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Dementia Coalitions in Wisconsin: A Best Practice Guide

Wisconsin Alzheimer's Institute
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH
Dementia Coalitions in Wisconsin: A Best Practice Guide

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INTRODUCTION

Vision
The idea that a group of committed and dedicated people would come together to address an issue of mutual concern is fundamental in our society. It is through the collaborative and thoughtful actions of such groups that significant gains are made in addressing a variety of problems faced daily in our communities. One such problem affecting communities across Wisconsin is the growing impact of Alzheimer’s disease and related dementias (ADRD). Current estimates indicate that approximately 115,000 Wisconsinites are living with a form of dementia, and another 193,000 are providing unpaid care for these individuals. Dementia is increasingly being understood as a significant public health issue affecting the health and well-being of the population, and one that will continue to increase in the years ahead. Given the number of people impacted by dementia across Wisconsin, dementia coalitions are a useful and effective mechanism for interested stakeholders to come together to help their communities become welcoming and friendly places for all citizens.

The purpose of this Best Practice Guide is to offer suggestions for starting a dementia coalition, provide action steps for sustaining a coalition, and to share ways that dementia coalitions are positively impacting Wisconsin communities. While the term “community” is used throughout the guide in order to match the terminology around dementia friendly communities, we acknowledge that many of the coalitions reflected are county-based. For our purposes here, the terms are occasionally used interchangeably.

Background
The topic for this Best Practice Guide came as the result of a September 2017 in-person educational meeting of the Wisconsin Dementia Resource Network (WDRN), a program of the Wisconsin Alzheimer’s Institute (WAI) at the University of Wisconsin School of Medicine and Public Health. The WDRN is a collaboration of stakeholders from across the state of Wisconsin who are committed to improving the quality of life of individuals living with dementia and their families. The group comes together twice each year to address best practices in dementia programs and services. The September 2017 meeting focused on the issue of dementia coalitions in Wisconsin, and the ways in which they are contributing to their communities becoming dementia friendly while also contributing to the broader goal of helping the State of Wisconsin become dementia capable. The Dementia Coalitions event was well-attended and interest in the topic was strong. The program involved presentations by a number of dementia coalition leaders from across Wisconsin who have successfully convened and maintained dementia coalitions in their communities. The presenters were asked to share the stories of their coalitions, including: history, leadership, membership, and challenges and resolutions.

There were a number of common themes across the presentations, as well as unique qualities that reflected the specific needs and resources of the communities in which the coalitions exist. Following the meeting, WAI staff invited the presenters, along with a number of other coalition leaders from across the state to serve as contributors to this guide. Between the fall of 2017 and the summer of 2018, WAI staff interviewed the content experts noted in the Contributors section of this guide.
Best Practices Informed by Content Experts

As mentioned, the information shared in this guide was developed following interviews with a group of twenty stakeholders from across Wisconsin, each with a broad base of experience developing, leading, and sustaining dementia coalitions. The recommendations reflect the collective wisdom shared by this dedicated group of content experts, many of whom offered very similar suggestions. We are tremendously grateful to each contributor for sharing their extensive experience and expertise. The conversations provided a rich opportunity to learn about the successes and challenges faced by the contributors through their efforts to create and sustain meaningful change in the lives of citizens in their communities living with dementia through the power of coalitions. The guide also draws from a number of published resources pertaining to coalitions. We sincerely hope that readers find the information included here helpful in forming and/or sustaining dementia coalitions in their communities.

Definitions and Terminology

**Best Practice:** This refers to a procedure or process that has been shown by experience and/or research to produce optimal results and that is established or proposed as a standard suitable for widespread adoption.

**Care Partners/Caregivers:** Anyone who provides care to a person with dementia is considered a care partner or caregiver. This may be a spouse, adult child, other family member, friend, or paid care provider.

**Dementia:** Dementia is a general term used to describe a group of symptoms affecting memory, cognitive function, thinking and processing skills, and social abilities which are significant enough to interfere with daily function. There are different types of dementia, with the most prevalent being Alzheimer’s disease.

**Dementia Friendly Communities:** Communities where businesses, public services, and other entities have been trained to understand the needs of people living with dementia in order to be truly welcoming and inclusive. These communities create systems that support the dignity of all individuals and reduce stigma by educating its citizens and businesses to compassionately interact with those living with dementia.

**Dementia Care Specialist (DCS):** The State of Wisconsin employs a team of Dementia Care Specialists in a number of county Aging and Disability Resource Centers, Departments on Aging, and tribal communities who provide education, outreach, information, and resources to the communities they serve.

**Dementia Coalition:** A group or network comprised of individuals and organizational representatives who come together with the shared goal of improving the lives of individuals in their community who are impacted by dementia.

**Dementia Leads:** In counties that do not have a Dementia Care Specialist, a staff member from the county’s Aging and Disability Resource Center (ADRC) has been designated to provide services, information, and resources to community members impacted by dementia.
DEVELOPING A DEMENTIA COALITION

The People Served
The people who potentially benefit from a community’s dementia coalition are numerous. First and foremost, dementia coalitions are convened with the primary goal of improving the lives of people living with dementia and those who care for and about them. Beyond those directly affected by dementia, one could argue that an entire community benefits when its citizens collectively work together to become dementia friendly. In other words, a dementia friendly community is a more welcoming community for all.

The People Involved
Depending on the size of the community and the resources available, the people involved in a dementia coalition may vary. When starting a dementia coalition, it is helpful to be intentional about including people living with dementia and caregivers as part of the coalition, keeping in mind the expression, “nothing about us without us.” Be equally as intentional about including individuals who represent all facets of the community, especially those who come from traditionally underserved or underrepresented groups. Informal or formal community leaders should also be considered, especially if they have a genuine interest in the issue of dementia. Examples of people who serve on dementia coalitions include the following:

- Individuals living with dementia
- Caregivers
- Aging and Disability Resource Centers
- Departments on Aging, County Public Health Departments
- Alzheimer’s Association Chapters
- Alzheimer’s and Dementia Alliance of Wisconsin
- Tribal communities
- Healthcare organizations
- Managed care organizations
- Those serving the population of people living with intellectual and developmental disabilities
- Transportation units
- Law enforcement
- Fire departments
- Emergency medical services
- Assisted living facilities
- Skilled nursing facilities
- Faith communities
- Chambers of Commerce
- Museums
- Parks
- Arts and music
- Technical colleges
- K12 education
- Universities
- Community leader--formal and informal
The Purpose

The primary reason most communities organize a dementia-specific coalition is with the ultimate goal of improving the lives of people living with dementia and their loved ones. Given the growing awareness of and concern around the issue of dementia, more and more communities are recognizing the benefit of developing a dementia coalition. As with other issues, greater success can be accomplished through collective action rather than individual people or organizations acting alone. By opening conversations between people living with dementia, caregivers, and professionals, silos can be broken down and partnerships can be formed. It is important that all perspectives are given voice. Each dementia coalition will have different issues their group will address based upon the unique problems, needs, and assets of the community.

Getting Started

Following are suggested guidelines for starting a dementia coalition. While the points are listed sequentially, some activities may actually need to occur simultaneously or perhaps in a different order than proposed here. Your group may decide to bypass some steps altogether. The main point is that these are important steps to consider when planning your dementia coalition.

1. **Convene a Founding Task Force:** Select a small group of stakeholders (3-6) representing key organizations, sectors, and groups within your community. The individuals involved should have a true passion and interest in the issue of dementia, with the time available to commit to this effort. Depending on the level of knowledge the group has regarding dementia friendly community efforts, you may wish to provide a brief training session regarding what a dementia friendly community is, the state of Wisconsin plan to become dementia capable, and specific nuances of your community to assure a shared understanding of key issues. Matters this group will determine include:
   a. Overall purpose and initial goals for the coalition
   b. Coalition leadership, coordination, and facilitation
   c. Membership, specifically who will be invited to participate
   d. Logistics, including: meeting location, day of the week, time, refreshments (if any)
   e. Tasks, including: who will schedule meetings, prepare and send out agendas and minutes, handle internal and external communications, etc.
   f. Structure, including: meeting frequency, meeting dates and times, committees (if any), geographic reach
   g. Initial goals, specifically what the coalition hopes to accomplish
   h. Funding needed and potential funding sources
   i. Planning the kick-off meeting or event (eg: community conversation, listening session, or stakeholder meeting)
2. **Conduct a Needs Assessment:** Many, but not all, of the coalitions represented in this guide started with either a formal or informal needs assessment to understand what community members viewed as priorities for dementia education, services, programs, and resources. This can be done as part of a kick-off event or through a survey distributed by mail, via email, online, at senior centers or meal sites, or as part of an initial meeting. Whatever method is chosen, be sure to include people living with dementia and caregivers to truly understand their point of view. Also, be mindful to assure that individuals representing underserved and underrepresented groups are invited so that you are gaining a complete and accurate assessment of the needs of the full community.

3. **Determine Themes:** Review, analyze, and prioritize the results of the needs assessment to understand themes. This will help determine who should be involved in the coalition, and provide information for the development of sub-committees. For example, if a common theme is crisis response, then you know it will be imperative that individuals representing police, fire, or EMS be invited.

4. **Invite Coalition Members:** Consider who should be involved. This is a question you will want to revisit on an ongoing basis, even as the dementia coalition begins its work. Be open to new members who can bring additional energy, passion, ideas, and resources. As mentioned previously, be sure to include people living with dementia and caregivers as part of the coalition, keeping in mind the expression, “nothing about us without us.” Also, remember to be intentional about including individuals who represent all facets of the community, especially those who come from traditionally underserved or underrepresented communities. Invite “movers and shakers” in your community, including formal and informal leaders who have the capacity to make a difference. See the list of possible members listed in **The People Involved** section for suggestions.

5. **Set Goals:** As the coalition begins its work, discuss what the group hopes to achieve. Some coalitions start by developing mission and vision statements as part of this process. Others decide to bypass this step and dive into discussions of what could be accomplished quickly to help gain or spur momentum. These discussions would be based on the needs identified during the needs assessment process. If your group opts to start by creating mission and vision statements, consider assigning this task to a small group of volunteers as this will streamline the process. They can then bring the statements to the larger group for review and comment. Either way, it will be helpful to have at least some sense of direction, which often comes as a result of discussing initial goals.

6. **Determine a Committee Structure:** A coalition’s committee structure will very much depend on its purpose and goals. For example, a coalition with the goal of educating businesses about dementia will be well-served to develop an Education or Business Training Committee. A coalition looking to host memory cafés may be interested in forming a Memory Café Committee. Keep the number of committees workable and manageable for your members.

7. **Decide on a Meeting Structure:** Determine the frequency, dates, times, and location of coalition meetings.

8. **Determine a Starting Point:** Look for what might be described as “low-hanging fruit” as a place to start. That is to say, what is your coalition most poised to do? Perhaps there are group members interested in starting a memory café. Or, maybe there is a local business interested in learning about dementia in order to be more dementia friendly. It is often helpful to have an activity that serves as a starting point to focus the energy of the group and to launch your work together.
9. **Develop an Action Mindset:** Set a tone of action from the very beginning. While many coalitions will include a time for sharing information about activities of member organizations as part of their meetings, there needs to be a commitment to accomplishing something through the collective action of members in order for the coalition to truly make a difference in the community. Being goal-oriented will help to boost this action state.

10. **Branding:** Consider developing a distinct identity or branding for the coalition, separate from any of the member organizations. This communicates to the community that the coalition operates in the best interest of the broader population and is independent of specific organizations.

**Operational Considerations**

1. **Meeting Frequency:** Some coalitions meet monthly, while others opt for an every-other-month or quarterly time frame. If a less frequent option is selected, you may wish to have committee meetings take place on the “off” months. Keep in mind that meeting frequency can affect momentum. It will be helpful to consider this issue when deciding how often the coalition will meet.

2. **Meeting Structure:** Determine the day of the week and time of day that works best for the majority of your members. Also, decide on your meeting agendas. Are there standing issues you want to address at each meeting?

3. **Meeting Location:** Determine the meeting location. Of course, it is important to have a room large enough to comfortably seat all interested participants. If possible, try to find a central location that is convenient to all who wish to attend, and assure that convenient and adequate parking is available.

4. **Meeting Leadership and Staffing:** Decide on who will lead the coalition meetings. Will you have a single leader or a co-lead arrangement? There are certainly benefits to a co-lead arrangement, if that option is available. Determine who will develop the agendas, take and distribute minutes, and communicate with members.

5. **Subcommittees:** As the coalition begins its collective work, determine whether it will be helpful to engage subcommittees. If yes, what specific issues will they address? And, who will participate?

6. **Amenities:** Depending on the time of day and length of your meetings, it may be helpful to have light refreshments available. If you choose to do so, who will make the arrangements and cover the costs will be important considerations. Some groups decide to hold their meetings as a working lunch, and simply ask members to bring their own.
Sustaining a Coalition

Once a dementia coalition is established, the challenge becomes how to keep it running effectively over the long-term. It is best to think about this preemptively, and to create a sustainability plan from the very beginning. Suggestions may include:

1. Keep coalition members motivated and engaged by giving members specific tasks or action items to accomplish. In general, people tend to be more engaged when they feel they are being useful. Work to find a balanced and manageable approach where members are given enough to do to remain energized, but not so much that they become overwhelmed. You may consider finding smaller or less time-consuming tasks for those who have little time to devote.

2. Confirm each member’s action items and duties at the end of each coalition meeting so everyone leaves knowing what will be expected.

3. Develop subcommittees. This is another means of keeping members engaged and task-oriented. In many cases, smaller groups can be more productive. This also allows members to work on an issue or topic of particular interest and to utilize their unique talents, skills, and networks.

4. Create expectations for accountability of coalition members. One way to accomplish this is simply by devoting time at each meeting for members to report on the actions they’ve taken since the prior meeting.

5. Adhere to your mission and goals, and avoid the temptation to work beyond the scope of your coalition.

6. Leadership succession planning. Keep in mind that the individual(s) currently leading your group may not always be available, so it is helpful to think about who else could take on that role if circumstances change.

7. Products and activities. As mentioned earlier, one way to keep people engaged is to keep them busy. Another is by accomplishing what the group set out to do, or through your programs, products, and activities. Examples of the types of activities successful coalitions do include: hosting community or professional education programs, memory cafés, memory screening events, SPARK! Program activities, bus tours, dementia-friendly choirs, outdoor activities, annual reports, etc.

8. Engage the media and use them to promote and support your dementia-friendly efforts. Especially in smaller communities, local newspapers, radio, and TV stations are often looking for stories of interest. Give the media something to talk or write about!

9. Engage community members to provide real-life input regarding needs and gaps in information, resources, programs, and services. Again, the expression, “nothing about us without us” comes to mind, so include community members as much as possible.

10. Contact coalition leaders in other counties to learn about their best practices and lessons learned.
Challenges

Being aware of and anticipating potential challenges in advance can be beneficial as it allows coalition leaders and stakeholders to plan and prepare. Contributors shared a number of challenges they have faced over the course of their involvement with the coalitions they represent. That list is included here.

- Staffing was mentioned by a number of contributors. The reality is that there is a certain amount of person-power required to keep a coalition on-track, action-focused, and accomplishing what its members have set out to accomplish.

- Funding is an issue for some coalitions, especially when in-kind or other support by those involved is not available. In other cases, the partners involved are able to provide in-kind support in the form of meeting space, staff support, materials, photocopying, etc. to advance the work of the coalition.

- Maintaining the engagement of people living with dementia and/or care partners on an ongoing basis, especially as dementia progresses.

- Time commitment for busy caregivers, professionals, and volunteers to continuously be involved.

- Commuting to meetings can be long in rural areas making consistent attendance at meetings difficult, especially during winter months.

- Commitment of coalition members to consistently participate in coalition-sponsored events.

- Losing dementia champions to health issues or other life events.

- Engaging more dementia champions to be involved.

- Coalition members being mindful that they are working on behalf of the collective effort rather than their affiliate organizations.

- Recognizing that no one “owns” the coalition or other dementia-friendly initiatives.
COALITION EXAMPLES

The following examples were provided by the wonderful contributors to this guide, and illustrate a variety of approaches to what we are generally referring to as Dementia Coalitions. The different models reflect the unique qualities of each community, county, or region they represent. In general, the examples note the history, development, structure, and accomplishments of each coalition, along with links or contact information for those wishing to learn more. Readers will note that some of the coalitions presented are led or supported by a Dementia Care Specialist, while others are led by another professional or community volunteer.

Ashland Bayfield Dementia & Caregiver Network

The Ashland Bayfield Dementia & Caregiver Network is a multi-county coalition initiated in 2013 by a local physician and her team who operate a memory diagnostic clinic in the city of Ashland focusing primarily on local community dementia needs. Members represent both counties and include: the Aging and Disability Resource Center of the North, including the Regional Dementia Care Specialist, Wisconsin Indianhead Technical College, tribal communities, Health and Human Services, Aging Services, managed care organizations, care facilities, volunteer groups, transportation, and the Alzheimer’s Association. The group meets monthly and involves approximately 20 participants. In 2017, the group merged with the Ashland Bayfield Caregiver Coalition to effectively meet the overall needs of aging communities. Members of the coalition provide tools and resources to enhance the work of the coalition and minimize duplication of services.
In general, the coalition is grass-roots and action-driven, so the meetings involve updates regarding upcoming educational events, memory screenings, health fairs, and other projects. There is no formal committee structure. Meetings are led by a staff member from the memory diagnostic clinic, or by another member of the coalition, as necessary. Agendas are developed by the group and members are not mandated to attend, but encouraged as schedules allow. Meetings are intentionally designed to be informal to allow room for discussion and brainstorming. The Ashland Bayfield Dementia & Caregiver Network focus areas currently include, Healthy Aging, Dementia Friendly Communities and Caregiving. Activities and accomplishments to date include:

- Memory screening events
- Community and professional education programs held at the local hospital or technical college
- Participation in health fairs
- Dementia friendly business trainings
- Marketing and public awareness campaign
- Memory Cafés
- Dementia Friendly Libraries

To learn more about the work of the Ashland Bayfield Dementia Network, visit their Facebook page at www.facebook.com/Ashland-Bayfield-Dementia-Network-1560199730885581/

**Brown County Dementia Coalition**

The Brown County Dementia Coalition began in 2014 following discussions with a number of key partners and stakeholders led by the Brown County Aging and Disability Resource Center (ADRC). In addition to the ADRC, the group included the Alzheimer’s Association Greater Wisconsin Chapter, University of Wisconsin-Green Bay Social Work Department, local non-profit provider, adult day care provider, and the gerontology program at Northeast Wisconsin Technical College. The group performed an informal readiness assessment and determined that the community was indeed poised to begin working on becoming dementia-friendly. Memory Cafés were one of the first projects the Coalition undertook, with the local technical college serving in a lead role. The Memory Café was a success and additional Memory Cafés were started. Currently, there are 5 Cafés operating in the county.

In 2015, Brown County was awarded one of the Dementia Care Specialist (DCS) positions supported by the State of Wisconsin Department of Health Services. With the DCS in place, the Dementia Coalition was positioned to expand its work and extend its reach as part of the DCS role is to help build the coalition. The DCS participates on each of the coalition’s five sub-committees, and supports the work of the coalition by leading the meetings, meeting with sub-committee chairs, developing the agendas, note-taking and distribution, and coordinating between-meeting communication. Additional support to the coalition comes from the Dementia Care Specialist Assistant, a newly created position that provides overall assistance, along with specific support to the Memory Café and Purple Angel programs. The ADRC Director also plays a significant role in supporting the work of the coalition. The coalition meets every other month with sub-committee meetings held on alternate months. The coalition’s 5 subcommittees are: Memory Café, Purple Angel, Community Education, First Responder/Crisis, and
Down Syndrome & Alzheimer’s. In addition to Memory Cafés, other accomplishments and activities include:

- Presentations to the county board
- Grant submissions
- Creation of a sensory garden
- SPARK! Program events
- Educational conferences
- Memory walks

Also important to note is the engagement of the Tribal DCS for the Oneida Nation, who is an active member of the coalition and who participates on the Memory Café, Community Education, and Purple Angel subcommittees.

To learn more about the Brown County Dementia Coalition, visit their website at www.co.brown.wi.us/departments/page_edef024e498b/?department=db50c2508c43&subdepartment=1dfd7417eea9

Dane County Dementia Friendly Communities Leaders

Dane County has taken a unique approach with its dementia friendly community’s efforts. Rather than a single county-wide group, it has instead encouraged and supported many local communities within the county to establish their own dementia friendly initiatives. As these grass roots initiatives began to grow, the Dementia Care Specialist recommended that a collaborative group be formed to share best practices and provide education to the leaders of city or town dementia friendly groups. In 2015, the DCS began to convene the Dane County Dementia Friendly Communities Leaders group to encourage greater community-to-community mentoring and collaboration. Currently there are 16 separate dementia friendly communities in the cities, towns, and villages of Dane County. The Dementia Care Specialist chairs the monthly meeting of the Dane County Dementia Friendly Communities Leaders, which also includes other community stakeholders (professionals and volunteers) interested in supporting the group’s efforts. The purpose of this monthly meeting is to learn from and share strategies, ideas, approaches, and lessons learned by each community. The meetings often include a guest presenter, along with reports and updates from attendees. Topics addressed by guest speakers have included: the Silver Alert Program, Music and Memory, Library Initiatives, Crisis Response, SPARK! (museum-based programs), Dementia Friendly Financial Institutions, and Dementia Friendly America. In addition to the monthly meetings, the DCS and a representative from the Alzheimer’s Association South Central Chapter offer a dementia friendly train-the-trainer program.

The DCS, in collaboration with the Dane County Aging and Disability Resource Center, the Alzheimer’s Association, and the Alzheimer’s and Dementia Alliance of Wisconsin, hosts an annual breakfast meeting to acknowledge and celebrate the accomplishments of the individual communities and their collective efforts. The DCS also coordinates the Dane County Dementia Friendly Community Annual Report highlighting the achievements of the communities involved: www.daneadrc.org/doc/DFC%20Annual%20Report%202017.pdf

To learn more about dementia-friendly community efforts in Dane County, visit the Dane County ADRC website at www.daneadrc.org/dementia_friendly.aspx
Dementia Coalition of Eau Claire County

The groundwork for the Dementia Coalition of Eau Claire County began in 2013 when the Aging and Disability Resource Center (ADRC) noticed an increasing number of calls coming into their agency from people seeking information regarding their loved ones with dementia. Many of the calls focused on behavioral issues and the struggles families were having in helping their loved ones. The ADRC began convening a workgroup, initially involving primarily Adult Protective Services (APS) and law enforcement, along with staff from the ADRC. In May of 2014, Eau Claire County was awarded a Dementia Care Specialist (DCS) position, with part of the DCS’s mandate to include a focus on dementia friendly community initiatives. At that time, the Eau Claire County Dementia Coalition was formally developed.

The coalition meets on an every-other-month basis, and is led by the DCS. Membership is open to community members and professionals interested in helping support an optimal quality of life for people living with dementia. The coalition includes action teams that meet outside of the regularly held coalition meetings, including: Engaging Healthcare Providers; Dementia Awareness and Marketing; and Dementia Friendly Business. Some of the activities and accomplishments of the coalition include:

- Development of a Facebook page and dedicated logo
- A community survey conducted in 2016 that solicited over 400 responses
- A community summit with 130+ attendees held in response to the survey to further understand the community’s needs related to dementia
- Extensive dementia-friendly business training

Visit the Eau Claire County Dementia Friendly Facebook page at www.facebook.com/dementiafriendlyecc

Fox Valley Memory Project

The groundwork for what would eventually become the Fox Valley Memory Project (FVMP), which supports Outagamie, Waupaca, Calumet, and Winnebago counties, began when a small group of key stakeholders formed a task force in 2011 after identifying that dementia put older adults at risk for poverty and other challenges. One of the group’s initial actions was to apply for and receive a number of small planning grants to design a community forum. The purpose of the forum was to engage community members to identify the needs and aspirations of people living with dementia. The event included 25 participants for a breakfast meeting followed by a “think tank” session. Following this meeting, two grants were written and obtained in 2012 that provided funding to develop the FVMP. The funding allowed the group to hire a part-time staff member and to start the first Memory Café.

The group engaged an executive coordinating committee that meets monthly to review financials, set policies, and provide general oversight. In spring of 2018, the FVMP hired a full-time Executive Director to work with the
The FVMP includes three action teams: 1) Programs; 2) Marketing and Fund Development; and 3) Finance. They also engage additional ad hoc action teams as other needs and projects emerge. For example, a rural needs assessment action team was developed to address the specific needs of rural areas covered by the FVMP. The FVMP is also working on a 501c3 application which would allow it function as a non-profit organization. Lutheran Social Services previously served as the group’s fiscal agent.

The FVMP has continued to grow since its early days and has become a role model for other communities seeking to become dementia friendly. Some of the activities and accomplishments achieved over the years include:

- 10 Memory Cafés per month in 9 different locations
- Informal gatherings of people living with dementia and their care partners, called “Meet Ups”, that serve to normalize life with dementia
- Arts events outings
- A chorus comprised of individuals living with dementia and their care partners
- Bus trips/field trips
- Memory Camp (multi-generational 3-day wilderness experience)

To learn more about the Fox Valley Memory Project, visit their website at www.foxvalleymemoryproject.org/ or their Facebook page at www.facebook.com/FoxValleyMemoryProject/

**Grant County Dementia Coalition**

The Grant County Dementia Coalition started in 2001 and is led by a staff member from the Alzheimer’s and Dementia Alliance of Wisconsin (ADAW) who chairs the meetings, develops the agendas, takes and distributes minutes, and facilitates between meeting communications. The Coalition’s goal is to support people living with dementia and their care partners, reduce stigma, and raise awareness of dementia through education, support, and service. The 12-14 coalition members meet monthly to share updates, work on projects, and coordinate activities. Key partners include staff from the Aging and Disability Resource Center, Adult Protective Services, UW-Platteville, Southwest Wisconsin Technical College, and local nursing homes, community based residential facilities, public health and home care agencies.

Accomplishments and activities of the Grant County Dementia Coalition include:

- Mission Statement (see Appendix)
- Providing local hospitals, clinics, and primary care physicians with information regarding resources and organizations
- Hosting an annual education conference for professionals and community members that draws approximately 180 attendees
- Always seeking to include family care partners or persons with dementia to serve on the coalition, though this is often challenging
- Hosting an annual Alzheimer’s Walk (sub-committee)
For more information regarding the Grant County Dementia Coalition, contact Becky Debuhr of the Alzheimer’s and Dementia Alliance of Wisconsin at Becky.Debuhr@alzwisc.org.

Dementia Friendly Community Coalition of Marinette County

The Dementia Friendly Community Coalition of Marinette County began as an off-shoot of the county’s Caregiver Coalition, a large and active group addressing the needs of caregivers in the county. In January of 2016, the topic of a dementia coalition was discussed at the monthly caregiver coalition meeting, resulting in twelve people expressing interest in being part of developing a dementia friendly coalition. Following the caregiver coalition meeting, the dementia friendly coalition group met and began by authoring a mission statement using guidelines provided by the Wisconsin Department of Health Services. They also started work on a survey to assess the community’s needs, awareness, and resources around dementia. Next steps involved website development and establishing a Facebook site, along with discussions of how best to train local businesses and establishment of the coalition as a non-profit. The group also decided to establish an executive committee comprised of a President (social worker at skilled nursing facility), Vice President (community volunteer), Secretary (ADRC supervisor), Treasurer (county elderly services specialist), and Member-at-large (owner, elderly services agency), to help guide the coalition in moving forward.

The Dementia Friendly Community Coalition (DFCC) of Marinette County was intentionally set up as an independent entity, separate from any specific organization or agency. The purpose is threefold: 1) to allow the Coalition to operate autonomously, 2) to allow the Coalition to be unbiased in its work, and 3) to allow the Coalition to have operational flexibility that is often difficult within county or other organizational structures. The Coalition was granted 501c3 status in 2017, so is able to operate as a non-profit. The Coalition currently meets on a monthly basis, although the group met more frequently during the initial start-up period. The coalition is in the process of planning other dementia related projects specific to making Marinette County more dementia friendly. Activities to date have included:

- Business trainings
- Longest Day events
- DFCC Awareness presentations & exhibits
- DFCC Fundraising events (grocery bagging, basket raffle)
- Grant awards (United Way & M & M Community Area Foundation)
- Other opportunities as they emerge throughout the year

To learn more about the Dementia Friendly Community Coalition of Marinette County, visit their Facebook page at www.facebook.com/Dementia-Friendly-Community-Coalition-of-Marinette-County-1220593847962213/
Milwaukee County Alzheimer’s Action Network

The Alzheimer’s Action Network in Milwaukee County was formed in September of 2014 as a collaboration initiated by the Wisconsin Alzheimer’s Institute’s (WAI) Regional Milwaukee Office, the Southeast Chapter of the Alzheimer’s Association, and the Milwaukee County Department on Aging (MCDA). Representatives from the WAI and the Alzheimer’s Association lead the Network, while the MCDA provides vital in-kind support. Recognizing the importance of the Alzheimer’s Action Network to Milwaukee County, the MCDA included the Network in its three-year plan. The Dementia Care Specialist for Milwaukee County started shortly after the kick-off meeting of the Alzheimer’s Action Network, and an additional DCS was hired the following year. The two DCS’s quickly became important partners of the Network.

While located in Milwaukee County, the Network represents all of southeastern Wisconsin, including the 11 county service area of the Alzheimer’s Association Southeastern Chapter. The goal of the group is to form a dementia friendly and dementia capable region, by raising awareness, reducing stigma, and connecting people living with dementia to needed social supports. The name “Action Network” was chosen rather than “Coalition” to convey that the group intended to take an action-focused approach, involve action-oriented participants to identify needs and gaps in services and resources, and work to alleviate those gaps.

After sending out an “all-call” invitation to key stakeholders, the first meeting included 25+ people and involved extensive brainstorming. The leaders conveyed that the purpose of the Network was to be a non-competitive collaboration, with the intent not to set standards, but to establish and share best practices. The group was asked to respond to questions such as: What do you/your agency do to assist persons living with dementia and their families? What does dementia capable and dementia friendly mean to you or your organization? Why did you agree to attend today’s meeting and what are your expectations? Also discussed was the creation of a statement of purpose, and other priority items such as: stigma reduction, raising awareness, and identifying gaps and needs in Milwaukee County.

The Alzheimer’s Action Network meets quarterly and involves two subgroups: Feedback from Families, and Dementia Friendly Businesses. The agendas for the quarterly meetings typically include subgroup reports, activity updates, Action Network member updates, topical presentations, and discussions of specific projects/initiatives. The meetings involve between 20-40 people.

One of the group’s first actions was to invite a panel of people living with dementia and caregivers to share their concerns. The Network was intentional about assuring that the panel represented the racial and cultural diversity of the community. Network members found this discussion to be very helpful in setting a direction for their efforts. Over the course of the Network’s collaboration, external presenters have occasionally been invited to share best practices from their communities. Alzheimer’s Action Network accomplishments to date include:

- Definitions of dementia friendly and dementia capable for Southeast Wisconsin communities
- The Village of Greendale established as Dementia Friendly
- Multiple Memory Cafés established throughout the County
Multiple libraries designated as hubs for dementia-related information and resources
- Dementia added to the Living Well with Chronic Conditions program
- Education provided to Police, Fire, and EMS Departments
- Partnerships established with Racine and Kenosha Counties

To learn more about the Alzheimer’s Action Network in Milwaukee County, contact Gina Green-Harris (greenharris@wisc.edu) or Nia Norris (ncnorris@wisc.edu), both of the Wisconsin Alzheimer’s Institute’s Regional Milwaukee Office, or Wendy Betley (wbetley@alz.org) of the Alzheimer’s Association Southeastern Wisconsin.

Portage County Dementia Coalition

The Portage County Dementia Coalition began shortly after the county was awarded a Dementia Care Specialist position in 2014. The DCS, working within the Aging and Disability Resource Center, took the lead to initiate the coalition with the priority to expand dementia friendly community efforts. The DCS develops the agendas, takes and distributes minutes, and coordinates communication with coalition members. The meetings are co-led by the DCS and the county’s Caregiver Services Manager. The group meets every-other-month, with attendance of 10-15 professionals and community members. The coalition has 5 subcommittees, including: Safety and Security, Resources, Training, Marketing, and Employer Outreach, that meet following the main coalition meeting.

Activities and accomplishments to date include:
- Training over 30 businesses, organizations, clubs, and faith-based communities
- Training adapted to meet the specific group or organization
- Engagement of police, fire, and EMS
- Training of urgent care and emergency departments of a new health clinic in Plover

To learn more about the Portage County Dementia Coalition, contact Carley Prochaska at prochasc@co.portage.wi.us.

St. Croix County Dementia Friendly Coalition

The St. Croix County Dementia Friendly Coalition was founded around the issue of raising awareness and reducing the stigma of dementia. This was a cooperative effort of the St. Croix Valley Foundation (SCVF) and the Aging and Disability Resource Center of St Croix County. In 2014, the St. Croix Valley Community Foundation offered to host a series of plays about dementia in several towns throughout the St Croix River Valley. The plays were held in four communities, with more than a 1,000 area residents attending. These hour-long performances called “The MemoryCare Plays: Steering into the Skid,” were sponsored by local providers and agencies, and were performed in multiple locations throughout the community. The performances were followed by a question and answer session.
involving professionals and community members. Following these successful events and great community interest, the Foundation inquired whether there was more that could be done to further their dementia friendly community efforts. The Dementia Care Specialist suggested the development of a dementia coalition, and the SCVF Board agreed. SCVF arranged a community lunch event, which was held in 2015 and involved over 80 community members and professionals to understand the community’s met and unmet needs related to dementia care, support, and programs. Three key topics emerged: business training, caregiver support, and community collaboration and communication. From this event, the St. Croix County Dementia Friendly Coalition was formed, with the first meeting held in June of 2016.

The coalition is led by a staff member (development director) from the St. Croix Valley Community Foundation in collaboration with the Dementia Care Specialist and other community partners. The full coalition, which involves 15-25 members, began meeting every other month with committee meetings taking place on alternate months. Members signed up for one of the three key topic areas. After a year members decided to meet together every month and this has generated more activity accomplishing the goals efficiently. The coalition functions with action in mind. Meetings involve committee updates, discussion of new initiatives, guest speakers, community news and announcements, and action priorities. Activities and accomplishments to date include: business training; engagement of faith communities with an event titled, “Dementia Sunday: Music by Heart”; creating a Facebook site; developing display boards that will be moved through all county libraries; and a 5-episode educational series aired on public access TV featuring:

- Daughter of 40 year old man diagnosed with Frontal Temporal Dementia (FTD)
- Wife of husband diagnosed with Alzheimer’s disease in his late 50’s
- Physician discussing the importance of early diagnosis and healthy lifestyle habits
- Attorney addressing financial Power of Attorney
- Adult protective services

To learn more about the work of the St. Croix Valley Dementia Friendly Communities initiative, visit their Facebook page at www.facebook.com/stcroixvalleydementiafriendlycommunities/

Waukesha County Dementia Friendly Coalition

Under the leadership of the Dementia Care Specialist, Waukesha County is actively working to become dementia friendly. Rather than creating a centralized county coalition, dementia coalitions are being developed at the local level. From the perspective of the DCS, it is important that these local coalitions are grass roots so that the community truly own them and take an active role in addressing local needs. To date, two communities, Oconomowoc and Pewaukee, have developed Dementia Friendly Community coalitions, addressing the unique needs, resources, and strengths of their communities. Two additional communities, Sussex/Lisbon and Brookfield, have begun the initial process of developing leadership teams, while other cities and villages in Waukesha County have expressed interest in becoming dementia friendly.
The Dementia Care Specialist takes a strategic, step-by-step approach to coalition development by bringing together a group of approximately 10 action-oriented community members who are invested in the community and who have the energy, time, and passion to get things done. Within this initial meeting, the DCS:

2. Seeks to recruit 2-3 people to form the coalition leadership team.
3. Engages participants to consider the formation of workgroups based upon community resources, needs, and interests.
4. With assistance from attendees, generates a list of individuals from the community that should be a part of the coalition.

Once the coalitions are established they meet quarterly, and the workgroups meet as often as necessary, typically 1-2 times per month. Each workgroup has a defined leader and members, however, it is not required that workgroup members be part of the larger coalition. Workgroups vary by community based on the interests and needs expressed by individuals with dementia and their caregivers. The workgroups in these two existing dementia friendly communities include: Education/Business Training; Faith-Based; Daytime Engagement; Care Transitions; and Marketing and Public Awareness. Some of the activities and accomplishments to date are:

- Community presentations
- Business trainings
- First Responder crisis training
- Memory screens
- Memory Cafés
- Educational forums


**SUMMARY**

The authors and content experts featured in this guide hope that readers find the information helpful in thinking about convening a dementia coalition. The examples highlight a number of successful coalitions and provide varying approaches to coalition leadership, development of sub-committees or action teams, and community impact or accomplishments. With regard to leadership, the examples include staff from the following types of organizations:

- Alzheimer’s Association chapters
- Alzheimer’s and Dementia Alliance of Wisconsin
- Memory Diagnostic Clinic
- Private Foundation
Readers will have noted the various examples of sub-committees or action teams highlighted. These include:

- No formal committee structure
- Memory Café
- Purple Angel or Dementia Friendly Business Training
- Community Education
- First Responder/Crisis
- Down Syndrome & Alzheimer’s
- Engaging Healthcare Providers
- Dementia Awareness and Marketing
- Programs
- Marketing and Fund Development
- Finance
- Rural Needs Assessment
- Feedback from Families
- Faith-Based
- Daytime Engagement
- Care Transitions
- Marketing and Public Awareness

Finally, there are numerous examples of community impact and accomplishments highlighted across the featured coalitions. These include:

- Development of vision and mission statements
- Definitions of dementia friendly and dementia capable
- Community surveys
- Dementia friendly business training/Purple Angel training for:
  - Pharmacies, banks, grocery stores, medical settings
- Education programs, conferences, and forums
- Community breakfast
- Community Dementia Friendly Summit
- Community Forum
- Training of police, fire and EMS departments
- Memory screening events
- Participation in health fairs
- Dementia added to the Living Well with Chronic Conditions program
- Marketing and public awareness campaign
- Dementia Friendly Resource Guide
- Development of Facebook pages
- Logos
- Television programs addressing issues of dementia
• Presentations to the county board
• Hosting annual Alzheimer’s Walk
• Longest Day events
• Dementia Friendly Community Coalition presentation and exhibits
• Dementia Friendly libraries
• Grant submissions and grant awards
• Dementia Friendly Community Coalition fundraising events
• Non-profit organization status
• Tribal education and events
• Annual Report
• Faith community engagement and events
• Community activities and programs
  • Memory Cafés
  • Meet Ups - Informal gatherings of people living with dementia and their care partners, that serve to normalize life with dementia
  • Dementia Friendly Art Fair
  • Arts Outings
  • Bus Trips/field trips
  • Poetry Programs
  • Dementia Friendly Chorus
  • Fishing Outings
  • Creation of a Sensory garden
  • SPARK! Program events
  • Memory Walks
  • Memory Camp – multigenerational 3 day wilderness experience
  • Theater performances/plays

As these examples show, there is no limit to the ways in which action-oriented, passionate, mission-focused people working together can create a positive impact for their communities. As Wisconsin communities work to become dementia friendly, developing a dementia coalition can be an important building block in this process. Dementia coalitions are convened with the primary goal of improving the lives of people living with dementia and those who care for them. Beyond those directly affected by dementia, many believe that all members of a community benefit when it’s citizens collectively work together to become dementia friendly. In other words, a dementia friendly community is a friendlier and more welcoming community for all.
REFERENCES AND RESOURCES

RESOURCES:

Developing Effective Coalitions: An Eight Step Guide, Prevention Institute, Oakland, CA
www.countyhealthrankings.org/sites/default/files/eightstep.pdf

Wisconsin Counties by Population
www.wisconsin-demographics.com/counties_by_population

Wisconsin Dementia Care System Redesign: A Plan for a Dementia-Capable Wisconsin, February 2014
www.dhs.wisconsin.gov/publications/p0/p00586.pdf

Wisconsin Department of Health Services Dementia Care System Redesign Website
www.dhs.wisconsin.gov/dementia/index.htm

Wisconsin’s Healthy Brain Initiative (HBI) Project
A Toolkit for Building Dementia-Friendly Communities

REFERENCE:
1. National Plan to Address Alzheimer’s Disease 2016 Update

APPENDICES

Sample Mission Statements

Brown County Dementia Coalition: Develop cooperative partnerships which raise awareness, educate, and engage all to create a dementia friendly community that enhances quality of life for everyone.

Eau Claire County Dementia Coalition: Making life better for those living with memory loss, dementia, their support system, and the community of Eau Claire County through advocacy, resources, support, and education.

Fox Valley Memory Project: The Fox Valley Memory Project collaborates with other organizations to offer programs and services that improve quality of life for persons with dementia, as well as their family care partners and friends. We encourage practices of hospitality and inclusion that make our community dementia-friendly.

Grant County Dementia Coalition: We will build an educated community poised to support people with dementia and their families through information, assistance, and direct services. Link to medical and social services to promote early diagnosis and treatment, increase access to appropriate social services, enhance referrals for families across the county.
Marinette County Dementia Coalition: To create a dementia friendly community that is safe, respectful, and welcoming for people living with dementia through awareness, education, and community engagement.

Waukesha County: Oconomowoc Dementia Friendly Community Project: The Oconomowoc Dementia Friendly Community Project is creating a community where those with dementia will be enabled to live as independently as possible and continue to be engaged in community life.

Sample Logos

Resources to Live Well with Dementia
Sample Needs Assessments
Dementia Friendly Community Coalition of Marinette County

Dementia Friendly Community Survey

The Dementia Friendly Community Coalition of Marinette County is a group of healthcare professionals, community members, and advocates for senior health and wellness who support Wisconsin's statewide efforts to improve the lives of those living in our communities who suffer from dementia related illnesses. Dementia is a term used to describe the symptoms of a group of more than 100 conditions characterized by a decline in memory or other thinking skills that affects a person's ability to perform everyday activities. Alzheimer's disease is the most common type of dementia.

Our mission: “To create a dementia friendly community that is safe, respectful, and welcoming for people living with dementia through awareness, education, and community engagement.”

A Dementia Friendly Community is a place where individuals with dementia and their caregivers are met with understanding and given support in order to feel safe and welcome. In a Dementia Friendly Community, individuals should be able to function and maintain their ability to access local facilities and services.

This survey is designed to assess the needs of the Marinette County community at large. Your participation is very important, since accurate survey data will be used to plan community initiatives as well as secure grants and funding.

Thank you for your time and consideration.

Return this survey to: Meghan Rutherford @ 831 Pine Beach Rd. Marinette WI 54143 Dementia Friendly Community Survey c/o meghan@dfcwi.com
Or Fax to: (715) 732-5833
Or Mail to: Meghan Rutherford (Please remember to fax both sides.)

You may also complete the survey on-line at: dfcwi.com

**This survey may also be returned to the location you received it from**

1. Have you had experience with someone with a dementia related illness?
   Yes _____ No _____ Unsure _____
   If Yes: Personal _____ Professional _____ Both _____

2. Please rate your knowledge of dementia related illnesses.
   High Moderate Low Unsure

3. Please rate your knowledge of what it means to be part of a dementia friendly community.
   High Moderate Low Unsure

4. How would you rate your awareness of community resources for those with dementia related illnesses?
   High Moderate Low Unsure

5. How would you rate your ability to access resources in our community for dementia related illnesses?
   High Moderate Low Unsure

6. Please rate the areas where you believe our community needs dementia friendly services:

   Strongly Agree | Do Not Know | Strongly Disagree
   Healthcare 5 | 4 | 3 | 2 | 1
   Emergency Services 5 | 4 | 3 | 2 | 1
   Legal and Financial 5 | 4 | 3 | 2 | 1
   Stores/Restaurants 5 | 4 | 3 | 2 | 1
   Public Areas/Venues 5 | 4 | 3 | 2 | 1
   Faith Organizations 5 | 4 | 3 | 2 | 1
   Other: __________ 5 | 4 | 3 | 2 | 1
7. Rank your top five choices for where you believe the Dementia Friendly Community Coalition should begin to focus. (Please rank as 1 = Most Important and 5 = Least Important.)

___ Support groups  
___ General community education about dementia  
___ Awareness of available resources  
___ Activities for those with dementia related illnesses  
___ Healthcare training  
___ Signage indicating dementia friendly organizations/areas  
___ Dementia awareness training for community businesses  
___ Physicians/providers specializing in dementia related illness  
__ Other: ____________________________

For accurate survey results, please provide your zip code. Thank you.

Your Zip Code: ____________  
Please circle: Rural Area  
City Area

Please describe yourself. (Circle all categories which apply to you)

Personal Caregiver  
Profession Caregiver  
Healthcare Provider  
Healthcare Professional  
Business Owner  
Business Employee  
Retail Worker  
Restaurant Worker  
Insurance Agent  
Financial Service Provider  
Clergy  
Social Services Provider  
Faith Community Member  
Educator  
Student  
Professional Services Provider  
Other: ____________________________

Gender (Please circle)  
Female  
Male  
Age Range (Please circle)  
<30  
31-50  
51-70  
>70

Would you be interested in supporting projects or initiatives organized by the Dementia Friendly Community Coalition of Marinette County?  
Yes ______  
No ______  
Maybe ______

Optional information

Please print your name and contact information if you would like email notifications from the Dementia Friendly Community Coalition. (Your personal information and/or email will not be shared.)

Name: ________________________________
Address: ________________________________  
City: ____________________________  
State: ____________  
Zip Code: ____________
Phone: (Home) _______________________ (Cell) ____________________
Community Survey About Dementia

The Dementia Coalition of Eau Claire County is investigating what citizens know about dementia and the current system of care for people with this challenging condition. The following survey takes less than five minutes to complete. All responses are confidential.

To complete the survey, put an “X” in the appropriate box to the right of each question.

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
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</thead>
<tbody>
<tr>
<td>1. I am comfortable discussing dementia with a friend or colleague.</td>
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<td>2. I have enough knowledge about dementia to interact with people living with the disease.</td>
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<td>3. I have skills to feel comfortable interacting with people with dementia.</td>
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<td>4. I have received education or training on recognizing the signs of dementia in the past 12 months.</td>
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<td>5. In my work or personal life, I have regular contact with someone with dementia or significant memory loss.</td>
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<td>6. I am aware of what it means to be a dementia friendly community.</td>
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<td>7. I feel knowledgeable about how to access dementia related resources in our community if I need them.</td>
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<tr>
<td>8. If I encounter a person with dementia who I believe is experiencing a crisis, I know how to respond.</td>
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<tr>
<td>9. Eau Claire County has enough resources in the community to provide education about dementia.</td>
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<tr>
<td>10. Eau Claire County has enough resources in the community to treat people with dementia.</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>
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