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Wisconsin Dementia Care Guiding Principles

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Introduction

The Wisconsin Dementia Care Guiding Principles describe the values and practices necessary to provide high-quality and effective care and support for all people with dementia. Each person with dementia has the right to the highest quality of life possible consistent with the person's need for care and with the least restrictions placed on his or her personal liberty. In Wisconsin, this includes:

- Care options that are sufficient and appropriate to meet the range of individual needs and preferences.
- High quality, coordinated care in all settings.
- Individualized care with the least intrusion in the person's life.
- A focus on prevention or mitigation of crisis situations that may arise.

The Wisconsin Dementia Care Guiding Principles support care coordination, consumer awareness, quality of life and person-centered care, safety and community engagement. The guiding principles apply to all people in Wisconsin with dementia, their caregivers, health care providers, medical personnel, first responders and all community members who serve and interact with persons with dementia.

Purpose of Guiding Principles

The Wisconsin Dementia Care Guiding Principles articulate and document appropriate and high quality care for all people with dementia in the State of Wisconsin. These guiding principles provide an effective framework for designing and implementing a state-wide model that provides a dementia-capable Wisconsin.

Establishing dementia care guiding principles is essential and important to people with dementia, their families and the community, healthcare and social service providers and staff, other entities, stakeholders and potentially all citizens of Wisconsin. The guiding principles provide a common language to assure consistency across the State of Wisconsin and enhance understanding of rights, responsibilities and available support to enable a dementia-capable Wisconsin. The guiding principles also bring confidence and capability to businesses, consumers and government resulting in increased knowledge and awareness, improved efficiency and quality, and more streamlined and effective care delivery, safety and quality outcomes.

What the Guiding Principles mean to you:

If you are a person with dementia or someone who cares for a person with dementia:

Wisconsin Dementia Care Guiding Principles are based on your rights. They exist to assure you receive the care, treatment and support you need.

If you are a care provider facility:

Wisconsin Dementia Care Guiding Principles let your employees who are providing services for people with dementia know what is expected of them as well as how to maintain and improve the quality of that service.

If you are a first responder or member of the community:

Wisconsin Dementia Care Guiding Principles provide a link to critical resources that can help assure you have the skills, knowledge and confidence to interact in the most conducive and supportive way with persons with dementia.

After each guiding principle in this document, there is a list of resource references that provides additional information to assist you.

The Wisconsin Dementia Care Guiding Principles do not replace the many existing high-quality programs, practices and tools already available to Wisconsin citizens. Instead, the Wisconsin Dementia Care Guiding Principles supplement these resources and initiatives, and provide common terminology and an understanding of the values that are shared by all stakeholders.

The Wisconsin Dementia Care Guiding Principles are not regulatory in nature. In some specifically-defined situations and settings, there may be other governing provisions that regulate applicable programs and services.

Definitions

ADVANCE CARE PLANNING

This planning promotes discussion between people with dementia, those close to them and those who provide care related to their future health and personal and practical aspects of care.

ALZHEIMER'S DISEASE

Alzheimer's disease is a progressive disease that destroys memory and other important mental functions. It is the most common cause of dementia — a group of brain disorders that result in the loss of intellectual and social skills. These changes are severe enough to interfere with day-to-day life. In Alzheimer's disease, the brain cells themselves degenerate and die, causing a steady decline in memory and mental function.

ALZHEIMER'S DISEASE: 7 STAGES

Persons with Alzheimer's disease typically exhibit cognitive and functional impairments associated with seven stages. Symptoms vary from individual to individual and generally become progressively more debilitating with the passage of time.

Stage 1: No impairment

Stage 2: Very mild decline

Stage 3: Mild decline

Stage 4: Moderate decline

Stage 5: Moderately severe decline

Stage 6: Severe decline

Stage 7: Very severe decline

Seven Stages of Alzheimer's Disease

http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp

CARE PLANNING

This planning provides services and support to assure the desired outcomes and to meet the assessed needs of the person with dementia.

CAREGIVER

A caregiver is a family member or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction.

DEMENTIA

Dementia is a general term that describes a group of symptoms, such as loss of memory, judgment, language, complex motor skills and other intellectual function, caused by the permanent damage or death of the brain's nerve cells, or neurons.

Alzheimer's disease is the most common cause of dementia in persons over the age of 65. It represents about 60 percent of all dementias. The other most common causes of dementia are vascular dementia, caused by stroke or blockage of blood supply, and dementia with Lewy bodies. Other types include alcohol dementia, caused by sustained use of alcohol; trauma dementia, caused by head injury; and a rare form of dementia, frontotemporal dementia.

LIFE STORY

A life story is an account of the events that make up a person's life and which are meaningful to her/him. A person's life story also includes references to people who are important to him or her.

PERSON-CENTERED CARE

Person-centered care is an approach to caregiving that respects those receiving care as individuals with unique needs and preferences. Person-centered care promotes respect, engagement, individuality, independence and a better quality of life for those receiving care, and addresses the changing needs of each person with dementia.

PURPOSEFUL LIVING

Purposeful living can be described as the ability to “engage in life every day” and to “find purpose and joy in daily life.” An emphasis on purposeful living recognizes that persons with dementia are capable of performing a variety of activities that fulfill their needs to be active and involved in their daily lives. These activities include exercise and other gross motor activities, grooming, socialization, meal preparation, housework, crafts, light work and special events. Activities should be tailored to the individual's personality and interests. Praise and compliments for any achievement help maintain the person's self-esteem and encourage self-participation in activities of daily living.

Dementia Care Guiding Principles

The Wisconsin Dementia Care Guiding Principles are focused on providing quality of life, person-centered care and support to all people with dementia and creating a dementia-capable Wisconsin.

Guiding Principle #1: All individuals should have access to early screening for dementia, accurate assessment and diagnosis and prompt appropriate referral for services.

Guiding Principle #2: People with dementia should have the highest degree of autonomy and choice possible.

Guiding Principle #3: The rights of people with dementia, their families and caregivers should be recognized and protected.

Guiding Principle #4: People caring for individuals with dementia should have the knowledge, skills and abilities to provide needed services in an effective manner.

Guiding Principle #5: People with dementia should have access to person-centered, culturally-competent care and services that help maintain their physical health, mental health and well-being.

Guiding Principle #6: Caregivers should understand that behaviors exhibited by a person with dementia may represent unmet needs and will address those needs appropriately.

Guiding Principle #7: People with dementia should have opportunities to take part in activities that are meaningful to them.

Guiding Principle #8: The environment and living space for a person with dementia should be designed to ensure both comfort and safety.

Guiding Principle #9: Dementia-related education, information, guidance and resources for community members should be easily accessible.

Guiding Principle #10: People with dementia, their families and those caring for them should have access to the delivery of integrated services.

Guiding Principle #1

All individuals should have access to early screening for dementia, accurate assessment and diagnosis, and prompt appropriate referral for services.

Early detection, and accurate assessment and diagnosis of dementia, as well as, appropriate and prompt referral for health and social support services are the key components involved with the initial identification and treatment of dementia.

Community awareness regarding memory loss and dementia will significantly support early detection efforts. This includes awareness of dementia signs and symptoms by family members, caregivers, first responders, law enforcement, medical personnel, physicians and social workers.

Also increased education and training regarding dementia will enable families, communities and professional service providers to understand dementia and the importance of taking appropriate action to help people at risk for dementia receive the early screening and assessment that leads to an accurate diagnosis.

Following a diagnosis of dementia, it is critical that people with dementia, and if the person consents, their families or others, receive information about the illness and the treatments, supports and services available to them. Based on an assessment of the specific needs of the person with dementia they should be promptly referred to appropriate services and be made aware of proposed treatment options. This may include referrals to:

- specialized assessments;
- specialized doctors such as neurologists;
- social services;
- mental health services;
- support groups; and/or
- physical therapy and other type of therapy services.

Receiving an early diagnosis and specialized, person-centered information, treatments and support services allows the person in the early stages of dementia to live a quality life and be involved with decisions that are important to them now and in the future.

Valid, evidence-based, multi-culturally appropriate dementia screening and assessment tools developed specifically for a variety of situations and settings for Wisconsin's diverse population are available. This includes tools for people who do not have English as their first language. The U.S. Department of Health and Human Services National Institute for Health (NIH) website at:

<http://www.nia.nih.gov/search/site/Dementia%20Screening> references a wide-array of

studies and information about screening tools, instruments and tests such as computerized and non-computerized self-tests, community screening instruments, and primary care and cognitive assessment screening tools. Appropriate tools need to be well-understood and routinely used by all types of persons who interact with people at risk for dementia. This includes, but is not limited to, people at risk for dementia, family members, caregivers, community health workers, first responders, law enforcement, medical personnel, physicians and social workers. Effective early screening will help support an accurate diagnosis which is critically important to ensure high-quality health and social care.

Additional information on diagnosis including the benefits of early diagnosis can be found at the NIH website at: <http://www.nia.nih.gov/alzheimers/topics/diagnosis#options>

EXAMPLES AND BEST PRACTICES

The United Kingdom and Scotland are recognized leaders in developing comprehensive standards for dementia care. Both have quality standards for dementia that include guidance regarding accurate and timely diagnosis, assessment and referrals for health and social care services. Each country's standards include statements and actions needed to support the standards as well as quality measures and outcomes. These standards may provide insightful examples and practices that Wisconsin may wish to build on. Below is high-level information about each of the countries' standards regarding diagnosis:

- The United Kingdom Dementia Quality Standard (QS1) pathway has a dementia diagnosis and assessment path that starts with "Persons with suspected dementia" and goes through investigation, assessment, diagnosis, needs and interventions. The path provides information about the items on the path, resources and related quality statements. Detailed information can be found at the following website: <http://pathways.nice.org.uk/pathways/dementia>.
- The Scotland Standards of Care for Dementia states that "As a person with dementia I have the right to a diagnosis". Under the guidance for that statement it includes information about receiving an accurate and timely diagnosis, pre-diagnosis, what should happen at the time of diagnosis, the need to receive information about the illness and supports and services, and the opportunity to make plans for the future. Specific information can be found on pages 6-12 in the document at the following website: <http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>

A recent Wisconsin Statewide Screening and Diagnosis Project titled the *Memory Screening Initiative* provides information on potential best practice ideas regarding a systems approach to improving the diagnosis and treatment for dementia. The initiative was funded by the Centers for Medicare and Medicaid Services (CMS). The Wisconsin Alzheimer's Institute and the Wisconsin Department of Health Services collaborated with county-based Aging and Disability Resource Centers (ADRC) and Care Management Organizations (CMO) located in Richland, La Crosse and Milwaukee

Counties, and the Wisconsin Alzheimer's Association Chapter Network to develop a systematic approach to promoting the early screening, diagnosis and treatment of dementia and Alzheimer's disease. Below are highlights of the initiatives:

- Goal was to develop a simple but effective cognitive screening protocol in which Wisconsin county staff participating in the initiative performed an abbreviated cognitive screen (60-second animal naming task) to all clients age 65 and over and a second more thorough cognitive screen (Cognistat/Neurobehavioral Cognitive Status Examination-NCSE) to those who scored positive on the animal naming task. There was no charge to the clients for this service.
- Cognistat test results were provided to the client's primary care physician who was offered training in the interpretation of the tests and the differential diagnosis of cognitive impairment.
- Physicians had the option to determine the cause of cognitive impairment or to refer for additional testing to a dementia diagnosis consultant.
- After diagnosis, the counties, in collaboration with the Wisconsin Alzheimer's Association Chapter Network, provided care management, education and support to clients and their families.
- Funding for this initiative is no longer available to the counties. However, some of the counties continue to screen for dementia and refer people with positive screens to their primary care physicians or to local memory assessment clinics.

Detailed information can be found at the following Wisconsin Alzheimer's Institute website: http://www.wai.wisc.edu/education/msi_initiatives.html. In addition, valuable information about memory clinics, and the benefits of early diagnosis can be found at: <http://www.wai.wisc.edu/clinics/overview.html>.

RESOURCE REFERENCES

A beneficial publication that may be used to promote general awareness is the National Institute on Aging (NIA) booklet titled "*Understanding Memory Loss: What to do when you have trouble remembering*" available at http://www.nia.nih.gov/sites/default/files/understanding_memory_loss.pdf. The booklet provides information about

- the difference between mild forgetfulness and more serious memory problems;
- causes of memory problems and how they can be treated; and
- how to cope with serious memory problems.

Copies of the booklet are available through the National Institute on Aging.

African-Americans & Alzheimer's Disease - the Silent Epidemic

http://www.alz.org/national/documents/report_africanamericanssilenteidemic.pdf

Benefits of Early Diagnosis

<http://www.alzwisc.org/Importance%20of%20an%20early%20diagnosis.htm>

<http://www.nhs.uk/Conditions/dementia-guide/Pages/dementia-early-diagnosis-benefits.aspx>

<http://www.wai.wisc.edu/clinics/overview.html>

Dementia Screening

U.S. Department of Health and Human Services National Institute for Health (NIH)

<http://www.nia.nih.gov/search/site/Dementia%20Screening>

Dementia Diagnosis and Assessment

<http://pathways.nice.org.uk/pathways/dementia/dementia-diagnosis-and-assessment>

<http://www.nia.nih.gov/alzheimers/topics/diagnosis#options>

Dementia Standards of Care Scotland, I have the right to a diagnosis (pages 6-12)

<http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>

Hispanic/Latino & Alzheimer's Disease

http://www.alz.org/national/documents/report_hispanic.pdf

New Diagnostic Criteria and Guidelines for Alzheimer's Disease

http://www.alz.org/research/diagnostic_criteria/overview.asp

Recognition and Management of Dementia. In Evidence-based geriatric nursing protocols for best practice

<http://www.guideline.gov/content.aspx?id=43921>

Statewide Screening & Early Diagnosis Projects (Memory Screening Initiative and Memory Care Connections)

http://www.wai.wisc.edu/education/msi_initiatives.html

World Alzheimer's Report

http://www.alz.org/documents_custom/world_report_2012_final.pdf

Guiding Principle #2

People with dementia should have the highest degree of autonomy and choice possible.

People with dementia and their caregivers need choice and control over decisions regarding the care and support they receive throughout their lives. This includes choices having to do with care and treatment, care arrangements, place of residence, legal matters and other decisions important to the person and his or her family.

Person-centered care ensures that autonomy and choice are preserved to the greatest extent possible for each person. Changing conditions and progression through dementia will necessitate advanced planning and coordination with the person's family to ensure care that is individualized and appropriate.

The Wisconsin Department of Health Services offers on-line access to important advance directive forms which are essential in developing a plan to support autonomy and choice after a dementia diagnosis. These forms are available from the agency website (<http://www.dhs.wisconsin.gov/forms/AdvDirectives/index.htm>) and include:

- Declaration to Physicians (Wisconsin Living Will)
- Power of Attorney for Health Care
- Power of Attorney for Finance and Property
- Authorization for Final Disposition

Service providers in residential treatment and care facilities will ensure that the actions of their staff and their policies and procedures demonstrate the following:

- Care plans are person-centered and strive to maintain the relationships, natural supports and routines that are important to the person with dementia.
- Systems are in place to collect and share information from the person with dementia and/or their caregiver about their personal preferences, choices and expectations of the services provided.
- Knowledge of whether the person with dementia has legally appointed someone to represent him or her in decision-making.
- Offering the person with dementia as much choice as possible in day-to-day activities, e.g. what and when to eat, when to get up and go to bed, and when to go outside.
- Staff use a variety of aids to help with communication, including the use of life story books, talking mats, digital stories, interpreters as appropriate and referral to speech and language specialists.

EXAMPLES AND BEST PRACTICES

Many excellent tools and resources already exist to assist persons with dementia, their families and caregivers in obtaining necessary information and support to assure the highest degree of autonomy and choice possible.

One example of an effective tool offered by the Alzheimer’s Association to support choice and autonomy for persons with dementia is the “I have Alzheimer’s” link to comprehensive information, assessment tools, coping strategies, training and local community resources. This information can be found at: <http://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp>

Available Information targets key areas that are essential to developing an early plan to prepare for living well throughout health transitions. Areas that relate particularly to autonomy and choice include:

- know what to expect,
- treatment and support,
- programs and support,
- plan for your future (including medical, financial and legal matters),
- live well, and/or
- local community resources.

In the United Kingdom, the National Institute for Health and Care Excellence has developed another useful tool, an on-line checklist designed to promote independence and maintain function by focusing on individual needs of persons with dementia in developing a care plan. The on-line checklist can be found at:

<http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-promoting-independence-and-maintaining-function>

The checklist is intended to assure that individual needs are addressed in preparing a care plan by addressing the following items:

- Diversity, including gender, ethnicity, age (younger or older), religion and personal care.
- Health, physical disability, sensory impairment, communication difficulties, nutrition, oral health and learning ability.
- The life story and preference of the person with dementia and caregivers, including diet, sexuality and religion.
- Maintaining independence.
- Information needs.

RESOURCE REFERENCES

Advanced Directives

<http://www.dhs.wisconsin.gov/forms/AdvDirectives/index.htm>

Alzheimer's Association – If you have dementia

http://www.alz.org/alzheimers_disease_publications_have_dementia.asp

Alzheimer's Disease International: World Alzheimer Report 2013 Journey of Care (Chapter 5)

<http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>

Dignity in Care

<http://www.scie.org.uk/publications/guides/guide15/factors/choice/>

Promoting Choice

<http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-promoting-choice>

Promoting Independence and Maintain Function

<http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-promoting-independence-and-maintaining-function>

Respect for Autonomy

http://www.alz.org/documents_custom/statements/respect_for_autonomy.pdf

Rights of People and Families Alzheimer's Association – Financial/Legal

http://www.alz.org/alzheimers_disease_publications_financial_legal.asp

Voices of Alzheimer's Disease

http://www.alz.org/national/documents/report_townhall.pdf

Guiding Principle #3:

The rights of people with dementia, their families and caregivers should be recognized and protected.

Recognizing and protecting the rights of people with dementia and their families provides a foundation for quality of life and care. Person-centered dementia care ensures protection of individual and family rights, and focuses on the whole person rather than the disease of the brain. The abilities, emotions and cognitive capacities of the person with dementia are maximized. Psychosocial and physical/medical care are kept in balance.

The rights of all people with dementia and their families include:

- The right to a timely, accurate diagnosis.
- The right to be regarded as a unique individual and to be treated with dignity and respect.
- The right to access a range of treatment, care and support.
- The right to participate in care and treatment decisions, including the use of medication and medical procedures.
- The right to be included and supported by the community.
- The right to have compassionate and competent caregivers who are well educated about dementia.
- The right to care that maximizes independence, inclusion and individualism.
- The right to cultural awareness, communication access, linguistic considerations, religious practices and to maintain lifestyle choices.
- The right to freedom from abuse, neglect, self-abuse/neglect and financial exploitation.

EXAMPLES AND BEST PRACTICES

In Scotland, the Cross Party Group in the Scottish Parliament on Alzheimer's has created the Charter of Rights for People with Dementia and their Carers in Scotland. The Cross Party Group recognized that, in addition to the impact of dealing with a dementia diagnosis, people with dementia and their caregivers often face cultural, social and economic barriers to full recognition of their rights. The Cross Party Group believed the Charter of Rights was necessary to:

- Ensure that those who provide health and social care and other services understand and respect the rights of people with dementia and their caregivers.
- Empower people with dementia and their caregivers to assert their rights in their daily lives.
- Ensure the highest quality of service provision to people with dementia and their caregivers.

The *Charter of Rights for People with Dementia and their Carers in Scotland* reflects the standards already set by the United Nations and other international instruments by recognizing and supporting the rights of people with dementia and those who care for them. The Charter also reflects the views of over 500 people (including people with dementia, those who care for them, and experts) who took part in the widespread consultation carried out on behalf of the Cross Party Group in the Scottish Parliament on Alzheimer's, and is guided by the relevant general principles from the Convention on the Rights of Persons with Disabilities and Adults with Incapacity Act 2000 (Scotland).

Public support of the Charter is actively solicited via the Charter of Rights website – which invites on-line registration to provide support to the Charter initiative and to help raise awareness. The website can be found at: <http://www.dementiarights.org/charter-of-rights/>

The Alzheimer's Association offers useful on-line information on legal rights, as well as key legal forms/documents to assist persons with dementia and their families in asking the right questions about medical, financial and legal decisions and taking essential steps to assure that all rights are respected and protected.

Legal documents can help to ensure that the rights of every person with dementia are honored and that his or her wishes are respected even as changes in health make it necessary for others to make decisions on his or her behalf. Information can be found at: <http://www.alz.org/care/alzheimers-dementia-legal-documents.asp#ixzz3B2vXfuvf>
http://www.alz.org/documents_custom/statements/right_to_treatment.pdf

RESOURCE REFERENCES

Dementia: Supporting people with dementia and their carers in health and social care
<http://publications.nice.org.uk/dementia-cg42/introduction>
<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>

Dementia Standards of Care Scotland, I have the right to be regarded as a unique individual and be treated with dignity and respect (pages 13-18)
<http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>

Legal rights/documents

<http://www.alz.org/care/alzheimers-dementia-legal-documents.asp>

Palliative and End-of-Life Care

<http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-palliative-and-end-of-life-care>

Right to Treatment

http://www.alz.org/documents_custom/statements/right_to_treatment.pdf

Guiding Principle #4

People caring for individuals with dementia should have the knowledge, skills and abilities to provide needed services in an effective manner.

A wide variety of comprehensive training and educational opportunities are available and readily accessible to various target audiences, including people with dementia, their families and caregivers, health care professionals, law enforcement and community members.

It is critical that staff from the health, social care services and other fields that interact with, or care for, people with dementia have appropriate training to ensure the proper knowledge, skills and abilities to provide services. The training and education of staff facilitates professionals to provide proper information, resources, care and support services to promote quality of life and decision-making for people with dementia and their families. Training and education will emphasize person-centered care and techniques for using individual life stories to maximize purpose and joy for people with dementia.

Training curricula are targeted to specific audiences and provide conceptual information, as well as practical tools and methods for providing effective care and services. Training delivery methods are utilized to ensure that those who complete the training demonstrate competency in caring for people with dementia in daily situations. The use of hands-on and experiential training, case studies, mentoring and supervised practical application ensures that training and educational objectives are met. On-line training is available and accessible to reach diverse and geographically dispersed audiences.

EXAMPLES AND BEST PRACTICES

The Alzheimer's Association offers the *Dementia Care Practice Recommendations for Professionals Working in a Home Setting*, a comprehensive manual for providing home care to individuals with dementia. The manual can be found at:

http://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf

The guide details best practice recommendations for home professionals providing care in a home setting, which represent the latest research as well as the experience of care experts.

In addition, three previously published manuals providing guidance for nursing home and assisted living care and be found at:

http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf

Specifically, the Alzheimer’s Association used the following information to develop its home care practice recommendations:

- A summary of research findings from *Dementia, a NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care*; commissioned by the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) and published by The British Psychological Society and Gaskell in 2007.
- The combined knowledge of Alzheimer’s Association chapter members, its early stage advisor team, and experts from more than 20 national associations. These individuals worked collaboratively to translate research, knowledge and experience into practical recommendations.

The National Certification Board for Alzheimer Care (NCBAC) offers a voluntary, credentialing procedure to validate the competence of Alzheimer caregivers and educators based on practice-based knowledge, and application of that knowledge. Information can be found at: <https://www.ncbac.net/content/certified-alzheimer-caregiver>

The NCBAC Certification is beneficial because:

- It is a quality indicator.
- It builds confidence in a person’s professional ability to care for those with dementia.
- It demonstrates meeting national standards.
- It validates knowledge of dementia care.
- It shows dedication to dementia care as a profession.
- It provides potential career opportunities.

RESOURCE REFERENCES

Alzheimer’s Disease International: World Alzheimer Report 2013 Journey of Care (Chapter 5)

<http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>

Evidence-Based Practice Recommendations for Dementia: Educating Caregivers on Alzheimer’s Disease and Training Communication Strategies

<http://www.asha.org/Members/ebp/compendium/reviews/Evidence-Based-Practice-Recommendations-for-Dementia--Educating-Caregivers-on-Alzheimer-s-Disea---.htm>

Staff Training in Dementia Care

<http://beta.pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-staff-training>

Standards of Care for Dementia in Scotland, I have the right to have carers who are well supported and educated about dementia (page 35-39)

<http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>

Wisconsin Department of Health Services – Dementia Care System Redesign
<http://www.dhs.wisconsin.gov/Dementia/index.htm>

Wisconsin Department of Health Services – Services for the Elderly
<http://www.dhs.wisconsin.gov/aging/index.htm>

*A reference will be included listing the website for the recently developed Dementia Care training.

Guiding Principle #5

People with dementia should have access to person-centered, culturally-competent care and services that help maintain their physical health, mental health and well-being.

People with dementia should have access to person-centered care and services that help maintain their physical and mental health and well-being in their individual care setting. The needs and preferences of people with dementia are reflected in their care plans and in their care management. The person's strengths, abilities, and life stories ensure that physical, mental and psychosocial needs are met. Other important factors include access to knowledgeable physicians and health care professionals, caregivers and care staff that are responsive to the person's unique changing needs, physical activity and exercise, and treatment free from unnecessary medications. Advanced planning is discussed and considered early after diagnosis and before crisis events occur.

Caregivers' health and personal care are also important. The use of respite programs and support services help maintain the quality of care being provided to the person with dementia.

EXAMPLES AND BEST PRACTICES

The Agency for HealthCare Research and Quality has developed evidence-based geriatric nursing protocols for best practice for recognition and management of dementia located at: <http://www.guideline.gov/content.aspx?id=43921> . The agency provides detailed recommendations for those providing care and service to persons with dementia related to cognitive parameters, mental status screening tools, functional assessment, behavior assessment, physical assessment, caregiver/environment, nursing care strategies and follow-up monitoring.

Examples of the recommended protocols related to mental status screening and nursing care strategies follow as well as descriptions of potential benefits:

Mental Status Screening Tools

- Folstein Mini-Mental State Examination (MMSE) is the most commonly used test to assess serial cognitive change. The MMSE is copyrighted and a comparable tool called the [St. Louis Medical Status \(SLUMS\) Examination](#) is in the public domain.
- Clock Drawing Test (CDT) is a useful measure of cognitive function that correlates with executive-control functions.
- Mini-Cognitive (Mini-Cog) combines the Clock Drawing Test with the three-word recall.

When the diagnosis remains unclear, the patient may be referred for more extensive screening and neuropsychological testing, which might provide more direction and support for the patient and the caregivers.

Nursing Care Strategies

The Progressively Lowered Stress Threshold (PLST) provides a framework for the nursing care of individuals with dementia.

- Monitor the effectiveness and potential side effects of medications given to improve cognitive function or delay cognitive decline.
- Provide appropriate cognitive-enhancement techniques and social engagement.
- Ensure adequate rest, sleep, fluid, nutrition, elimination, pain control and comfort measures.
- Avoid the use of physical and pharmacologic restraints.
- Maximize functional capacity: maintain mobility and encourage independence as long as possible; provide graded assistance as needed; provide scheduled toileting and prompted voiding to reduce urinary incontinence; encourage an exercise routine that expends energy and promotes fatigue at bedtime; and establish bedtime routine and rituals.
- Address behavioral issues: identify environmental triggers, medical conditions, caregiver–patient conflict that may be causing the behavior; define the target symptom (i.e., agitation, aggression, wandering) and pharmacological (psychotropics) and nonpharmacological (manage affect, limit stimuli, respect space, distract, redirect) approaches; provide reassurance; and refer to appropriate mental health care professionals as indicated.
- Ensure a therapeutic and safe environment: provide an environment that is modestly stimulating, avoiding overstimulation that can cause agitation and increase confusion and understimulation that can cause sensory deprivation and withdrawal. Utilize patient identifiers (name tags), medic alert systems and bracelets, locks, and wander guard. Eliminate any environmental hazards and modify the environment to enhance safety. Provide environmental cues or sensory aids that facilitate cognition, and maintain consistency in caregivers and approaches.
- Encourage and support advance-care planning: explain trajectory of progressive dementia, treatment options, and advance directives.

- Provide appropriate end-of-life care in terminal phase: provide comfort measures including adequate pain management; weigh the benefits/risks of the use of aggressive treatment (e.g., tube feeding, antibiotic therapy).
- Provide caregiver education and support: respect family systems/dynamics and avoid making judgments; encourage open dialogue, emphasize the patient's residual strengths; provide access to experienced professionals; and teach caregivers the skills of caregiving.
- Integrate community resources into the plan of care to meet the needs for patient and caregiver information; identify and facilitate both formal (e.g., Alzheimer's associations, respite care, specialized long-term care) and informal (e.g., churches, neighbors, extended family/friends) support systems.

Potential Benefits:

Patient

The patient remains as independent and functional in the environment of choice for as long as possible, the co-morbid conditions the patient may experience are well managed and the distressing symptoms that may occur at end of life will be minimized or controlled adequately.

Caregiver

Lay and professional caregivers demonstrate effective caregiving skills; verbalize satisfaction with caregiving; report minimal caregiver burden; are familiar with, have access to, and utilize available resources.

Institutions

Institutions reflect a safe and enabling environment for delivering care to individuals with progressive dementia; the quality improvement plans address high-risk, problem-prone areas for individuals with dementia, such as falls and the use of restraints.

The Alzheimer's Association offers on-line and classroom Dementia Care Training and Certification found at: http://www.alz.org/professionals_and_researchers_11176.asp

These training programs utilize the practice recommendations described in the Alzheimer's Association *Dementia Care Practice Recommendations* which promote the principles of person-centered care.

Helpguide.org is a non-profit on-line resource offering expert information and support for many health challenges, including dementia. Helpguide.org provides comprehensive online access to tools, information and resources intended to help provide the best care

to persons with dementia. More information can be found at:

http://www.helpguide.org/elder/alzheimers_disease_dementias_caring_caregivers.htm

At this website, under the heading *Dementia & Alzheimer's Care: Planning and Preparing for the Road Ahead* information and resources target the following important areas of dementia care:

- preparing care,
- developing routines,
- engaging the patient in activities,
- planning activities,
- handling challenges,
- considering long term care, and
- assisted living or nursing homes.

Also located at this website is a link to *Caregiving Support and Help*.

RESOURCE REFERENCES

Aging and Disability Resource Centers in Wisconsin

<http://www.dhs.wisconsin.gov/adrc/>

Alzheimer's Association – Quality Care

http://www.alz.org/alzheimers_disease_publications_quality_care.asp

Bath without a Battle (nursing homes)

<http://bathingwithoutabattle.unc.edu/>

Dementia Care Practice for Professionals Working in Home Settings

http://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf

Dementia Care Practice – Recommendations for Assisted Living, Nursing Homes & Residential

http://www.alz.org/national/documents/brochure_dcprphases1n2.pdf

Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes--Phase 1 and Phase 2

http://www.alz.org/documents/national/brochure_dcprphases1n2.pdf

Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes--Phase 3

http://www.alz.org/national/documents/brochure_DCPRphase3.pdf

Hand in Hand (nursing homes)

<http://www.cms-handinhandtoolkit.info/Index.aspx>

Key Elements of Care

http://www.alz.org/professionals_and_researchers_key_elements_of_care.asp

Namaste care

<http://www.namastecare.com/namaste-care-program.html>

Preparing for Alzheimer's and dementia care

http://www.helpguide.org/elder/alzheimers_disease_dementias_caring_caregivers.htm

Recognition and Management of Dementia. In Evidence-based geriatric nursing protocols for best practice

<http://www.guideline.gov/content.aspx?id=43921>

Respite Care

<http://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp>

Wisconsin Clinical Resource Center (WCRC) (nursing homes)

<https://wrc.chsra.wisc.edu/>

Guiding Principle #6

Caregivers should understand that behaviors exhibited by a person with dementia may represent unmet needs and will address those needs appropriately.

Changes in the behaviors of a person with dementia are common as dementia progresses and may create challenging situations. Dementia is a result of changes that take place in the brain and affects the person's memory, abilities, mood, communication and behavior. In addition, there may be changes occurring in the capacity to perform activities of daily living such as dressing or bathing. These changes, along with changes in environment including living arrangement, health, medication and lifestyle, may trigger challenging behaviors. Behavior is often an expression of unmet needs in people who cannot effectively communicate verbally. Recognizing these unmet needs and providing person-centered approaches best equips family and community caregivers, as well as first responders, medical personnel and law enforcement, to respond appropriately to people with dementia in challenging situations. Compassion and efforts to identify the root cause(s) of behaviors are important to understand in order to provide high-quality care. Understanding life stories and a person's history are also important tools used to understand and effectively deal with people exhibiting challenging or eccentric behaviors. The use of medication is minimized and, when possible, transitions that can create confusion and anxiety are minimized.

EXAMPLES AND BEST PRACTICES

The Province of British Columbia developed the *Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care – a Person-Centered Interdisciplinary Approach* in 2012 in response to public concerns that antipsychotic drugs and similar medications were being over-prescribed for persons with dementia in care facilities. The guideline was the effort of a multi-disciplinary team including representatives from the Interior Health Authority, Vancouver Coastal Health Authority, the Ministry of Health and other experts within the province.

The guideline reflects a focus on person-centered interdisciplinary care and decision making that involves physicians, nurses, pharmacists, caregivers, family members, care staff and persons in care, and was developed based on the Canadian Coalition for Seniors Mental Health document, *National Guidelines for Senior's Mental Health: the Assessment and Treatment of Mental Health Issues in Long-Term Care Homes* and the British Columbia (BC) *Clinical Practice Guideline on Cognitive Impairment in the Elderly: Recognition, Diagnosis and Management*. This guide can be found at: <http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf>

This guide serves as a practical, electronic decision tool to support clinical assessment and care decisions for persons with behavior and psychological symptoms of dementia. Those caring for persons with dementia are encouraged to recognize the dementia-

related behaviors as communication efforts rather than trying to control or extinguish the behaviors. Emphasis is placed on determining underlying causes of behaviors and utilizing any of a number evidence-based standardized assessment tools to assist in determining the appropriate course of treatment.

The Alzheimer's Association created *How to Respond When Dementia Causes Unpredictable Behaviors*, a three step model to assess and identify common dementia-related behaviors and their potential causes. This model can be found at: https://www.alz.org/national/documents/brochure_behaviors.pdf

The guide addresses the following behavior categories, exploring possible root causes and offering practicable recommendations for responding appropriately – Aggression, Anxiety or Agitation, Confusion, Repetition, Suspicion, Wandering and Getting Lost and Trouble with Sleep.

RESOURCE REFERENCES

Alzheimer's Australia – Behavior Changes
<http://www.fightdementia.org.au/understanding-dementia/behaviour-changes.aspx>

Alzheimer's Association – How to Respond when Dementia Causes Unpredictable Behaviors
https://www.alz.org/national/documents/brochure_behaviors.pdf

Alzheimer's Association – Treatments for Behavior
http://www.alz.org/alzheimers_disease_treatments_for_behavior.asp

Alzheimer's Association – Types of Dementia, Characteristics, Symptoms
<http://www.alz.org/dementia/types-of-dementia.asp>

Best Practice Guideline for Accommodating and Managing Behavioral and Psychological Symptoms of Dementia in Residential Care – A Person-Centered Approach
<http://www.health.gov.bc.ca/library/publications/year/2012/bpsd-guideline.pdf>

Tips for Managing Common Symptoms and Problems in Dementia Patients
http://www.helpguide.org/elder/alzheimers_behavior_problems.htm

United Kingdom's Alzheimer's Society – Dealing with Challenging and Unpredictable Behavior
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1211&pageNumber=7

The Wisconsin Department of Health Services Person-Directed Dementia Care Assessment Tool (a guide for creating quality of life and for refocusing behavior for people with dementia in long term care settings)
<http://www.dhs.wisconsin.gov/aging/Genage/Pubs/pde0084.pdf>

Guiding Principle #7

People with dementia should have opportunities to take part in activities that are meaningful to them.

People with dementia can take part in activities that are meaningful to them. This is essential as all people have different interests and preferences related to the manner in which they spend their time. Most people with dementia will need the support of others to fully participate in activities that help to maintain and improve their quality of life. Positive behavior support is the foundation of quality care. Person-centered care focused on personal choices and preferences to “engage in life every day” and to “find purpose and joy in daily life” will enrich the person’s life. Life stories, along with cultural, ethnic, religious and other personal preferences, are important factors in creating an environment where purposeful living is ensured.

EXAMPLES AND BEST PRACTICES

A powerful example of supporting purposeful and engaged living can be found in the efforts of MUSIC & MEMORYSM, a non-profit organization that brings personalized music into the lives of elderly or ailing individuals through digital music technology.

Executive Director Dan Cohen founded MUSIC & MEMORYSM with this idea: Someday, if he ended up in a nursing home, he wanted to be able to listen to his favorite ‘60s music. Drawing on his background in using technology to benefit those who would otherwise have no access, Mr. Cohen volunteered at a local nursing home in Greater New York, creating personalized playlists for residents. The effort, a success with residents, staff and families, became the prototype for a larger effort.

With additional funding, Mr. Cohen brought 200 iPods to residents of four more New York nursing homes and tested the program on a larger scale. Since then MUSIC & MEMORYSM has implemented iPod personalized music programs in hundreds of facilities throughout the United States and Canada.

In April 2012, a documentary about this effort, *Alive Inside: The Story of Music and Memory*, was screened at the Rubin Museum of Art in New York City. A video clip of Henry, , one of the residents reawakened by listening to his Cab Calloway favorites has become an inspiration and resource to many. This video clip can be found at: https://www.youtube.com/watch?v=fyZQf0p73QM&feature=player_embedded

The Alzheimer’s Association offers helpful on-line tools to support structured and pleasant activities for persons with dementia. These tools can be found at: <http://www.alz.org/care/dementia-creating-a-plan.asp#writing>

Templates can assist caregivers with planning a day for persons with dementia and checklists for key considerations can help in establishing daily plans that include

activities which provide meaning and enjoyment. These structured and pleasant activities can also often reduce agitation and improve mood.

RESOURCE REFERENCES

Alzheimer's Association -- Activities

<http://www.alz.org/care/alzheimers-dementia-activities.asp>

Alzheimer's Association – Music, Art and Alzheimer's

<http://www.alz.org/care/alzheimers-dementia-music-art-therapy.asp>

LEEPS (Language Enriched Exercise Program and Socialization)

<http://www.ncbi.nlm.nih.gov/pubmed/17534004>

MUSIC & MEMORYSM

<http://musicandmemory.org/>

Standards of Care for Dementia in Scotland, I have the right to be as independent as possible and be included in my community (page 31-34)

<http://www.scotland.gov.uk/Resource/Doc/350188/0117212.pdf>

Wisconsin Music and Memory Program

<http://www.dhs.wisconsin.gov/music-memory/>

Guiding Principle #8

The environment and living space for a person with dementia should be designed to ensure both comfort and safety.

The physical design of the living setting for people with dementia plays an important role in the person's safety and quality of life. The environment and living space must ensure both comfort and safety. In-home care settings and residential treatment facilities must provide a home-like environment. Access to safe spaces both indoors and outdoors for walking and other activity is important for high-quality care. An appropriate environment provides space for the person to be alone and provides orientation reminders. In addition to the physical setting itself, a person with dementia needs an environment that is responsive to his or her emotional, financial and social needs. Safety measures for physical safety need to be determined on an individual basis and incorporated in both home and other residential settings. Changes, modifications and adaptations of the living environment may be required to deal with changing behaviors and capabilities.

EXAMPLES AND BEST PRACTICES

A Descriptive Study of Home Modifications for People with Dementia and Barriers to Implementation is available through the National Institute of Health. Information can be found at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3167170/>

This study, a collaboration between Dresden University of Technology, Dresden, Germany and the Johns Hopkins University School of Medicine, Baltimore, MD., describes home environmental features, safety issues and health-related modifications in a community dwelling sample of 82 elderly people with dementia.

An eight-item questionnaire was implemented which solicited information on environmental modifications, use of spaces, behavioral issues such as wandering and wayfinding abilities, whether the person with dementia was able to find four places (bedroom, bathroom, living room/den, kitchen) within the home independently as well as caregivers' perceptions of barriers and facilities to adapting the environment to the needs of the person with dementia.

The study identifies several major categories of physical/environmental obstacles and safety issues (such as entrance and interior stairs, bathroom safety, excess furniture and clutter) and suggests strategies to address them. For example, when considering new building and renovations to existing buildings - architects, developers and city planners need to consider the accessibility of homes in their designs as well as mobility within the home. In addition to changing the structural design, other low cost modifications may be helpful in the care of those with dementia.

The study concludes that further research is warranted on ways of increasing the acceptance of home modifications by both caregivers and care recipients and in

addressing the need to inform caregivers about the possible scope and benefits of home modifications for persons with dementia.

Available through the Alzheimer’s Association is *Staying Safe – Steps to Take for Persons with Dementia*, which offers important safety guidance for the home environment, during travel and in emergencies or disaster situations. Also included are practical suggestions for initiating productive discussions around changes in access (to the car for example) and recommendations for organizing important documents and supplies kits for unexpected situations. This publication can be found at:

http://www.alz.org/alzheimers_disease_publications_safety.asp

RESOURCE REFERENCES

A Descriptive Study of Home Modifications for People with Dementia

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3167170/>

Alzheimer’s Association – Staying Safe at Home, Medic Alert and Safe Return, Driving

http://www.alz.org/alzheimers_disease_publications_safety.asp

Designing Environments for Dementia/Alzheimer’s Disease

http://www.alz.org/library/downloads/designenviron_rl2010.pdf

Home Safe Home – Creating a Dementia Friendly Environment

<http://www.socialworktoday.com/archive/111610p22.shtml>

Innovative Designs in Environments for an Aging Society

<http://ideasconsultinginc.com/>

United Kingdom Alzheimer’s Society – Safety in the Home

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1793

Guiding Principle #9

Dementia-related education, information, guidance and resources for community members should be easily accessible.

Community awareness, access to services and support are available to all persons with dementia in Wisconsin. Three out of four people with dementia live at home in their local communities, and of these 22 percent are living alone. Support from the community is an essential resource in the dementia care system. Community capacity and responsiveness may help delay or prevent the need for institutional care and promote quality of life for people with dementia and their caregivers. Education, information and guidance for community members are widely accessible and readily available. Many community members, businesses, organizations, and groups interact with and provide service to people with dementia. Understanding dementia and its impacts, respecting the needs and rights of people with dementia, reducing stigmatization and creating opportunities to successfully engage in community activities is an important focus for all Wisconsin communities.

EXAMPLES AND BEST PRACTICES

In response to the 2013 G8 Dementia Summit in the United Kingdom, which elevated dementia onto the global political stage, Australia has designated dementia as one of the country's National Health Priority Areas – with the ultimate goal to create a dementia-friendly country. Information can be found at:
http://www.fightdementia.org.au/common/files/NAT/FDC_Budget_2014_FINAL.pdf

The Australian Government has acknowledged that aged care reforms legislated by Parliament were only a first step and that there is a need for careful implementation to build on these reforms to ensure that people with dementia and their families and caregivers are provided with high quality, dignified care.

The Fight Dementia Campaign – Creating a Dementia-Friendly Australia, published in February 2014, articulates the visionary and specific action plan which has been created to move Australia forward to its goal with a series of critical steps, including:

- creating a national program of dementia advisors,
- expanding dementia-specific respite,
- improving the quality of residential care,
- building dementia-friendly communities and organizations, and
- establishing health priorities.

Also in Australia, *The Research and Action to Pioneer Dementia-Friendly Communities and Organisations Project*, conducted in conjunction with Alzheimer's Australia, focuses on the implementation and evaluation of two pilot dementia-friendly communities and organizations in Australia with researchers collecting data from both communities and

organizations during 2014. Information on the pilot program can be found at:
<http://globalchallenges.uow.edu.au/living/UOW164792>

This project has the potential to change both the way people with dementia interact with their social, cultural and physical environments and, in turn, the way society responds to those living with dementia.

The project, which brings together researchers from a range of disciplines, will use an action-research approach to develop a model to guide the implementation of the initiative and collect data from pilot communities and organizations. Their focus is on how to improve the health, homes, technology, social interaction, access to shops and banks, way-finding and physical surroundings to support the active participation of people with dementia on a global level.

In April 2014, the Wisconsin Department of Health Services announced the expansion of the Dementia Care Specialist Program across the state. The Dementia Care Specialist Program, embedded within select Aging and Disability Resource Centers (ADRC), has three goals. The first goal is to support the staff within the ADRC and county programs to be better prepared to support individuals with dementia and their family caregivers, the second goal is for the specialist to be a catalyst to create a dementia friendly community that includes businesses, employers, local organizations, etc. and raise awareness of the unique needs of people with dementia and their families. And the third goal is to assist individuals and families living with dementia to continue to be active and remain in their homes for as long as they chose. Additional information on this program is found at:

<http://www.dhs.wisconsin.gov/dementia/index.htm>

To learn more about a specific community's Aging and Disability Resource Center, a map of existing and developing programs is available at:

<http://www.dhs.wisconsin.gov/publications/P0/P00658.pdf> .

RESOURCE REFERENCES

Checklists for dementia-friendly environments

<http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf>

Dementia-Friendly Communities

<http://www.actonalz.org/dementia-friendly>

Goals of the Dementia Care Specialist

<http://www.dhs.wisconsin.gov/dementia/index.htm#anchor1>

The Importance of Building Dementia-Friendly Communities –

<http://www.alzheimers.net/2013-12-12/building-dementia-friendly-communities/>

Making a Town Dementia-Friendly

<http://www.aarp.org/health/conditions-treatments/info-01-2014/dementia-friendly-neighborhood.html>

Minnesota -- Act on Alzheimer's – Awareness of Alzheimer's/Dementia
<http://www.actonalz.org/awareness>

Numbered publications (with full copyright permission)
<http://www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx>

United Kingdom Innovations in Dementia – Dementia Friendly Communities
http://www.innovationsindementia.org.uk/projects_communities.htm

Wisconsin Aging and Disability Resource Centers Dementia Care Specialists
<http://www.dhs.wisconsin.gov/adrc/>

*A reference will be included listing the website for the recently developed Dementia Care training.

Guiding Principle #10

People with dementia, their families and those caring for them should have access to the delivery of integrated services.

An integrated approach to the provision of services for people with dementia, and their caregivers, is fundamental to the delivery of high-quality care. Often people with dementia, their families and caregivers are unaware of services, treatments and supports that are available from health and social care providers. Professionals, service providers and care agencies must coordinate services and support to ensure quality care. This promotes effective treatment, assessment and/or support coordination for the person with dementia and his or her family. This reduces the burden for families and caregivers. A systematic, comprehensive and easily-understood process for access to, and delivery of, services is one of the most important features of high-quality care for people with dementia in Wisconsin.

EXAMPLES AND BEST PRACTICES

In the United Kingdom, *The Whole System Integrated Care and Support Toolkit Project* was commissioned in July 2013 by the Local Government Association (LGA) as part of the National Collaborative, which includes NHS England, the Association of Directors of Adult Social Services (ADASS), the Association of Directors of Children's Services (ADCS), Monitor, Public Health England (PHE), the NHS Confederation and the Department of Health (DH). The purpose of the project was to develop a practical support package for local authority and health leaders working on “whole system” integrated care.

The overall intention was to enable local areas to bring health and social care services together, around service users and patients making better coordinated, person-centered care a reality at scale and at pace. The project was a key part of the National Collaborative’s work plan to support the development of integrated care systems in every locality in England, with the intention to support localities to:

- overcome identified barriers to integration,
- access and make best use of existing local and national information and evidence,
- understand the implications of different interventions or models of integrated care related to decisions and resource allocation across a local health and care economy, and
- support Health & Well-being Boards in tailoring and replicating successful models within their own localities.

The toolkit was designed during three half-day engagement workshops which were held in London, Leeds and Bristol. Representatives of health, local government and third sector from across the country participated in the workshops. The events were used as

a platform for communication, engagement and co-design, drawing on local experiences to help prioritize and develop support options for whole-systems integration. The workshops also gave attendees the opportunity to share learning around different ways that they had managed to overcome barriers to integrated care already. The outputs from the workshops were used to develop the contents of the toolkit. The toolkit can be found at:

<http://dementiapartnerships.com/resource/integrated-care-value-case-toolkit/>

In Scotland, The 8 Pillars Model, researched and written by Alzheimer Scotland, articulates an integrated and comprehensive, evidence-based approach to supporting people with dementia living at home during the moderate to severe stages of the illness. This model can be found at:

http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf

The 8 Pillars Model was designed to support and build the resilience of people with dementia and their caregivers to enable them to live in the community for as long as possible. The model is based on the following assumption:

Because each aspect of dementia influences every other aspect, and impacts on the overall health and well-being of the individual and their caregiver - excess disability is created when people with dementia do not receive appropriate care and treatment for the symptoms of the illness. Without the right support, there is a gap between how people actually function and how they could potentially function.

The 8 Pillars Model is intended to provide each person with the best possible support to live in their own home. The integration of health and social care provides an opportunity to create a structured, coordinated and strategic approach to community support for people with dementia and their caregivers. The 8 Pillars Model provides local authorities and NHS boards with a blueprint for restructuring integrated dementia care so that resources are used to greatest effect and is currently being piloted in five regions of Scotland.

RESOURCE REFERENCES

Alzheimer's Disease International: World Alzheimer Report 2013 Journey of Care (Chapter 5)

<http://www.alz.co.uk/research/WorldAlzheimerReport2013.pdf>

Alzheimer Scotland – Action on Dementia – 8 Pillars Model of Community Support

http://www.alzscot.org/campaigning/eight_illars_model_of_community_support

Dementia Partnerships – Integrated Care Value Case Toolkit

<http://dementiapartnerships.com/resource/integrated-care-value-case-toolkit/>

Integrated Care Pathways for People with Dementia

<http://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/Integrated-Care-Pathways.pdf>

Integrated and Coordinated Care and Service Provisions

<http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-integrated-and-coordinated-care>