Supporting Faith Organizations

This section offers resources and strategies for faith organizations to implement dementia friendly practices in their congregations and support those in their congregations living with dementia and their caregivers.

TN Department of Health

DEMENTIA FRIENDLY COMMUNITIES TENNESSEE

SUPPORTING FAITH ORGANIZATIONS

Empowering Faith Leaders & Congregation Members

ROLE OF FAITH ORGANIZATIONS IN COMMUNITIES

Faith can play an important role in the lives of people with dementia and their family caregivers. Attending a service may be one of the few outings people with dementia and their family caregivers make throughout the week. Maintaining a connection to faith-based activities can prevent isolation and improve quality of life. It is likely that a faith community has members who care for someone with dementia or have dementia themselves. Becoming dementia-friendly will allow a more open and welcoming environment to better serve all within the community.

Given the scale of the issue, many people who are part of faith communities will be affected by dementia either directly or indirectly. At the same time, faith communities have something important to offer. Not only can they help support, in many ways, people living with dementia and their careers; they can also help promote brain and cognitive health through healthy lifestyles education.

Some people with dementia may stop attending regular worship services to avoid social situations they fear or no longer understand, or fear of the stigma often associated with this disease. Others will find peace and comfort in a place of worship. Caring for a loved one who has dementia can span many years, leaving family caregivers weary, isolated, frustrated and depressed. Some may feel embarrassed or reluctant to ask for help from their place of worship.

Many of our faith communities have older adults that currently suffer or will suffer from Alzheimer's and other forms of dementia, so preparation is important.

WHAT DO FAITH COMMUNTIES OFFER?

SPIRITUAL & EMOTIONAL SUPPORT FOR INDIVDIUALS AFFECTED BY DEMENTIA

- A rhythm of life and a way to connect people with their faith and with others from their community, based on their deep-rooted memories, such as music and prayers known for many years;
- A sense of belonging, identity, and safety;
- Pastoral support for people as they face issues connected with dementia, perhaps for the first time;
- Help with thinking through the big questions of life that dementia can raise: Am I still me? Why am I here?
- The ability to uplift people through connection with others and spiritual practices such as prayer.

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PRACTICAL SUPPORT FOR INDIVIDUALS AFFECTED BY DEMENTIA

- Provision of activities or services to support people living with dementia and their careers;
- A way of connecting people with others so they are not isolated and can continue to function as part of the community, and providing opportunities for them continue to do the activities they enjoy such as volunteering, serving others or making and sharing food;
- Support with day-to-day living, such as transport (faith community van and driver to take individual and caregiver to medical appointments) and helping with grocery shopping, light yard work, or sitting with the individual while the caregiver runs errands;
- Provide a separate service for individuals living with dementia to allow caregiver to attend main service;
- Post signage related to the disease, opportunities to help those in the congregation, and available community resources.

A DEMENTIA-FRIENDLY FAITH COMMUNITY WITHIN THE WIDER COMMUNITY

- A group of people who are passionate, motivated and available to help other people, who have the capacity to respond innovatively to issues connected with dementia, who share values such as care, compassion and love and who can create a feeling of welcome, calm, and inclusion;
- A supportive network that works across generations, akin to an extended family- teaching children how to be good friends to older people, and offering support to people up to the very end of their lives;
- Help with challenging attitudes- for example- promoting the idea that people with dementia have something valuable to offer the community by fostering spiritual connection and meaningful engagement for those living with dementia;
- An opportunity to reach large groups of people, through trusted messengers, to raise awareness about dementia and to support people to live healthy lifestyles;
- An embedded presence in communities, with the ability to link with other people and organizations locally to help build a dementia-friendly community in the wider sense.

Many people do not realize that around a third of cases of Alzheimer's disease could be prevented. Faith groups can play an important role in making this message better known and in helping people with the things that will reduce their risk for cognitive decline. They can do this by:

Helping people stay socially active- through opportunities for social engagement, such as meeting others and volunteering; through stimulating their brains through activities such as reading and through helping people by stimulating their brains.

Helping people adopt and follow a healthier lifestyle- especially through stopping smoking. Other factors that will help are: regular physical activity; eating a healthy diet (low in saturated fat, sugar, and salt); reducing alcohol consumption; losing weight if necessary and maintaining a healthy weight. It is also important to get the right treatment promptly for conditions such as cardiovascular disease, hypertension, and depression.

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HOW CONGREGATIONS CAN ENGAGE

KNOW YOUR CONGREGATION MEMBERS

Keep track and keep in touch. Taking note of attendance is a critically important basic step in developing connections to families who may be facing dementia.

EDUCATE CONGREGATGION MEMBERS AND YOUR COMMUNITY

Education empowers and prepares community members to serve the needs of those living with dementia and their care partners, reduces stigma and increases awareness about cognitive health:

- Invite a person living with dementia to speak about his or her personal experience;
- Speak and share materials about the Alzheimer's crisis, dementia, brain health and clinical trial opportunities.

CREATE A SAFE AND FRIENDLY ENVIRONMENT

- Assess congregation facilities for safety and accessibility for people living with dementia;
- Display signs clearly identifying areas, such as restrooms;
- Accept and be sensitive to behaviors that people with dementia may display, such as talking, calling out, or walking about at inappropriate times. Respond flexibly to encourage people to remain involved or help them to another area if necessary.

INVITE MEMBERS FACING DEMENTIA TO CONGREGATIONAL EVENTS

- Make a special effort to invite individuals living with dementia and their families to participate in congregational events, such as study groups, concerts, plays, outings and preschool programs;
- Greet them warmly and participate with them;
- Offer a volunteer companion for a member with dementia when extra support is needed;
- Wear name tags;
- Provide a quiet area where the person with dementia may go during the service as needed;
- Adapt worship series to be welcoming and supportive of people living with dementia;
- Arrange worship at home or in care facilities if a member can no longer attend in person.

ENCOURAGE MEMBERS WITH DEMENTIA TO PARTICPATE IN ACTIVITIES

Enable members living with dementia to continue engaging in roles allowing them to serve God and others. As their dementia progresses, consider new ways to engage and involve them in the life or ministry of your community.

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ENCOURAGE PARTICPATION IN COMMUNITY & FAITH OPPORTUNITIES

Invite people living with dementia and their caregivers to join in service projects and faith-based opportunities for as long as possible. Feeling a sense of purpose and the satisfaction of using given skills to help others is invaluable.

ASSESSING THE NEEDS OF THE CONGREGATION

The next step to become a fully welcoming church for those with dementia is to evaluate the current settings and programs. Dementia caregivers and maintenance staff should do an environmental assessment. Involving caregivers in the process conveys support and acceptance.

Assess physical settings. Look around your building for objects that could cause injury or be hazardous for those who have physical challenges, difficulties in judgement, or declining sensory perception. Identify areas of possible danger. Look for dangerous areas such as steps, HVAC, kitchen, and restroom areas. Look at areas that might affect sensory perception- lighting, sound systems- and areas that might cause a fall. Focus on adaption the church can make rather than expecting a person with dementia to make the adaptions.

	WHY?
Make sure buildings are well lit.	We all make better sense of situations and are less confused when we can easily see what is happening. Well-lit areas may also help prevent falls or other accidents for people with dementia.
Have a comfortable environment.	Keep the building at an appropriate temperature and provide comfortable seating to create a relaxed environment.
Have enough open space to walk around.	In the worship area and other rooms, make sure there is enough space for people to get up and walk around if they become restless.
Use information/notice boards.	On notice boards, include visual information and text about the building and church community. You could also post photographs of your faith community's worship leaders and staff.
Use clear signage.	Use simple images or color-coded signs to indicate different spaces so a person with dementia can find their way through the building. Contrasting colors can be helpful.
Have a unisex facility.	A family/unisex restroom will allow someone to be assisted without causing embarrassment to them or another user.

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Simplify activities and programs. Break up activities into simple, step-by-step tasks, and allow individuals plenty of time to complete them. Have extra help available for tasks that may be difficult for people who have dementia. Respect the dignity of all by not asking dementia sufferers to do complicated or public tasks they are unable to complete successfully.

Support the individual's reality. This is called validation. If, because of memory impairment, a person begins to live in an earlier life stage or forgets key details of his/her life- do not correct the memory unless the person is in danger. For instance, if a wife believes her departed husband is still alive, do not correct her by saying, "He died a long time ago." Monitor behavior, especially the tendency to wander, and gently reorient the person with dementia to different locations or to the activities of the group.

Affirm individuals and their gifts, but note their limitations. Encourage church members not to condemn the mistakes of those with dementia, but to acknowledge they still have gifts to offer the community. Remember, the point of being a welcoming church for those with dementia is to prolong their active relationship with congregation members and to encourage their faith. Yes, even those with dementia can still have a growing faith. It is okay to celebrate the relationship that has been, even if it is changing daily because of dementia.

Anticipate Challenges. It's impossible to prevent problems from arising, but anticipating the challenges is important. For example, some who suffer with dementia are prone to wander, so providing alarms on doors is one solution. Another approach would involve covering doors that lead outside with a mural that looks like a bookcase.

EASY STRATEGIES

- Large print text;
- Adult daycare;
- Utilization of vans for doctors' appointments;
- Volunteer Committee;
- Caregiver meetings;
- Educating congregation members;
- Fast Facts' in each Sunday's bulletin;
- Paying for a few congregation members to be trained.

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QUICK IDEAS: DEMENTIA FRIENDLY CONGREGATION . . . . . .

- Host Alzhiemer's and dementia caregiver's support group meetings;
- Offer a monthly respite time or day for caregivers of members with dementia. Include activities for those who have dementia besides sitting, sleeping, or watching television.
- Help people with dementia and caregivers of members look good by sponsoring a quarterly makeover day with area volunteers and cosmetologists;
- Offer a weekly or monthly special worship service for members with dementia, or designate special Dementia Sundays where the main worship service is designed specifically for those with dementia. Include familiar hymns rather than new ones in the service;
- Look for talents and abilities in people with dementia that they can develop and share with other people in the church. Affirm them in performing their service by acknowledging and thanking them before the entire church;
- Train church leaders and members in dementia awareness and strategies for dealing with potential challenges that might arise;
- Consider a workshop on making memory boxes for members with dementia and their caregivers;
- Have leaders of the church agree to and sign a code of behavior for interacting with members with dementia;
- Offer a resource or reading center on dementia as well as dementia newsletter with a review of some of the latest news on Alzheimer's;
- Develop a visitation team to visit members with dementia when they become homebound or move to a skilled medical center. Include regular Communion delivery and videos of worship services in the visits;
- Print copies of community resources guide and have them available for caregivers and those living with cognitive decline;
- Develop a daily or weekly prayer chain and checking-in program for the families and caregivers of those who have dementia to minister to their mental, emotional, and spiritual well-being;
- Altar call for individual prayer requests collected and lifted up;
- Adopt a family (organizations or individuals within the church will "adopt" a family affected by Alzheimer's Disease or other memory problems and will continuously lift them up in prayer and/or minister to their needs).

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SUPPORTING CAREGIVERS

- Don't wait for family members to ask; offer some support possibilities;
- Ask family members how they are and how their loved one is doing;
- Encourage family caregivers to express feelings of loss, frustration, joy, and love;
- Form a caregiver support group;
- Suggest ways to take a break from daily caregiving responsibilities, such as having congregation members make home visits or using a formal community service like adult day care;
- Offer to help the family get their loved one ready to worship services or help arrange transportation.

BEING WELCOMING

- Always be respectful toward the person with Alzheimer's;
- Wear a name tag and greet the person warmly, using a calm voice;
- Be patient and accepting of the person's behavior and appearance;
- Respond in supportive ways;
- Help unite the person with family members if he or she appears disoriented or lost;
- Send "thinking of you" notes and cards; include worship bulletins and newsletters to help the family stay connected;
- Provide ongoing prayer support for the person with Alzheimer's and family members;
- Host a Dementia Friends Information Session for the congregation.

ADDITIONAL STRATEGIES

CHALLENGES

- Reading signs that contain references to each piece;
- Following along with the service;
- Finding transportation to and from services.

ACTIVITIES

- Educating members- when members of faith communities are educated on dementia, behaviors of those with dementia can be more readily accepted, resulting in less stigmatizations for people with dementia and their families;
- Reviewing navigability of the environment;
- Holding a "dementia day" service of worship.

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VOLUNTEERS

- Assist members who may have difficulty following the service or finding the proper passages in books;
- Sit near these individuals and offer to let them following along;
- I.D volunteers who are willing to provide rides, or use a van or bus, if available.

PROVIDING OPPORTUNTIES FOR ENGAGEMENT

- A special chorus consisting of people with dementia and their caregivers or friends- emerging research underscores the validity of music programs for people with dementia. Consider developing choirs and bands tailored for people with dementia and their caregivers.
- Starting a memory café- this is a safe, supportive gathering for caregivers and those with cognitive impairments to engage in fun and engaging activities- enjoying the company of others as they interact, share concerns, celebrate, cry and find friendship (http://wai.wisc.edu/pdf/memorycafeguide.pdf)
- Host a caregiver support group- organize or host a support group for caregivers.

DEMENTIA FRIENDLY SERVICES

	WHY?
Keep services short and simple.	Services of 30 minutes or less (with a clear beginning and end) can help someone with dementia feel more engaged and better able to concentrate.
Keep print large and simple.	It is helpful when written materials are provided in large print with black letters on white paper and are not overwhelming in content.
Use traditional songs.	People with memory loss can often remember things from earlier in their life.
Christian Faith: Use Old Testament (of the Hebrew) scriptures or translations and encourage interaction.	The person may not relate to newer, international versions.
Provide accessibility.	Provide worship services at the family's home or provide an audio or video recording of service.
Provide flexibility.	Get the person involved in activities that match his or her changing abilities and involve interaction with others, such as attending choir concerts, participating in intergenerational programs, and doing repetitive tasks.

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CONGREGATION EDUCATION & TRAINING

Educating your congregation about Alzheimer's and other dementias is a critical part of becoming a dementia friendly faith organization. Congregations should consider making pamphlets and other educational materials available and easily accessable to congregation members. In addition to making information available, churches should consider having trainings and educational seminars for congregation members. Five key areas are affected by dementia. Training should include how to design programs that take these 5 key areas into consideration:

Judgment: For example, forgetting to turn off the stove or making irrational decisions.
Time and Spatial Relationships: Getting lost or being unable to recognize where they are.
Unusual Behaviors: Being agitated or fearful.
Physical Challenges: Having difficulty with balance and hand-eye coordination.
Decline in Sensory Perception: A decline in vision or hearing or depth perception; sensitivity to temperature.

To keep momentum going, congregations can identify a few congregation members to serve as "champions" to help organize educational sessions, engagement events, support groups, and other activities to support those living with Alzheimer's and dementia and their caregivers. Online trainings are offered through the Alzheimer's Association (https://training.alz.org/) for those living with cognitive decline, their caregivers, and the community at large Encourage members of your faith organization to take advantage of the free trainings, or host meetings where groups can go through the trainings together. Alzheimer's Association encourages churches and places of worship to participate in Praise in Purple events to raise awareness of Alzheimer's and other dementias. Contact your local Alzheimer's Association for educational materials,promotional items, and for information about Praise in Purple. Alzheimer's Tennessee offers training specifically designed for faith communities along with educational materials. Contact your local Alzheimer's Tennessee Chapter to learn more.

FAITH COMMUNITY CHECKLIST

- [ ] Are all areas of the church clutter-free, well lighted, and mapped out or marked where they lead? Are there adequate storage places available for unused items? Is there a process for checking to make sure items are put away when they are not in use in public areas?
- [ ] Are classrooms free of complicated and misleading stimuli? Have you minimized background noise (radio, TV, computer, overhead speakers)?
- [ ] What are the expectations of caregivers when church members visit their family members who has dementia? Are caregivers' needs being met with support groups? Are respite programs available? What strategies have been developed to deal with behavioral difficulties of those with dementia?
- [ ] Have you simplified tasks and directions so that everyone, including people with dementia, can follow them?
- [ ] In what ways is the church engaging people with dementia to prevent boredom, depression, and agitation while they are present? In what ways are church program helping members with dementia experience service to others, purpose, joy, and hope? How can the skills and abilities of those with dementia be best used during their time at church to give them a sense of being normal?
- [ ] What activities does the church offer that help to maintain the current cognitive function and spirituality of members with dementia? What new activities could a church offer, such as art therapy or dementia-oriented worship, which could be a family event?
- [ ] What role can the church play in preserving the history and relationship of people with dementia with other members of the church? (For example, recording their memories before they are lost). What opportunities exist to help those with dementia continue to express who they have been in life? Do activity designs allow people to be remembered for who they are, and not for their illness?
- [ ] What is a church's "Plan B" for ministering to members with dementia and caregivers when they are no longer able to continue to participate in church activities? How will the church continue to minister effectively to, for, and with members when they become homebound or move to a skilled medical center?
- [ ] Have you completed educational programs and training for leaders about dementia? Have you taken into consideration the needs of church members with dementia and their caregivers?

FAITH COMMUNITY CHECKLIST

☐ **Restrooms**

- Have you set the hot water heater temperature at 100ºF or lower?
- Have you installed grab bars?
- Have you added textured stickers to slippery surfaces?
- Have you removed locks from the bathroom doors?

☐ **Kitchen**

- Is there a designated area for storage of cleaning supplies that is kept locked?
- Can electricity be turned off to the garbage disposal and any appliances when not in use?
- Are knives and other utensils stored in locked areas?
- Can appliances such as toasters, microwaves, and blender be locked up or turned off?
- Can gas services to gas appliances be switched off when not in use? Or can the stove be connected to a hidden gas valve or electric switch, so it is impossible for it to accidentally be turned on?
- Is there a fire extinguisher nearby?
- Are the refrigerators cleaned out regularly?

☐ **Storage Areas**

- Is there a plan to ensure that doors to storage areas are locked from the outside?
- Are tools such as drills, axes, saws, and picks locked up?
- Is there only limited access to large equipment, such as lawn equipment?
- Are all poisonous chemicals, such as paints and cleaners, locked up?

☐ **Throughout the Building**

- Have you disguised doors or set door alarms to the outside to prevent people with dementia from wandering?
- Have you removed or taped down the rugs?
- Have colored stickers been applied to large windows and sliding glass doors?
- Have you removed poisonous plants or other items that might accidently get eaten?
- Is there sufficient lighting near doorways, stairways, and between rooms?
- Have you removed objects that block walking paths?

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ACCESSING RESOURCES & SUPPORT

ALZHEIMER'S ASSOCIATION 24/7 HELPLINE (800.272.3900)

West TN Regional Office: Memphis, 901-565-0011
Middle TN Regional Office: Nashville, 615-315-5880
Southeast TN Regional Office: Chattanooga, 423-265-3600
East TN Regional Office: Knoxville, 865-200-6668
Northeast TN Regional Office: Kingsport, 423-928-4080

ALZHEIMER'S TENNESSEE 888-326-9888 OR 24/7 HELPLINE 1-800-259-4283

East TN Office: Knoxville, 865-544-6288
Cumberland Office: Cookeville, 931-526-8010
Northeast TN Office: Johnson City, 423-232-8993
Middle TN Office: Nashville, 615-580-4244
South Central TN Office: Tullahoma, 931-434-2348
West TN Office: Jackson, 731-694-8065

TENNESSEE COMMISSION ON AGING AND DIABILITY (1-866-836-6679)

ACMS AAAD: Memphis, 901-222-4150
Northwest TN AAAD: Martin, 731-587-4213
Southwest TN AAAD: Jackson, 731-668-7112
Greater Nashville AAAD: Nashville, 615-862-8828
South Central TN AAAD: Mount Pleasant, 931-379-2929
Upper Cumberland AAAD: Cookeville, 931-432-4111
Southeast TN AAAD: Chattanooga, 423-266-5781
East TN AAAD: Knoxville, 865-691-2551 Ext. 4216
First TN AAAD: Johnson City, 423-928-3258

VETERANS AFFAIRS

You can call (888) 777-4443 to receive assistance locating your local county Veteran Service Officer. Information about veteran's benefits may be found at: https://www.va.gov/

SHARE YOUR STORY & RECEIVE SUPPORT

If your faith organization is particpating in dementia friendly activities, please share your information! Click here to tell us about your story and become part of the TN dementia friendly network.

Need help getting started? Contact the TN Department of Health Office of Patient Care Advocacy to help you develop a plan for implementation. Patientadvocacy.Health@tn.gov

TN Department of Health

DEMENTIA FRIENDLY COMMUNITIES TENNESSEE

References & Resources

1. **Act on Alzheimer's: Dementia Friendly Community**
https://actonalz.org/sites/default/files/documents/ACT-SectorGuide-Faith.pdf
2. **Alzheimer's Association and African Methodist Episcopal Church Announce New Partnership to Increase Access to Alzheimer's Information and Resources:**
https://www.alz.org/news/2019/alzheimer-s-association-and-african-methodist-epis
3. **Dementia-Friendly Faith Communities**:
https://www.dhs.wisconsin.gov/publications/p01269b.pdf
4. **Dementia Friendly Communities Resource Guide:**
http://www.nr-foundation.org.uk/downloads/Dementia-Friendly-ResourceV8-Final.pdf
5. **Developing a Dementia-Friendly Church A Practical Guide**:
https://actonalz.org/sites/default/files/documents/Dementia-Friendly-Church-Guide.pdf
6. **Faith Action: Building Dementia-Friendly Faith Communities**:
https://dfmassachusetts.org/wp-content/up-loads/sites/6/2019/06/Faith-Action-Building-Dementia-Friendly-Faith-Communities-UK.pdf
7. **Faith-Related Programs in Dementia Care, Support, and Education**
https://nadrc.acl.gov/sites/default/files/uploads/docs/-FaithRelatedDementiaPrograms%20FINAL%20FullRpt%20021317.pdf
8. **Know the 10 Warning Signs**:
www.alz.org/alzheimers_disease_know_the_10_signs.asp
9. **Memory Sunday: A Guide for Pastors and Church Leaders**:
https://www.uky.edu/coa/adc/community-outreach-and-information/educational-products
10. **The Dementia Friendly Church**:
https://www.umcdiscipleship.org/resources/the-dementia-friendly-church
11. **Us Against Alzheimer's Creating Dementia Friendly Faith Communities**:
https://www.usagainstalzheimers.org/networks/faith
12. **Wisconsin Healthy Brain Initiative**:
https://www.dhs.wisconsin.gov/publications/p01000.pdf