

charis

A Care and Counseling Initiative



Supporting People

Affected by Alzheimer's Disease or Other Dementias



Charis is an Urban Alliance initiative. www.urbanalliance.com

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Many people who are struggling with their relational, emotional and mental health do not receive the support they need. They often do not know where to turn for help, or are embarrassed to acknowledge they are struggling. Additionally, a lack of resources in the community, poverty and stigma are barriers that keep people from receiving help.

Research shows that the church is one of the most common places people go to seek help when they are struggling emotionally. This is why it is so important for pastors and care providers to be equipped to offer care and connect people to appropriate help. Many churches offer support groups, care ministries or pastoral care. And, professional counselors who offer care from a Christian perspective provide services in the community.

Through Charis, Urban Alliance works with churches and parachurch organizations to help them communicate about mental health in ways that offer hope and create safe environments where people feel comfortable seeking help. Urban Alliance also equips care providers to respond sensitively, effectively connect people who are seeking care to appropriate support, and provide care, so they may cope well and heal.

The Charis website is a tool, managed by Urban Alliance, that can be used by individuals and organizations to help connect people in need of support to high-quality professional counselors, support groups and specialized support services offered from a Christian perspective.

These collaborative efforts have helped hundreds of people overcome barriers and more effectively cope, have ongoing support, strengthen their relationships, experience hope, joy and peace, and persevere despite life’s challenges.

*To learn more about Charis, visit www.urbanalliance.com/charis.
To visit the Charis website, visit www.charisnetworkct.org.*



What is Dementia?

Dementia is a general term for a decline in mental ability severe enough to interfere with daily activities. It is used to describe symptoms such as memory loss, problems with reasoning, disorientation, difficulty learning or loss of language skills. Often, people with dementia also exhibit changes in their personality and behaviors such as anxiety or agitation. There are a number of disorders that cause dementia, the most common of which is Alzheimer's disease which affects 1 in 10 people over age 65. Alzheimer's disease accounts for 60%-80% of all dementia cases. Vascular dementia, which occurs after a stroke, is the second most common. Currently, 5.7 million Americans are living with Alzheimer's and 1 in 3 seniors die with Alzheimer's or another dementia.

What is Alzheimer's disease?

While Alzheimer's disease can present in a number of different ways, for many people, the first problem they notice is forgetfulness that interferes with work, hobbies or recreational activities. Other symptoms may include confusion, difficulty organizing and expressing thoughts, misplacing things, getting lost in familiar places and personality changes. The majority of people with Alzheimer's are 65 years or older; however, people in their 40's and 50's can have early-onset Alzheimer's. Up to 5% of the more than 5 million Americans with Alzheimer's experience an early onset.

Alzheimer's is a progressive disease, which means it continues to worsen over time. In the early stages, memory loss is mild, however, at later stages, the individual loses the ability to have conversations and respond to their environment. On average, people live an average of eight years once their symptoms become noticeable to others. Currently, there is no cure for Alzheimer's, but treatments are available. Treatments can not stop the disease from progressing, but they can temporarily slow the progression and worsening of symptoms.

10 Signs of Alzheimer's or Other Dementias

<i>Signs of Alzheimer's or Other Dementias</i>	<i>Typical Age-Related Changes</i>
1. Memory loss that disrupts daily life. One of the first signs of Alzheimer's disease is forgetting recently learned information, important dates or events, asking for the same information over and over, and increasingly needing to rely on memory aids.	Sometimes forgetting names or appointments, but remembering them later.
2. Challenges in planning or solving problems. Some people may experience changes in their ability to follow or develop a plan or work with numbers. This may result in difficulties with finances or cooking. They may also have difficulty concentrating and take much longer to do things than they did before.	Making occasional errors when balancing a checkbook.
3. Difficulty completing familiar tasks. People with Alzheimer's often find it hard to complete daily tasks such as driving to a familiar location or completing familiar tasks at work.	Occasionally needing help to use the settings on a microwave or record a television show.
4. Confusion with time and place. People with Alzheimer's can lose track of dates, seasons and the passage of time. They may also forget where they are or how they got there.	Getting confused about the day of the week but figuring it out later.
5. Trouble understanding visual images and spatial relationships. Some people with Alzheimer's have difficulty reading, judging distance or determining color contrast. This may make driving difficult.	Vision changes related to cataracts, glaucoma or age-related macular degeneration.
6. New problems with words while speaking or writing. It may be difficult for a person with Alzheimer's disease to follow or join a conversation. They may struggle to find the right words or may stop in the middle of a conversation and not know how to continue.	Sometimes having trouble finding the right word.
7. Misplacing things and losing the ability to retrace steps. A person with Alzheimer's disease may misplace things or put them in unusual places.	Misplacing things from time to time and retracing steps to find them.
8. Decreased or poor judgement. Changes in judgement or decision making is a common sign of Alzheimer's. A person with Alzheimer's may use poor judgement in spending money or struggle with hygiene.	Making a bad decision once in a while.

10 Signs of Alzheimer's or Other Dementias

<i>Signs of Alzheimer's or Other Dementias</i>	<i>Typical Age-Related Changes</i>
<p>9. Withdrawn from work or social activities. It is common for a person with Alzheimer's to withdraw from activities they previously enjoyed. Their symptoms may make it difficult to fully engage or keep up with others.</p>	<p>Sometimes feeling weary of work, family and social obligations.</p>
<p>10. Changes in mood or personality. Mood and personality changes are a symptom of Alzheimer's disease. A person may become confused, anxious, irritated, suspicious, depressed or fearful. They may become emotional or easily upset when they are not in a comfortable environment.</p>	<p>Developing very specific ways of doing things and becoming irritable when a routine is disrupted.</p>

Taken from Alzheimer's Association, *10 Signs of Alzheimer's Disease*. For more information about the symptoms of Alzheimer's, visit alz.org/10signs

Stages of Alzheimer's

People with Alzheimer's disease generally progress through three stages: mild Alzheimer's disease (early-stage), moderate Alzheimer's disease (middle-stage) and severe Alzheimer's disease (late-stage). The charts below provide an overall idea of how abilities change

once symptoms appear as well as ways caregivers can support people after a diagnosis; however, it is often difficult to place a person in a specific stage because each person's symptoms may vary and the stages often overlap.

Mild Alzheimer's disease (early-stage): 2-4 years

Initially, a person in early-stage Alzheimer's may function independently. They may drive, prepare meals and engage in recreational activities; however, close friends and family may begin to notice difficulties. Doctors may be able to detect memory and concentration problems during medical appointments.

Symptoms

- *Problems coming up with the right word or name*
- *Trouble remembering names when introduced to new people*
- *Challenges performing tasks in social or work settings*
- *Forgetting information that one has just read*
- *Losing or misplacing a valuable object*
- *Increasing trouble with planning or organizing*
- *May experience mood or personality changes*

Strengths

- *Has the ability to use senses for enjoyment of taste, touch and smells*
- *Maintains physical abilities*
- *Can engage in conversations and provide insight*
- *May be able to drive and hold a job*
- *Is able to volunteer and engage in most recreational activities*
- *Enjoys relationships with friends and family members*

Stages of Alzheimer's

How Caregivers Can Help

- *Try to understand their anger and confusion, and offer support*
- *Simplify daily routines and do things one step at a time*
- *Encourage independence, but do not push beyond their capability*
- *Help them engage in meaningful relationships and activities as long as possible (e.g. recreational activities, clubs, friendships or church events)*
- *Caregiver can engage in self-care behaviors such as getting rest, eating nutritious food, building a support network or engaging in a support group so they are better able to offer care and support*
- *Learn as much as possible about the disease and its progression*
- *Help the person diagnosed with Alzheimer's find the support, encouragement and comfort they need (e.g. meeting with a counselor, participating in a support group, regularly see friends or receive support and prayer for their church).*

Moderate Alzheimer's disease (middle-stage): 2-10 years

Moderate Alzheimer's is typically the longest stage and can last for many years. During the middle stage it becomes difficult for persons with Alzheimer's to carry out daily activities. A person may struggle with personal care and hygiene (e.g. brushing their teeth, bathing, eating regular meals or dressing). Family members often begin providing a great deal of assistance during this phase. Memory problems increase. A person with Alzheimer's may not remember a visit right after it happened and may not recognize family, friends or familiar places. During this stage, people with Alzheimer's become vulnerable to fraud and struggle with concentration, planning and judgement. Mood, personality and behavior changes may increase. They may say inappropriate things, hallucinations may cause them to see something that is not there or they may look for people who are deceased.

Symptoms

- *Increasing memory loss and confusion, forgetfulness of events or about one's own personal history*
- *Difficulty recognizing family and friends*
- *Making repetitive statements*
- *Difficulty organizing and communicating thoughts*
- *Inability to find the right word, trouble with reading and numbers*
- *Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior, like hand-wringing or tissue shredding*
- *Poor impulse control*
- *The need for help choosing proper clothing for the season or the occasion, and/or resistance to bathing and changing clothing*

Strengths

- *Enjoyment of music and prayer*
- *Relates well to routine and familiar surroundings*
- *Often enjoys and finds reassurance in relationships*
- *Able to help with some tasks of daily living, such as folding laundry or washing dishes*
- *May enjoy talking about happy memories from the past or telling stories*
- *Often able to engage in basic activities with some direction or support*

Stages of Alzheimer's

Symptoms (continued)

- *Feeling moody or withdrawn, especially in socially or mentally challenging situations*
- *Being unable to recall their own address or telephone number or the high school or college from which they graduated*
- *Changes in sleep patterns, such as sleeping during the day and becoming restless at night*

People with Alzheimer's generally progress through three stages: mild Alzheimer's disease (early-stage), moderate Alzheimer's disease (middle-stage) and severe Alzheimer's disease (late-stage).

How Caregivers Can Help

- *Use simple memory aids like names under family photos or labels on the outside of cabinets with lists of contents*
- *Keep a routine, do the same things in the same way each day*
- *Give one-step instructions*
- *Remind and repeat gently without sounding angry or frustrated*
- *Limit distracting noise and activity*
- *Avoid lengthy plays, movies, concerts or church services*
- *Speak in a gentle, low, slow voice*
- *Do not attempt to reason or argue*
- *When upset or resistant, use distraction or come back later and try again*
- *Reassure through kind, gentle touch, hand holding or hugs*
- *Allow them to do as much as they can for as long as they are able*
- *Attend a support group and care for yourself*

Severe Alzheimer's disease (late-stage): 1-3 years

During the late stage, a person with Alzheimer's disease experiences a number of physical and neurological changes. These may include losing their ability to walk, carry on a conversation and eventually, control movement. During this stage, a person with Alzheimer's is not able to care for themselves and often needs care outside of their home. At this point in the disease, the world is primarily experienced through the senses. Care can be expressed through touch, sound, sight, taste and smell.

Symptoms

- *Needs help bathing, dressing, eating and toileting*
- *May groan, scream or make grunting noises*
- *May put things in mouth or touch everything*

Strengths

- *Ability to hear and enjoy music*
- *Responds to touch and smiling faces*
- *Able to experience a range of emotions*

Stages of Alzheimer's

Symptoms (continued)

- *Experiences changes in physical abilities, including the ability to walk, sit and eventually, swallow or toilet*
- *Loses weight even with a good diet*
- *Loses awareness of recent experiences as well as of their surroundings*
- *Become vulnerable to infections, especially pneumonia*

Strengths (continued)

- *Often enjoys being in the presence of family and close friends*
- *May enjoy favorite foods*
- *May enjoy being outside*

How Caregivers Can Help

- *Repeat often and give lots of time to respond*
- *Show them instead of asking (i.e. show a cup when asking if they are thirsty)*
- *Monitor eating to help maintain nourishment*
- *Plan for toileting difficulties and provide needed support*
- *Keep talking even if a verbal response is not given*
- *Use both touch and words to communicate*
- *Read portions of books that have meaning or listen to music together*
- *Sit outside together on a nice day*
- *Brush the person's hair or put lotion on their skin*
- *Provide opportunities for spiritual needs to be met by praying for them, playing worship music or reading scripture*
- *Help make decisions about late-stage care and the best place for that to occur, because in many cases, this care exceeds what can be provided at home and a person may need to move into a facility.*
- *Educate yourself about end-of-life decisions. Ideally, discussions about end-of-life care wishes take place while the person with the dementia still has the capacity to make decisions and share wishes about life-sustaining treatment. However, if this is not the case, family members may need to consult with doctors when making important decisions.*

Respecting the Dignity of People Alzheimer's or Other Dementias

Human beings are created by God in His image. Therefore, every person, from conception to death, possesses inherent dignity and immeasurable worth. Respecting the dignity of a person with dementia and the sanctity of their life is consistent with Biblical values and a practice that is honoring to God.

All too often, value is assigned to others based on their intellect, accomplishments or abilities; however, God sees and values things quite differently than people. Each person, regardless of their ability, has intrinsic value greater than any person can comprehend. Therefore, we need the Holy Spirit to help us see what God sees and value what He values.

Respecting the Dignity of People Alzheimer's or Other Dementias

Dr. John Dunlop, a physician specializing in geriatrics and author of *Finding Grace in the Face of Dementia*, offers a number of suggestions for people as they support and care for a person with dementia or Alzheimer's.

When God looks at each person He sees something beautiful that He created. We must strive to do the same. It is important to not focus on the disease, and lose sight of the person.

- **Give the gift of your time.** Humans are social and need relationship to thrive. People with dementia are no different. Struggles with memory, finding the words and, at later stages of the illness, the ability to speak may make relationships challenging for people with dementia. These struggles can result in loneliness and isolation. Being present is one of the more significant gifts we can provide a person with dementia.
- **Focus on the person.** As a person loses abilities and functioning, it is often easy to forget they are people with needs, abilities and potential. When God looks at each person He sees something beautiful that He created. We must strive to do the same. It is important to not focus on the disease and lose sight of the person.
- **Learn to communicate.** Dementia impedes a person's ability to communicate. As the disease progresses, conversations become increasingly difficult. Caregivers must adjust the way they communicate according to the progression of the disease. Initially, a person with dementia can engage in conversations, but may repeat themselves or have difficulty retrieving words. Caregivers can use short sentences, speak slowly, and maintain a positive and cheerful tone. The goal is to help a person feel connected and cared for. Regarding communication, in a Huffington Post article, Marie Marley suggests five things to never say to a person with Alzheimer's or dementia: 1) Don't tell them they are wrong about something, 2) Don't argue with them, 3) Don't ask if they remember something, 4) Don't remind them that their spouse, parent or other loved one is dead, and 5) Don't bring up topics that may upset them. If a person with dementia gets facts wrong or forgot events it is best not to correct them or bring attention to these things. These types of questions and interactions can cause them to feel embarrassed, discouraged or agitated.
- **Respect their autonomy and dignity.** Respecting autonomy and dignity will look different at various stages of the disease. Initially, it is important for people with dementia to make as many decisions

People with dementia find meaning and purpose when they are reminded how much they mean to the people around them.

and live as independently as possible. However, as the disease progresses, it is also important to also protect them from making mistakes that would discredit their dignity or reputation, or cause harm (e.g. buying a new car when finances are tight and they do not need one or driving a car when they are not able to do so safely). All of these things require prayer, wisdom and discernment.

- **Help them find meaning.** When God created man and woman he gave them work to do. He told them to take dominion over the earth and this assignment provided meaning to their days. However, people with dementia are limited in their ability to accomplish tasks. While limited, they often are able to help with tasks such as folding laundry, washing dishes and playing with children. These activities can help them to feel they are making a contribution. More importantly, it is important to remember that a sense of meaning also comes from who we are and what we feel. People with dementia find meaning and purpose when they are reminded how much they mean to the people around them. This can be through a smile, hug or expressing gratitude for their contributions in our lives.

Prayer

“Heavenly Father, respecting the dignity of others gets very complicated, and I have a lot to learn. Grant me the wisdom and creativity I need to follow the example of Jesus and serve others as he would. Transform my view of those with dementia and allow me to see Jesus in them and treat them with the same dignity that I would see in my Savior. I pray this for my good, the good of those I know with dementia and for your honor. Amen.” (Dunlop, p125)

How Should Churches Respond?

Dr. John Dunlop offers a number of suggestions for ways churches can respond and support people with dementia and their caregivers.

Establish Christians firmly in the practices of their faith. One of the best ways a church can prepare people for the challenges of dementia is to instill a deep faith in Christ and strong spiritual disciplines. When Christians memorize Scripture, repeatedly sing hymns and worship songs or regularly engage in disciplines such as prayer, these expressions of their faith become part of their emotional and procedural memories. This makes it more likely that they will be recalled even after

How Should Churches Respond?

a dementia diagnosis. Faith also is important for caregivers, as it provides peace, hope and a firm foundation to stand on in the face of life's trials. While there is no guarantee a person with dementia will continue spiritual practices throughout the course of the disease, if they were not practiced before the onset of the disease they will not be practiced after.

Proactively teach a theology of suffering. Dealing with dementia, whether it is from the perspective of the person diagnosed, a caregiver or friend, involves a great deal of suffering and emotional pain. Therefore, it is important for leaders to teach Christians how to think about suffering, walk through seasons marked by pain and trials, and grieve and express their sorrow to God.

Care for caregivers. "Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves receive from God. For just as we share abundantly in the sufferings of Christ, so also our comfort abounds through Christ." (2 Corinthians 1:3-5). God offers his comfort to us, so we can offer it to others. It is important for churches to offer support, comfort and prayer to all people who are struggling, including those caring for a person with dementia. This requires key leaders to be knowledgeable about the disease and the unique needs of caregivers, and have an internal process or ministry structure that connects people to needed support. Some of the specific ways churches can help caregivers include prayer, pastoral visits, providing respite help at home, connecting caregivers to needed community services, financial help, transportation or offering a support group.

Provide spiritually for those with dementia. People with dementia have spiritual needs just like everyone else. It is important for churches and leaders to recognize and respond to those needs. People with dementia have need to worship. As the disease progresses, participating in a church service may become overwhelming. Churches can offer accommodations such as allowing the person to sit in an overflow room so they are able to attend services as long as possible. Churches can also offer prayer and visitation to support, encourage and comfort a person with dementia who is no longer able to participate in regular worship services.

Connect to resources. Families impacted by dementia need support from within the church as well as support outside of the church. Church leaders can help by connecting families to resources in the community that can meet medical, emotional, and practical needs. Additionally, the Alzheimer's Association is an excellent resource for reliable information, education, referral and support.

Helpful Resources

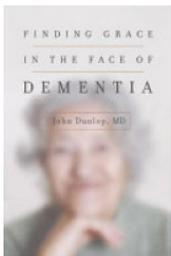


alzheimer's
association

Alzheimer's Association

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. A wealth of information and education is available on their website for people diagnosed with Alzheimer's and dementia as well as their caregivers. They also have a 24/7 helpline.

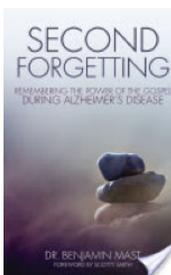
Website: www.alz.org, 24/7 Helpline: 1.800.272.3900



John Dunlop, MD

Finding Grace in the Face of Dementia

A diagnosis of dementia in a loved one can be both frightening and frustrating. Only a biblical foundation fuels a Christian response that both honors the patient and glorifies God. Drawing on years of professional experience working with Alzheimer's patients, Dr. John Dunlop wants to transform the way we think about dementia. Rooting his vision of care in the inherent dignity that stems from the fact that all people are made in the image of God, he explains biblical principles, describes the experience of dementia, and answers common questions about the condition. With a plan for how to care for patients with compassion and respect, this book helps caregivers, family members, and anyone else affected by dementia honor God as they improve the quality of care to patients.

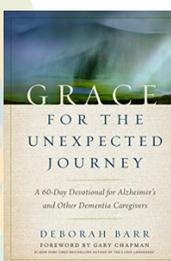


Dr. Benjamin T. Mast

Second Forgetting: Remembering the Power of the Gospel During Alzheimer's Disease

Alzheimer's disease has been described as the "defining disease" of the baby boomer generation. Millions of Americans will spend much of their retirement years either caring for a loved one with Alzheimer's disease or experiencing its effects on their lives firsthand. When a person is diagnosed with Alzheimer's, they face great uncertainty, knowing that they can expect to live their remaining years with increasing confusion and progressively greater reliance upon other people to care for them. As the disease advances it seems to overwhelm a person, narrowing their focus and leading them to forget critical truths about the Lord, their life with him, and his promises.

Through the personal stories of those affected and the loved ones who care for them, Dr. Benjamin Mast highlights the power of the gospel for those suffering from Alzheimer's disease. Filled with helpful, up-to-date information, Dr. Mast answers common questions about the disease and its effect on personal identity and faith as he explores the biblical importance of remembering and God's commitment to not forget his people. In addition, he gives practical suggestions for how the church can come alongside families and those struggling, offering help and hope to victims of this debilitating disease.



Deborah Barr

Grace for the Unexpected Journey

If you are a caregiver to someone with Alzheimer's or another type of dementia, you carry a heavy load. On top of having to watch someone you love suffer, you are probably losing sleep, growing frustrated, and struggling with loneliness or even depression. With little to no help and no time for a break, this unrelenting stress is hard to carry. Whether that's you or someone you know, the caregiver needs care, too. *Grace for the Unexpected Journey: A 60-Day Devotional for Alzheimer's and Other Dementia Caregivers* provides that support.

Debbie Barr is a speaker, health educator, and the author of multiple books, including *Keeping Love Alive As Memory Fades* (coauthored with New York Times bestselling author Gary Chapman). As a health educator with a deep concern and compassion for dementia caregivers, she saw their need for faith-based encouragement. With compassion and understanding she uses Scriptures to address their practical hardships and spiritual concerns.

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