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Creating a communal environment where dementia is discussed and understood is a first step in addressing the needs of those living with or caring for someone with such a condition.

Bringing the Light of Christ to Those Living with Dementia

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Faith is a source of light in the darkness of dementia. When a person is diagnosed with dementia, family and friends may wonder how long the individual will remember and welcome them. They may wonder how long the intertwining of their lives will be recalled. But no matter a person's cognitive functioning, God's love is steadfast. Even when the familiar is no longer recognized, God continues to know every fiber of the person's being. Our faith assures us that our being known and loved is not dependent on our neurocognitive state. Through our faith too, we know our responsibility to reflect God's love. This understanding has been at the heart of my formation of the ministry, *The Hem of Christ: Accompanying You on the Journey of Dementia and Faith*.

START WITH RELATIONSHIP

Often, the God-given gifts and the dignity of those who live with dementia are overlooked, and these individuals are seen as a problem to be treated. Even amid ongoing physical and mental decline, however, the possibility exists for a full life with dignity, purpose, and beauty. Such a life is enjoyed when people living with dementia are seen as God sees them. Appreciating the goodness of another as God does occurs when people are in relationship. At nine years old, I witnessed such care in a relationship as a deacon visited my grandfather after his massive stroke. The two of them conversed, even when my grandfather could no longer verbally respond. The visits from the deacon from my grandfather's lifelong parish communicated care and desire to support a parishioner at the end of life. In a world that tries to unsee our elders as human beings, the deacon truly saw, knew, and cared for my grandfather.

The deacon's visits not only benefited my grandfather; they also brought the light of Christ to my grandmother. The surrounding of a community of faith uplifted her during a difficult time. Firsthand, I witnessed that the support of the community is essential to families caring for their loved one with dementia. Members of the Body of Christ, lay and religious, are called to accompany both the person with the dementia diagnosis and their care partner. Through these relationships, burdens are eased and families are nurtured. Parishes can play a powerful role in supporting fellow parishioners on the journey with dementia, even filling the relational gaps that often arise after a diagnosis. Sadly, it is not uncommon for visits from family and other friends in the community to fade as the disease progresses. It is essential that the faith community step up and answer the call of companionship when everyone else has gone.

That being said, spending time with someone living with dementia can be awkward. So, what can be done to start building a relationship with them and their care partners? The following considerations will help pastoral staff, parish volunteers and parishioners, family, and friends:

- **Forget dementia.** While we understand that dementia exists, approach each person with the same love and respect you would anyone. When the care partner is around, continue to speak directly to and with the person with dementia. Avoid speaking around the person with dementia. See both the person with dementia and their care partner as part of your ministry.
- **Introduce yourself.** If you don't know the individual or sense that you are not recognized, approach the individual from the front, say hello, state your name, smile, and position yourself at their eye level (that is, stand if the person is standing, sit if the individual is sitting). Understand that he or she will likely mimic the same emotion and energy you bring to your time together, so calmly enter with joy, warmth, and with a tone of close friends gathering. Remember also that when working with individuals with dementia, it is important to slow down, repeat, write words down, and rephrase or change language.
- **Work with what is given to you, in words and body language.** All behavior is a form of communication, including all movements and sounds. Enter the person's world and be relaxed with silence while looking out a window, going for a walk, or sharing a meal.
- **Break bread together.** Food shared in good company is one of the best ways to build a relationship and leave a lasting, positive emotional memory. The meal can be simple, with a cup of tea, baked goods, or even a piece of chocolate or two.
- **Engage the care partner.** Your relationship with care partners is as important (at times more important) as it is with the person living with the diagnosis. Their world is fading also, and they may need you after their loved one has passed away. Don't be afraid to talk about dementia with those to whom you are ministering, but also don't be shocked if people try to hide or are ashamed of their (or their loved one's) diagnosis.



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Including prayer intentions in the universal prayer for individuals living with dementia and their care partners alerts parishioners to the presence of the condition in their midst.

- **Bring your faith!** Use your common faith as the thread that connects you to the individual and family. Pray together, offer to bring them to Mass, or bring them Communion and a parish bulletin. Talk about your faith and current events in the Church. Read aloud Scripture, a book about the saints, or another religious book. Allow a dialogue of faith, expressed both verbally and nonverbally, to be your guide. Don't worry about how much the individual may be able to participate or what may be remembered. Live in the moment.

It is important to remember that people with dementia will be in various stages of the condition and will have different needs, desires, and gifts. The book *Start with Yes! A Unique Way to Communicate with Persons Living with Dementia*, by Cathy Braxton and Tami Neumann (Blurb, 2017), provides assistance in learning how to communicate with someone living with dementia in ways that can be adapted and applied to each person's needs.

SEEK TO UNDERSTAND DEMENTIA

While earlier it was suggested to forget dementia while visiting someone with the disease (so as to treat them with the dignity each person deserves), knowledge of this disease and awareness of the various types of dementia will assist ministers.

Dementia is not a part of the normal aging process, but it is common as people age. Surprisingly, it can also affect younger people, with some individuals diagnosed as early as their mid-twenties. The young age at which dementia may occur should be considered when forming a parish dementia ministry. It would



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Parish members can play a powerful role in supporting fellow parishioners with dementia, even filling the relational gaps.

be unwise to include an age limit for the ministry or to assume everyone above a specific age would participate in the ministry. Some people with a diagnosis of dementia will not want to share that information. Creating a communal environment where dementia is talked about and understood is a first step in addressing the needs of those living with or caring for someone with dementia.

Dementia itself is not a specific diagnosis but an umbrella term for a number of cognitive-loss conditions such as Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia, and many others. Determining diagnosis can take time as one's primary-care physician may not have the same skill level as a specialist in identifying cognitive loss. Families should be encouraged to reach out for additional medical support as needed.

In general, this terminal disease involves a shutting down of the body as the brain shrinks and stops sending proper signals. The progression of dementia typically spans eight to twelve years, but individuals can live anywhere between six months to twenty years after diagnosis. The unpredictable nature of the disease often takes a toll on the care partners, many of whom have made great financial, physical, social, emotional, and even spiritual sacrifices to care for their loved one. Dementia can remove the ability to retrieve memories, learn new routines, use language, logic, and social filters, control impulses, and eventually most forms of movement. While research for a cure is ongoing, experts estimate that it is decades away. Unfortunately, current drugs offer limited help for only a small portion of the population affected by the disease.

Common Types of Dementia

Alzheimer's disease. This disease is the most common cause of dementia. During the disease, the chemistry and structure of the brain change, leading to the death of brain cells. Problems with short-term memory are usually the first noticeable sign.

Vascular dementia. If the oxygen supply to the brain falls due to vascular disease, brain cells are likely to die and cause symptoms of vascular dementia. These symptoms can occur suddenly, following a stroke, or over time through a series of small strokes or due to consistent high blood pressure.

Lewy body dementia. This form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning, and problem-solving. Memory can be affected to a lesser degree. This form of dementia shares some of the characteristics of Parkinson's disease. Sleep becomes difficult, as the brain no longer signals to the body that it is tired.

Frontotemporal dementia. In frontotemporal dementia, the damage is usually focused in the front part of the brain. At first, personality and behavior changes are the most obvious signs. This disease is often diagnosed during a person's forties or fifties.

These are just a few types of dementia. It is also possible to have a combination of two types of dementia, frequently referred to as mixed dementia. More information on positive approaches with people with dementia and the types of dementia

can be found on the website of Teepa Snow (teepasnow.com/about-dementia/).

A diagnosis of dementia is one of the more feared aspects of aging, perhaps because of the many unknowns associated with the condition. Every person with dementia will have a different experience. As the fear and stigma associated with dementia are better understood, parishes can improve their ministry to those who are part of this journey.

CREATING A NETWORK OF SUPPORT

Families facing a diagnosis of dementia need support in several areas. This presents the Christian community with many opportunities to step up and become true partners in care. While the onset of dementia cannot be stopped, symptoms sometimes can be eased through strong social networks and by encouraging a healthy lifestyle. Parishes can offer ongoing services to families that change as needs evolve. Support groups, ministry programs, educational events, memory cafes, and other social gatherings can strengthen the sense of community for the family living with dementia. None of this needs to be costly, and some of the resources and support services may already be part of the parish.

Parish ministers should not be afraid to ask the family or individual with dementia how the parish can offer assistance. Still, some families will be reluctant to request help. The stigma associated with the condition can be eased through awareness, discussion, and an open attitude. Prayer intentions for individuals living with dementia and their care partners can be among the petitions in the universal prayer, information about parish and community services can be inserted in the bulletin and on the parish website, and information on community services can be located in the narthex.

With the cost of caregiving for people with dementia outpacing that of care for cancer patients, many families affected by dementia face great financial need. It may be helpful for parishes to consider how to address the financial needs of families living with dementia. A system could be devised for volunteers to offer to cook meals, run errands, or do chores in the home to ease the burden of the caregiver.

Financial difficulties may continue after the individual with dementia dies. A caregiver who has been away from the job market for many months or years may need assistance finding a position that will provide a steady income. Is there someone in the community who could connect them with job opportunities or assist with resume preparation?

RESOURCES FOR SPIRITUAL CARE

Most importantly, parishes need to respect and nurture faith by offering ongoing spiritual care to individuals with dementia and their families. That the liturgy is central to Catholic life needs to be kept in mind. Quoting the *Pastoral Statement of US Catholic Bishops on Persons with Disabilities*, the *Guidelines for the Celebration of the Sacraments with Persons with Disabilities* asserts that everyone must be included in the liturgy:

It is essential that all forms of the liturgy be completely accessible to persons with disabilities, since these forms are the essence of the spiritual tie that binds the Christian community together. To exclude members of the parish from these celebrations of the life of the Church, even by passive omission, is to deny the reality of that community. Accessibility involves far more than physical alterations to parish buildings. Realistic provision must be made for Catholics with disabilities to participate fully in the Eucharist and other liturgical celebrations.

Resources can aid parishes with including everyone in both liturgical and devotional prayer. Parishes can look to:

- the *Guidelines for the Celebration of the Sacraments with Persons with Disabilities*, revised edition (United States Conference of Catholic Bishops, 2017), which can be found in English and Spanish at <https://www.usccb.org/committees/divine-worship/policies/guidelines-sacraments-persons-with-disabilities>
- the National Catholic Partnership on Disability, which offers a number of resources to assist parishes with dementia-friendly worship services at <https://ncpd.org/search/node/dementia>
- *The Peace with Dementia Rosary*, by Matthew Estrade (Peace with Dementia Press, 2019), which assists with praying and ministering to those living with dementia. Besides guiding prayer, the book can be a catalyst for ideas on building a community of faith that includes those living with dementia and their care partners.

Ultimately, the support parishes provide those living with dementia in the Church does not require a medical or clinical background; it asks only of our love, time, and creativity as the light of Christ is shared with each person at every moment of their journey. ♦

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At www.PastoralLiturgy.org

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