

# Caregiving During the Dementia Tsunami



*“Come to me all you who are weary and burdened and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart, and you will find rest for your souls.” (Matthew 11:28-29)*

*Caregiver Sunday, November 8, 2015*  
*A resource from the Presbyterian Health Network*



## Caregiver Sunday, November 8, 2015



As our society continues to age we hear more and more about the challenges of dementias like Alzheimer's disease. Although we recognize the suffering and distress that Alzheimer's and other dementias can cause, we sometimes forget the family members, friends, and fellow church members who help to carry these burdens. These caregivers report feeling weary, overwhelmed and burdened by the physical, emotional and spiritual demands of providing care to those who are forgetful and confused.

The Presbyterian Health Network has chosen to focus on the theme of **Caregiving During the Dementia Tsunami** as a way of recognizing the storm of those people afflicted with this condition and the burden of care carried by those who care for them. Please feel free to utilize these resources on any Sunday appropriate for your congregation throughout the year.



## *Caregiving During the Dementia Tsunami*

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A Resource from the Presbyterian Health Network (PHN) - A Network of the Presbyterian Health, Education and Welfare Association (PHEWA) , Presbyterian Mission Agency, Presbyterian Church (U.S.A.)

<http://www.pcusa.org/phewa> and <http://www.phewacommunity.org/>



## *Caregiving During the Dementia Tsunami*

*Dedicated to Benjamin T. Mast, Ph.D., ABPP, Associate  
Professor & Acting Chair Psychological & Brain Sciences,  
University of Louisville*

*and*

*all those who provide care for others.*

# *Caregiving During the Dementia Tsunami*



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### **Introduction to Caregiver Sunday 2015**

As our society continues to age we hear more and more about the challenges of dementias like Alzheimer's disease. There is good reason. There are now about 5 million people living with Alzheimer's in the United States today, and that number is expected to continue to grow to nearly 15 million by 2050. Alzheimer's disease is the most feared medical condition among older people, and there is still no cure. What starts as forgetfulness, becomes increasing disability, disconnection, dependence and death.

Although we recognize the suffering and distress that Alzheimer's and other dementias can cause, we sometimes forget the family members, friends, and fellow church members who help carry these burdens. There are approximately 15 million caregivers for people with dementia in the United States and they provide an estimated 17.9 billion hours of unpaid care each year. These caregivers report feeling weary, overwhelmed and burdened by the physical, emotional and spiritual demands of providing care to those who are forgetful and confused. Many also feel alone and that no one truly understands the challenges they face.

Today is Caregiver Sunday – a day set aside to remember these sacrificial servants. Today, we mourn with those who mourn, and we seek to carry each others' burdens. Most importantly, we remember the God who cares for them, provides for their daily need, and who through the life of his son Jesus Christ, demonstrated the ultimate sacrificial love. For those who experience the challenges of caregiving, we remember the words of Jesus who said, "Come to me all you who are weary and burdened, and I will give you rest. Take my yoke upon you and learn from me, for I am gentle and humble in heart, and you will find rest for your souls." (Matt 11:28-29).

Information drawn from:

Alzheimer's Association. 2015 Alzheimer's Disease Facts and Figures. Alzheimer's & Dementia 2015;11(3)332+.

Mast, B.T. (2014). *Second Forgetting: Remembering the Power of the Gospel in Alzheimer's Disease*. Grand Rapids, MI: HarperCollins/Zondervan.

# *The Dementia Tsunami*



## *What Churches Can Do*

As our society continues to age we hear more and more about the challenges of dementias like Alzheimer's disease. There is good reason. There are now about 5 million people living with Alzheimer's in the United States today, and that number is expected to continue to grow to nearly 15 million by 2050. Alzheimer's disease is the most feared medical condition among older people, and there is still no cure. What starts as forgetfulness, becomes increasing disability, disconnection, dependence and death.

Although we recognize the suffering and distress that Alzheimer's and other dementias can cause, we sometimes forget the family members, friends, and fellow church members who help carry these burdens. Caregivers report feeling weary, overwhelmed and burdened by the physical, emotional and spiritual demands of providing care to those who are forgetful and confused. Many also feel alone and that no one truly understands the challenges they face. People with dementia are loved by God and are able to enjoy a relationship with God, other people and the wider creation. It is incumbent upon the church community to support both the individual and the caregivers and to provide a safe and loving environment.

### **Here are ways that churches can help:**

- **Be positive about what people with dementia can do.** It is easy to think of what people with dementia cannot do, rather than what they can do.
- **Support people with dementia in making choices.** People with dementia can find making choices difficult. Giving them time to choose between coffee and tea at the fellowship time or asking what they drink at breakfast is an example of guiding them to choose.

• **Listen to what people with dementia are saying.** People with dementia often are vague and difficult to follow. It is important to listen attentively and not move on to another topic too quickly so that they feel valued and respected.

• **Pay attention to body language.** Everybody expresses themselves through their body. People with dementia, particularly in the latter stages often find themselves using their body to help them say what they mean. Sometimes you can read what people are saying in their faces, sometimes you can see what they mean by something they do.

• **Avoid correcting what people with dementia say.** People with dementia often say things that are not accurate. It is important to not tell them directly that they are wrong if it can be avoided. They may become angry and uncooperative and they may not remember the correction anyway. Rather, try to redirect or distract.

• **Assume people with dementia know what you are saying.** Talking about or “over” a person can be discouraging and hurtful.

• **Show people with dementia love.** Everyone flourishes when they know that others care about them. What better place to mirror God’s love than in the church community.

• **Help people with dementia look good.** Everyone likes to look neat and tidy. Gently assisting with clothing, such as straightening an overturned collar or putting on a sweater properly will help in making the person feel presentable.

• **Encourage people with dementia to be creative.** People, including those with dementia, like to share in ways possible. They might create cards for others or even be encouraged to share ideas in group discussions.

• **Support people with dementia to worship.** Large print bulletins and hymnals, and using a finger to point to words in the hymnal may help the person to follow along more easily. Often, people with dementia remember the words and music of hymns long after other patterns of speech are gone.

- See more at:

[http://www.mindandsoul.info/Articles/355251/Mind\\_and\\_Soul/Resources/Topics/Dementia/10\\_tips\\_for.aspx#sthash.dI3AZ13A.dpuf](http://www.mindandsoul.info/Articles/355251/Mind_and_Soul/Resources/Topics/Dementia/10_tips_for.aspx#sthash.dI3AZ13A.dpuf)



Suggested Litanies for Caregiver Sunday 2015  
Caregiving During the Dementia Tsunami



**Litany/Responsive Reading #1\***

Congregation reads the underlined portion

On this Caregiver Sunday, we remember those who are confused and forgetful  
Lord, help us remember

Today, we also remember the families who care for them day and night  
Lord, help us remember

We remember those who humble themselves in service and love sacrificially  
Lord, help us remember

Today, we are also reminded of the humble and sacrificial service of Jesus  
Lord, help us remember

The creator of the universe humbled himself to wash the feet of his disciples and called us to do likewise  
Lord, help us remember

For those who struggle with weariness and weakness, we hear him remind us that his power is made perfect in weakness  
Lord, help us remember

For those who feel burdened, he calls "Come to me all who are weary and burdened and I will give you rest."  
Lord, help us remember.

Though our caregiving and service may seem unnoticed, he reminds us, "Whatever you have done for the least of these brothers and sisters, you have done for me."

Lord, thank you that you remember.

\*adapted from Mast, B.T. (2014). Second Forgetting: Remembering the Power of the Gospel in Alzheimer's Disease. HarperCollins/Zondervan. 2014.

## **Litany/Responsive Reading #2\***

Congregation reads the underlined portion

Heavenly Father, on this Caregiver Sunday, we praise you that in your grace and love you always care for us.

We praise you Lord – you are the great caregiver

We confess that we have often overlooked and forgotten the most vulnerable among us. In our busyness and distraction, we often forget others who need our care and support the most.

Lord, by your grace, forgive us.

We give thanks that you are a God who promises never to forget, even when we seem to forget you.

Lord, help us to remember your faithfulness, your presence and your promises.

Forgive us for our lack of concern for those with dementia and those who carry the heavy burdens of caregiving.

Lord, forgive us and awaken our hearts and minds to the need around us.

Teach us how to love as you loved us through the humility and sacrifice of Jesus Christ. Show us how to serve you by serving those you've placed around us.

Lord, teach us to love sacrificially.

Lord, strengthen and comfort those who give of themselves, taking care of others who can no longer care for themselves.

Lord, comfort and strengthen our brothers and sisters.

Today we commit to caring for people with dementia and their caregivers.

Lord, guide us and give us strength.

\*adapted from Mast, B.T. (2014). Second Forgetting: Remembering the Power of the Gospel in Alzheimer's Disease. HarperCollins/Zondervan. 2014.

## **Litany/Responsive Reading #3\***

Congregation reads the underlined portion

Today we remember family caregivers who care for others who cannot care for themselves. As we face the unending challenges of caregiving, we pray that you will help us follow the example that you gave with the power that only can give.

When we feel overwhelmed, weary, and burdened,

You call out, "Come to me all you who are weary and burdened, and I will give you rest."

When we feel humiliated by the tasks of caregiving,

You remind us that you humbly washed the feet of your disciples and teach us to do likewise.

When we have sacrificed our own time and energy and feel we have nothing left to give,  
You remind us that you gave your life in loving sacrifice on the cross.

When we have no strength to go on,  
You remind us that your power is made perfect in weakness.

When we feel anxious about the challenges we might face tomorrow,  
You remind us that your grace is new every morning.

When we are so confused that we don't know how to pray,  
You send your Holy Spirit to intercede with prayers on our behalf.

When we forget your faithfulness and promises,  
You promise to never forget us because our names are graven on your hands.

Lord, help us to remember your faithfulness in the past.  
Lord, help us to remember you are present with us today.  
Lord, help us to remember your promises for tomorrow.

Lord, though we may grow forgetful, we praise you because you will never forget us.

Lord, thank you that you never forget!

\*adapted from Mast, B.T. (2014). Second Forgetting: Remembering the Power of the Gospel in Alzheimer's Disease. HarperCollins/Zondervan. 2014.

## **Sermon Suggestions for Caregiver Sunday 2015 Caregiving during the Dementia Tsunami**

### **Sermon suggestion: #1 – God remembers the forgetful**

Though Alzheimer's and dementia may seem to separate us from others and even from ourselves, nothing is powerful enough to separate us from the love and care of God.

1. God knows the depths of our hearts and minds; he knows us better than we know ourselves (Psalm 139). God knows what we need before we speak (Psalm 139:4) or before we pray (Matthew 6:8). This is a beautiful source of comfort for those who take care of people who have difficulty with communication.
2. Not only does God know the depths of our hearts, but the Holy Spirit intercedes with prayer, in groans that we cannot comprehend (Romans 8:26-27). When people with dementia seem unable to pray, we can take comfort that the Holy Spirit continues to search the depths of their being and prays intercessory prayers on their behalf.
3. Though we grow forgetful, God never forgets us. (Isaiah 49:15-16). Caregivers and people with dementia can take great comfort in knowing that they are not forgotten by God, no matter how much they may seem to forget him. Nothing, not even Alzheimer's, can separate us from his love (Romans 8:37-39)
4. Though we may suffer and groan, longing for redemption and restoration of our bodies and brains, we wait for what God is preparing for us (2 Cor 5:1-5). Alzheimer's and dementia do not get the last word. God is making all things new (Revelation 21: 1-5).

This sermon is based upon material from Chapter 4 – “The Gospel For Those With Alzheimer's” in [Second Forgetting: Remembering the Power of the Gospel During Alzheimer's Disease](#) (2014; Zondervan/HarperCollins)

## **Sermon suggestion: #2 – Jesus the Caregiver**

Many dementia caregivers sacrifice their own interests and time to take care of other people and are left feeling depleted, burdened, and sometimes overwhelmed. The life, example and provision of Jesus can be a source of hope and encouragement on this long journey.

1. The greatness of Jesus is shown both in his power in creating the universe (John 1) and in his humble service (John 13). The greatest man who ever lived washed the disciples' feet (an unpleasant task to be sure!) and encouraged us to do likewise, promising a blessing for those who humble themselves in service to others. He taught in word and deed that whoever wants to become great must become a servant (Matthew 20:26-28; see also Phillipians 2:3-7).
2. Although sacrificial love is good, you are not called to be a savior. We cannot do it all alone. We need help from other people and from the Lord. We all have limits and we need to trust in the Lord, not ourselves, for strength (Jeremiah 17:5-8).
3. Jesus is the source of our comfort and strength (see Matthew 11:28-30). Come to me all who are weary and burdened and I will give you rest. God's grace is sufficient for us and his power is made perfect in weakness (2 Corinthians 12:9-10).
4. Caregiving as ministry to one – see Matthew 25

Excerpt from chapter entitled, "God's Grace For Caregivers" in Second Forgetting: Remembering the Power of the Gospel During Alzheimer's Disease:

"One caregiver wrote, "One morning as I awakened, I heard, 'Some minister to thousands and some minister to one.' I instinctively knew that familiar still small voice of the Holy Spirit. He was telling me that my life and service unto the Lord and my loved one was significant." Indeed she is right. Consider the words of Jesus in Matthew 25:

Then the King will say to those on his right, "Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me."

Then the righteous will answer him, "Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? When did we see you a stranger and invite you in, or needing clothes and clothe you? When did we see you sick or in prison and go to visit you?" The King will reply, "Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me."

(vv. 34 – 40)

What might the Savior of your life say when you stand before him?

*When I was forgetful, you remembered for me.*

*You answered my anxious questions even though I had asked them many times already.*

*When I was lost, you helped me find my way.*

*You helped take care of my money and gave me my medications when I couldn't.*

*When I lost my judgment, you kept me safe.*

*You even changed my clothes and helped me bathe.*

*“Truly I tell you, whatever you did for one of the least of these brothers and sisters of mine, you did for me.” (Second Forgetting, pp 102-103).*

This sermon is based upon material from Chapter 6 – “God’s Grace for Caregivers” in Second Forgetting: Remembering the Power of the Gospel During Alzheimer’s Disease (2014; Zondervan/HarperCollins)

# Sample Sermon for Caregiver Sunday 2015

## JESUS' HEALING MINISTRY

Mark 7: 24-37

Medicine, acupuncture, chiropractic treatments; faith, hope, and love. All of these have, at one time or another, been a human choice for trying to heal. People get a backache, for example. Some try pain relievers, some exercise, and some hope it will just go away! People get cancer. Some try chemotherapy, or radiation, or prayer, or forms of holistic medicine while some just wait it out. In recent years the rise of dementia and Alzheimer's disease has been alarming. Once vibrant couples turn into one caregiver and one care receiver. Retirement plans change dramatically. Whether our aging population faces broken bodies, or broken minds, where memories have been ruthlessly cut off from the brain cells that store them, our aging population faces a host of new issues with their longer lives.

When we study passages in the gospels of Jesus' healings, some background would be helpful. In Jesus' day most people believed they were sick because of sin: that is, what they had done wrong in their life made them sick. When it came to mental illness or medical conditions that could cause delirium or tremors, people believed the devil was at work. So if they heard that there was a man who could heal in an age of sorcery and suspicion, people lined up to check him out. If he "performed" as advertised, then word would spread like wildfire. Today's text from Mark reminds us that Jesus did not just heal the people of Israel; today Jesus healed no one from Galilee! He healed a girl whose mother was a Gentile—Greek by origin—in a region north of Galilee. He then healed a man who was in the

Decapolis. The **Decapolis** (Greek: Δεκάπολις, Ten Cities) was a group of ten cities on the eastern frontier of the Roman Empire, but southwest of the Sea of Galilee. Gentiles lived there.

Even as we have reporters and photographers today, I'd imagine there was quite a stir wherever Jesus went once he was named as a "healer." He wanted to be a "Savior" but they named him their "healer." So I'm wondering if the Gospel writers did not just give the "highlights" of Jesus' encounters in one area? Do you notice as I notice that we generally hear about just one specific healing in an area? Jesus does not set up a clinic, but he heals those who are pointed out to him or who call out to him. Surely there are people who are not healed in those towns or villages! Is it likely that except for the few, the others went through life living with, or living through, their afflictions? For example, we know from the Book of Acts that Paul had a visionary encounter with Jesus on the road to Damascus. Yet Paul, who almost single handedly carried the message of Jesus to areas like Rome and Corinth and Ephesus, has some affliction he calls his "thorn in the flesh." In 2 Corinthians 12:7 he says "In order to keep me from becoming conceited, I was given a thorn in my flesh." Could it be that our afflictions sometimes keep us coming back to Jesus, dependent on him because we are weak on our own? Listen to this description from author Carol Hamblet Adams in her book *My Beautiful Broken Shell*:

It is low tide and I watch, mesmerized, as the ocean rises slowly ... curls ...and then spills its white-laced foam onto the shore. I walk by a broken scallop shell ... and leave it to search for more perfect ones. But then I stop ... go back ... and pick up the broken shell. I realize that this shell is me with my broken heart. This shell is people who are hurting ... people who have lost loved ones ... people who are frightened or alone ... people with unfulfilled dreams.



This shell has had to fight so hard to keep from being totally crushed by the pounding surf ... just as I have to. Yet this shell is still out on the beautiful sandy shore ... just as I am. "Thank you, Lord, that I haven't been completely crushed by the heaviness in my heart ...."

Carol Adams' brokenness is her connections with others who are broken. Your brokenness, and my brokenness, not only connect us with other broken people, it causes us to realize how much we need Jesus! Could it be that our brokenness is our power to connect with others; and our reminder that we need Jesus? And could it be that many followers of Jesus, even in the Bible, lived with their illnesses rather than being healed from them? I am a broken man: my diabetes has driven me to workout with a trainer twice a week. My energy does not return as fast as it does with some people. Yet in my illness and my training I have connected with others, and have talked about Jesus with others who I would never have met otherwise. In 1987 I experienced burnout and wrote about it for my dissertation. In preparation for the dissertation, I invited other ministers, chaplains, and laypeople to talk with me if they had ever felt burned out. Dozens responded. Most days I am anxious about many things, even thought I know Jesus said "Do not be anxious about your life." I am not perfect; like that shell on the beach, I am the broken one, not the perfect one. How about you?

Henri Nouwen, in his book *The Wounded Healer*, gives this account:

The Talmud [a collection of Jewish Laws and traditions has a] story that suggests that, because he binds his *own* wounds one at a time, the Messiah would not have to take time to prepare himself if asked to help someone else. He would be ready to help. Jesus has given this story a new fullness by making his own broken body the way to health, to liberation, and new life. Thus like Jesus, [those] who proclaim liberation [are] called not only to care for [their own] wounds and the wounds of others, but also to make [their] wounds

into a major source of [their] healing power.

Isaiah, in describing the characteristics of s suffering servant, declared:

“By his stripes we are healed.” [Isaiah 53:6] Christians believe that those words describe Jesus too. Perhaps it is through our own brokenness that we reaffirm our dependence on Jesus. We need one another; and we need our Savior, not just a man who healed people in front of the public’s eye.

Today perhaps our ministry to others has the most power, and the most authenticity, in our brokenness. Do people really feel the need to seek perfect people with whom to share their problems? Or do they want someone who says, “I’ve been where you are;” or “Put your hand in mine;” or “I hear you;” or “I thirst.” Here is this church, we have people who will say that to you and mean it. Because they found support here in their brokenness, they will help others. They have chosen Jesus as I have chosen Jesus: the one who was broken on a cross of wood; who suffered far more anguish than many people have; and yet the one who has the power to save me, and to save you; to give me life beyond this life; and to give you life beyond this life. I choose the one the church has described as “The Lamb of God who takes away the sin of the world.” I chose the one who loves broken people and comes along side of them. I choose Jesus.

Jeffrey A. Sumner

September 6, 2015

## Resources for Churches for Caregiver Sunday, November 2015 Caregiving During the Dementia Tsunami



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Campbell, Glen and Kim (2014). DVD.v

Alzheimer's Association  
<http://www.alzheimers.net>

National Institute on Aging, About Alzheimer's Disease Caregiving  
<https://www.nia.nih.gov/alzheimers/topics/caregiving>

Ten tips for creating dementia-friendly churches  
[http://www.mindandsoul.info/Articles/355251/Mind and Soul/Resources/Topics/Dementia/10\\_tips\\_for.aspx](http://www.mindandsoul.info/Articles/355251/Mind_and_Soul/Resources/Topics/Dementia/10_tips_for.aspx)

Growing dementia-friendly churches. A practical guide.  
[http://www.mha.org.uk/files/3814/0931/8295/Growing Dementia Friendly Churches.pdf](http://www.mha.org.uk/files/3814/0931/8295/Growing_Dementia_Friendly_Churches.pdf)

Churches seek to help ease stress on caregivers

<https://www.baptiststandard.com/news/faith-culture/14754-churches-seek-to-help-ease-stress-on-caregivers>

(Presbyterian) Church offers service for dementia patients, caregivers

<http://www.the-dispatch.com/article/20150918/ENTERTAINMENT/150919814>

Handbook for worship for services with persons experiencing dementia

<http://www.calvin.edu/cicw/resources/pdf/Dementia-HandbookforWorship.pdf>

Still a child of God: resources for worship Calvin Institute of Christian Worship

<http://worship.calvin.edu/resources/resource-library/still-a-child-of-god/>

Church services for people with dementia in care homes (Anglican, UK)

[http://www.sheffield.anglican.org/UserFiles/File/Dementia\\_Action/Summary\\_Services\\_for\\_Residents\\_with\\_Dementia.pdf](http://www.sheffield.anglican.org/UserFiles/File/Dementia_Action/Summary_Services_for_Residents_with_Dementia.pdf)



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