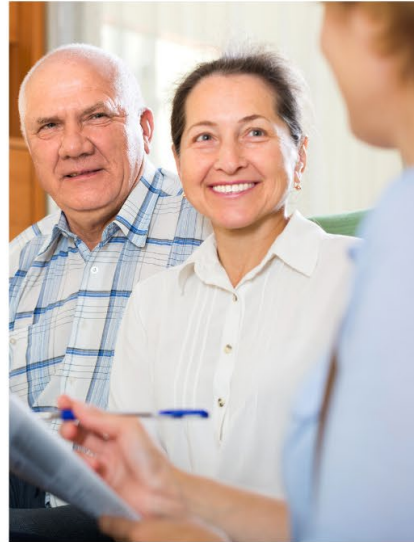


Community Conversation Guide

A toolkit to gather feedback from
your community about dementia
care systems and to influence
development of the 2024–2028
State Dementia Plan.



State Dementia Plan Community Conversation Guide

Purpose

We invite you to engage members of your community in sharing their experiences with dementia care to influence development of the 2024-2028 State Dementia Plan. Through these conversations, we hope to identify challenges and solutions that will help us improve our dementia care systems. Notes from conversations will be compiled and analyzed to shape the next plan, published in early 2024. **These conversations must be held prior to December 31, 2022, to be included in the State Dementia Plan.**

We have also created an [online survey](#) that you can share to collect more feedback. Please use the online survey when possible; however, a printable version is available for [download](#); please email Angela Miller (angelak.miller@dhs.wisconsin.gov) if you need pre-paid envelopes to return surveys to DHS.

Context

In 2018, the Department of Health Services (DHS) published the [2019 – 2023 State Dementia Plan](#). The plan was developed during a statewide summit that brought together diverse stakeholders from the dementia care system. The plan is being implemented by a Steering Committee and four leadership teams focused on Care in the Community, Health Care, Crisis Response, and Facility-Based Care. Membership on the teams is open to anyone and includes caregivers, advocacy organizations, health and human services agencies, elected officials, researchers, and providers.

Despite the significant challenges caused by the pandemic, the teams have made an impact. For example, team members have created guides for dementia-friendly communities and businesses. Members have also championed grant programs to fund caregiver support groups, expand research hubs in rural areas, strengthen memory screening programs, and create a brain health curriculum for K-12 schools. Recommendations advanced by team members have created the statewide dementia care specialist program, created new opportunities to train certified nurse aides, and increased funding for long-term care agencies. DHS is now working with the Steering Committee, leadership teams, and communities to build on these successes and identify remaining challenges as we develop the 2024-2028 State Dementia Plan.

Planning a Community Conversation

First, consider who your audience will be and when the conversation will occur. The conversation could be held during a pre-planned caregiver support group meeting, dementia coalition meeting, a residents' meeting at an assisted living facility, or at a separate meeting with partners. Decide how long the event will last (generally 1-2 hours) and pick a convenient time for the group (some may prefer regular business hours, while others will be available on evenings and weekends). Decide if you will provide childcare. Please [register your event](#) with DHS so we can keep track of all conversations happening across the state.

Consider whether the conversation will be in-person or virtual. If in-person, decide on a location and whether refreshments will be provided (restaurants may be interested in donating food). The pandemic has enabled more connection to happen virtually, but it has also isolated those without high-speed internet. Please contact Angela for help with hosting a meeting using DHS Zoom. If you would like assistance with translation services, please contact Angela well in advance.

Decide how you will promote the conversation to participants. Send invitations by email, listserv, social media, flyer, and/or newspaper. Consider inviting reporters from your local newspaper and local elected officials to attend. See Attachment D for template flyers and social media posts.

It is important to make sure that you have a notetaker present during the conversation. The notes will be critical for communicating what is said during the meeting. The notetaker can either take notes by hand with pen and paper or electronically but will ultimately need to be sent electronically to Angela.

Facilitator Tips

Your role as a facilitator is very important. Your ability to make everyone comfortable, encourage everyone to speak up, enforce a respectful tone, and manage the pace will determine the quality of the discussion and the information you gather. You will have the help of a notetaker to allow you to focus your attention on the discussion while also ensuring accurate notes. The next page has an outline for the event.

Facilitation Tips

Ask questions clearly.

- Remind people that there are no wrong answers
- If the group needs help getting started, the questions list has guidance on examples to provide

Try to acknowledge responses in the same way for all answers.

- If you say “OK” to one answer, say “OK” to all answers
- If you nod to one answer, nod to all answers
- Remain neutral (try to not react positively or negatively to an answer)

Understand what is said and get people to talk.

- Use probing questions such as "Would you explain further?", "Would you give an example?"
- Restate a participants' response with actual words as much as possible
- Ask if anyone else has any comments on that question

Pay attention to non-verbal signals.

- Someone might be sending a cue that she/he is uncomfortable or might have something to say

Engage all participants in the discussion.

- Ask, “Who else has something to say?” or “I would like to hear more from...”
- Allow time for participants to think about their answers. A little silence is OK.

Redirect the discussion when it strays too far off topic.

- Say something like, “These are important and interesting points. However, we need to bring the discussion back to our main focus on...”

Avoid.

- Asking leading questions. An example of a leading question is “Don’t you think...”
- Sharing your own opinions (verbally or non-verbally).

Community Conversation Outline

Introductions

- Thank people for coming and agreeing to be part of the conversation.
- Introduce yourself and your notetaker. Have participants identify themselves and their classification as it relates to dementia (family caregiver, person living with dementia, professional caregiver, health care professional, local government staff, unsure, or other).
- **Share the purpose of the conversation, how the information will be used, and make sure everyone understands the terms dementia and caregiver:**
 - We are partnering with the Department of Health Services to update the state's dementia plan. Communities across the state are holding conversations about dementia care. The notes from these conversations will influence local decisions and the state plan. What you say will be shared with our partners, but your name will not be attached. Participation is voluntary.
 - Through these conversations, we hope to identify problems with the current system and to figure out innovative ways to improve dementia care and support caregivers.
 - To make sure everyone is on the same page, when we talk about dementia, we are referring to loss of memory, language, and other thinking skills that is severe enough to interfere with daily life. Alzheimer's is the most common cause of dementia. Caregivers provide care to people who need some degree of assistance with everyday tasks on a regular or daily basis. The term caregiver refers to both those who are paid to provide care (such as home health aides) and those who are not paid to provide care (such as family members).
- Explain the operating agreements for the conversation. These will set the tone and expectations for behavior so that everyone will feel safe and willing to participate.
 - Please allow one person to speak at a time.
 - There are no right or wrong answers.
 - Please no side conversations.
 - Please respect the opinions of others and be thoughtful about speaking.
 - Try to stay on topic; we may need to interrupt so that we can cover all the material.
 - Ask if there are any additional ground rules the group would like to add.

Conversation Questions

- See Appendix A for a list of questions. Feel free to include additional questions or exclude questions depending on your audience and time.

Closing the session

- End the discussion by summarizing the main points. The notetaker can assist.
- Ask if they have any additional thoughts to share. Thank the group for sharing their insights, and affirm that the information will be used to influence programs at the state and local levels.
- Tell attendees that the State Dementia Plan will be published in early 2024, and that you will follow-up to make sure they receive a copy (be sure to record email addresses for those who want a copy.)

After the attendees leave, have a debrief discussion with the notetaker. You can also share the [online survey](#) with those who attended or were invited to collect additional information.

Notetaker Tips

Preparation

- Bring materials that you are comfortable with using to take notes, including writing utensils (more than one) and a lot of paper or a computer with charger.
- See Appendix C for a notetaker template that you can fill out and email to DHS.

Notetaking Tips

Record observations of the group.

- Do people have a lot to say, or are they reluctant to speak?
- Are some people dominating the discussion while others are silent? Is the group cohesive or are there great differences of opinion?
- Do the above factors change depending on the question?
- Group composition (if known): who is participating in this conversation? What communities (geographic or demographic) does this conversation include?

Include direct quotes when possible.

- There is much value in capturing the exact words that are used by participants.
- Try to capture as much of the conversation as possible using the actual words as much as possible, that people speak. Avoid the temptation to paraphrase.
- This will show each participant that his/her ideas are unique and important.
- If you need to ask for clarification to make sure your note is accurate, please do so sparingly, respectfully, and with as little disruption to the conversation as is possible.

Summarize key discussion points.

- As each question is posed, individuals will offer their opinions, but there is often some nonverbal communication that also relays the group's perceptions and thoughts on the issue.
- Reactions should be captured and summarized along with the general discussion.

Don't:

- Include personal commentary, opinion, subjective reasoning, or critical analysis if it wasn't provided by the participants.
- Audio or video record group discussions.
- Be selective about what to document in your notetaking because all interactions are important.

After the attendees leave, have a debrief discussion with the facilitator. Review the notes and write down any new insights that came up from the discussion. After the notes are complete, email them to Angela Miller at DHS (angelak.miller@dhs.wisconsin.gov).

Appendix A: Questions for Community Conversations

1. Of the following options, what do you think the next state dementia plan should focus on to improve dementia care in Wisconsin? *[If feasible, please have these options pre-written on a board or notepad for those who process information best by reading it.]*
 - a. We will read the list twice: once so you can hear all the options, then a second time more slowly so you can vote by show of hand. During the second reading, please raise your hand if you think this should be a priority for our work.
 - Educate the public about dementia and brain health.
 - Provide more local community support for people living with dementia.
 - Support family caregivers (for example, by providing more respite care).
 - Increase appropriate diagnosis of dementia and memory loss.
 - Improve the quality of dementia care at assisted living facilities and nursing homes.
 - Improve help for people with dementia experiencing a crisis.
 - Other.
 - b. Would anyone like to say more about their answer?
2. What is the biggest challenge facing your community right now related to supporting those living with dementia and their caregivers? *[Please ask for clarity on which community people are referencing; for example, are they referring to a geographic area (such as their region or town) or a demographic group (Black community, nurses, family caregivers, etc.)? Also, if the group needs help getting started, the facilitator can share a few examples, such as that it's hard to find someone to help with daily care at home, to find transportation, or to find enough socialization for the person living with dementia.]*
3. What does your community do now that makes life better for people living with dementia and their caregivers? *[In other words, what are helpful programs in your community?]*
4. What would make it easier to live with dementia or to be a caregiver where you live? *[In other words, what ideas do you have about how to fix some of the problems we discussed before?]*
5. How did the pandemic affect your community, particularly thinking about how the pandemic changed support systems for those living with dementia and their caregivers? *[If the group needs help getting started, the facilitator can share a few examples, such as that people living with dementia and their caregivers are more isolated, help with personal care is harder to find, or remote work has made it easier to be a family caregiver.]*
6. We need your help to improve dementia care. Please let our notetaker know if you would like to continue this conversation. *[Join a team, participate in a statewide summit in 2023, etc.]*

Appendix B: Questions for Facilities

If you plan to lead a conversation with professionals and residents in a facility-based care setting, here are questions specific to that audience.

Care in Facilities

1. How does dementia affect your facility and your work?
2. What does your facility do now that makes life better for people living with dementia and their caregivers?
3. The last two years have been extremely difficult given the pandemic and related workforce challenges. We would love to hear more about the top challenges facing your facility right now related to supporting those living with dementia. In addition, what priorities have you not been able to focus on because of the workforce challenge?
4. How did the pandemic affect your facility, particularly reflecting on how it changed support systems for those living with dementia and their caregivers?
5. Are you aware of any communities or organizations that are practicing innovative solutions to make life better for those living with dementia in facility-based settings? What would help your facility provide more effective care?

Appendix C: Notetaker Template

Observation Details

Facilitator name: Who is facilitating this conversation?

Notetaker name: Who is taking the notes during the conversation?

Date completed: When did the conversation occur?

County/tribal area: Name of the county(ies) and/or tribe(s)

Communities included: Name of the communities included (Is this a general educational event for the public, or is it directed to a specific group (family caregivers, regional coalition, Black community, etc.)

Virtual/In-person/phone:

Location (if in-person):

Additional comments:

Attendance

Total number of attendees: Enter the number of people present, not including the facilitator or notetaker. Then, “classify” each person in the following categories. A person can be counted in multiple categories, if applicable. You may need to ask that people identify themselves by show of hands during the introduction to accurately capture this information.

Family caregiver:

Person living with dementia:

Professional caregiver:

Health care professional:

Local government staff:

Unsure:

Other:

Additional comments:

Question: Enter the actual question that was asked by the facilitator

Provide a detailed description using participants' own words and direct quotes.

Discussion points: Capture the content of the discussion. What did participants say? Please include direct quotes and each person's classification when possible (family caregiver, local government, etc.).

Total number of people responded:

Time spent in minutes:

Notes/comments: What about this subject was particularly important to participants? Was this question difficult to answer?

Observations: Document observational information. This can include participants' demeanor, tone, complexity of thought in communication ideas, or if they changed their opinions based on group input.

Repeat this format to take notes on each question.

After the Conversation

- Take extensive notes on everything you remember directly after the conversation.
- Reflect on quality of responses. Note any weaknesses such as poor rapport, interruptions, etc.
- Note ideas, impressions, thoughts, and insights about what you have observed and speculate as to why you believe that is. Record details about setting, observations, rapport, etc.
- Explain why any questions were skipped or not asked.
- Indication any emphasis or length of time the interviewee spent on a questions/answer/topic.
- Check the responses: try to distinguish between fact (can be substantiated), opinion (a person or group view on a topic), and rumor (unsubstantiated information from an unknown source).
- Include any unanswered questions or concerns that have arisen from the conversation.
- Results of the notes and summary should be completed to a point that if anyone were to pick it up, they would understand the content and the conversation.
- Include names and contact information for any attendees who indicated an interest in continued participation.

Submitting Notes

After you have completed the notes, please submit electronically (as a Word document) to Angela Miller at DHS (angelak.miller@dhs.wisconsin.gov).

Attachment D: Social Media Posts and Flyer Templates

Twitter:

What would make it easier to live with #dementia or to be a #caregiver where you live? Share your story with us and we will include your ideas in the next State Dementia Plan! *[Link to event information]*

To make life better for those affected by #dementia, we are helping to create the 2024 State Dementia Plan and we want to hear from you! Share your story: *[Link to event information]*

Caring for a family member with #Alzheimers disease or #dementia can be challenging. Please share your story with us to help improve dementia care in Wisconsin! <https://tinyurl.com/sdplan>

What do you think the next State Dementia Plan should focus on to improve #dementia care in #Wisconsin? Please share your thoughts through a short online survey today! <https://tinyurl.com/sdplan>

Are you caring for a person living with #Dementia? Share your caregiving story today to help us improve dementia care in Wisconsin! <https://tinyurl.com/sdplan>

Did you know there are about 120,000 people living with #Alzheimers and related #dementia in Wisconsin? That's enough to fill Lambeau Field AND American Family Field! Take our short online survey to help us figure out how to make life better for those living with dementia. <https://tinyurl.com/sdplan>

Facebook:

To make life better for those living with #dementia and their caregivers, we are partnering with the Department of Health Services to create the 2024-2028 State Dementia Plan. We want to hear from you! Tell us how dementia affects your life and community, and we will include your story in the next State Dementia Plan! *[Link to event information]*


Your opinion matters. Join us for a community conversation to help us assess community dementia care needs and build a dementia care system that works for everyone. *[Link to event information]*

Did you know there are approximately 120,000 people living with #Alzheimers disease or related #dementia in Wisconsin? That's enough people to fill both Lambeau Field and American Family Field! Whether you are a family caregiver, healthcare professional, first responder, or a community member, we want to hear from you today about how dementia affects your life. Please take our short survey to help us figure out how to make life better for those living with dementia and their caregivers. <https://tinyurl.com/sdplan>

The last State Dementia Plan brought together caregivers, advocacy groups, local agencies, elected officials, and providers from across the state. Together, we helped fund support groups, expand rural research hubs, strengthen memory screenings, create dementia- friendly toolkits, and design a school curriculum. Together, we helped create the statewide dementia care specialist program, design opportunities to train nurse aides, and secure funding for long-term care agencies. Working together, we can build on these successes to support everyone affected by dementia! <https://tinyurl.com/sdplan>

See attached for photos to accompany these posts, sized for each social media platform.

Images for Twitter (see attached file for high quality images):



**YOUR
OPINION
MATTERS**

Please share your story!



How has dementia affected your life and community?

Your Opinion Matters!

Share your story to help us build a dementia care system that works for everyone!

Images for Facebook (see attached file for high quality images):



**YOUR
OPINION
MATTERS**

Please share your story!

How has dementia affected your life and community?

Your Opinion Matters!

Share your story to help us build a dementia care system that works for everyone!



JOIN US FOR A **COMMUNITY CONVERSATION**

[Organization]

[Date]

[Time]

[Location]

Dementia, or the loss of memory, language, and other thinking skills severe enough to interfere with daily life, affects families across the state. In **2020**, an estimated **114,000** Wisconsin residents had dementia, and that is expected to grow to **200,000** residents by **2040**.

We are hosting a listening session to hear from you as we help to assess community dementia care needs and to build a dementia care system that works for everyone.

Please join us to share your experiences and thoughts on:

- Challenges related to supporting people living with dementia and caregivers.
- Innovative solutions to make life better for those affected by dementia.
- Your priorities for the next State Dementia Plan, such as public education, local community support, help for family caregivers, and access to quality care.



The last state plan brought together caregivers, advocacy groups, local agencies, elected officials, and providers from across the state. Together, we helped fund support groups, expand rural research hubs, strengthen memory screenings, create dementia-friendly toolkits, and design a school curriculum. Together, we helped create the statewide dementia care specialist program, design opportunities to train nurse aides, and secure funding for long-term care agencies. **Working together, we can build on these successes to support everyone affected by dementia!**

[ORGANIZATION NAME]

JOIN US FOR A COMMUNITY CONVERSATION

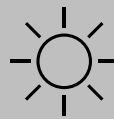
We are hosting a listening session to hear from you as we help assess community dementia care needs and build a dementia care system that works for everyone.



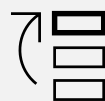
JOIN US TO SHARE:



CHALLENGES: Difficulties you've experienced related to supporting those affected by dementia.



SOLUTIONS: Innovative ideas to make life better for people living with dementia and their caregivers.



PRIORITIES: What we should focus on in the next State Dementia Plan, such as public education, local community support, help for family caregivers, and access to care.

JOIN US!

[Date]

[Time]

[Location]

For questions, contact: [Name and contact]



If you can't make the event, we would still love to hear from you!

Please take our short survey to share your experiences.

Open your camera app and tap on the image of the code to the left, or visit tinyurl.com/sdplan

Your Opinion Matters!

State Dementia Plan

Community Survey



Please take a short survey to share your experiences and help us build a dementia care system that works for everyone!

Open your camera app and tap the image of the code above or visit: **tinyurl.com/sdplan**