

Wisconsin Dementia Care Guiding Principles

Draft Dementia Care Guiding Principles

There must be a widely shared understanding of appropriate and high quality care for people with dementia in order to have a dementia-capable system of care. The Wisconsin Department of Health Services Dementia Care Guiding Principles articulate, document and share a common understanding of these values.

Prior to completing this survey, it may be best to review the principles in full by printing the .pdf version of the survey attached to the email. Once you have read and noted your responses, please click on the link again to open the survey and provide your feedback.

Please record all of your responses via this survey tool. The survey will only be open from September 9, 2014 to 11pm CST on September 19, 2014.

Thank you for your time and effort in providing responses and comments to these draft Guiding Principles.

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>.

1. Is the Guiding Principle clear?

- Yes
 No

2. Please indicate whether the Dementia Care Guiding Principle #1 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

3. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

4. Is the Guiding Principle clear?

- Yes
 No

5. Please indicate whether the Dementia Care Guiding Principle #2 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to | <input type="radio"/> | <input type="radio"/> |

caregivers/providers of all types?

6. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

7. Is the Guiding Principle clear?

- Yes
 No

8. Please indicate whether the Dementia Care Guiding Principle #3 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

9. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

10. Is the Guiding Principle clear?

- Yes
 No

11. Please indicate whether the Dementia Care Guiding Principle #4 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

12. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

13. Is the Guiding Principle clear?

- Yes
 No

14. Please indicate whether the Dementia Care Guiding Principle #5 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

15. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

16. Is the Guiding Principle clear?

- Yes
 No

17. Please indicate whether the Dementia Care Guiding Principle #6 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

18. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

19. Is the Guiding Principle clear?

- Yes
 No

20. Please indicate whether the Dementia Care Guiding Principle #7 adequately addresses the areas noted below.

| | Yes | No |
|--------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality | <input type="radio"/> | <input type="radio"/> |

dementia care service delivery?
Does it provide useful guidance to caregivers/providers of all types?



21. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

22. Is the Guiding Principle clear?

- Yes
 No

23. Please indicate whether the Dementia Care Guiding Principle #8 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

24. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

25. Is the Guiding Principle clear?

Yes No

26. Please indicate whether the Dementia Care Guiding Principle #9 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

27. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

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.

28. Is the Guiding Principle clear?

 Yes No

29. Please indicate whether the Dementia Care Guiding Principle #10 adequately addresses the areas noted below.

| | Yes | No |
|----------------------------------------------------------------------------------|-----------------------|-----------------------|
| Does this Guiding Principle promote high quality dementia care service delivery? | <input type="radio"/> | <input type="radio"/> |
| Does it provide useful guidance to caregivers/providers of all types? | <input type="radio"/> | <input type="radio"/> |

30. Please share your edits or suggestions regarding the above Guiding Principle, noting anything you feel should be included or omitted.

31. How would you describe your affiliation(s)? Please check all that apply.

- Person with long-term support needs
- Caregiver or family member
- Community-based service provider

- Facility-based service provider
- Aging and Disability Resource Center / Aging Unit
- Managed Care Organization / IRIS Consulting Agency
- Healthcare professional
- Attorney
- Law enforcement
- Academic/researcher
- Elected official
- Tribal representative
- County agency
- State agency
- Adult protective services professional
- Mental health professional
- Other, please specify