



# Wisconsin Dementia Care Guiding Principles **2015**



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## Introduction

In October of 2013, the Wisconsin Department of Health Services (WI DHS) convened a Dementia Care Stakeholder Summit to launch a redesign of Wisconsin's dementia care system. Summit participants identified top priorities, which were then used to guide the development of the DHS "Dementia Care System Redesign Plan."

The plan was finalized in February of 2014 and included the important step of developing dementia care standards, now referred to as "guiding principles," for Wisconsin. The following strategies were used to design quality, comprehensive dementia care guiding principles:

- **Existing guidelines, resources and best practices were thoroughly researched to establish a foundation for Wisconsin's development of dementia care guiding principles.** Sources included the National Institute on Aging (NIA), the Alzheimer's Association, academic research studies, health provider associations, consumer and advocacy organizations, the State of Wisconsin and other states. In addition, international resources were examined, including the comprehensive United Kingdom Dementia Quality Standards and Scotland Standards of Care for Dementia. Both the United Kingdom and Scotland are leaders in the development of dementia standards including guidance statements, practices, quality measures and outcomes.
- **Input from partners throughout the dementia care network was collected to provide direction and focus areas as an initial step for the development of guiding principles.** Three stakeholder work groups were established by DHS to provide feedback and insight on what was important to include and emphasize in the guiding principles. The three workgroups consisted of experts in: 1) *crisis intervention*; 2) *service provision*; and 3) *dementia programs*. These experts participated in a three-hour discussion held in May of 2014. Workgroup participants from all three groups offered their experiences, expertise and insights. Each workgroup provided important and informative input that was essential in the development of the Wisconsin Dementia Care Guiding Principles.
- **The draft Guiding Principles was shared with dementia care partners to solicit comments and feedback.** In September of 2014, the draft was shared with stakeholders through a web-based survey. The survey link that also allowed stakeholders the opportunity to provide feedback. The responses were analyzed and considered in creating the final Guiding Principles document.

The Wisconsin Dementia Care Guiding Principles describe the values and practices necessary to provide high-quality, effective care and support for all people living with dementia. Each person



living with dementia should have access 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. This includes care options that are individualized, high quality, and well-coordinated regardless of setting, and present the least intrusion in a person's life.

The Wisconsin Dementia Care Guiding Principles also include a strong emphasis on prevention or mitigation of crisis situations that may arise, and an

emphasis on consumer awareness, person-centered care, and community engagement. The Guiding Principles are for all people in Wisconsin living with dementia, their families, their caregivers, health care providers, medical personnel, first responders and all community members who serve and interact with people living with dementia.

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.

The Guiding Principles also do not replace the many existing high-quality programs, practices and tools already available. 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.

While numerous examples and resources related to dementia care are available, those included within this document have been selected with the following objectives in mind: they illustrate the particular guiding principle they accompany, they can be replicated in Wisconsin, they provide helpful guidance, tools and templates that can be utilized by a broad base of users and they offer hope and inspiration.



## Purpose of Guiding Principles

The Wisconsin Dementia Care Guiding Principles represent the fundamental values associated with a high quality, dementia-capable system of care for people living with dementia. The Guiding Principles create a foundation for professional practice and guidance for those living with or caring for a person living with dementia.

Establishing dementia care guiding principles is essential to people living with dementia, their families and their community, healthcare and social service providers and staff, and other organizations and stakeholders. The Guiding Principles provide a common language to assure consistency across the State of Wisconsin, and enhance the understanding of rights, responsibilities and available supports necessary for a dementia-capable Wisconsin. All of the Guiding Principles are equally important and are not intended to stand alone. They have been developed to serve as an integrated whole with the collective purpose of facilitating a dementia-capable Wisconsin.

### **What the Dementia Care Guiding Principles mean to you:**

#### **If you are a person living with or caring for someone with dementia:**

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

#### **If you are a care provider:**

The Wisconsin Dementia Care Guiding Principles can assist you in orienting and training your staff and designing new programming to maintain and improve the quality of your services.

#### **If you are a first responder:**

The 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 supportive way with people living with dementia.

#### **If you are a member of the community:**

The Wisconsin Dementia Care Guiding Principles provide resources to help you to become more aware of people living with dementia in your community and provide information on ways you may be able to connect with and support them.

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



## Dementia Care Guiding Principles

**Guiding Principle #1-Personal Liberties:** People with dementia deserve the highest quality of life possible with the least restrictions placed on their personal liberties.

**Guiding Principle #2-Community Awareness:** Dementia-related education, guidance and resources for community members should be easily accessible.

**Guiding Principle #3-Early Detection and Diagnosis:** All individuals deserve to have access to early screening for dementia, followed by an accurate assessment, diagnosis and prompt referral for services.

**Guiding Principle #4-Independence and Choice:** People living with dementia deserve to have the highest degree of independence and choice possible.

**Guiding Principle #5-Individualized Care and Services:** People living with dementia deserve to receive care and services designed around their unique preferences, culture and values.

**Guiding Principle #6-Meaningful Activities:** People living with dementia deserve to have opportunities to engage in meaningful activities.

**Guiding Principle #7-Coordinated Systems:** Caregivers and health care professionals should work as a team to provide effective care for people living with dementia.

**Guiding Principle #8-Education and Training:** People caring for individuals living with dementia should have the knowledge, skills and abilities to provide effective support.

**Guiding Principle #9-Communication through Behaviors:** Caregivers should view behaviors as a form of communication and strive to identify the cause and solutions.

**Guiding Principle #10-Environment and Living Space:** The living space for people with dementia should provide safety and the comforts of home.

## Guiding Principle #1 – Personal Liberties

**People living with dementia deserve the highest quality of life possible with the least restrictions placed on their personal liberties.**



The focus of this Guiding Principle is on people living with dementia and the balance needed for them to achieve the highest quality of life with the least restrictions placed on their personal liberties. The balance is in ensuring safety and appropriate care while responding to the person's changing abilities to make choices and decisions. This Principle is the overarching goal of the Wisconsin Dementia Care System Redesign and each of the Guiding Principles in this document.

People living with dementia have unique health and emotional challenges. They need special support to continue to live a fulfilling life with the most freedom and independence possible as their health situation evolves.

Rather than focus on decline and loss, it is essential for those supporting individuals living with dementia to recognize and emphasize current abilities. In addition, people living with dementia need the maximum involvement possible in developing a plan of care that meets their individual needs. This is a critical step in developing a plan of support that will help the person living with dementia maintain abilities for as long as possible while compensating for challenges in day-to-day living. Also it is important to include the person living with dementia in current and future legal and financial decisions as well as in establishing advance planning directives. This will help to assure that his/her wishes and preferences, value as a person, and his/her experiences and relationships are not overlooked or diminished.

In order to achieve the highest quality of life with the least restrictions, people living with dementia need to:

- Be regarded as unique individuals and be treated with dignity and respect.
- Participate in care and treatment decisions, including decisions about the use of medication and about medical procedures.
- Receive care that maximizes independence, inclusion and individualism.
- Receive culturally competent care that includes linguistically appropriate communication access, respect, opportunity to pursue one's religious or spiritual beliefs, and practices, and opportunity to maintain lifestyle choices.
- Be free from abuse, neglect, self-abuse/neglect and financial exploitation.



- Freely participate, without undue influence, in political activity and voting (unless constrained by statute or judicial order).
- Be able to refuse medication and treatments (unless constrained by statute or judicial order).
- Participate in legal, financial and advance planning.



## EXAMPLES AND BEST PRACTICES

### Alzheimer's Association Legal Rights

The Alzheimer's Association offers useful online information on legal rights, as well as key legal forms and documents to assist people living 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 information can help to ensure that the rights of every person living 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](http://www.alz.org/documents_custom/statements/right_to_treatment.pdf)

### Eden Alternative™

The Eden Alternative™ is a non-profit organization dedicated to creating quality of life for elders and their care partners. The Eden Alternative asserts that care is a collaborative partnership. All caregivers and care receivers are considered care partners, each an active participant in the balance of giving and receiving. Focused on changing the culture of care, this approach to person-directed care initially started in nursing homes. It has since expanded its reach to all care settings. Additional detailed information is available at:

<http://www.edenalt.org/>

## International Examples

### Alzheimer's Society England, Wales and Northern Ireland - Equality, discrimination and human rights

The Alzheimer's Society is a membership organization that works to improve the quality of life of people living with dementia in England, Wales and Northern Ireland. The Society has a detailed website that includes beneficial information regarding people living with dementia related to equality, discrimination and human rights. This information can be found at the following website:

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1674](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1674)

**Scotland's Charter of Rights for People with Dementia and Their Carers in Scotland**

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 living with dementia and their caregivers often face cultural, social and economic barriers to full recognition of their rights. The Cross Party Group believed a 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 living with dementia and their caregivers.
- Empower people living with dementia and their caregivers to assert their rights in their daily lives.
- Ensure the highest quality of service provision to people living 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 living with dementia and those who care for them.

The Charter of Rights website can be found at: <http://www.dementiarights.org/charter-of-rights/>

**RESOURCE REFERENCES**

1. 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>
2. Dementia: Supporting people living with dementia and their caregivers in health and social care  
<http://publications.nice.org.uk/dementia-cg42/introduction>  
<http://www.scie.org.uk/publications/misc/dementia/dementia-fullguideline.pdf>
3. Legal rights/documents  
<http://www.alz.org/care/alzheimers-dementia-legal-documents.asp>
4. 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>
5. Right to Treatment  
[http://www.alz.org/documents\\_custom/statements/right\\_to\\_treatment.pdf](http://www.alz.org/documents_custom/statements/right_to_treatment.pdf)

## Guiding Principle #2 – Community Awareness

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



This guiding principle ensures that communities have access to resources to understand dementia and its impact.

It is estimated that one in nine people over the age of 65 has a form of dementia. Seventy percent of people with dementia are living in their homes, in the community, and not in care facilities. They go about their lives using public services, patronizing businesses and attending social events as they have always done.

Encountering someone with dementia in day-to-day life is not uncommon, yet few people seem to know much about dementia or how to be a friend to someone with dementia.

A lack of understanding about dementia has led to stigmatization of the condition. As a result, individuals are often reluctant to talk about their own concerns or concerns for a loved one, which contributes to increased levels of fear about the disease (e.g. fear of the unknown, fear of being judged negatively and fear of being told there is nothing that can be done to preserve abilities, social inclusion and respect). The remedy to the fear and isolation created by stigma is education, both at the community and individual levels.

Many community members, businesses, organizations and other groups interact with and provide service to people living with dementia. These members and groups can play an essential role in the quality of life of a person living with dementia and his or her caregivers. When the community understands dementia and its impacts, it can lead to greater respect for the needs and rights of people living with dementia and can reduce stigma while creating opportunities for people living with dementia to successfully engage in community activities.

There are many options already available for training and education. Increasing community awareness of dementia should be an important focus for all Wisconsin communities.

## EXAMPLES AND BEST PRACTICES

### The Fox Valley Memory Project

The Fox Valley Memory Project collaborates with other organizations to offer programs and services that improve the quality of life for people living with dementia, as well as their family, care partners, and friends. The Memory Project encourages practices of hospitality and inclusion that make the community dementia-friendly. The Memory Project's vision for living

well with dementia includes Memory Cafés, a Memory Loss Resource Center, Workplace Enrichment, Long-Term Care Outreach, Community Education, a Memory Assessment Center and Dementia Research. The Memory Project also supports area businesses and organizations in providing dementia-friendly service. Additional information can be found at:

<http://www.foxvalleymemoryproject.org/index.php#sthash.40UdLCz2.dpuf>

### **Jefferson County, Wisconsin Dementia Care Network**

The Dementia Care Network of Jefferson County, Wisconsin is a network of individuals and organizations who are working together with people living with dementia to ensure that their families, employers, caregivers, care providers and communities support them in living a full and meaningful life. Network meetings are hosted by the Alzheimer's Association and the Aging and Disability Resource Center (ADRC) of Jefferson County. The network assists local communities in providing a high-level of public awareness and understanding of dementia. It supports the creation of dementia-friendly businesses through education and training. The training for businesses and their employees is a half hour in length and includes material on how to identify and interact with people living with dementia, and information on what resources are available for people living with dementia.

As an offshoot of the Dementia Care Network, the Person-Centered Dementia Care Mentors Alliance (PCDMA) of Jefferson County was started early in 2014. The Alliance is a pilot project which is funded through an Extendicare Foundation Grant and is a consortium of allied organizations that meet regularly and mentor each other in implementing and sustaining culture change. The Alliance empowers each organization to develop expert coaches for person-centered dementia care, and guide the organization through making meaningful change. Another goal is to establish a replicable model for other counties to build supportive infrastructure for implementing promising practices in person-centered dementia care within their local communities. The Alliance further seeks to create collaborative community expertise and resources for preventing and alleviating distressful behavior.



### **Chippewa Falls, Wisconsin Dementia-Friendly Business Project**

The Chippewa Health Improvement Partnership, Chippewa Falls Main Street and the Chippewa County Dementia Coalition launched an initiative to help Chippewa Falls businesses become dementia-friendly in July of 2014. Janet Rubenzer-Pike, Partners of St. Joseph's Hospital member and mother of a daughter who has a form of Alzheimer's disease, brought the concept to members of Chippewa Health Improvement Partnership and St. Joseph's Hospital. The Chippewa County Dementia Coalition was then formed consisting of the ADRC of Chippewa

County, Alzheimer's Association Greater Wisconsin Chapter, St. Joseph Hospital and Dove Healthcare.

Community education and training has been implemented in Chippewa Falls through the efforts of the Coalition. A half hour training course for business employees is available. The purpose of the training is to provide employees of local businesses with the information they need to assist customers who exhibit signs of dementia. The members of the Coalition oversee the training initiative with the ADRC providing the coordination and set up of the sessions. The Alzheimer's Association Greater Wisconsin Chapter presents the training. Businesses exhibit window clings to show they are dementia-friendly. See additional information at:

[http://www.chippewafallsmainst.org/Dementia\\_Friendly.html](http://www.chippewafallsmainst.org/Dementia_Friendly.html)

### **Dementia Care Specialists**

Dementia Care Specialists are available in ADRCs in 26 counties in Wisconsin. The Dementia Care Specialist Program has three goals. The first goal is to support the staff within the ADRC and in other county programs to be better prepared to support individuals living 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 and other local organizations while raising awareness of the unique needs of people living with dementia and their families. 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 possible.

Additional information about ADRCs and dementia care specialists can be found at:

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

A map showing the location of ADRCs with dementia care specialists can be found at:

<http://www.dhs.wisconsin.gov/publications/p0/p00658.pdf>

### **International Examples**

#### **Australia - The Fight Dementia Campaign – Creating a Dementia-Friendly Australia**

*The Fight Dementia Campaign – Creating a Dementia-Friendly Australia*, published in February of 2014, articulates the visionary and specific action plan which has been created to move Australia forward to its goal of a dementia-friendly country. The action plan has 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.
- Establishing health priorities.

Additional information on the campaign can be found at:

[http://www.fightdementia.org.au/common/files/NAT/FDC\\_Budget\\_2014\\_FINAL.pdf](http://www.fightdementia.org.au/common/files/NAT/FDC_Budget_2014_FINAL.pdf)



## Australia - The Research and Action to Pioneer Dementia-Friendly Communities and Organisations

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 dementia-friendly communities and organizations in Australia with researchers collecting data from both communities and organizations during 2014. The focus is on how to improve the health, homes, technology, social interaction, access to shops and banks and physical surroundings to support the active participation of people living with dementia on a global level. Information on this pilot program can be found at: <http://globalchallenges.uow.edu.au/living/UOW164792>

## RESOURCE REFERENCES

1. Checklists for dementia-friendly environments  
<http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/Dementia-friendly%20Environmental%20checklists.pdf>
2. Dementia-Friendly Communities  
<http://www.actonalz.org/dementia-friendly>
3. Goals of the Dementia Care Specialist  
<http://www.dhs.wisconsin.gov/dementia/index.htm>
4. The Importance of Building Dementia-Friendly Communities –  
<http://www.alzheimers.net/2013-12-12/building-dementia-friendly-communities/>
5. Making a Town Dementia-Friendly  
<http://www.aarp.org/health/conditions-treatments/info-01-2014/dementia-friendly-neighborhood.html>
6. Minnesota- Act on Alzheimer's – Awareness of Alzheimer's/Dementia  
<http://www.actonalz.org/awareness>
7. Numbered publications (with full copyright permission)  
<http://www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx>
8. United Kingdom Innovations in Dementia – Dementia Friendly Communities  
[http://www.innovationsindementia.org.uk/projects\\_communities.htm](http://www.innovationsindementia.org.uk/projects_communities.htm)
9. Wisconsin Aging and Disability Resource Centers Dementia Care Specialists  
<https://www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm>
10. Wisconsin Dementia Care Project Training <https://wss.ccdet.uwosh.edu/stc/dhsdementia>

### Guiding Principle #3 – Early Detection and Diagnosis

**All individuals deserve to have access to early screening for dementia, followed by accurate assessment, diagnosis and prompt referral for services.**

Currently it is estimated that around 50 percent of people living with dementia are undiagnosed. Early detection, accurate assessment, diagnosis and prompt referral for services are essential for people living with dementia. Doing so helps promote quality of life and provides an opportunity to receive necessary physical and emotional care. There are many other benefits to early detection and diagnosis, such as the opportunity for people living with dementia and their families to:

- Plan for now and the future.
- Determine living arrangements.
- Take care of financial and legal matters.
- Develop support networks.
- Determine and receive needed healthcare.



#### Early Detection

Early detection of cognitive issues helps lead to early and accurate diagnosis. Community awareness of dementia signs and symptoms significantly supports early detection efforts; this includes awareness by family members, caregivers, medical personnel, physicians and social workers.

Effective early memory screening also helps support early detection and diagnosis. An early memory screen serves as a baseline to measure and help determine future changes in memory. A screening result that indicates some cognitive impairment does not constitute a diagnosis, but can be used to communicate a need for further examination by a physician. With the permission of the person screened, the professional who performs the screening should communicate the results to the person's primary care physician. The physician should then do an assessment and make a diagnosis if appropriate, and may also refer the person to a diagnostic clinic or other specialist for further diagnosis.

Valid, evidence-based, culturally appropriate dementia screening and assessment tools have been developed for use in a variety of situations and settings. The U.S. Department of Health and Human Services National Institute for Health's (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 community screening instruments and primary care and cognitive assessment screening tools. Some of these screening and assessment tools need to be performed by professionals while others may be performed by non-professionals who are trained to use the tools.

Only properly validated screening tools administered with the supervision of a properly credentialed professional should be used when providing community screening.

Community-based screening is available in Wisconsin in a variety of settings using a variety of tools. Memory screens can be performed by Wisconsin Aging and Disability Resource Center staff, Primary Care Physicians and other healthcare professionals.

### Diagnosis

After screening, if a primary care doctor suspects cognitive impairment, he or she may refer the person to a specialist who can provide a detailed diagnosis. Specialists can be found at memory clinics and centers or through local organizations or referral services such as the Wisconsin ADRCs or local Alzheimer's and dementia organizations. Specialists include:

- **Geriatricians**, who manage health care in older adults.
- **Geriatric psychiatrists**, who specialize in the mental and emotional problems of older adults and can assess memory and thinking problems.
- **Neurologists**, who specialize in abnormalities of the brain and central nervous system and can conduct and review brain scans.
- **Neuropsychologists**, who can conduct tests of memory and thinking.



Memory clinics and centers, including [Alzheimer's Disease Research Centers](#), offer teams of specialists who work together to diagnose problems.

### After the Diagnosis

Once a dementia diagnosis has been made, it is critical to provide the person, the family and others with information about the illness and available supports and services. Based on an assessment of the specific needs of the person living with dementia, he or she should be promptly referred to appropriate information and services and be informed of available options. This may include referrals to:

- Aging and Disability Resource Centers.
- Alzheimer's agencies.
- Specialized medical services.
- Support groups.
- Community programs.



It is also important to understand that, once a diagnosis has been received, it is the beginning of a journey that will change over time for that person. Regular cognitive reassessment and health evaluations are important in managing health conditions and understanding changes in abilities and behavior that accompany an illness with progressive decline. Changes in behavior for a person with dementia can be related to a variety of issues, including untreated medical issues such as infection, medication interactions and side effects, miscommunication and misunderstanding, and triggers in the environment. Determining the cause of a decline in ability or a change in behavior requires a thorough evaluation of the possible medical, social and environmental issues that could be the primary contributor. Determining the root cause of a change is the best way to ensure the response will be effective and to provide the assistance, support and care the individual with dementia needs at any given time.

## EXAMPLES AND BEST PRACTICES

### Wisconsin ASSIST Project

The Assistance, Screening and Support: Integrating Services Together (ASSIST) research project occurred in 2009 and 2010 at the Aging and Disability Resource Center of Portage County. The ADRC offered voluntary cognitive screening for people age 65 and over when a concern about memory loss was expressed or cognitive changes were noted. The screening occurred at the ADRC office, in the person's home or at the local primary care clinic. Screening results were discussed with the person and, if the screen indicated some cognitive impairment, the offer was made to send the results to the person's primary care physician to arrange for an assessment, possible treatment of non-dementias, and diagnosis.

Important findings from the research include:

1. Of all older adults who were offered the screen, 96 percent agreed to be screened.
2. Of all people who received a screen, 62 percent had positive screen results.
3. Of persons with a positive screen result that received a diagnostic evaluation during the project, 83 percent were diagnosed with dementia or other related conditions.

These findings demonstrated that individuals in the community were open to receiving memory screens and that the screening program was effective in identifying individuals who were experiencing the symptoms of dementia. The ASSIST Project resulted in the expansion of community cognitive screening to most ADRCs across the state, following the same model and using the same tools that were used in the ASSIST Project.

### Wisconsin Alzheimer's Institute (WAI)-Affiliated Dementia Diagnostic Clinic Network

The Wisconsin Alzheimer's Institute's (WAI) was established in 1998 as a center within the University of Wisconsin School of Medicine and Public Health (UWSMPH). WAI is committed to creating a public health environment in which Alzheimer's disease and related dementias are widely recognized, well understood and aggressively and appropriately treated. One of the major programs offered by the WAI is to support the development of accessible, quality multidisciplinary dementia diagnostic services in Wisconsin that will promote early diagnosis and treatment as well as support for caregivers. The need for more accessible diagnostic

services may be indicated by local community organizations, physicians or nurse practitioners or by other professionals or community members who recognize the need. In response, the WAI outreach staff convenes groups of concerned people to discuss needs and plan how to meet them. This may include the development of additional memory clinics and/or community education programs to increase public awareness about dementia signs, and symptoms, and the need for early diagnosis. See more information on the development of memory clinics at: <http://www.wai.wisc.edu/clinics/networkoverview.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>

### **Wisconsin Alzheimer's Disease Research Center**

The Wisconsin Alzheimer's Disease Research Center is part of a network of 30 federally funded centers that work together to prevent or cure Alzheimer's disease. These Alzheimer's Disease Research Centers are located at leading medical institutions around the country, including the Mayo Clinic in Minnesota, Northwestern University in Chicago and Harvard University in Massachusetts. The Center in Madison is the only Alzheimer's Disease Research Center in the state of Wisconsin and is affiliated with the University of Wisconsin–Madison. With 22 research faculty and more than 50 affiliated researchers, the Wisconsin Alzheimer's Disease Research Center's focus on prevention puts the Center on the leading edge of Alzheimer's research both nationally and internationally. The primary mission of the Wisconsin Alzheimer's Disease Research Center is to provide comprehensive care for older adults with dementia, by offering services that include:

- Detailed cognitive testing for early detection of memory disorders.
- Multidisciplinary diagnostic clinical evaluations.
- A review of treatment options.
- Education and referral services for caregivers and families.
- Research opportunities for patients, families, and caregivers.

For more information about the Center or to learn how you can participate in studies, visit <http://www.adrc.wisc.edu/> or call (608) 263-2582.

### **International Examples**

#### **World Alzheimer's Report 2011 Executive Summary – The benefits of early diagnosis and interventions**

The full report with detailed information can be found at the following website: [http://www.alz.org/documents\\_custom/final\\_world\\_alz\\_report\\_2011\\_summary.pdf](http://www.alz.org/documents_custom/final_world_alz_report_2011_summary.pdf)

#### **United Kingdom and Scotland**

The United Kingdom and Scotland specifically, have developed comprehensive standards for dementia care. Below is high-level information about each of the countries' standards regarding diagnosis:

- The United Kingdom Dementia Quality Standard (QS1) pathway is a dementia diagnosis and assessment path. It includes modules for assessment, diagnosis, needs and interventions. The path provides information about modules, 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 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>

## RESOURCE REFERENCES

1. 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](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.
- How to cope with serious memory problems.

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

2. Adaption of Dementia Screen for Vision-Impaired Older Persons  
[http://www.jclinepi.com/article/S0895-4356\(02\)00449-3/abstract](http://www.jclinepi.com/article/S0895-4356(02)00449-3/abstract)
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## Guiding Principle #4 – Independence and Choice

**People living with dementia deserve to have the highest degree of independence and choice possible.**



People living with dementia and their caregivers need choice and control over decisions regarding the care and support they receive throughout their lives. This includes choices for care and treatment, care and support arrangements, place of residence, legal matters and other decisions important to the person and his or her family. Health care organizations, long-term care organizations, government entities and communities have a collective

responsibility to ensure that people living with dementia and their families have choices available to them.

One approach to planning a person's care and support is person-centered planning. This is an approach that respects the person living with dementia as an individual with unique strengths, needs and preferences. Person-centered care plans promote respect, engagement, individuality, independence and a better quality of life for those receiving care and support. This type of planning also addresses the changing needs of each person living with dementia as the changes occur. Person-centered planning incorporates the person's physical, social, and spiritual needs and preferences into the care and support plan. In order to ensure the plan is person-centered, detailed information needs to be collected from the person living with dementia and family members about personal preferences, choices and expectations. This information should be included in the care and support plan and shared with caregivers. Person-centered planning ensures that autonomy and choice are preserved to the greatest extent possible. Changing conditions and progression through dementia will necessitate coordination with the person's family to update the plan and ensure care is individualized and appropriate.

Another way to ensure that people with dementia have control over their care decisions is through advance care planning. It is important for family and friends to have conversations with people living with dementia about advance care planning. Ideally these conversations take place at times when individuals with dementia are able to express their preferences and opinions about what they would like to have happen in the future. Such conversations are a way for all family members to reach an understanding and can help minimize disagreement and the need for painful decisions that may occur if these topics are not discussed in advance. After

a discussion on advance care planning has taken place, legal documents can be created to help ensure that the plan will be followed. While these documents do not need to be completed by an attorney, they must meet certain requirements under Wisconsin law to be considered valid. Resources are available to assist both in advance planning discussions and in completing the legal documents (see “Examples and Best Practices” below).

The Wisconsin Department of Health Services has advance directive forms available online: <http://www.dhs.wisconsin.gov/forms/advdirectives/index.htm>

A variety of other organizations offer alternative forms that are specifically designed to be easy to understand and to document an individual’s choices in a wide variety of circumstances (see “Examples and Best Practices” below).

People living with dementia sometimes reside in residential or long-term care facilities. Facilities ensure the highest level of autonomy and choice when:



- Care is based on the person’s desires and needs, and strives to maintain the relationships, natural supports and routines that are important to the person living with dementia.
  - Information from a person with dementia and/or his or her caregiver about personal preferences, choices and expectations is collected and shared to ensure that these are reflected in the care and services provided.
  - Facility staff knows whether the person living with dementia has legally appointed someone to represent him or her in decision-making and consults a legally appointed representative when appropriate.
  - A person living with dementia is offered as much choice as possible in day-to-day activities. This includes decisions such as determining what and when to eat, when to get up and go to bed, and when to go outside.
- Caregivers use a variety of strategies to help with communication, including life storybooks, talking mats, digital stories, interpreters as appropriate and referral to speech and language specialists.



## EXAMPLES AND BEST PRACTICES

### **Alzheimer's Association - "I Have Alzheimer's Disease"**

One example of an effective tool offered by the Alzheimer's Association to support choice and autonomy for people living with dementia is the "I have Alzheimer's" link to comprehensive information, assessment tools, coping strategies, training and local community resources. The website targets key topical information that is essential to the development of an early plan to prepare for living well through health transitions. This information can be found at:

<http://www.alz.org/i-have-alz/i-have-alzheimers-dementia.asp>

### **Dementia Action Alliance – Advancing Person-Centered Living**

The Dementia Action Alliance is a national initiative for individuals, organizations, and communities who are interested in improving dementia care in the United States. The vision of the Alliance is to improve dementia care in the United States, make person-centered dementia care practices the standard of care and help people live fully with dementia. A video titled "Person-Centered Matters" and additional information on the Alliance is available at:

<http://www.ccal.org/dementia-action-alliance/>

### **Honoring Choices Wisconsin – An Initiative of the Wisconsin Medical Society**

Honoring Choices Wisconsin is an initiative established by the Wisconsin Medical Society to promote the benefits of advance care planning and to improve the planning process. This initiative is engaged in system change, advocacy and education about advance care planning. The Society serves as organizer, coordinator and means to build clinical improvements and outreach in communities across the state. The organizations participating in the initiative offer facilitated advance care planning conversations to patients under the guidance of the Respecting Choices® First Steps® program. This includes a common emphasis in improving advance care planning conversations with healthcare patients, using patient-tested forms and informational materials, sharing lessons learned formally and informally and supporting community outreach. Additional information is available at:

<https://www.wisconsinmedicalsociety.org/professional/hcw/>

### **Wisconsin Guardianship Support Center**

The Wisconsin Guardianship Support Center (GSC) provides information and assistance on issues related to guardianship, protective placement, advance directives and more. Operated by the Greater Wisconsin Agency on Aging Resources, the GSC responds to requests for information through a toll-free helpline or by e-mail.

<http://www.gwaar.org/guide-to-elder-law-and-benefits-in-wisconsin.html>



### **Gunderson Health System**

The Gunderson Health System was a leader in developing an idea for community wide advance care planning. In 1991, health care leaders in La Crosse, Wisconsin came together to develop and test a model for community wide advance care planning. The model developed by that group served as the basis for development of the Gunderson Health System's Respecting Choices Organization and Community Advance Care Planning Course. The approach has been so successful at increasing awareness and participation in advance care planning that it has been adopted by over 80 communities and organizations throughout the world, including Honoring Choices initiatives in Wisconsin and other states (see below). Additional information on the Respecting Choices model can be found at:

<http://www.gundersenhealth.org/respecting-choices>

### **International Examples**

#### **Alzheimer Society of Canada - Guidelines for Care: Person-centred care of people with dementia living in care homes**

The goal of the Guidelines for Care is to improve the quality of care of people living with dementia in care homes through a person-centered philosophy. The guidelines include information on what person-centered care philosophy means, the core concept of person-centered care, how to ensure family inclusiveness, and provide care through a person's changing needs, and how to help support people living with dementia and their families.

Detailed information on these topics can be found in the complete guidelines document at:

[http://www.alzheimer.ca/~media/Files/national/Culturechange/culture\\_change\\_framework\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/Culturechange/culture_change_framework_e.pdf)

#### **United Kingdom – Checklist to promote independence and maintain function**

In the United Kingdom, the National Institute for Health and Care Excellence has developed an online checklist designed to promote independence and maintain function for people with dementia by focusing on individual needs when developing a care plan. The online checklist can be found at: <http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-promoting-independence-and-maintaining-function>

The care plan checklist addresses 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 living with dementia and caregivers, including diet, sexuality and religion.
- Independence.
- Information needs.



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## Guiding Principle #5 – Individualized Care and Services

**People living with dementia deserve to receive care and services designed around their unique preferences, culture and values.**

People living with dementia should have access to person-centered care and services that help maintain their physical and mental health and well-being, whether in the community, at home or in a facility. It is important to include the needs and preferences of people living with dementia in their care and service plan. Focusing on the person's strengths, abilities and life stories ensures that physical, mental and psychosocial needs are met. Other important factors to consider for person-centered care are:

- Cultural background and traditions.
- Access to knowledgeable physicians and health care professionals.
- Caregivers and care staff who are responsive to the person's unique changing needs.
- Physical activity and exercise.
- Freedom from unnecessary medications.



Discussing and considering advance planning early after diagnosis and before crisis events occur is also important for ensuring care and services are delivered in the way the person prefers, especially as their needs and abilities change over time.

In addition, caregivers' health and personal care are important. The use of respite programs and support services help maintain the quality of care being provided to the person living with dementia.



By providing caregivers a temporary rest from caregiving and time to spend with friends and family, run errands, take care of personal appointments or manage other responsibilities. Respite services support and strengthen the ability of caregivers to continue to provide on-going quality care while the person living with dementia receives care in a safe environment.

Respite care also benefits the person living with dementia by providing

opportunities to interact with others having similar experiences, and participate in activities designed to match personal abilities and needs.

People living with dementia come from diverse backgrounds; therefore, caregivers must be culturally competent. It is important for caregivers to be aware of and also accepting of differences based on the culture of the person.

Additional specific information related to cultural competency and culturally sensitive dementia care is available at:

[http://www.alz.org/resources/diversity/downloads/gen\\_edu-10steps.pdf](http://www.alz.org/resources/diversity/downloads/gen_edu-10steps.pdf)

Another area that is essential to quality care and services is a knowledge of issues associated with the aging process. Effective caregiver education and training specifically incorporates these issues in the curriculum. Important training topics include, but are not limited to:

- Physical, mental and social changes in people as they age.
- The aging process.
- Social and psychosocial impacts of aging.
- Psychological effects on aging.
- Interface of normal aging and age-related disease.
- Effect of aging population on society.
- Applying knowledge of the aging process to the development of policies and programs.

## EXAMPLES AND BEST PRACTICES

### Dementia Care Training and Certification

The Alzheimer's Association offers online and classroom Dementia Care Training and Certification found at: [http://www.alz.org/professionals\\_and\\_researchers\\_11176.asp](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.

### Evidence Based Nursing Protocols

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 people living with dementia.

**Tools for People Living Alone**

Many people living with dementia continue to live independently in their own homes and often care for themselves. Resources have been developed to provide information on self-care and how to live alone safely. These resources include, but are not limited to, the Alzheimer's Association "If You Live Alone" and the United Kingdom's National Health Service (NHS) Dementia Guide "Living Well with Dementia."

<http://www.alz.org/i-have-alz/if-you-live-alone.asp>

<http://www.nhs.uk/Conditions/dementia-guide/Pages/living-well-with-dementia.aspx>

In addition, [Helpguide.org](http://www.helpguide.org) is a non-profit online resource offering expert information and support for many health challenges, including dementia. [Helpguide.org](http://www.helpguide.org) provides comprehensive online access to tools, information and resources to help provide the best care to people living with dementia. More information can be found at:

[http://www.helpguide.org/elder/alzheimers\\_disease\\_dementias\\_caring\\_caregivers.htm](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.

Also located at this website is a link to *Caregiving Support and Help*. This site describes five tips for making family caregiving easier. Topics include attending to the caregiver's needs, taking advantage of community services and providing long distance care.

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3. Bathing without a Battle <http://bathingwithoutabattle.unc.edu/>
4. Dementia Care Practice for Professionals Working in Home Settings  
[http://www.alz.org/national/documents/Phase\\_4\\_Home\\_Care\\_Recs.pdf](http://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf)
5. Dementia Care Practice – Recommendations for Assisted Living, Nursing Homes & Residential [http://www.alz.org/national/documents/brochure\\_dcprphases1n2.pdf](http://www.alz.org/national/documents/brochure_dcprphases1n2.pdf)
6. Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes--Phase 1 and Phase 2  
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10. Key Elements of Care  
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14. Respite Care <http://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp>
15. Wisconsin Clinical Resource Center (WCRC) <https://wrc.chsra.wisc.edu/>

## Guiding Principle #6 – Meaningful Activities

### **People living with dementia deserve to have opportunities to engage in meaningful activities.**

It is essential that people living with dementia take part in activities that are meaningful to them regardless of the degree of the illness. All people have different interests and preferences related to how they spend their time. Ideally activities should be available daily and throughout the day.

People living with dementia need high-quality approaches to meaningful and enjoyable activities. This is a key part of promoting a good quality of life and can play a part in preventing behavioral issues. Meaningful activities can provide:

- Stimulation.
- Social interaction.
- An opportunity to be productive.
- A creative outlet.
- An opportunity to maintain physical and mental capacity at the highest level possible.

Examples of different activities that may be individually appropriate include:

- Music therapy.
- Art classes.
- Indoor and outdoor walks.
- Making cookies and other food items.
- Swimming.
- Gardening.
- Aerobics.
- Folding clothes and other household chores.
- Recreational therapy.
- Reminiscing.
- Intergenerational activities.
- Dancing.
- Playing cards and other games.
- Pet therapy.



Most people living with dementia will need the support of others to fully participate in individualized and group 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 will enrich the person's engagement in daily life.



Incorporating life stories, along with cultural, ethnic, religious and other personal preferences, is important in creating an environment where purposeful living is ensured.

## EXAMPLES AND BEST PRACTICES

### Music

Music has a powerful influence on brain functioning, and has the ability to help people with dementia connect with something they are familiar with; even after language skills are limited. To people living with dementia, music creates memories from the past. The right music, carefully selected based on familiarity of the individual and his or her mood, can increase alertness, engagement and joy. Personalized musical playlists can be created for a person living with dementia and shared with them using digital technology, e.g., iPods. The benefits of using this type of music therapy include:



- Giving pleasure to a person living with dementia.
- Providing an enjoyable, fulfilling activity for persons with physical limitations.
- Increasing cooperation and attention and reducing resistance to care.
- Reducing agitation.
- Enhancing engagement and socialization.
- Fostering a calmer social environment.
- Reducing reliance on anti-psychotic and anti-anxiety medications.

A powerful example of supporting purposeful and engaged living with music can be found in the efforts of MUSIC & MEMORY<sup>SM</sup>, a non-profit organization that brings personalized music into the lives of elderly or ailing individuals through digital music technology. For additional information regarding MUSIC & MEMORY<sup>SM</sup> visit: <http://musicandmemory.org/>

The Wisconsin Music & Memory Program has been designed to bring personalized music to individuals diagnosed with Alzheimer's disease and other related dementias. The program has successfully funded 250 nursing homes to become certified MUSIC & MEMORY<sup>SM</sup> facilities and has provided 3,000 residents with dementia with equipment for personalized music. For additional information regarding the Wisconsin Music & Memory Program, visit: <https://www.dhs.wisconsin.gov/music-memory/index.htm>

### Activity Tools

The Alzheimer's Association offers helpful online tools to support structured and pleasant activities for people living with dementia. These tools can be found at:

<http://www.alz.org/care/dementia-creating-a-plan.asp#writing>

### Physical Activity

Physical therapy and general physical activity can have significant benefits for people living with dementia and can be helpful in the following ways:

- To slow cognitive decline. Several recent studies of people living with dementia have shown that exercise seems to slow brain atrophy, especially in the hippocampus which influences memory and spatial navigation.
- To improve physical function. Movement aids flexibility and strength.
- To reduce the risk of falls. Exercise can help improve balance and reduce the fear of falling.
- To lift mood, ease stress and add calm. Moving the body during the day can help lessen incidents involving aggression and agitation, and can also reduce the effects of depression.
- To improve general cardiovascular health.
- To pass time in an enjoyable way. Movement fills the day and provides a sense of accomplishment for people living with dementia.
- To improve sleep.



Examples of physical activities that can be beneficial and that are also relatively easy to incorporate into a day include:

- Simple stretches and strength training. Canned goods can be used as light weights.
- Tai chi. DVDs are available for home use. Tai chi helps with balance as well as providing exercise.
- Taking walks. Walking outdoors when possible, or indoors, is beneficial.
- Gardening. Simply pulling weeds can be a satisfying source of exercise.
- Water exercise. Senior centers and other facilities may offer classes.
- Household chores. Examples include hanging and folding laundry, dusting, washing the car.
- Stationary bike. Senior centers and other facilities may have stationary bikes available.
- Exercise class. Senior centers and other facilities may offer classes specifically for people living with dementia.



### Tools for Caregivers in Planning Daily Activities

Templates are available that can assist caregivers with planning a day for people living with dementia, and checklists can help in establishing daily plans that include activities that provide meaning and enjoyment. These structured and pleasant activities can also reduce agitation and improve mood. People living with dementia have individualized needs, interests, abilities, backgrounds and preferences. Therefore, a variety of activity options need to be considered. Examples of best practices and reasons why they're effective are available at the websites listed below.

- **Art Therapy**

Alzheimer's Foundation of America -- Art

[http://www.alzfdn.org/EducationandCare/art\\_therapy.html](http://www.alzfdn.org/EducationandCare/art_therapy.html)

- **National Council of Certified Dementia Practitioners (NCCDP) – Activity Ideas for Alzheimer's/Dementia Residents**

<http://www.nccdp.org/resources/AlzheimersDementiaActivityIdeas.pdf>

- **Occupational Therapy**

American Occupational Therapy Association -- Dementia and the Role of Occupational Therapy

<http://www.aota.org/About-Occupational-Therapy/Professionals/MH/Dementia.aspx>

- **Pet Therapy**

Everyday Health: How Animal Therapy Helps Dementia Patients

<http://www.everydayhealth.com/alzheimers/how-animal-therapy-helps-dementia-patients.aspx>

Alzheimer's Project -- Pets and Dementia

<http://alzheimers.about.com/od/treatmentofalzheimers/a/The-Benefits-Of-Pet-Therapy-For-People-With-Dementia.htm>

- **Physical Therapy**

Kindred Healthcare Caring.com -- Why and How to Encourage Exercise for Someone With Dementia

<http://www.caring.com/articles/physical-exercise-therapy-dementia>

- **Recreational Therapy**

UK Alzheimer's Society -- Breaking the stereotype: Recreational activity as therapy for disturbing behaviours in dementia

[http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1513&pageNumber=3](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1513&pageNumber=3)

- **Reminiscence Therapy**

Research and Innovation in Social Services (IRISS) - Supporting those with dementia:  
Reminiscence therapy and life story work

<http://www.iriss.org.uk/resources/supporting-those-dementia-remembrance-therapy-and-life-story-work>

Trinity College Dublin -- Reminiscence Therapy

[http://livingwithdementia.tcd.ie/assets/pdf/Reminiscence\\_Therapy\\_for\\_carers\\_of\\_people\\_with\\_dementia.pdf](http://livingwithdementia.tcd.ie/assets/pdf/Reminiscence_Therapy_for_carers_of_people_with_dementia.pdf)

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## Guiding Principle #7 – Coordinated Systems

**Caregivers and health care professionals should work as a team to provide effective care for people living with dementia.**



An integrated approach to the provision of services for people living with dementia and their caregivers is fundamental to the delivery of high-quality care. Often people living with dementia, their families and caregivers are unaware of services 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 assessment and supports coordination for the person living with dementia and his or her family. An integrated approach reduces the burden for families and caregivers. A systematic, comprehensive and easily-understood process for access to and delivery of services from multiple sources is one of the most important features of high-quality care for people living with dementia.

## EXAMPLES AND BEST PRACTICES

### United Kingdom - The Whole System Integrated Care and Support Toolkit Project

In the United Kingdom, *The Whole System Integrated Care and Support Toolkit Project* was commissioned in July of 2013 by the Local Government Association (LGA) as part of a national collaborative. 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 for local areas to bring health and social care services to patients and service users. The project was a key part of the National Collaborative’s work plan to support the development of integrated care systems throughout England.

The toolkit was designed during three half-day engagement workshops that were held in London, Leeds and Bristol. Representatives of health, local government and third sector (voluntary or non-profit) organizations 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. 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/>

## The 8 Pillars

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

[http://www.alzscot.org/assets/0000/4613/FULL\\_REPORT\\_8\\_Pillars\\_Model\\_of\\_Community\\_Support.pdf](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 living 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 dementia impacts the overall health and well-being of the individual and their caregiver, excess disability is created when people living with dementia do not receive appropriate care and treatment for the symptoms of the disease. 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 living with dementia and their caregivers. The 8 Pillars Model provides a blueprint for restructuring integrated dementia care.

## RESOURCE REFERENCES

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2. Alzheimer Scotland – Action on Dementia – 8 Pillars Model of Community Support  
[http://www.alzscot.org/campaigning/eight\\_pillars\\_model\\_of\\_community\\_support](http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support)
3. Dementia Partnerships – Integrated Care Value Case Toolkit  
<http://dementiapartnerships.com/resource/integrated-care-value-case-toolkit/>
4. Integrated Care Pathways for People with Dementia  
<http://www.alzheimer.ie/Alzheimer/media/SiteMedia/ImageSlider/Fixed/Integrated-Care-Pathways.pdf>
5. Integrated and Coordinated Care and Service Provisions  
<http://pathways.nice.org.uk/pathways/dementia/dementia-overview#content=view-node%3Anodes-integrated-and-coordinated-care>

## Guiding Principle #8 – Education and Training

**People caring for individuals living with dementia should have the knowledge, skills and abilities to provide effective support.**

In 2013, an estimated 120,000 Wisconsin citizens had Alzheimer's disease or another dementia. Of that number, most lived in the community and a number of those people lived alone. Family caregivers in Wisconsin provided an estimated 215 million hours of care in 2013. It is therefore critically important that home and family caregivers, as well as other professionals, have the aptitude, knowledge, skills and abilities to effectively provide support and care.

It is equally critical that health care and social care staff and employees of other fields that interact with, or care for, people living with dementia have the necessary aptitude for working with individuals who are undergoing memory loss and facing increasing disability and illness. Although aptitude as an underlying attitude and approach that a person brings to his or her role in providing care grows over time it can be enhanced and reinforced with training. Appropriate training is needed to ensure caregivers have the proper knowledge, skills and abilities to provide services. Training and education equips and empowers professionals to provide proper information, resources, care and support services that promote a high-quality of life and informed decision-making for people living with dementia and their families.



Training curricula should be tailored to specific audiences and provide conceptual information, practical tools and methods for providing effective care and services. Instructional methods should ensure that those who complete the training are able to demonstrate competency in caring for people living with dementia in daily situations. Using hands-on and experiential training, case studies, mentoring and supervised practical application is ideal for ensuring that training and educational objectives are met.

It is also important that resources and training are available for caregivers from diverse backgrounds and cultures. Although hands-on training is preferred, online training is also an effective way to reach both culturally diverse and geographically dispersed audiences. Online training resources can be found in the following “Resource References section.”

## EXAMPLES AND BEST PRACTICES

### **Alzheimer’s Association Dementia Care Practice Recommendations for Professionals Working in a Home Setting**

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 living with dementia. The manual can be found at:

[http://www.alz.org/national/documents/Phase\\_4\\_Home\\_Care\\_Recs.pdf](http://www.alz.org/national/documents/Phase_4_Home_Care_Recs.pdf)

The guide details best practice recommendations for professionals providing care in a home setting, and incorporates 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 can be found at:

[http://www.alz.org/national/documents/brochure\\_DCPRphases1n2.pdf](http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf)

Specifically, the Alzheimer’s Association developed its home care practice recommendations using the following information:

- 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.

### **Alzheimer’s Association EsseniALZ Certification Program**

The Alzheimer’s Association offers an online individual certification program called essentiALZ that provides recognition for quality dementia care practices. EssentiALZ uses the Alzheimer’s Association Dementia Care Practice Recommendations and offers two levels of certification – essentiALZ and essentiALZ Plus. Details are available at: <http://www.alz.org/essentialz/>





### **National Certification Board for Alzheimer Care Certified Alzheimer's Caregiver**

The National Certification Board for Alzheimer Care (NCBAC) offers voluntary credentialing of Alzheimer caregivers and educators. Information can be found at: <https://www.ncbac.net/content/certified-alzheimer-caregiver>

The NCBAC Certification is beneficial because it provides the caregiver with

EssentiALZ and the credentialing through NCBAC are two credentialing options. Other organizations also offer voluntary credentialing.

## **RESOURCE REFERENCES**

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<http://www.asha.org/Members/ebp/compendium/reviews/Evidence-Based-Practice-Recommendations-for-Dementia--Educating-Caregivers-on-Alzheimer-s-Disea---.htm>
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<http://pathways.nice.org.uk/pathways/dementia#content=view-node%3Anodes-staff-training>
4. 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)  
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[www.dhs.wisconsin.gov/publications/p0/p00586.pdf](http://www.dhs.wisconsin.gov/publications/p0/p00586.pdf)
6. Wisconsin Department of Health Services – Services for the Elderly  
<http://www.dhs.wisconsin.gov/aging/index.htm>
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## Guiding Principle #9 – Communication through Behaviors

**Caregivers should view behaviors as a form of communication and strive to identify the cause and solutions.**

Changes in the behaviors of a person living with dementia are common as the disease progresses. Changes in the brain may affect a person's memory, abilities, mood, communication and behavior. In addition, there may be changes in an individual's capacity to perform activities of daily living such as dressing or bathing. Changing abilities, along with potential changes in a person's environment, health, medications and lifestyle, may lead a person living with dementia to



react in ways that are confusing or present challenges for caregivers and others. Examples of such behaviors include: wandering, rummaging, hiding objects, anger, aggression, hallucinations, suspicion, paranoia, sleep problems and eating difficulties.



People living with dementia often lose their ability to effectively express themselves before they lose their ability to understand. They may not be able to express verbally what they want or need, and non-verbal behavior may become a primary means of communication. Behaviors by individuals with dementia that present challenges for caregivers might be triggered by something another person did or said, or by the experience of pain or physical distress, or a disorienting change in the physical environment. They may also be indications of unmet needs related to hunger, thirst, emotional discomfort and/or the need for attention. It is important to attempt to learn what need a person with dementia might be trying to express and to accommodate that need if possible.

Recognizing that behavior is a form of communication and utilizing person-centered approaches best equips caregivers, as well as first responders, medical personnel and law enforcement, to respond appropriately to people living with dementia. Compassion and focusing on the root cause(s) of puzzling or frustrating behaviors are important elements of quality care for individuals with



dementia. Learning about a person's life story and history is also a tool for understanding and effectively working with people exhibiting behaviors that are challenging for caregivers.

When a person living with dementia exhibits behavior changes, or experiences other life changes, such as changes in medication, caregivers, environment or living settings, it is important to do a comprehensive reassessment of the support and care plan. The reassessment ensures that the person living with dementia is given the assistance, support and care needed based on current circumstances.

## EXAMPLES AND BEST PRACTICES

### **Best Practice Guideline for Accommodating and Managing Behavioural and Psychological Symptoms of Dementia in Residential Care – a Person-Centered Interdisciplinary Approach**

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 people living 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. The guideline 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>

The 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 people living with dementia are encouraged to recognize behaviors as communication rather than trying to control or extinguish 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 care.

**Alzheimer's Association How to Respond When Dementia Causes Unpredictable Behaviors**

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](https://www.alz.org/national/documents/brochure_behaviors.pdf)

The guide addresses various kinds of behavior, explores possible root causes and offers practical recommendations for responding appropriately to aggression, anxiety, agitation, confusion, repetition, suspicion, wandering and getting lost, and trouble with sleep.

**RESOURCE REFERENCES**

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8. Dr. Tim Howell – Medical Illnesses in Geriatric Mental Health and Substance Abuse: The Wisconsin “Star” Method  
[http://www.uwgb.edu/bhttp/tools/STAR\\_Assessment\\_Method.pdf](http://www.uwgb.edu/bhttp/tools/STAR_Assessment_Method.pdf)
9. Hand in Hand Toolkit  
<http://www.dementiacarerresourceca.org/hand-in-hand-toolkit/>
10. Phillip McCallion – Evidence Based Approach to Dementia Care with Intellectual Disability

[http://www.indabook.org/preview/9W7coO-imW\\_fKLt7M5ijLt-NKf6\\_p2EjL9zMgHSMdU,/Evidenced-Based-Approaches-to-Dementia-Care-in-Persons.html?query=What-works-in-Challenging-Behaviour-What-care-staff](http://www.indabook.org/preview/9W7coO-imW_fKLt7M5ijLt-NKf6_p2EjL9zMgHSMdU,/Evidenced-Based-Approaches-to-Dementia-Care-in-Persons.html?query=What-works-in-Challenging-Behaviour-What-care-staff)

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12. 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](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1211&pageNumber=7)
13. 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 living with dementia in long-term care settings)  
<http://www.dhs.wisconsin.gov/publications/p2/p20084.pdf>

## Guiding Principle #10 – Environment and Living Space

### The living space for people with dementia should provide safety and the comforts of home.

The physical design and layout of the living setting for people living with dementia must ensure both comfort and safety. High quality care settings provide a comfortable, home-like environment, access to safe spaces, both indoors and outdoors for walking and other activity, space for the person to safely be alone, areas for wandering, and orientation reminders. In addition to the physical setting itself, high quality care settings provide a person living with dementia with an environment that is responsive to his or her emotional and social needs. 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 must be balanced with the person's evolving capabilities and behaviors.



### EXAMPLES AND BEST PRACTICES

#### Home Modifications

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 living with dementia. Highlights of the study include:

- Identification of several major categories of physical/environmental obstacles and safety issues (such as entrance and interior stairs, bathroom obstacles, excess furniture and clutter) and suggested strategies to address them.
- Recommendation that additional research is warranted on ways to increase the acceptance of home modifications by both caregivers and care recipients and to address the need to inform caregivers about the possible scope and benefits of home modifications for people living with dementia.

This study solicited information from caregivers of people living with dementia on environmental modifications to ensure safety and to meet individualized needs. The findings are applicable to new construction as well as to renovations of existing buildings. In addition,



the study shows that changing structural design, along with other low-cost modifications, can be helpful in providing high-quality care.

### Staying Safe

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, for 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), 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](http://www.alz.org/alzheimers_disease_publications_safety.asp)

### ABCs of Universal Design

The ABCs of Universal Design, developed by Cynthia Leibrock, describe optimal physical design considerations for buildings and facilities that maximize health, quality of life and longevity. Specifications included relate to accessible routes, bathrooms and kitchens, controls, doors, electrical/mechanical/acoustical items, and furniture and fixtures. More information is available at: <http://agingbeautifully.org/ABCs/>

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3. Dementia Friendly Environments  
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4. Designing Environments for Dementia/Alzheimer's Disease  
[http://www.alz.org/library/downloads/designenviron\\_rl2010.pdf](http://www.alz.org/library/downloads/designenviron_rl2010.pdf)
5. Home Safe Home – Creating a Dementia Friendly Environment  
<http://www.socialworktoday.com/archive/111610p22.shtml>
6. Innovative Designs in Environments for an Aging Society  
<http://ideasconsultinginc.com/>

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## Appendix-Definitions

### ADVANCE CARE PLANNING

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

### ALCOHOL-RELATED DEMENTIA

Alcohol-related dementia (ARD) is a form of dementia caused by long-term, excessive drinking, resulting in neurological damage and impaired mental processing.

### 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 can become 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: SEVEN STAGES

Persons living 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

More information regarding the Seven Stages of Alzheimer's Disease can be found at:

[http://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](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 living with dementia.

### CAREGIVER

A caregiver can be a family member such as a spouse or child, a friend, a professional or others who provide care to a person living with dementia whether in the community, at home or in a facility. A caregiver may assist and provide support with such matters as care planning, direct care, financial concerns, health care decisions and other relevant personal affairs.

**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 include, but are not limited to, vascular dementia caused by stroke or blockage of blood supply, and dementia with Lewy bodies. Other types include alcohol-related dementia, caused by sustained use of alcohol; trauma dementia, caused by head injury; and a rare form of dementia, frontotemporal dementia.

**DEMENTIA WITH LEWY BODIES**

Dementia with Lewy bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time.

**FRONTOTEMPORAL DEMENTIA**

Frontotemporal dementia (FTD) is a group of related conditions resulting from the progressive degeneration of the temporal and frontal lobes of the brain. These areas of the brain play a significant role in decision-making, behavioral control, emotion and language.

**LIFE STORY**

A life story is an account of the events that make up a person's life that are meaningful to him or her. 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 strengths, 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 living 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 people living 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. Purposeful activities that are appropriate to the individual's age, culture and abilities should be tailored to their personality and interests.

Praise and compliments for achievements can help support the person's self-esteem, while encouraging self-participation in activities of daily living.

**TRAUMATIC BRAIN INJURY DEMENTIA**

Traumatic brain injury (TBI) is a type of dementia that results from an impact to the head that disrupts normal brain function.

**VASCULAR DEMENTIA**

Vascular dementia is a type of dementia caused by an impaired blood flow to the brain often caused by a series of small strokes. Vascular dementia can lead to problems with reasoning, planning, judgment, memory and other thought processes.





