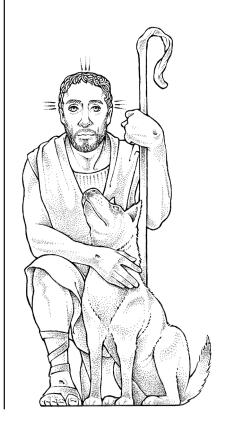
### A WORD TO SHEEPDOGS

AMIDST THE MYRIAD TASKS that fill up the average pastor's weekly calendar, caring for caregivers doesn't automatically show up. We've got our hands full visiting the sick, tending the homebound, counseling the troubled, teaching the catechumens, preparing for preaching and worship — to say nothing of parish and office administration. So people who care for loved ones often escape our radar. Tyler Arnold brings these caregivers into our field of vision. Many are able-bodied and in regular attendance at the Divine Service, after all; isn't that enough? Pastor Arnold responds: "not necessarily." He introduces us into the private world of these unsung heroes and heroines who provide essential services 24/7 for the bodily and emotional care of their spouses, family members or friends. Via his perceptive pastoral mind and heart, we gain a window into the private fears, frustrations, doubts and uncertainties of caregivers — the misbeliefs that often lead them to despair or other great shame and vice, in other words. Rather than leaving them alone to their own devices, Pastor Arnold shows us how to extend loving and sensitive privatseelsorge to these brave souls who too frequently soldier on all by themselves. Try it; your ministry will be all the more rewarding as you give to others the gifts the Lord has given into your hands and mouth to bestow.

Dr. H. L. Senkbeil



# Comforting the Comforters: Pastoral Care for Family Caregivers of the Elderly

Pastor Tyler C. Arnold

### Introduction

WITH THE AVERAGE AGE OF PARISHIONERS on the rise, pastors are increasingly faced with serving the spiritual needs of families who care for elderly loved ones. Approximately 34.2 million caregivers have provided unpaid care to an adult, age 50 or older, within the last 12 months. Added to the aging of America, significant challenges to familial caregiving have emerged within the past few decades. The responsibility of caregiving is exacerbated

<sup>&</sup>lt;sup>1</sup>The average age of an LCMS baptized member in 2015 was 47. Compared to U.S. Census estimates, our congregations are disproportionately long on seniors 65 and older (they make up 24% of total baptized membership) and short on young adults ages 18–34 (15%). Baby Boomers and Generation X adults (20% and 17%, respectively) are roughly proportional to the general population. https://blogs.lcms.org/2016/annual-statistical-reporting.

<sup>&</sup>lt;sup>2</sup> National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S. https://www.caregiver.org/caregiver-statistics-demographics. Three in five care recipients have a long-term physical condition (59%), more than a third have a short-term physical condition (35%), and a quarter have a memory problem (26%). Many care recipients have more than one ongoing problem or illness (37%)When caregivers are asked what they perceive to be the main reason their recipient needs care, the top three problems reported are "old age" (14%), Alzheimer's or dementia (8%) or surgery/wounds (8%). Some other common conditions include: cancer (7%), mobility (7%) and mental/emotional health issues (5%). Although Alzheimer's or dementia is cited by only 8 percent of caregivers as the main condition for which the care recipient needs help, a total of 22% report their loved one does suffer from this type of condition. http://www.caregiving.org/wp-content/uploads/2015/05/2015\_Caregivingin-theUS\_Final-Report-June-4\_WEB.pdf

The mercy of the cross is joined with man's greatest needs of forgiveness, freedom from sin, acceptance and reconciliation. Through the cross, the Lord instills hope for a lost people. He grants help for the lonely. He embodies the true substance of the Gospel for the indignant heart that cries out for God's relief.

by the vanishing American nuclear family, as the average number of people per household dropped from 3.1 in 1970 to 2.5 in 2013.3 What was once the shared family affair of caregiving too often falls on the shoulders of one, and "when a caregiver in the nuclear family becomes ill or exhausted, then there may be no one to take up the slack."4 Those caregivers experience a hodgepodge of ever-present afflictions and explicit emotions that need the attention of an experienced physician of souls. The practitioner will need to be well-versed in the art of cura animarum, specifically in the discipline of the theology of the cross.

The Word of God prepares the way to Golgotha, and that is where we will meet many of these precious servants who are overwhelmed with a responsibility for which they are most likely unprepared. They stand perched on top of Calvary's Holy Mount feeling as if they are being crucified alongside the one who epitomizes suffering. Despair devours their conscience because caregivers believe they have a moral obligation to succeed at a task they may feel utterly inadequate to accomplish. Dread of the task itself, resentment regarding the loss of freedom, and anger at other family members or even toward God — are common emotions. Yet, as we know, it is in THE ONE crucified on that blessed tree that relief is found. That relief is hidden in the pain and suffering of

This paper is intended to enlighten, encourage, and support pastors who will inevitably be engaged in the care of those who care for elderly loved ones. It is important to set the stage by reviewing some of the challenges that face family caregivers today. Then, a few "matters that matter" will be discussed: these include a biblical understanding of Christian vocation, giving and receiving forgiveness within caregiving, as well as a word on hope. To conclude, we will review relevant theological and practical applications for the sake of carrying out pastoral care for caregivers.

### The Challenges Facing Caregivers

Centuries ago the likelihood of caring for a dependent wife or husband

How American families are changing.

http://www.philly.com/philly/news/

a Savior who knows the deep agony of carrying out the ultimate Christian vocation. The theology of the cross reveals the reality hidden by sin: God as he is, his Word, his works, his ways, his Christ in the incarnation and suffering, as well as man's absolute dependence upon God, his standing before God, his suffering and his service within creation.5 The mercy of the cross is joined with man's greatest needs of forgiveness, freedom from sin, acceptance and reconciliation. Through the cross, the Lord instills hope for a lost people. He grants help for the lonely. He embodies the true substance of the Gospel for the indignant heart that cries out for God's relief.

html. In 1970, 40% of households were married couples with children. Such households made up just 19% of homes in 2013.

<sup>4</sup> Stephen G. Post, *The Moral Challenge of Alzheimer Disease* (Paltimore)

<sup>&</sup>lt;sup>4</sup> Stephen G. Post, *The Moral Challenge of Alzheimer Disease*. (Baltimore: The Johns Hopkins University Press, 1995), 47.

<sup>&</sup>lt;sup>5</sup>Ross Edward Johnson, John T. Pless, ed. "A Merciful Servant of the Cross: Theology of the Cross for Christian Caregivers," The Mercy of God in The Cross of Christ: Essays in Honor of Glenn Merritt, (St. Louis: The Lutheran Church—Missouri Synod, 2016), 264.

was quite small: of the sacred wedding vow, "in sickness and in health, until death parts us," death often intervened quickly. Today, family caregiving is a way of life for many as the burdens of caring for incapacitated loved ones consume those we serve. Family caregivers may experience emotions of sadness, fear, anger, guilt, grief, ambivalence, embarrassment or even helplessness and hopelessness.<sup>6</sup> Additionally, physical requirements needed for procuring care and financial strain all combine to accentuate what has been termed, "caregiver burden."7 During early stages of dependency, depression is often common in both the caregiver and the recipient. With this, the onset of grief emerges for the patient as certain essential capacities diminish, even as the caregiver realizes that he faces an arduous, demanding task.

Although caregiving obligations, capabilities, and capacities are often largely hidden within families, we still witness a great deal of personal sacrifice borne out of explicit love. Though, wracked at times with despair at the prospect of a dramatic life-changing shift, caregivers may also adapt and find their niche within the exercise of this God-given vocation. Stephen Post gives the example of one mother who cared for a child with a mental handicap, who reveled in self-pity, a sense of overwhelming tragedy and anger because society was not providing adequate services in support of the care that her son needed. As this stressful combination gave way to acceptance, she was led to become a political advocate for the sake of those who needed care.<sup>8</sup>

Pastors will encounter caregivers who thrive in their role because they find caring to be the most rewarding and meaningful activity they could possibly imagine. They find much joy where God has opened doors for Christ-like service to loved ones. Yet others will find themselves poorly suited to be the family caregiver, finding their task arduous and emotionally agonizing. For most, caring for a family member will be a mix, both a rich blessing brimming with joy and a tremendous struggle.

An additional, heartbreaking situation is the family member who wants to care for an incapacitated spouse or parent but lacks the ability to do so sufficiently. The old myth pervades their minds that the American family, like the American individual, must be self-reliant.<sup>9</sup>

As we will note later, the pastor must be active in the care of souls for all types of caregivers. Although the distressed caregiver will require more time, attention and energy, all caregivers will need the full delivery of God's gifts — both within the confines of *Privatseelsorge* as well as in the greater liturgical life of the communion of saints.<sup>10</sup>

The pastor must be active in the care of souls for all types of caregivers. Although the distressed caregiver will require more time, attention and energy, all caregivers will need the full delivery of God's gifts — both within the confines of Privatseelsorge as well as in the greater liturgical life of the communion of saints.

<sup>&</sup>lt;sup>6</sup>These particular emotions plus the positive emotions of laughter, love and joy are described by Marty Richards in *Caregiving: Church and Family Together* (Louisville, Geneva Press, 1999), 19-24.

<sup>&</sup>lt;sup>7</sup> Donna Mann, "Into the Abyss: A Review of the Literature Related to the Spiritual Care of Family Caregivers In Community Hospice and Palliative Care," *Consensus* 35, no. 2 (2014), 2.

<sup>&</sup>lt;sup>8</sup> Post, The Moral Challenge of Alzheimer Disease, 45.

<sup>&</sup>lt;sup>9</sup> Kenneth Keniston, *All Our Children: The American Family Under Pressure* (New York: Harcourt Brace Jovanovich, 1977), as found in Post, *The Moral Challenge of Alzheimer Disease*, 46.

<sup>&</sup>lt;sup>10</sup> A 2006 quantitative study by Pearce, Singer and Prigerson examined the relationship between religious coping and the experience of caregiving in a sample of 162 in-

Pastors may discover that the majority of caregivers they serve are women (though this trend is changing<sup>11</sup>). Women tend to outlive their

formal caregivers of terminally ill cancer patients. "When the caregivers perceived God's love and care, their burden of caring, though not lifted, became not only bearable, but was also deemed a positive and enriching experience" (p. 755). However, when negative religious coping was present, the effects on caregiver well-being and the caregiver experience were significant. "Caregivers who felt abandoned or punished by God or felt that God was powerless to help, were more likely to report greater burden and a poor quality of life, and to experience little caregiving satisfaction" (p. 755). These authors also recommend that such caregivers receive appropriate support from religious and healthcare professionals. Mann, Into the Abyss, 8.

<sup>11</sup> Social workers and gerontologists have assumed that a synonym for "caregiver" of the frail elderly is "daughter or daughter-inlaw." In the past the overwhelming majority of family caregivers has been women. This, however, is rapidly changing. Russell (2007) estimates that, currently, one million male caregivers have left their careers to care for spouses with some form of disability. According to the National Alliance for Caregiving in collaboration with the AARP (2000), family caregivers constitute 29% of the U.S. adult population (65.7 million) and 34% of these are males. The gender balance shifts to nearly equal participation among 18 to 49 year-old-care recipients (47% of caregivers are male), while among the 50+ recipients, it tips to females (32% male, 68% female). Recently, Smith (2012), using data from National Family Caregivers Association (2012), estimated that 44% of caregivers are men. These reports affirm that there has been a rapid increase in the number of men providing in-home care for a frail elderly family member since the Chang and White-Means (1991) report that 27% of informal caregivers were males. A comparison of this older data with the 44% reported by Smith (2012) yields a 17% increase over the 21 years.

The majority of men who are providing care are husbands of frail, elderly women, and the number of men taking on the caregiving role of loved ones with Alzheimer's disease has more than doubled since 1996 from 19% to 40% (Alzheimer's Association, 2008). Derrel Watkins, Christina Lee, "Family Caregiving by Sons and Husbands: Impli-

male counterparts as well as take on the role of nurturer much more than men: further, studies indicate that daughters and daughters-in-law are more than three times as likely as sons to assist an elderly caregiver with a disabled spouse, and outnumber men as the caregivers for severely disabled parents by a ratio of 4 to 1.12 Experts have noted a historical problem for women caregivers: they tend to be selfless and self-abnegating as well as naturally gifted nurturers.13 While these characteristics are advantageous for the caregiver/ receiver relationship, women also tend to overextend themselves with the individual concerns of another and thereby deny themselves the ability to develop as an independent person. Thus, a little later, we will discuss dependency verses interdependency as they relate to the spiritual needs of the caregiver.

Studies have found that about half of women caregivers experience stress in the form of depression, sleeplessness, anger and emotional exhaustion. At the same time, other women find caregiving meaningful and inspiring and will, perhaps, only experience the above depletions minimally. Most women will experience both the joys and the sorrows of caregiving. Women have been harmed by the expectation that they, more than men, must embrace caregiving as a way of life when

cations for Ministry, Journal of Family and Community Ministries 27, (2014), 46-47.

<sup>&</sup>lt;sup>12</sup> Elaine M. Brody, *Women in the Middle: Their Parent-Care Years.* (New York: Springer Publishing, 1990), 35. Though the gap may have closed a bit since this study was conducted, women still make up a majority of familial caregivers.

<sup>&</sup>lt;sup>13</sup> Post, The Moral Challenge of Alzheimer Disease, 53.

<sup>&</sup>lt;sup>14</sup> Brody, Women in the Middle: Their Parent-Care Years, 42.

needs arise. Stephen Post identifies this particular caution and encourages consideration that caregivers remain identifiably autonomous:

If caregivers are denied all personal interests and serve only the interests of others rather than of self, this is patently unjust. Nevertheless, our pedagogy of the oppressed must not go so far as to ignore the remarkable depths of genuine idealism and the possibilities of fulfillment that caregiving affords when taken up with a sense of vocation.<sup>15</sup>

Again, here is an indication that soul care for caregivers is not created equal. Some women will require soul care with emotional needs in view, while others might need to recover a sense of self within an all-consuming vocation. In a society where there is gender inequality within the realm of caregiving as well as a culture that devalues caring in general, the curate of souls has his work cut out for him. The pastor, with the support of the faith community, will play an integral role in supporting the needs of those who care for others.

### Matters that Matter -- Of Christian Caregiving

Christian caregivers often think their work is relatively insignificant compared to other impactful vocations that assist people in need. Additionally, they may feel inadequate because they are not as well-versed in psychological or physiological knowledge like health professionals. They believe themselves to be amateurs who try their best to maintain a consistent level of support and, most important, not to mess anything up

too severely. However, only the caregivers who do not understand their unique identity have the right to feel ashamed. To be effective, caregivers need only to have a clear understanding of their identity as a Christian caregiver and actively live out this unique orientation.<sup>16</sup>

Spouses and adult children in the United States remain at the center of caregiving and usually provide a haven for those who are in need of unique quality care, even though not all are emotionally and physically able to do all they would desire to accomplish and provide. While solicitude functions as the primary locus for the family caregiver, the quality of care family members are able to provide should never be underestimated. Added to this, the Christian family caregiver has at his or her fingertips an essential resource through the greater faith community to help with support and encouragement. Interdependence, not independence, is necessary for the caregiver to have success in providing for their loved one. Here marks an intersection between valuable physical and spiritual care, as well as support, that is provided by health care professionals and spiritual leaders. What is more, spiritual interdependence, built around the liturgical life of the church, becomes vital for the wellbeing of familial caregivers especially when excessive burdens begin to consume them. The need for physical/emotional support and spiritual connectedness will prove most beneficial for the caregiver who may feel overwhelmed by his or her feelings of inadequacy.

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<sup>&</sup>lt;sup>15</sup> Post, The Moral Challenge of Alzheimer Disease. 45.

<sup>&</sup>lt;sup>16</sup> Kenneth C. Haugk, *Christian Caregiving: A Way of Life*. (Minneapolis: Fortress Press, 1984), 46.

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### Matters that Matter --Understanding Christian Vocation

Christian caregiving is not a vocation that belongs to us. It is the work that Jesus does through his precious instruments for the sake of those he serves. And since caregiving is the work of the Lord, it is important for those who are in this servant role to understand their calling as such.

For most caregivers, the onset of providing care for a loved one may feel like a prison sentence. What appears to be the all-consuming responsibility of active care threatens personal autonomy; and as the Old Adam pulls toward the path of pleasure and selfish gratification, Christian vocation seems like bondage. Yet through Christian vocation, the Heavenly Father leads us out of ourselves and into the service of others. In Christ's righteousness, the Christian caregiver is made free to serve. The Old Adam is put to death in Christ so that he may enter into service through the means by which he chooses for the sake of the needy.

Freedom to carry forth a God-given vocation of service to a family member in need is an important topic to address with familial caregivers. Luther says, "A Christian is a perfectly free lord of all and subject to none." This part of Christian liberty is rarely forgotten. However, Luther also reminds us that a Christian is a "perfectly dutiful servant of all and subject to all." This part forms the foundation of Christian vocation in general and the life of the caregiver specifically. Luther puts servanthood and joy in perspective when he says:

Behold, from faith thus flow forth love and joy in the Lord, and from love a joyful, willing and free mind that serves one's neighbor willingly and takes no account of gratitude, of praise or blame, of gain or loss. For a man does not serve that he may put men under obligations. He does not distinguish between friends and enemies or anticipate their thankfulness or unthankfulness, but he most freely and most willingly spends himself and all that he has, whether he wastes all on the thankless or whether he gains a reward. As his Father does, distributing all things to all men richly and freely, making "his sun rise on the evil and on the good" [Matt. 5:45], so also the son does all things and suffers all things with that freely bestowing joy which is his delight when through Christ he sees it in God, the dispenser of such great

Christian caregivers are called to freedom - a freedom from coercive obligation and a freedom for servanthood. There are few aspects of the Christian life that are more misunderstood than the call to be a servant. Therefore, it is necessary to put forth a distinction between what true "servanthood" actually entails and what it does not. Kenneth Haugk calls this basic distinction the confusion of servanthood and servitude.19 Servitude connotes bondage, slavery and involuntary labor. Servanthood incorporates willingness, opportunity and joy-filled God-given devotion.

A person who acts out of servitude does so out of obligation and fear, but the person who is living in ser-

benefits.18

<sup>&</sup>lt;sup>17</sup> Luther, *The Freedom of a Christian* (1520), AE 31:344.

<sup>&</sup>lt;sup>18</sup> AE 31:367.

<sup>&</sup>lt;sup>19</sup> Haugk, Christian Caregiving, 71ff.

vanthood acts out of a sense of commitment and love. The snare of servitude may be unhealthy and can create deep problems for both the caregiver and recipient. Servanthood is healthy and motivated by the Gospel work of Jesus for the sake of sinners. This does not mean that servanthood is easy: the caregiver's workload is not lessened by making proper distinctions, but the caregiver who understands the root-source of their service will be more likely to take on their job with gladness of heart as they serve Christ by serving his or her spouse or parent.

Servitude has pitfalls that caregivers will want to avoid. Pastors can help identify these pitfalls through listening and diagnosing the source of the problem, and then leading them away from the problem and toward a solution. For example, servitude will lead a caregiver to despair through the loss of personal identity. Caregivers may take on the problems and responsibilities of those they care for to such a great degree of emotional entanglement that they will experience the pains and the problems of the other - the care receiver's burdens become the caregiver's burdens. This might achieve emotional solidarity, but at an expensive price: when caregivers jump in full-bore and become submerged in every problem, they forfeit the objectivity necessary to help the other out of the mud-hole.

Servanthood allows the caregiver to express difficult challenges through empathy. Yes, the caregiver servant will occasionally jump in the mudhole with the other, but must not lose grip on the tree root so that he or she may retain a sense of objectivity. That objectivity will be necessary when stressors reach full poten-

tial and the full delivery of despair is at the doorstep.

Pastoral visitation provides objective support to caregivers, especially the essential act of listening. Through listening, the pastor learns the needs of the caregiver while not making hasty presuppositions about his or her situation — but seeks to understand what the specific hurts are. This takes time and effort. However, this is pastoral care. It is how God's ordinary gifts are delivered within extraordinary situations — applying the familiar balm directly to the aching soul experiencing a particular malady.

Here we call to mind the example of our Savior. Christian caregivers take their cue from the Lord Himself, who willingly washed the feet of his disciples. This apparently demeaning task was actually a unique expression of selfless love that Jesus defines as servanthood when he said that "the Son of man came not to be served, but to serve, and to give his life as a ransom for many" (Matt 20:28). Caregivers are "freed" to serve because they are being served most of all by a Savior who defines what it means through a gift unmatched.

# Matters that Matter – A Life of Forgiveness

The Christian life — and all that is accomplished through it — is predicated upon the forgiveness of sins. Our entire relationship with both God and man always hinges on this central reality. "Faith toward God and love toward neighbor find common nourishment in forgiveness through Jesus Christ our Lord."<sup>20</sup> In fact, the

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<sup>&</sup>lt;sup>20</sup> Harold L. Senkbeil, *Dying to Live: The Power of Forgiveness.* (St. Louis: Concordia

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authentic self is more clearly defined in relation to God. The self is always in relationship with God from whom we discover our true identity.21 We are constantly in need of recapturing this relationship, and the only way this happens is through the forgiveness that God provides.

component of the life of the Christian, but the substance and foundation. Caregivers need to understand that forgiveness is an absolute prerequisite for caring, and forgiving is a "lived in" daily task that cannot be taken for granted. "It is difficult to care for another without forgiving that person, removing the barriers in the relationship."22 Caregivers may grow to resent those for whom they care. They may grow angry with God daily as the struggle to keep up with demands becomes increasingly oppressive. Forgiveness does not mean that caregivers ignore hurts they suffer or sugar-coat the difficulties they encounter. Rather, it means breaking down a barrier that prevents Christ's love from running free course from provider to receiver. Faith toward God and love toward neighbor are brought together through the gift of forgiveness of

The caregiver will experience the temptations and the trials of living daily along with the burden of caring for a loved one. Whether this has become their full-time job or a second one, the Christian caregiver benefits from knowing that such trials are not an indication of insufficient faith or an impoverished prayer life. Indeed,

Forgiveness of sins is not merely a sins in Jesus Christ.

Publishing House, 1994), 163.

such trials may indicate that one belongs to Christ: as Luther writes, "Satan has no need of enticing or ensnaring those who already belong to him."23 Luther goes on to say that such trials are necessary and should be expected. Struggles bring knowledge that we are totally dependent on the only One who can cure our disrupted hearts.

One of the biggest problems today is that Christians rarely let others know who they really are. We are afraid to reveal our sins and imperfections for fear of great judgement and rejection. For this reason the pastor does well to listen first to caregivers who need to unburden themselves from the guilt they carry around. He uses his words judiciously so that he doesn't get in the way of listening, nor does he offer forgiveness too soon. It is vital to allow caregivers time to reflect on how their thoughts and deeds affect their relationship with both God and their loved one. Pastors will offer individual confession and absolution when appropriate. Whether or not the offer is accepted, the Holy Spirit is at work daily showing them the importance of forgiveness.

### Matters that Matter – A Message of Hope

Christianity extols selflessness and procures heaven for the meek and lowly, not through human merit but rather by the grace of God. For that reason God created humans to be caregivers. He has given this challenging vocation to all kinds of people — the old, the young, the strong, the weak, the rich and the poor. Caregivers have been given

<sup>&</sup>lt;sup>21</sup>Dennis Ngien, Fruit for The Soul: Luther on the Lament Psalms (Minneapolis: Fortress Press, 2015), 253.

<sup>&</sup>lt;sup>22</sup> Haugk, Christian Caregiving, 82.

<sup>&</sup>lt;sup>23</sup> John T. Pless. Martin Luther: Preacher of the Cross. (St. Louis: Concordia Publishing House, 2013), 46.

the opportunity to do so much more than supporting the physical needs of those who depend on them. They also prepare the ground, they pave the way for the Great Curegiver.24 The caregiver is the instrument, but the providence of emotional support, physical needs and spiritual growth belongs to the Curegiver. Caregiving is a process. Curegiving is the result. If the caregiver does not rely on the Curegiver to give results, the caregiver will be in trouble for two reasons. First, the caregiver can become selforiented by forcing others to change through his or her help. Second, the caregiver may attempt to place responsibility of success on the one receiving care, thereby attempting to deflect blame and garner self-relief. However, true success is not self-reliant but rather Christ-reliant. Trusting God to provide results releases the caregiver from a tremendous burden and frees them to carry out their task with the understanding that God brings the cure. The hard work has not concluded, yet success in Christ has already been won. The caregiver is not free to stop working, but is free to give every care and concern over to the One who carries them all. Yet even with the assurance procured by the Great Curegiver, the constant tending of caregivers needs to continue. Individuals will need to pray for the Spirit of God daily and wrestle with the temptation to regard the grand "God Plan" as insufficient. Pastors will likely need to reiterate such messages of comfort and hope with great regularity, since the sheer strain of caring will deplete caregivers mentally, emotionally and spiritually.

Luther said, "God both loves and hates our afflictions. He loves them when they provoke us to prayer. He hates

them when we are driven to despair by them."25 In despair the believer renders his life to God knowing that God remains true to his word. He will not cast off those who hope in his mercy. He will not forsake the weak, the lonely, or the oppressed. He will comfort those who faithfully carry out a burdensome duty, because they were called by God into this special yet difficult vocation. St. Paul reminds caregivers to be "steadfast and immovable, always abounding in the work of the Lord, knowing that in the Lord your labor is never in vain" (1 Cor 15:58 ESV). This labor is pressed upon them and they did not choose it. Yet in Christ, hope prevails. It's exactly what is needed for caregivers who find themselves stuck in the abyss of someone else's dying.<sup>26</sup> Hope takes the caregiver from the tribulations associated with a dying loved one, right into the arms of the dying Savior who would rise again and show how sickness and death have no mastery over him. Hope resides in the coming resurrection on the last day when everyone in Christ will be rescued and healed.

# Pastoral Insights and Strength for Encouragement

Pastors may encounter caregivers during moments of great strength and confidence or dreadful weakness and despair. It is important to remember that these giving souls are in desperate need of being receivers, no matter their current state of being. They are not one-person

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<sup>&</sup>lt;sup>24</sup> Haugk, Christian Caregiving, 19ff.

<sup>&</sup>lt;sup>25</sup> Theodore Tappert, ed. Luther's Letters of Spiritual Counsel. (Philadelphia: Westminster Press, 1955), 87.

<sup>&</sup>lt;sup>26</sup> A phrase coined by L. R. Phillips and P. G. Reed, "Into the abyss of someone else's dying: The voice of the end-of-life caregiver," *Clinical Nursing Research* 18, no. 1 (2009): 80.

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miracle workers, nor the Savior of another, but simply servants who are attempting to incorporate God's diverse gifts into humble, merciful care for a loved one.<sup>27</sup> We dare not leave these caring children of God to solitude where their mind is unguarded against the threats of the evil one who will surely plant seeds of destructive hopelessness.

Unification with the worshipping community is vital. Caregivers experience solitude and often feel fragmented from the church as a result of their time-consuming duties. Over time, the caregiver becomes that one singular ember set away from the fire, cut off from that which keeps it warm and aglow. A Christian caregiver cannot distribute God's gifts without first receiving them. Therefore, they must be continually tied to the church and patiently catechized so that they understand that their lifeline for service relies on regular doses of God's word and sacrament. Caregivers are God's amazing instruments who stand ready to pour out God's mercy for the sake of another. However, an empty vessel has no ability to dispense God's mercy work. So, if a caregiver is unable to attend Divine Service because they must remain with their family member, pastors need to keep in mind that these workers of mercy need regular Privatseelsorge as much as those they are caring for. What is more, the caregiver will need engagement with the people who make up the worshipping community. So, if they are unable to attend the Divine Service on Sunday morning, it is helpful to remind parishioners to include caregivers in social outings, or to visit the caregiver if they are completely homebound. These are but a few ways to emotionally and spiritually engage caregivers into the community of faith during the burdensome times of dependency.

Caregivers within the family unit are a precious resource — so precious that they should not be exhausted. The nuclear family may be the only means of care for a particular person in need, and so spiritual and emotional support is vital for both the caregiver and the receiver. There must be a balance between what is best for each. It is unwise to allow a caregiver to say, "I will do what is in the best interest of my sick spouse," without any concern for what is best for the one providing care. Pastors do well to be astutely attuned to these expressions.

Since caregivers and patients are practically and ethically interwoven together to serve a basic need. they become interdependent.<sup>28</sup> For this reason the family cannot be burdened beyond reason as both persons within this dynamic have particular needs that must be addressed. If one is emphasized over the other, the interdependent relationship suffers as a whole. A careful balance of care for both the patient and caregiver must remain at the forefront. This is difficult since most fear and try to avoid dependence on others. Ultimately, though, we are all interdependent humans in need of another. This relational dynamic is true with both our faith community and, of course, our Savior.

In today's society, the elderly are seen as the source of a problem. They are often considered a burden in a world that measures selfworth through economic value. To-

<sup>&</sup>lt;sup>27</sup> Ross Edward Johnson, John T. Pless, ed. *The Mercy of God in The Cross of Christ:* Essays in Honor of Glenn Merritt, 275.

<sup>&</sup>lt;sup>28</sup> Post, The Moral Challenge of Alzheimer Disease, 43.

day's culture ascribes value through what humans produce - yet the Church offers a counter message. Worth has more to do with what has been achieved by God for humanity rather than what humanity has accomplished. Self-worth, therefore, rests on the cross of Christ and faith procured through the Word of God. Those who depend on the care of others are a reminder that God's people live by grace, not merit.29 Their lives are an indication that all people are totally dependent on God for heavenly redemption. God hides Himself in the midst of suffering and distress. Today he does not walk alongside of the sick and weary in the garden like he did in the Book of Genesis, but rather makes Himself known through ordinary means. All rely completely on the Son of Man who was defenseless on a tree. bleeding and dying for servants like caregivers. God does not reveal his majesty through power and significance; rather, he is revealed to the weak in weakness. He reveals an unending love through death. In short, the elderly in need of special attention are a stark reminder of the theology of the cross.

With the gifts of God at hand and with the certainty of the presence of God hidden within ordinary means, pastors are equipped to bring hope to the hopeless. It is important in private soul care that the pastor take care to properly divide the word of God. Wilhelm Loehe reminds us that, "Just like a doctor first gets to know the sick person and his sickness before he prescribed medication and makes the medication fit the sickness, a pastor should search

for the condition of the person and his level..."30 For this reason and, as it was mentioned before (but cannot be overstated), the pastor must first be completely an ear and resist the temptation to prescribe the cure before he knows the precise ailment. Caregivers may find themselves in complete despair and weakness or consumed with selfish anger that leads to the necessity of individual confession and absolution. Or, they may find themselves sinned against by the patient. These conditions will need to be treated differently according to the properly divided word of God. Only by fully listening to what people are thinking and feeling, and helping them to either realize their deep need for God's strength or the consequences of their actions, can the pastor truly help bear the burdens of others. Pastors should be mindful that their first priority is to provide care and support through listening, not to investigate sin. Though pastoral care may involve admonishment for sins committed, his ultimate goal is to bring a word of peace and hope.

Familial caregivers become many things for their loved one. They become nurse, advocate, companion, appointment maker, chauffer, event planner and a host of other things along with the more natural vocations of spouse or child. It is impossible for the caregiver to be an expert in every detail. Because of the vast skillset needed to care for a loved one, these precious servants must understand they cannot do this godly work alone. Pastors must understand this fact as well: they should maintain a list of referrals as emotional distress surpasses their own skillset and abilities.

Pastors should be mindful that their first priority is to provide care and support through listening, not to investigate sin. Though pastoral care may involve admonishment for sins committed, his ultimate goal is to bring a word of peace and hope.

<sup>&</sup>lt;sup>29</sup> Richard C. Eyer, *Pastoral Care under the Cross: God in the Midst of Suffering.* (St. Louis: Concordia Publishing House, 2014), 76.

<sup>&</sup>lt;sup>30</sup> Wilhelm Loehe, *The Pastor*. (St. Louis: Concordia Publishing House, 2015), 301.

Many caregivers would profit from emotional support and encouragement. Early assistance could take the form of a support group. Pastors should endeavor to learn about area mental health professionals in whom they have confidence for referral. Such professionals would not replace pastoral care, but address the genuine signs and symptoms of depression, anxiety or other issues that may be emerging. Physical needs will need to be provided by employed services or volunteers from the church.31 While they are called primarily to attend to spiritual needs, pastors do well to keep in mind that the whole person is in need of care. Therefore, more needs exist than the pastor has time or the ability to attend. A mindful holistic understanding through the gathering of information from the caregiver, friends and relatives will procure the information needed to apply the proper remedy to the situation at hand.

One final thought: Sunday morning petitions are often loaded with prayers for the homebound and the hospitalized. Why not include caregivers by name as well? What a wonderful way to keep them before the hearts and minds of parishioners and, especially, the Lord!

Conclusion

In terms of ministry, there are no secret formulas for pastoral care to caregivers. They suffer the burdens of hopelessness and helplessness, anger and resentment, grief and despair, just like so many others. The pastor will encounter a wide range of

emotions and maladies that require him to be actively present, as well as actively listening. Bringing God's healing word with prayer and blessing is not be underestimated. Uniting the caregiver to the liturgical rhythm of the church as well as members of the faith community is vital. So much of the distress that caregivers experience is a result of being separated from friends and family, isolated from those who facilitate strength, give support and encouragement. Jesus' words, "Never will I leave you, never will I forsake you," specifically apply to the one consumed with such a lonely task. Our Lord is an ever-present help in the day of trouble. Pastors have a special calling to share in the joyful burden of caregivers. What a blessing for these precious workers in the vineyard! **£** 

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<sup>&</sup>lt;sup>31</sup> www.dailycaring.com is a website that helps caregivers find support in their specific location and area of need. For additional helpful online resources, see the other websites listed at the end of Appendix 1.

### Appendix I

Below are a few practical suggestions pastors and congregations may wish to consider in order to better serve caregivers within the parish-family.<sup>32</sup>

### **Identify Caregivers**

Church leaders need to find a way to discover who is serving as family caregivers. Create some sort of instrument that can record basic contact information for caregivers, as well as their loved ones.

### Identify what they need.

Effective ministry development begins with assessment:

- 1. Identification of caregivers is the first step in finding out about their everyday realities and struggles.
- 2. Intentional conversations with caregivers, congregational members and community care providers identifies their personal, relational and spiritual/religious assets and needs, as well as gaps in resources and the unique ways the congregation can minister to them.
- 3. Prayerful contemplation and deep awareness of the joys and struggles of caregivers.

An effective match between caregiving needs and congregational responses rests on the extent to which congregational leaders have an indepth understanding of the real lives and stories of those challenged by the call to caregiving.

# Determine scope and number of caregiver needs and assets in the church and the community.

The congregation should recognize both the scope of the needs as well as the strengths resident in the identified caregivers. The caregiving situation will be unique to the disease process and the social situation of the individual. The caregiver may attend to one of many diseases such as cancer or some other form of chronic and/or acute illness; a cognitive impairment such as Alzheimer's disease; severe alcoholism or other drug addiction; or a victim of a severe accident who is unable to perform activities of daily living.

# Recognize caregiver, congregational and community assets

Congregational leaders will need to be asset-finders, just as attuned to what the caregiver offers as to what the caregiver needs. Paying attention to assets such as faith, faith practices, hope, sense of competency and social support provides often overlooked resources for energizing caregiving resiliency and for promoting need-meeting. Caregivers may have already formed informal support group relationships that can be the basis for expanding levels of relational support. Whatever the intended outcome, all ministry models with this population group should be informed by these questions: What assets are present or potentially present that can be activated and/or enriched? How will caregiver encouragement and growth be activated and/or empowered by the ministry?

<sup>&</sup>lt;sup>32</sup> Adapted from: Watkins and Lee, Family Caregiving by Sons and Husbands: Implications for Ministry, 53-55.

# Opportunities for congregations for addressing the needs of caregivers: 33

- ♦ Develop a clear understanding and definition of the church's role in providing care for caregivers.
- ♦ Identify the resources that the church can contribute
- Identify a person or committee in the church to provide leadership
- ♦ Identify what type of outreach the church already provides and how improvements for the sake of caregivers could be made.
- ♦ Identify a specific contact person within the church (pastor, elder, etc.)
- ♦ Identify any specific policies the church has regarding assistance within and outside the church membership.

### Understanding community resources and basic services:<sup>34</sup>

- ♦ Information for caregivers about available community services.
- ♦ Understand ways to assist and gain access to the available services.
- ♦ Individual counseling, support groups and caregiver training.
- ♦ Respite care.

♦ Supplemental services, on limited basis, to complement care provided by family and the congregation.

#### Learn from what works.

Resources such as those listed below may offer a framework of what is possible in congregational responses to caregivers.

1) Beach, Shelly, Ambushed by Grace: Help and Hope on the Caregiving Journey. Grand Rapids: Discovery House Publishing, 2008.

This best-selling book by Shelly Beach chronicles the needs of caregivers by an author with first-hand experience. Though her main thrust is to help caregivers through the difficult circumstances they are sure to face, Beach also shows how caregiving can also be a gift that changes a person's heart and transforms their life. This book offers practical advice, websites, phone numbers and wisdom from experts in the field of geriatrics and family counseling. Most importantly, this book also draws the reader into the word and helps to sensitize the reader to the work of the Spirit of God in their life. Though one will want to take exception to some of her theological conclusions, overall the book is helpful beyond its spiritual aspect.

2) Barton, David, *Dying and Death: A Clinical Guide for Caregivers.* Philadelphia: Williams and Wilkins, 1977.

While not specifically geared toward familial caregivers, this book does make use of broad helpful suggestions. The first part is intended to

<sup>&</sup>lt;sup>33</sup> Adapted from: Anna-Marie Madison and Brenda F. McGadney, "Collaboration of churches and service providers: Meeting the needs of older African Americans," *Journal of Religious Gerontology*, 11 no. 1 (2000): 23-37

<sup>&</sup>lt;sup>34</sup> Adapted from: Vicki Moore Northern, Family Caregiving of the Elderly Parent, Journal of Family Ministry, 16, no 1 (Spring 2002), 50.

provide an overview of basic material and an approach to caring for dying persons and their families. A central theme within the first part of the book is the concept that the problems and conflicts involving dying and death is a process for both the patient and caregiver. The second part of the book takes a look at varying caregiving disciplines and focuses on how to handle each case individually. The third part pertains to ethical issues and reads more like a theory of ethics than a "howto" tool. Each section has a large bibliography at the end for more research. This book is more of a clinical look at what to expect at the end of life than a practical guide. Though it touts that pastors may make use of this book, it doesn't really have a Christian overtone in and of itself.

3) Deane, B., Caring for Your Aging Parents: When Love Is Not Enough. Colorado Springs: NavPress. 1989.

This book focuses on the emotional and spiritual needs of caregivers and how they relate to the needs of the one who is receiving care. Topics such as love and healing, communication and forgiveness, along with the other common themes we would expect from a book on caregiving, are included. An advantage of this book is that there is a helpful section on finances coupled with situations regarding housing, medical circumstances and legal issues. The last chapter brings it all back to the emotional needs of the caregiver. Overall this is a well-rounded book. Practical scenarios are used to help illustrate specific answers to quandaries.

4) Hodges, Houston, *Circle of Years:* A Caregiver's Journal. Harrisburg: Morehouse Publishing, 1998.

This book is a thoughtful and honest appraisal of the joys and the challenges of caring for a parent slowly slipping away as a result of disease. This is not a how-to book, but a companion for all of those who struggle with taking care of their aging parents. Written honestly, this book expresses both the blessings of this time, and the tremendous strain it places on the caretaker. Described as a descriptive and heart-touching read, this book will help readers discover that they are not alone in their struggles.

5) Holstege, H. & Riekse, R., eds. Complete Guide to Caring for Aging Loved Ones. Wheaton: Tyndale House Publishers, 2002.

This book has a comprehensive "how to" approach for the Christian caregiver. Topics range from elder abuse to financial considerations as well as grief and medical resources. With even more detail for the experienced caregiver, this book focuses on the challenges facing a person's new role as familial caregiver by providing ways to honor the aging loved one as well as increasing their circle of support. It includes practical suggestions on what caregivers need to survive as well as physical and psychological changes to watch out for in patients. Stories pertaining to difficulties and success are intertwined within each section to help the reader prepare for the inevitable.

6) Kopp, Ruth, When Someone You Love is Dying. Grand Rapids: Zondervan, 1985.

Ruth Kopp is a physician concerned about helping caregivers in their times of need. The first section is about conflict and communication between the patient and the caregiver. The second part pertains to the patient-doctor relationship. Third, the family unit as a whole is addressed with an eye toward what is involved in the role of caregiver. Another section regarding how to prepare for death is also helpful. In this section, the author has outlined expectations and practical preparations for the patient's end of life. There is a section on a Christian's response to terminal illness. Added to this, the book addresses all the necessary topics of suffering and comfort, making it a well-rounded resource that is worth your time to consider. Though not as richly bent on the theology of the cross as you might expect, the author has a good understanding of suffering, which makes this material worthwhile.

7) McLeod, Beth, Caregiving: The Spiritual Journey of Love, Loss, and Renewal. New York: John Wiley & Sons, 1999.

Navigating the inner journey from personal crisis to the awakened heart of compassion, caregiving is interwoven by the author's personal story. The first part focuses on family communication dynamics. The second part chronicles the emotional struggles that are sure to confront the caregiver. The third part gives strategies such as support groups and professional help including alternative medicine and end of life ethical issues. The last part is about reclaiming life amid a new dynamic in a new relationship with the aged person and the community. Helpful suggestions are given regarding appropriate actions that might help the caregiver to chart the way through challenges.

8) Moore, S., *Two Tears: An Alzheimer's Caregiver's Journal.* Pittsburg: Rosedog, 2010.

Caregivers for Alzheimer's loved ones are great in number and yet rarely recognized. These caregivers are lonely and often deserted by families and friends without the support they need to cope with a terrible disease that slowly claims the ones they loved. Like other journals, this is not a how-to book but rather a recounting of a heart-wrenching journey of a caregiver and her husband. She mentions that after her husband's death she discovered his writings and realized that many of his thoughts were her thoughts. This book couples his words, both written and oral, with the words of the caregiver.

9) Myers, D. R., "Transformational parent care ministry: A resource guide for congregations," *Family and Community Ministry*, 17, no. 4 (2003): 11–34.

This article touts that "twenty-four million daughters and sons face the complexities and challenges of parent care without adequate preparation, effective guidance, and meaningful support." The reader discovers 11 guidebooks, eight websites, and three videos selected for their usefulness for congregations seeking to empower well-being and spiritual transformation for all in the crucible of parent care. This resource begins with a brief primer on the nature of parent caregiving and congregational responses, and a description of the selection criteria for recommended resources precedes the reviews. First evaluated are materials that provide a comprehensive view of the landscape of parental care. Other sources reveal the more intimate personal journeys of sons and daughters traversing the shadow lands of caregiving. Concluding the review are sources created specifically for family ministers, with special focus on developing empathic understanding, acquiring knowledge and exploring ministry options. This is a comprehensive review that will benefit congregations looking into ways to support caregivers.

10) Parker-Davis and Company, Caring for the caregiver – A guide to Living with Alzheimer's Disease. Detroit: Warner-Lambert, 1994.

An easy to use, step-by-step reference guide that is not extensively wordy but is very useful. Emotional and practical matters from understanding Alzheimer's to how to make the home a safe environment for the loved one is outlined point by point. A "notes" section at the end helps the caregiver keep track of accomplishments, activities, and appointments. This guide is not designed to be a comprehensive guide to caregiving. However, it is very useful as a "quick guide" reference designed as more of a "how-to" guide. It has easy to use tabs for quick references on topics such as finances, home safety, and support.

11) Potgieter, J.C. and Heyns, P.M., "Caring for a Spouse with Alzheimer's Disease: Stressors and Strengths," South African Journal of Psychology, 36, no. 3, (2006): 547–563.

This study focused on the experiences of eight female participants who

were responsible for the daily care of their husbands, all of whom were diagnosed with Alzheimer's disease. An essentially qualitative research approach, triangulated with certain quantitative measures, was used to identify both stressors and strengths reported by these caregivers. Results from mental health questionnaires showed that the comprehensive social, economic and health-related stressors experienced by caregivers put them at risk of developing serious mental health problems. However, qualitative data obtained from support group discussions, individual interviews and personal diaries highlighted the particular strengths that these caregivers showed and made use of during the caregiving process. These identified sources of resilience might, in the future, contribute towards the development of a program aimed at keeping this and similar groups known to be prone to the development of stress-related illnesses, psychologically strong.

12) Robertson, Betty Benson, Changing Places: A Christian's Guide to Caring for Aging Parents. Kansas City: Beacon Hill, 2002.

Changing Places includes resources for: organizing the caregiving process, selecting an appropriate housing option, untangling legal and financial issues, coping with the emotional challenges, finding help in the community, and nurturing your spiritual walk in the midst of difficult times. Includes forms, checklists, and "how-tos" for caring for your loved ones. At the end of each chapter there are discussion and reflection questions that can be useful in a Bible study setting.

13) Thompson, Gretchen, God Knows Caregiving Can Tear You Apart: Twelve Ways to Keep it All Together. Notre Dame: SorinBooks, 2002.

Thompson's book has been called informative and useful. The book contains short vignettes just a few pages long that can be read quickly. The segments are usually based on real-life experiences which are useful for discussion in a small-group setting. Each segment has a simple message that is not overly convoluted, allowing room for others to add to their thoughts to the stories. The tone is gentle and respectful and takes into account the very real human struggles of caregiving. Thompson uses a gentle, respectful, almost reverent tone toward the struggles of caregiving.

Websites such as those below may provide both comprehensive and focused information related to the health and psychosocial care needs of caregivers and vulnerable parents:

- 1. http://www.nfcacares.org/ This website helps caregivers connect with other caregivers for support and the sharing of resources. Embedded in this site are tips, videos, stories and other useful pointers. There is also an option to sign up for an e-newsletter.
- 2. http://www.careguide.com CareGuide is designed to help the user find various care providers ranging from babies and pets to older adults. This easy-to-use website takes the user step by step through the process and helps match the need with the appropriate person.

- 3. http://www.spry.org The SPRY (Setting Priorities for Retirement Years) Foundation functions as an "operating foundation" and carries out applied research and education programs designed to enable people to age with purpose, and to continue to have meaningful engagement in their lives. Of special concern are disadvantaged and vulnerable populations.
- 4. http://www.caregiving.org/ data/04finalreport.pdf - This resource is a study about the activities caregivers say they perform, the perceived impact of caregiving on their daily lives and the unmet needs of this population. Many charts with demographic material are included. This study is useful for those delving deeper into the many facets of caregiving. 5. http://www.stephenministries. com - Stephen Ministries is a one-to-one lay caring ministry that takes place in congregations that use the Stephen Series system. Program information along with care resources are available through this website.
- 6. http://www.caregiver.org Based in the San Francisco Bay area, the Family Caregiver Alliance was created to improve the quality of life for caregivers through information, services and advocacy. This website includes webinars, videos, research reports, retreat information as well as a host of other useful tools caregivers need to help cope with daily struggles.

### Appendix II

### **Case Study**

Bob and Mary are an elderly couple who still live in their own home, though this is becoming increasingly difficult. About a year ago, Bob was diagnosed with Lewy Body Dementia disease and Mary has become his primary caregiver. At first, Bob's symptoms are minimal. However, as time goes on, he is becoming more forgetful, physically weaker, and is having frequent hallucinations that cause fear and rage along with sleepless nights and restless days. As Bob's disease progresses, Mary has increasingly felt the pressure of paying more attention to Bob's needs, as well as taking care of almost all of the household chores. Mary is worried about how long she will be able to sustain care for Bob. She tires easily and feels the added pressure of increased responsibility daily. Added to this, Mary has health issues of her own that have caused her to endure a number of surgeries on her hip and knees. Fortunately, they have long-term health care insurance and Bob, at this time, understands that he will need full time professional care in the future. This has lessened the fear of the future but hasn't totally precluded it, as one might expect. Bob fears losing his mind and physical abilities to do the simplest tasks. Mary is afraid of losing her husband before she is ready and maintaining a normal way of life through Bob's health struggles and after he is gone. Although they have family close by, Mary feels as though they don't do a whole lot to help out. She says they are busy and have their own struggles. If she is resentful, she neither says so nor acts that way. The primary challenges

and concerns of Mary as the primary familial caregiver to her increasingly incapacitated husband are:

- ♦ Having someone stay with Bob while she runs errands
- Helping out with heavy lifting around the house
- ♦ Concern that she will not be able to control Bob's fear and rage as his hallucinations grow more and more vivid.
- ♦ Fear of what the future will bring for her and Bob as he grows weaker and more responsibility falls on her shoulders.
- Increased isolation from friends and family as caregiving has become dreadfully time consuming.

#### Pastoral Care Considerations

Bob and Mary do not know a lot of people at church. They became members as senior citizens and have not formed hardly any closeknit relationships with parishioners. Although they have family within the parish, they are nominal attenders at best and don't know many of their fellow members. Bob and Mary were regular attenders when healthy. Bob would even usher at church. However, since their health has been on the decline, their attendance at Divine Service has been sparse. The following are a few suggestions the pastor will want to consider during the ongoing care for the caregiver and her spouse.

Visit Regularly. Regular visitation will afford the opportunity for the pastor to listen to the needs of both the patient and caregiver so that proper diagnosis and application of spiritual care can be given. The pastor will want to help determine what sort of

support for the patient and caregiver benefits them the most in their current situation while also considering what might be helpful for the future. Continuous pastoral care through the administration of the Word and means of grace is essential to provide strength against spiritual attack.

Create a Strategy: It might be helpful to create a strategy for care with the caregiver. This plan will be for both the patient and the caregiver. Congregational members might be able to shop for essential goods or even visit with the patient while the caregiver runs errands or gets a much needed break. This plan may not be specific but rather highlight a few key needs with which others might be able to assist. Follow up regarding changing needs can be addressed during subsequent visitations.

Connecting Caregivers to Members: Connecting Bob and Mary with a care individual, team or committee within the parish-family provides support for ongoing and increasing physical and spiritual needs (see Appendix I). Since the pastor cannot serve every need the caregiver and patient has, he will need a supporting cast of willing/able congregational members to assist with the vast array of needs.

Connecting Caregivers to Community Resources: Civic and religious organizations within the community might have helpful resources like adult day care for patients, counselors, support groups or training for caregivers. A good place to start looking for available resources may be at the local city hall or wherever there is a community resource bulletin board. Further investigation might be necessary in order to ascertain the value of a particular resource.

Prayers for Caregivers: Make the parish-family aware of caregivers. If caregivers are willing, include them in weekly congregational prayers. This will help make more people aware of their situation as well as provide more opportunity for support through members who might like to get involved.

Nurturing the Spiritual Well-Being of Caregivers: The following is a list of considerations pastors may wish to consider when nurturing the spiritual well-being of familial caregivers.<sup>35</sup>

- ♦ Affirm to the congregation and the caregiver that caregiving is a holy vocation appointed by God for the sake of others.
- ♦ Unite the caregiver to the liturgical life of the congregation. When at all possible, assist the caregiver by helping him or her attend the Divine Service as often as possible. Connection to the faith community will help the caregiver avoid feelings of isolation and loneliness.
- ♦ Encourage members of the congregation to include caregivers in social functions of the parish-family.
- ♦ Be sensitive to identity needs. For example, a caregiver who has given up his or her career identity and was forced into early retirement will perhaps appreciate conversation that indicates a respect for and an interest in the caregiver's previous career achievements. It may feel to the caregiver that this part of self is unacknowledged and forgotten.

<sup>&</sup>lt;sup>35</sup> Adapted from Ilene Shamy, A Guide to the Spiritual Dimension of Care for People with Alzheimer's' Disease and related Dementias: More than Body, Brain and Breath (London and New York: Jessica Kingsley Publishers, 2003).

Validating the existence of difficult and seemingly unacceptable feelings will foster coping. Feelings are valid and someone who will listen to them without judgement is a blessing.

♦ Perhaps encouragement for the caregiver to indulge in a hobby, craft or other interest would be beneficial. These help the caregiver maintain an identity and can be arranged by the parish family.

### Appendix III

### A Prayer for Family Caregivers

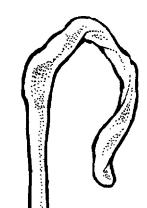
"Come to me, all you who labor and are heavy laden, and I will give you rest. Take my yoke upon you, and learn from me, for I am gentle and lowly in heart, and you will find rest for your souls. For my yoke is easy, and my burden light" (Matt 11:28–30 ESV).

Dear Heavenly Father, the healer of souls and the comforter of the weary and heavy laden, help, we beseech you, to lighten the burden of families who are caring for their sick loved ones. Accompany them on their daily journey and ease their worries and fears. Continue to surround them with the love and strength that you provide from their neighbors, so they may experience your profound providence through the communion of saints. Keep us ever mindful that we are daily enabled to call upon you in the day of trouble and that you promise to deliver us. In the midst of these daily struggles, strengthen \_\_ in her/his/their Christian vocation(s) so that they may take care of the daily needs of the one being cared for. We pray these things through Jesus Christ Your Son our Lord, who lives and reigns with you and the Holy Spirit, one God now and forever. Amen.

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### Reflection



"It's the toughest job you'll ever love," said the Peace Corps ad. It may have been true of that service, and it certainly could be said of caregiving. Caregivers can be catapulted from joy to heartbreak, from kindness to exhaustion. They can be filled with deeply touching moments and yet deep pain. It often ends with mourning and loss.

Pastor Arnold has listened carefully to caregivers, lets us into their lives and masterfully helps Seelsorgers apply Christ's sacrificial service and love in caring for these dear ones. He shows us that no caregiver or pastor of caregivers need walk alone: our Lord Jesus bears the burden with us no matter how dark the road.



Lord Jesus Christ, Great Physician of body and soul, you surrounded yourself by those broken and served them all; give your unrelenting care to those who serve the ill and make us competent and compassionate to these caregivers; for you live and reign with the Father and the Holy Spirit, one God, now and forever.

