DEFINING QUALITY DEMENTIA CARE
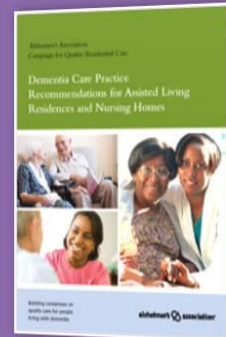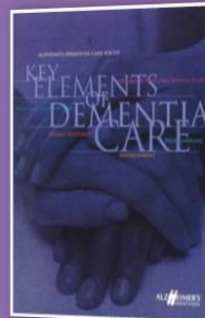
alzheimer's association®

800.272.3900   alz.org®

Defining Quality Care: | Dementia Care Practice Recommendations

alzheimer's association®

Quality Care: History

- Guidelines for Dignity
- Key Elements of Dementia Care
- Dementia Care Practice Recommendations

DCPR Review and Development

- Reviewed feedback on DCPR format and structure
- Drafted model for revision
- Conducted focus group with care experts
- Conducted thematic analysis of existing dementia care guidelines
- Revised format/model and shared with care experts for review and feedback
- Worked with expert researchers/authors to develop topic area articles with recommendations

alzheimer's association

Researchers/Authors

Person Centered Care Focus
Fazio, Pace, Flinner & Kallmyer

Detection and Diagnosis
Maslow & Fortinsky

Assessment and Care Planning
Moloney, Kolanowski, Van Haitsma & Rooney

Medical Management
Austrom, Boustani & LaMantia

Information, Education & Support
Whitlach & Orsulic-Jeras

Ongoing Care: ADLs
Prizer & Zimmerman

Ongoing Care: BPSD
Scales, Zimmerman & Miller

Staffing
Gilster, Boltz & Dalessandro

Therapeutic Environment and Safety
Calkins

Transitions/Coordination of Services
Hirschman & Hodgson

Quality Care: Today

- Evidence-based practices
- 56 recommendations by 27 expert authors
- Applicable to various care settings and throughout the disease continuum
- Published as a supplement to Feb 2018 issue of The Gerontologist
- Foundation for quality person-centered care

Dementia Care Practice Recommendations

PERSON CENTERED FOCUS

Recommendations

- Know the person
- Person's reality
- Meaningful engagement
- Authentic, caring relationship
- Supportive community
- Evaluation of care practices

Effects of Person-Centered Care

Individuals	Li and Porock (2014)	24 studies—15 culture change and 9 person-centered practices	Beneficial effects on psychological wellbeing. Significant effects on decreasing behavioral symptoms and psychotropic medication use
Staff	Barbosa, Sousa, Nolan, & Figueiredo (2015)	7 studies—PCC approaches, including DCM; stimulation-oriented approaches, emotion-oriented approaches; and behavioral-oriented approaches.	Reduction in stress, burnout and job dissatisfaction
Individuals and staff	Brownie and Nancarrow (2013)	9 articles—multi-component person-centered interventions	Positive influences on staff satisfaction and capacity to provide care; lower rates of boredom and feelings of helplessness and reduced levels of agitation in residents

DETECTION AND DIAGNOSIS

Recommendations

- Information about brain health and cognitive aging
- Signs and symptoms of cognitive impairment
- Concerns, observation and changes
- Routine procedures for assessment and referral
- Brief mental status test when appropriate
- Diagnostic evaluation follow-through
- Better understanding of diagnosis

alzheimer's association

ASSESSMENT AND CARE PLANNING

Recommendations

- Regular, comprehensive, person-centered assessments and timely interim assessments
- Information gathering, relationship building, education and support
- Collaborative, team approach
- Accessible documentation and communication systems
- Advance planning

alzheimer's association

Comprehensive PCC Assessment

Experience of the person/care partner

Function and Behavior

Health Status and Risk Reduction

MEDICAL MANAGEMENT

Recommendations

- Holistic, person-centered approach
- Role of medical providers
- Common comorbidities of aging
- Non-pharmacologic interventions
- Pharmacological interventions when necessary
- Person-centered plan for possible medical and social crises
- End-of-life care discussions
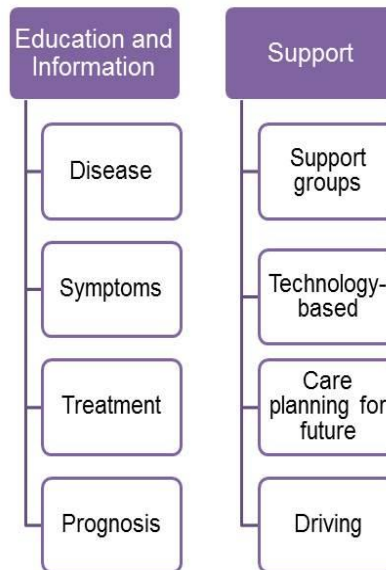
alzheimer's association

INFORMATION, EDUCATION AND SUPPORT

Recommendations

- Preparation for the future
- Work together and plan together
- Culturally sensitive programs
- Education, information and support during transition
- Technology to reach more families

alzheimer's association

Early Stage: Becoming Familiar

Education and Information
- Disease
- Symptoms
- Treatment
- Prognosis

Support
- Support groups
- Technology-based
- Care planning for future
- Driving

Middle Stage: Increased Care and Support Needs

Education and Information
- Family-centered
- Behaviors
- IADLs and PADLs

Support
- Support groups
- Counseling
- Care coordination
- Technology-based
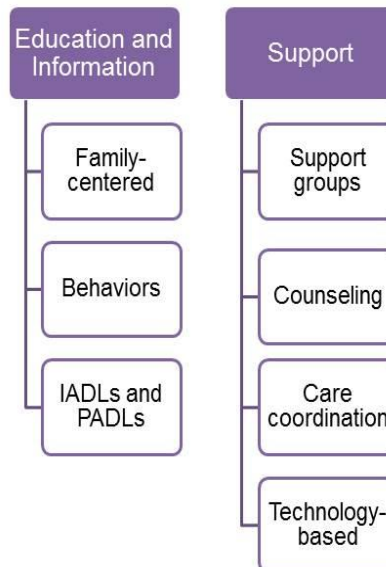
Late Stage: Relocation and End of Life Care

Education and Information

- Care needs
- Continue in-home care or relocate to an alternate care setting

Support

- Support groups or counseling
- End of life and hospice care
- Palliative care approach
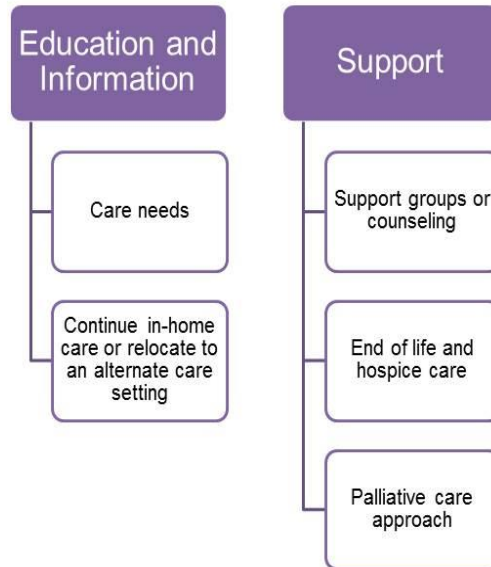
ONGOING CARE: ADLs

Recommendations

- Support for ADL function
- Person-centered care practices
- Dressing — dignity, respect, choice; process; environment
- Toileting — also health and biological considerations
- Eating — also adaptations and functioning; food, beverage and appetite

alzheimer's association

Themes in Evidence to Provide Support for ADLs

Dressing	Toileting	Eating and Nutrition
Dignity/respect/choice	Dignity/respect/choice	Dignity/respect/choice
Dressing process	Toileting process	Dining process
Dressing environment	Toileting environment	Dining environment
	Health/biological considerations	Health/biological considerations
		Adaptation/functioning
		Food/beverage/appetite

ONGOING CARE: BPSD

Recommendations

- Social and physical environmental triggers
- Non-pharmacological practices
- Investment for implementation
- Protocols
- Evaluation of effectiveness

alzheimer's association

Sensory Practices

Practice	Evidence	Outcomes
Aromatherapy	Moderate	Positive effect on agitation
Massage	Small	Positive effects on agitation, aggression, anxiety, depression, disruptive vocalizations
Multi-sensory stimulation	Large	Positive effects on agitation, anxiety, apathy, depression
Bright light therapy	Moderate	Mixed effects

Psychosocial Practices

Practice	Evidence	Outcomes
Validation therapy	Small	Positive effects on agitation, apathy, irritability, night-time disturbance
Reminiscence therapy	Moderate	Positive effects on mood, depressive symptoms
Music therapy	Moderate	Positive effects on a range of BPSDs, including anxiety, agitation, and apathy, particularly with personalized music practices
Pet therapy	Small	Preliminary positive effects on agitation, apathy, disruptive behavior
Meaningful activities	Moderate	Mixed--some positive effects on agitation; larger effect sizes for activities that are individually tailored

Structured Care Protocols

Practice	Evidence	Outcomes
Mouth Care	Small	Preliminary: positive effects on care-resistant behaviors
Bathing	Small	Positive effects on agitation

WORKFORCE

Recommendations

- Orientation and training, and ongoing training
- Person-centered information systems
- Teamwork and interdepartmental/interdisciplinary collaboration
- Caring and supportive leadership team
- Relationships
- Continuous improvement

alzheimer's association

Long-Term Care Workforce Principles

- ***Staffing levels*** should be adequate to allow for proper care at all times—day and night.
- Staff should be sufficiently ***trained*** in all aspects of care, including dementia care.
- Staff should be adequately ***compensated*** for their valuable work.
- Staff should work in a supportive atmosphere that appreciates their contributions to overall quality care. Improved ***working environments*** will result in reduced turnover in all care settings.
- Staff should have the opportunity for ***career growth***.
- Staff should ***work with families*** in both residential care settings and home health agencies.

SUPPORTIVE AND THERAPEUTIC ENVIRONMENT

Recommendations

- Sense of community
- Comfort and dignity
- Courtesy, concern and safety
- Opportunities for choice
- Meaningful engagement

alzheimer's association

TRANSITION AND COORDINATION OF SERVICES

Recommendations

- Education about common transitions in care
- Timely communication of information between, across and within settings
- Preferences and goals of the person living with dementia
- Strong inter-professional collaborative team to assist with transitions
- Evidence-based models

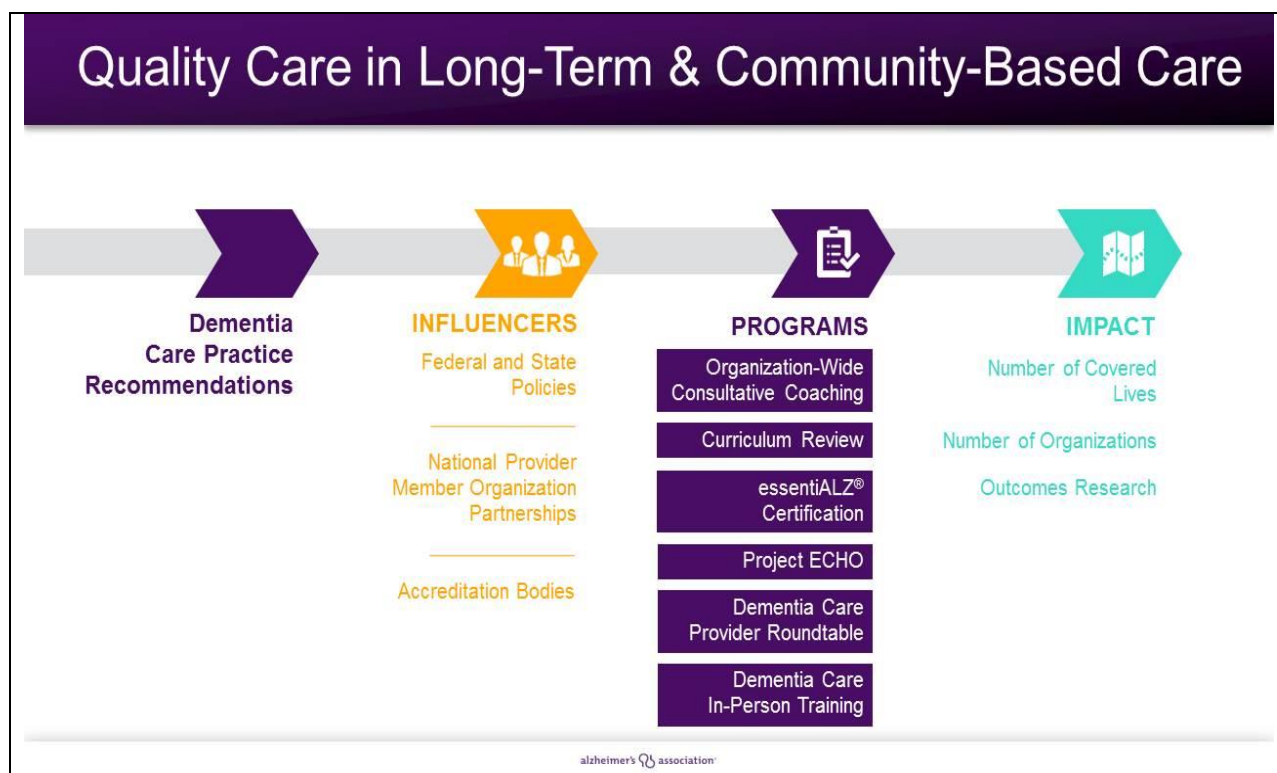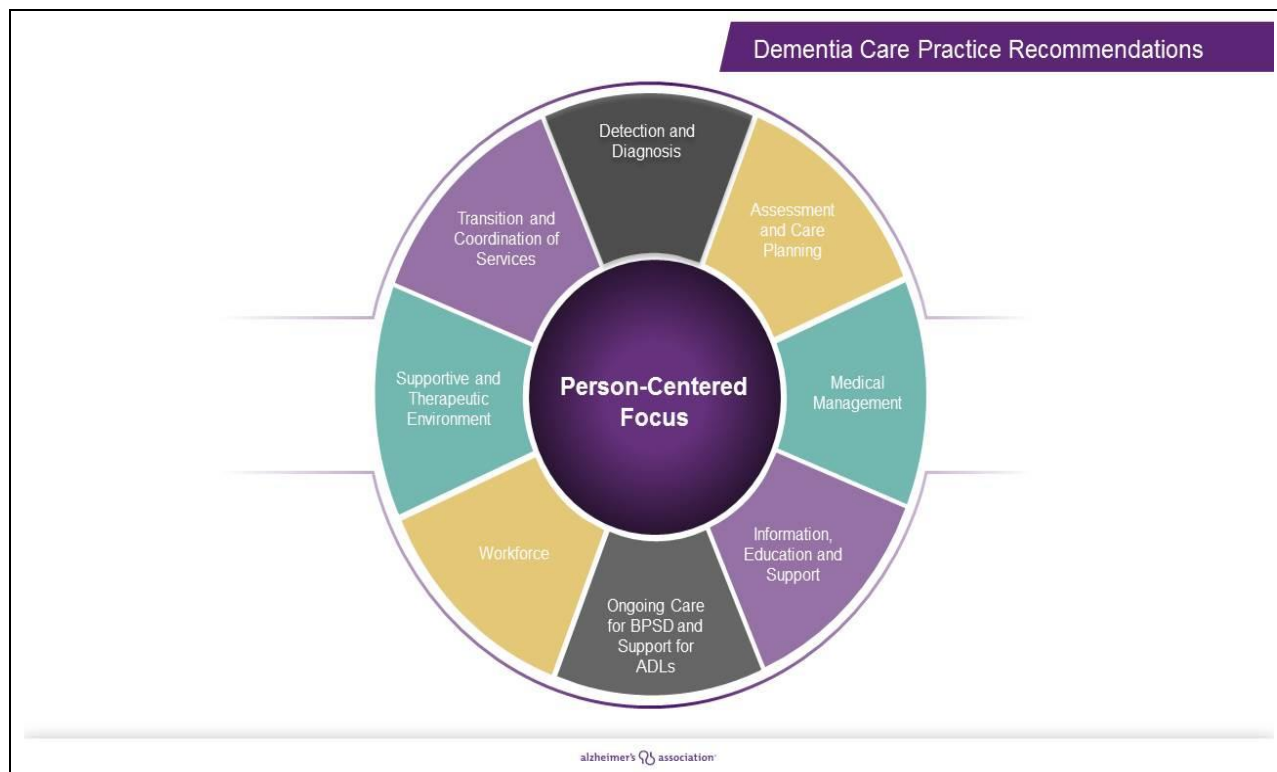alzheimer's association

Common Transitions

Hospital → Post Acute Care Services → Home → Hospice/Palliative Care

Long-term Care
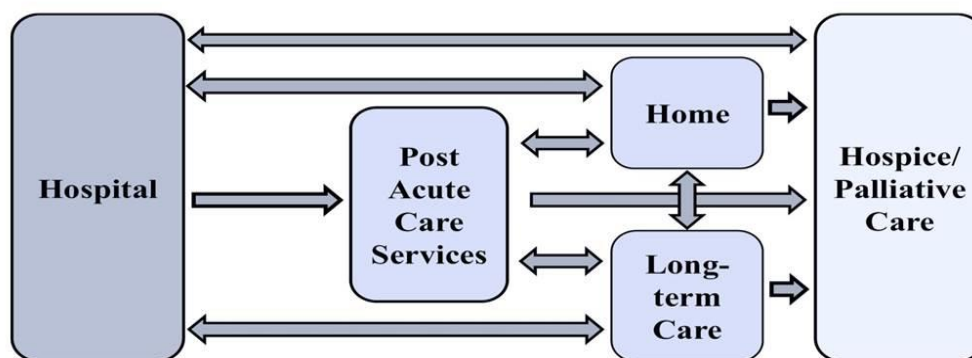
Psychosocial/Psychoeducational Interventions

Author	Setting	Intervention	Description	Outcomes
Mittelman et al. (2006)	Home	New York University (NYU) Model	Enhanced counseling and support intervention versus usual care	Time to was over 1.5 years longer than usual care group
Brodaty et al. (1997)	Psych hospital	Dementia Caregiver Training (DCT) Program	10 day intensive psycho-educational program for caregivers.	Time to placement was statistically significantly delayed
Hanson et al. (2017	Nursing home	Goals of Care (GOC) Intervention	OC video with structured care planning discussion versus informational video and standard care planning	Residents had half as many hospitalizations; Family members rated their overall quality of communication with staff higher at three months, and the quality of end-of-life care communication with staff higher at 9 months

Care Coordination Interventions

Author	Setting	Intervention	Description	Outcomes
Naylor et al. (2014)	Hospital to home	Transitional Care Model (TCM)	Augmented Standard Care versus Resource Nurse Care versus TCM	Time to first rehospitalization was longest for those in the TCM, and rehospitalization or death was accelerated for both other groups
Samus et al. (2014)	Home	MIND at Home	Dementia care coordination versus usual care	Significant delay in time to transition from home and remained in home 51 days longer
Bass et al. (2014)	Home	Partners in Dementia Care (PDC)	Care coordination program versus usual care	Fewer hospitalizations and fewer emergency department visits
Bellantonio et al. (2008)	Assisted living	Geriatrics Team Intervention (GTI)	Four systematic inter professional geriatric team assessments	Reductions in the risk of unanticipated transitions, including hospitalizations, ED visits and nursing home placement, as well as death

Person-Centered Focus

- Detection and Diagnosis
- Assessment and Care Planning
- Medical Management
- Information, Education and Support
- Ongoing Care for BPSD and Support for ADLs
- Workforce
- Supportive and Therapeutic Environment
- Transition and Coordination of Services

alzheimer's association

Quality Care in Long-Term & Community-Based Care

Dementia Care Practice Recommendations

INFLUENCERS
- Federal and State Policies
- National Provider Member Organization Partnerships
- Accreditation Bodies

PROGRAMS
- Organization-Wide Consultative Coaching
- Curriculum Review
- essentiALZ® Certification
- Project ECHO
- Dementia Care Provider Roundtable
- Dementia Care In-Person Training

IMPACT
- Number of Covered Lives
- Number of Organizations
- Outcomes Research

alzheimer's association

April 27, 2018 -- Advisory Council Meeting #28

The meeting was held on Friday, April 27, 2018, in Washington, DC. During the meeting, the Clinical Care Subcommittee took charge of the theme, focusing on advancing consensus on dementia care elements to guide new outcomes measurement. The Council heard speakers in two sessions, one focused on developing consensus about dementia care elements, and the second on models that are informing outcomes measurement. The meeting also included updates on work from the previous meetings, a presentation on the final report from the October 2017 Care Summit, and federal workgroup updates. Material available from this meeting is listed below and at https://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings#Apr2018.

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

General Information

Agenda	[HTML Version] [PDF Version]
Meeting Announcement	[HTML Version] [PDF Version]
Meeting Summary	[HTML Version] [PDF Version]
Public Comments	[HTML Version]

Handouts

Main Summit Recommendations	[HTML Version] [PDF Version]
National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers: Report to the National Advisory Council on Alzheimer's Research, Care, and Services	[HTML Version] [PDF Version]

Presentation Slides

Age-Friendly Health Systems	[HTML Version] [PDF Version]
Alzheimer's Disease and Related Dementias Research Update	[HTML Version] [PDF Version]
Care Planning and Health Information Technology: How to Aid Dementia Quality Care	[HTML Version] [PDF Version]

Clinical Care Subcommittee Agenda: Advancing Consensus on Dementia Care Elements to Guide New Outcomes Measurement	[HTML Version] [PDF Version]
Clinical Subcommittee Update	[HTML Version] [PDF Version]
Defining Quality Dementia Care	[HTML Version] [PDF Version]
Final Report to the NAPA Advisory Council	[HTML Version] [PDF Version]
Long-Term Services and Supports Committee Update	[HTML Version] [PDF Version]
Quality Care from the Perspectives of People Living with Dementia	[HTML Version] [PDF Version]
Research Summit on Dementia Care: Building Evidence for Services and Supports Process Report	[HTML Version] [PDF Version]
Testing the Promise of Primary Care: Comprehensive Primary Care Plus (CPC+)	[HTML Version] [PDF Version]
Updates and Follow-Up from January Meeting	[HTML Version] [PDF Version]

Videos

Introductions and Updates	[Video]
Clinical Care Agenda Session 1	[Video]
Public Comments	[Video]
Clinical Care Agenda Session 2	[Video]
Care Summit Final Report	[Video]
MEETING WRAP-UP: Final Report to the NAPA Advisory Council	[Video]