

The number of cases of dementia are estimated to more than triple by 2050



# The Stats are Staggering

The total number of new cases of dementia each year worldwide is nearly 7.7 million, implying 1 new case every 4 seconds

The high cost of dementia care will challenge health systems to deal with the predicted future increase of cases. The costs are estimated at US\$604 billion per year at present and are set to increase even more quickly than the prevalence



# Dementia is a Public Health Priority

- According to the WHO, actions that can be taken:
  - Promote a dementia friendly society
  - Make dementia a public health and social care priority everywhere
  - Improve attitudes to, and understanding of, dementia
  - Invest in health and social systems to improve care and services for people with dementia and their caregivers; and
  - Increase research on dementia



CARF standards support the WHO principles and guide organizations that are serving this population...

# 2018 Dementia Care Practice Recommendations

The Alzheimer's Association 2018 Dementia Care Practice Recommendations outline recommendations for quality care practices based on a comprehensive review of current evidence, best practice and expert opinion.



[alz.org/dementia-care-practice-recommendations/overview.asp](http://alz.org/dementia-care-practice-recommendations/overview.asp)



# Dementia Care Specialty Population Program Description Themes

Services focus on unique and changing needs of persons with dementia

Leadership fosters a relationship-centered culture

Decisions made in partnership based on preferences, strengths, needs of persons served

Quality of life - recognizing individuality of person served

Family and support system engagement and information

Person-centered philosophy is modeled

Current research informs practice

Increases awareness about dementia in the community at large

# What Settings Can be Accredited as a Dementia Specialty Program?

DCSP accreditation may be sought in conjunction with the following programs:

- Adult Day Services
- Assisted Living
- Person-Centered Long Term Care Community
- Home and Community Services
- Case Management
- AL or LTC levels in a Continuing Care Retirement Community

# Screenings/Assessment to Understand Persons Served

Written screenings/assessments of the persons with dementia are conducted

- Prior to service initiation
- At frequency consistent with needs of person
- In response to changing care needs and changing preferences of person

Initial and ongoing written screenings/assessments:

- Address many elements
- Identify prior daily routine, preferences, choices, goals
- Are used to develop person-centered plans

# Person-Centered Planning

Based on scope and identified needs, person-centered plans are implemented for persons with dementia

- Based on assessments, observations, preferences and choices of the person
- That address many elements
- Are monitored for progress toward accomplishment of goals
- Are shared in understandable manner with person with dementia, others they have identified, and appropriate personnel

# Who Does the Service Delivery Team Include?

- Based on scope of program, service delivery team
  - Is determined by:
    - Screening/assessments
    - Person-centered planning
    - Goals of the person with dementia
  - Includes
    - Persons with dementia
    - Families/support systems, in accordance with choice of person served
    - Personnel with the necessary competencies
    - Other stakeholders, as appropriate

# THE STANDARDS AND SUPPORTING INFORMATION FOR PERSON-CENTERED DEMENTIA CARE

....All concepts are based on field input

....Standards are designed for a specialty care program

# Empowered Decision-Making

- To empower persons with dementia to make decisions each day that are consistent with their abilities, the program on an ongoing basis
  - Assess ability to make decisions
  - Minimizes barriers to decision-making by person-served
  - Communicated with person re: immediate consequences
  - Facilitates appropriate support for decision-making by person with dementia
  - Documents significant discussions and decisions made by the person with dementia in their records
- Intent: While complex decisions may not always be feasible, there are more simple decisions that a person served may be able to make to maintain quality of life....

# Screenings/Assessments

- Ongoing screening/assessment process includes info about the person's:
  - History
  - Current status
  - Important memories
  - Favorite stories
  - Daily routines
  - Comfort/reminiscence objects
  - People of importance

Intent: To be used in combination with CARF standards focused on comprehensive screening/assessment standards to gather information useful in caring for person with dementia



# Education

- The program provides or arranges for education:
  - To the person served
  - To the families/support systems
  - In accordance with identified needs that addresses but isn't limited to
    - Progression of dementia
    - Types of dementia
    - Co-existing conditions
    - Lived experience of dementia
  - Maintaining relationships
- Skills training including:
  - Activities
  - Therapeutic approach to behavior
  - Communication skills, including communication with persons served and service providers
  - Caregiver self care

» Cont'd.

# Education

- Coping with changes
  - Driving
  - Falls
  - Incontinence
  - Loss and grief
  - Legal issues
  - Mobility
  - Palliative care
  - Planning for the future
  - Risk of elopement
  - Sexuality
  - Community resources
  - Payer sources
- While the program may not provide education on all topics, there are many potential educational resources identified in the CARF Aging Services standards manual

# Behaviors

Personnel implement a positive, therapeutic approach to behavior

- Intent: Behaviors are a response to current environment – caregiver approaches are positive and consider:
  - What external factors are influencing the person to exhibit the behavior?
  - Is the behavior a problem for the person served or for me?
  - Will the “solution” cause more anxiety than the behavior?



# Restraints

Program implements written procedures regarding use of chemical or physical restraints that address:

- Use of chemical or physical restraints only after non-pharma approaches have been exhausted
- Use of chemical or physical restraints only temporarily in an emergency to protect person served or others from injury or serious harm
- Who is responsible for authorizing use of restraints
- Time-limited use
- Disclosure when used
- Strategies and reviews for discontinuation
- Documentation in records of person served

# Palliative Care and End-of-Life care

As appropriate, program incorporates into the person-centered plan:

- A palliative approach to care
- End-of-life care



# Volunteer Training

If the program utilizes volunteers, it provides documented, competency-based training to volunteers that address:

- Communication
- Dementia
- Post-incident debriefing opportunities
- Therapeutic approach to behavior

Intent: It is important to have those volunteers who interact with person with dementia to receive competency-based training because the volunteers have an impact on service delivery



# Program Manager

Program manager for dementia care specialty program:

- Qualified by virtue of training and experience in dementia care
- Has responsibility and authority to direct:
  - Resource utilization
  - Performance improvement
  - Program development/modification
  - Education for program personnel
  - Stakeholder relationship mgmt
  - Advocacy activities
  - Developing ongoing community relationships
  - Promotion of program

# Physician Input

Ongoing input into the dementia care specialty program is provided by physician who:

- Serves program as at least 1 of the following:
  - Medical director
  - Chair or member of professional advisory committee
  - Consultant with formal arrangement
  - Medical liaison
- Is licensed by professional governing body
- Maintains his/her licensure, certification, privileges in the organization, if applicable
- Is qualified by virtue of his/her training and experience in dementia
- Participates in active clinical practice related to this population
- Demonstrates currency in medical practice concerning persons with dementia
- Demonstrates active learning and involvement in the profession
- Addresses, but is not limited to:
  - Developing ongoing relationships with medical community
  - Establishing policies and procedures addressing health issues including monitoring
  - Performance improvement activities



# Collaborative Decision-Making

Program facilitates collaboration in decision making:

- Opportunities for sharing information
- Accessible information
- Timelines for information exchange
- Determining if information is understood
- Documenting significant discussions with persons with dementia in their records

# Families/Support System

As needed for families/support systems, program provides, arranges for, or assists with arrangements for services:

- Advocacy education
- Assistive technology
- Community resources
- Counseling
- Emotional support
- Reasonable accommodations
- Respite
- Support for families and persons with dementia

# Rhythm of Daily Life

Within the scope of the program, the rhythm of daily life is directed by each person with dementia, as demonstrated by:

- Accommodating choices of the person regarding cycle of each day:
  - Bathing
  - Dressing
  - Eating
  - Hygiene
  - Oral care
  - Sleeping
  - Waking
  - Resting
- Choice of clothing and grooming style
- Each person's choice to participate in personally meaningful customary routines:
  - Cleaning
  - Community activities
  - Contact with pets
  - Cooking
  - Exercise/mobility
  - Gardening
  - Hobbies
  - Intimacy
  - Recreation
  - Relaxation
  - Social integration
  - Spiritual/religious activities

# Food Services

When program provides food services, it fosters independence through procedures:

- To manage social dynamics
- Allow persons with dementia to select what, when, where they want to eat
- To address necessary adaptations
- That balance the choices of the persons served and their health/nutrition needs



# Physical Environment

Environment addresses unique needs of persons with dementia:

- Maintaining their safety
- Maximizing their function in the following areas:
  - Behavioral
  - Cognitive
  - Mobility
  - Occupational
  - Physical
  - Sensory
  - Social
- Optimizing their independence
- Promoting the dignity and self-worth of the person served



# Personnel Training

The organization provides documented competency-based training for personnel, as appropriate to their roles, at orientation and regular intervals:

- That includes dementia including progression, types of dementia, co-existing conditions, and lived experience of dementia
- Delirium
- Depression
- Identifying personal preferences of persons served
- Loss and grief
- Communication
- Therapeutic approach to behavior
- Observation skills
- Sexuality
- Meaningful engagement of persons with dementia
- Therapeutic approach to activity development and implementation

# Measuring Satisfaction

The tools used to measure satisfaction and other feedback are appropriate to elicit input from persons with dementia.



# The Program as a Resource to the Community At Large

Within its scope of practice and expertise, the dementia care specialty program acts as a resource to the community.

To advance the field of dementia care, leadership supports:

- Program's participation in research opportunities
- Provision of information about available clinical trials and other research opportunities to persons with dementia, families/support systems, personnel



# The Program as a Resource to the Community At Large

Leadership demonstrates a partnership approach to person-centered dementia care through the exchange of resources and education with:

- Persons with dementia
- Personnel
- Families/support systems
- Governing board, when applicable
- Other stakeholders as appropriate

# The Program as a Resource to the Community At Large

Program works with community leaders in emergency preparedness concerning unique needs of persons with dementia to address:



Emergency preparedness



Evacuation



Shelter



Recovery

# The Program as a Resource to the Community At Large

Program maintains knowledge of and coordination with local, regional, provincial, national, or international resources to facilitate:

- Specialized dementia services
- Use of appropriate subspecialties
- Advocacy

# Resources

- Care Practice Recommendations: Alzheimer's Association: <https://alz.org/dementia-care-practice-recommendations/overview.asp>
- Dementia Info Page: National Institutes of Health: National Institute of Neurological Disorders and Stroke [www.ninds.nih.gov/disorders/dementias/dementia.htm](http://www.ninds.nih.gov/disorders/dementias/dementia.htm)
- About Dementia: United Kingdom National Health Service [www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx](http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx)
- 10 Facts on Dementia: World Health Organization [www.who.int/features/factfiles/dementia/en/](http://www.who.int/features/factfiles/dementia/en/)
- Alzheimer's Society of Canada [www.alzheimer.ca/en](http://www.alzheimer.ca/en)

# Thank You!

For additional information, contact....

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