

NAZARENE THEOLOGICAL SEMINARY

Care for the Dying - Involving Congregations in End-of-Life Care

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ABSTRACT

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"It has encouraged me not to forget these folks, but to help them finish feeling loved by the church." Those were the words from a seminar participant connected with this Project. Rev. James Brooks, in *The Unbroken Circle*, noted there comes a time, whether through serious illness or care giving for someone else with a serious illness, when there are those who are unable to participate in the congregation as they did before. In such circumstances these folks often lose their connection to their faith community.

The purpose of this Project was to encourage/challenge and equip the community of faith to become involved in a greater way in ministering to their fellow-parishioners and families at the end-of-life. The project dealt with presenting information and training to a group of participants regarding end-of-life issues and care for those at end-of-life in a two-session workshop. Each participant was provided a training manual to be used during

the seminar sessions. Pre and post-seminar questionnaires gauged participants' thoughts/understanding of death/dying, end-of-life issues/care, hospice, church involvement in these matters, and what they hoped to gain or did in fact gain from the seminar.

With knowledge, understanding, and training regarding death/dying and related issues, we, the church, can walk with our fellow-believers in more effective ways at the end-of-life.

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Chapter 1: Overview of the Study: Why End-of-Life Care in the Church

My first deeply involved contact with those at the end-of- life was during a pastorate in the late 1990's in Louisville, Kentucky. There were two men who were rounding the final turn of their lives and headed home, Joe and P.C. I visited these men, along with their wives, on a weekly basis and took them a bulletin from our previous Sunday's service, a tape of the service, offered words of encouragement and hope, and prayed for them. George, one of the members of our church, visited them as well. He had worked with both of these men and cared deeply for them.

Joe had no connection to our church other than George. He and his wife were very spiritual people, they had been very involved in another faith community in the past and maintained that affiliation the best they could with Joe's failing health and his wife being his constant caregiver. P.C. had no church connection other than ours. This had developed because of George and the fact that death was much more imminent. P.C. now desired to connect for the first time with God and spiritual matters, or perhaps reconnect with the faith of prior years that had been neglected.

I wondered then, but ponder much more deeply now the question, "Why wasn't Joe's community of faith more involved with him and his wife as his life was waning?" I wondered then and ponder now as well, "Why wasn't our church much more involved with Joe and P.C. and their wives as these men's lives here were coming to a close?" What could we have done? We could not have changed their prognosis. We could not have taken away their pain. However, we could have assured their dark hour was brighter. We could have been present to journey with them, and in community we would

have taught and learned what it meant to die well. The church must join the professional caregivers in meeting the needs of the dying and their families.

Rev. James Brooks, in *The Unbroken Circle*, spoke of folks falling from the circle of the care of the church at the end-of-life. In more than eleven years of pastoral ministry and nine years of hospice service, I have noted this as well. Brooks stated there comes a time, whether through serious illness or care giving for someone else with a serious illness, when there are those who are unable to participate in the congregation as they did before.¹ In such circumstances these folks often lose their connection to their faith community. Illness often takes a heavy toll on the body and strength is greatly diminished. The same can be said for giving care to one with a serious illness, there is not sufficient strength to accomplish all that one might desire. Often because of the lack of strength and energy and feeling overwhelmed by all they are facing, these folks become cloistered inside their home, isolated from those whom they were once vitally connected. In the midst of illness as well, the church tends to lose contact with its members especially when the illness is of a long duration. Yes, this is often the norm, but it need not be.

¹James L. Brooks, *The Unbroken Circle: A Toolkit for Congregations Around Illness, End of Life and Grief* (Durham, NC: Duke Institute on Care at the End of Life, 2009), 5.

²Fred Craddock and others, *Speaking of Dying: Recovering the Church's Voice in the Face of Death* (Grand Rapids: Brazos Press, 2012), 169.

I have not campaigned for something new and novel, but simply a return of the church to what has been a part of our heritage. We, as the body of Christ, must seek to refocus our efforts in caring for the dying and their families. Fred Craddock and his co-writers, in *Speaking of Dying*, commented that caring for the ill was a part of the Church from very early. I would affirm that it could be once again. Who better than the

community of faith to come alongside one of their own; and perhaps others as well, and participate in their care and their life at this critical juncture? I have not advocated for the church to be involved in what one would consider the physical hands-on care the dying need. Not many of us are equipped or qualified in this arena. This is most often attended to by family and the professional caregivers. However, I have pushed for us as the body of Christ to be present, to perform small tasks and jobs for the patient and family, to offer support and encouragement, to listen, to pray, and share God's word. This is far from an inclusive list of how we may minister to these. I have shared more in this regard in chapter two and the seminar participants' responses in chapter four offered helpful suggestions as well.

The need for being more aware in the church of end-of-life issues and end-of-life care is great. To recognize this, one need only stand in the balcony or back of a great many churches and more white and gray hair will be noted across the congregation than in past years. It is almost shocking to think here in 2016 that the first of the baby boomers have reached 70 years of age. I have been made aware as well from having ministered in hospice for these past nine years and having dialoged with our hospice nurses and physicians on a regular basis, that with advances in medicine, people are living longer and dying is slower.

A variety of folks are needed to give care to the dying, but the church is positioned to add what no one else can. Dying is much a spiritual matter and as such the family of faith is needed as death approaches. Despite the fact that we live in a death denying culture, the church can speak into this and walk alongside those (and their

families) who are making the transition from this life to the next. We will all go the way of the grave and the believer must have the presence of the body of Christ in this seeming dark hour. It is in community we continue to learn patience, hope, and compassion as members' lives come to a close. It is in community that we may see that the days of dying can be filled with meaning and purpose. It is in community that we may all learn what it means to finish strong as one has lived and die well. We face life and we face death together.

There are a couple of terms dealing with end-of-life issues and care that need to be defined as we move forward. The first is hospice. Hospice is a philosophy of care, not a place and can be based anywhere; private homes, nursing homes, assisted living facilities, and hospitals. Hospice focuses on care that enhances the quality of remaining life, provides relief or comfort, and supports the patient and family when there is no cure for the terminal condition. Hospice does not focus on curing the patient and the disease, rather on what is important to the patient and family. The hospice goal is to improve the ³ *ibid*, 40.

I have not wished to have sounded overly harsh in my criticism of the church in this arena, but the needs of the dying and their families must be pushed forward. If we are not aware of an issue or how to meet the need, then we cannot step forward and take action. Craddock and the Goldsmiths noted a similar sentiment. In their book, Craddock, Goldsmith, and Goldsmith could have been seen as being critical of the church in her neglect of the dying and their families, however they wrote, "If there is criticism in our words it is of the church's forgetfulness of its own treasures that can be brought to the

ministry of the dying."³ I speak from experience when I say what an awesome honor and privilege it is to minister to this group of 'the least of these.' I desire to bring this care along with end-of-life matters to the fore.

dying patient's treatment and care through the control of common symptoms of terminal illness. Hospice care is care for the whole person (body, mind, spirit) and care for the whole family. Only one has the terminal illness, but all are affected and need care and support. Hospice is not less care as many may believe, but is more care that is focused on the palliation of symptoms.

That brings up another term that needs an operational definition, palliative care. Palliative care and hospice care are sometimes used interchangeably, but are different. One can receive palliative care without being under hospice care. Palliative care in lay terms is simply care and treatment that will mitigate and alleviate adverse symptoms that result from a disease or illness. Palliative care, or the palliation of symptoms, is care given to people who are dealing with life-threatening illnesses. Most of these diseases or conditions cannot be cured and therefore require the management of symptoms. Unlike hospice care, which is given after diagnosis, palliative care may begin at the point of diagnosis or treatment and does not only deal with illnesses that inevitably lead to death. Like hospice care, palliative care treats the whole person (body, mind, spirit) and treats the symptoms to provide comfort, not necessarily the disease.

More than collecting data, my project dealt with presenting information and training to a group of seminar participants regarding end-of-life issues and care for those at end-of-life. This was done in a workshop format on two consecutive Saturdays. Each

Saturday session lasted approximately five hours. Each participant had a training manual in their possession at least a week prior to the first seminar date to begin familiarizing themselves with the information. As the leader, I utilized a power point presentation for the training.

Each participant had in their hands, at least two weeks prior to the first seminar date, a questionnaire. This assessment tool gauged their thoughts, feelings, knowledge, and understanding of death and dying, end-of-life issues, end-of-life care, hospice, church involvement in these matters, and what they hoped to gain from the seminar. They had a week to complete the nine questions and return the questionnaire to me. They were given the seminar training manual once the questionnaire was returned. I did not want anything in the training material to affect their answers on this first questionnaire. Several of the questions, along with the participants' responses were compiled and used as an entry point into the first seminar session. The remaining questions were used to introduce related training topics and as break-out group topics of discussion. This questionnaire appears in Appendix A and I have noted in a later chapter which questions were utilized where in the seminar.

Following the last seminar session, the participants were given the post-training questionnaire with instructions to return it to me within the next two weeks. There were six questions on this questionnaire that mirrored six of the nine on the first questionnaire. Now, the participants were to answer the questions in light of the seminar training and how it may have shaped their thinking as they answered them again. The answers here were used to gauge in part the effectiveness of the seminar and the impact it may have

had.

The research group I worked with was Pastor Jay Bessmer (Bethany Church of the Nazarene; Hutchinson, Kansas) and those from his congregation who desired to become more informed and understand in a greater way how to care for those at the end-of-life. He focused on recruiting those from his homebound/hospital visitation team.

The seminar was held at Bethany Nazarene. There were a number from my home church (Hutchinson First Church of the Nazarene), in addition to those from Bethany Nazarene, who signed up to participate as well. I also had interest from a third Nazarene church in town, New Life Church of the Nazarene. It was my desire to have a group often to twelve participate in the seminar. Again, these folks were individuals who desired to increase their knowledge pertaining to end-of-life issues and care and could be catalysts in spreading this type of ministry within their own congregation.

Many subjects dealing with end-of-life were worthy of consideration and were important to be considered, however the scope of my project would not allow a broad stroke to encompass all. This was certainly not an inclusive list, but a few such subjects were assisted suicide for the terminally ill, bereavement care, and that of advance directives. The topic of assisted suicide is a subject certainly on which the church should not be silent, but that would be another project. I did address the subject of grief and bereavement, but that was primarily because for the dying and their family, grief begins with the terminal diagnosis and must be addressed. In my opinion, bereavement care following the funeral and all the relatives leaving the bereaved and going back home needs to be addressed in the church, but again, another project. I also touched on advance

directives and making ones decisions known regarding treatments in a section on assisting the dying to get their affairs in order. However, that is a topic that needs to be addressed at greater length even in the church and perhaps long before a terminal diagnosis. That was another topic as well. My central focus here was to present an understanding of various end-of-life issues and related care, and to challenge the church to come alongside the dying and their loved ones as they face a terminal illness and minister to them in that context.

Is there a context within the church world in which a subject such as this might not be applicable? There are churches that are primarily focused on the younger generations and may have few if any elderly members, yet I am reminded that cancer and many other terminal diseases is no respecter of age. As the church, we must care for those within the body from cradle to grave.

The next four chapters will look as follows:

Chapter 2 "Precedents in Literature: The Word and Words on the Subject"

Caring for others, this includes end-of-life care, is well grounded in Scripture. I highlighted Matthew 25 and drew on commentaries and books/articles on theology and mission. The fact we live in a death denying culture often creates obstacles to care and allowing oneself to be cared for at the end-of-life. In the midst of this, we need to know and understand what it means to die well, to finish strong as believers. I gleaned from books and articles related to death/dying and looked into virtues that one may reap from Christ's death. We, the church, must come alongside the professional caregivers in meeting the needs of the dying and their families. I drew in this area from my nine years

of experience working in hospice and one particular book dealing with death and dying. The church is the presence of Christ in the world and this should be very evident in our presence with the dying. We must not only participate in this ministry, but also be equipped to do it well. In this area, I pulled from books and articles dealing with care for the dying, especially in the spiritual realm.

Chapter 3 "Research Design: Equipping the Church"

I highlighted in some detail the group that I worked with and training topics for the two-day seminar. I referenced in more detail the pre and post-seminar questionnaires that gauged attitudes regarding death/dying, experiences with death/dying, including caring for the dying, knowledge of end-of-life care, what the church's and believer's role are perceived to be in end-of-life care, and anticipated/actual learning from the seminar. These questionnaires appear in Appendix A. This chapter too focused on the seminar and related material. In addition to completing the pre-seminar and post-seminar questionnaires, a select number of the participants were interviewed four to five weeks following the training to gather additional data related to the issues and their thoughts and feelings post-seminar.

Chapter 4 "Research Data and Results: The Church Outfitted for End-of-Life Care"

I related the findings from the questionnaires both pre and post-training. I shared as well comments, questions, etc. that emerged during the training and in conversation and interviews following the training. I utilized written curriculum and made use of a power point presentation in leading the seminar.

Chapter 5 "Summary and Conclusions: Caring for These Least of These"

I evaluated and summarized major conclusions, spoke to the implications for ministry, noted limitations and needed alterations by others, recorded any unexpected results/commentary, and related where I go from this point. The dying and their families are not the only 'least of these'; however they are certainly one group of the 'least of these'. Caring for the dying and their families helps us be Christian and is a tremendous opportunity for the church to be the church.

Chapter 2: Precedents in Literature: The Word and Words on the Subject

We often hear, and speak of life-changing moments. These times impact us in such a way that we are profoundly affected and transformed. For me, this came in October 2006. I had left congregational ministry and began serving as a hospice chaplain less than a month prior. Our director, one of our nurses, and I had been spending more focused time with a patient and her family as the time of death was drawing close. Then, on that particular day, it occurred. I was present as this dear lady drew her last breath. I had experienced in person, for the first time, the dying of one who had been created in the image of God.

⁴ Quote from Frank McKinley, Director of Chaplains for Hospice Care of Kansas, during my interview in August 2006.

Death was not new to me, I had grown up on a farm where livestock had become ill and died. Yet this was very distinctive. It was very different when one created in God's image died and you were there in the midst of the event. I understood in a much deeper way the words spoken to me several weeks earlier. During my interview for the position

which I now occupied, the chaplaincy director for the company had made a statement in regard to death and dying. He said, "They say death is a physical matter with a spiritual component, but I would say death is a spiritual matter with a physical component."⁴ If the death of a person is a spiritual matter, and I firmly believe that no one who has been present when one has died would deny this, then one must ask, "Where the nurturers of the soul are in the midst of this experience." If we as the church are to

care for and nurture one another then, it has been my experience over these past nine years that this care is often strangely absent at the end-of-life.

We have within our rituals in The Church of the Nazarene "The Dedication of Infants or Small Children." After the family and infant/child are summoned to the front of the church before the congregation, the pastor reads a portion of Scripture. He/she offers a challenge to the parents to which they are to respond in the affirmative. The pastor then turns to the congregation and states: "I now ask you, the congregation; will you commit yourself as the Body of Christ to support and encourage these parents as they endeavor to fulfill their responsibilities to this child and to assist _____ by nurturing his (her) growth toward spiritual maturity?"⁵ The congregation is to respond with, "We will."⁶ It is often a very resounding, "We will!" However when life comes full circle, there is too often a strange silence from the congregation, the church. Could this

not become a more important moment for a congregation?

⁵ Church of the Nazarene, *Manual Church of the Nazarene 2001-2005 History, Constitution, Government, Ritual*, (Kansas City: Nazarene Publishing House, 2001), 253.

⁶ Ibid.

⁷ Brooks, 4-5.

James Brooks noted this silence from the church as well. He commented how some are born into the community of faith. There are others who come through conversion, baptism, a transfer of membership, or some other means. He adds that we nurture, educate, connect with, share together, etc. all throughout life as the community of faith. Yet he stated there comes a time, whether through serious illness or care giving for someone else with a serious illness, when there are those who are unable to participate in the congregation as they did before. This may develop slowly or be sudden, but the individual's or the family's relationship to the church undergoes a significant shift.⁷

Brooks wrote, "For many people, this is the moment when the circle of care is most likely to be broken." Folks slip from the circle of care unnoticed. Rev. Brooks illustrated this in a powerful way:

When Andrea was diagnosed with cancer three years ago, she moved in with her sister Lenora for support. Andrea was devastated a few months ago when it became clear that the cancer was no longer responding to the treatment.

The burden of illness and care giving had been so great for so long, Andrea and Lenora had not stayed connected with their faith community. At the same time, the congregation lost touch with them. Now that Andrea was dying, she and Lenora missed their faith community even more and longed to be a part of it.⁹

Brooks alluded to a vital point in this whole scenario. He noted the sisters did not stay connected and the church lost touch with them. Nothing intentional happened on anyone's part, it just tends to happen in the midst of circumstances and the busyness of

life (people entering and leaving the church, pastoral changes, etc.).

We, as the body of Christ, must seek to refocus our efforts in caring for the dying and their families. There are many New Testament examples for us of the sick and dying being cared for, especially in the Gospels and Acts; following are but a few. We find Jesus going to Jairus' daughter who was dying as recorded in Luke 8 and Mark 5. He even paused in route and attended to the woman who was hemorrhaging. Jesus came to the aid of a Centurion's servant who was sick and ready to die in Luke 7. Jesus went to minister to a Centurion's son who was sick in John 4. Jesus went to Bethany as Lazarus was sick and dying in John 11. Jesus commanded the Twelve as recorded in Matthew 10 and in Mark 6 to go forth and heal the sick. It is specifically stated in Mark that they anointed the sick as a part of that ministry. These instructions to the Twelve could have been where James drew from in his directive to the early Church as noted just below.

Peter and Paul, as well as other early disciples, reached out to those who were sick and healed them as recorded in Acts. Our inability to minister to the extent Jesus and His early followers did should not deter us from doing what we can. We must go and be present with the sick and dying.

Fred Craddock noted that caring for the ill was a part of the Church from the very early years of Christianity. "Illustrative in this respect is the history of the ways in which Christians have practiced the ministry of what Paul Ramsey calls 'only caring,' which is seen in Scripture in the practice of visiting and anointing the sick (James 5:14)".¹⁰

Craddock and his co-writers recorded that the *Rule of St. Benedict*, developed in the monastic tradition, formalized and maintained a community approach in caring for

those who were dying.¹¹ Chapter 36 of *The Rule of Benedict* stated, "Care of the sick must rank above and before all else so that they may truly be served as Christ who said: 'I was sick and you visited me' (Matt. 25:36) and, 'What you did for one of these least of my people you did for me' (Matt.25:40)." I saw this lived out first-hand in June 2013.

Along with two professors and other Nazarene Theological Seminary doctoral students,

¹⁰ Craddock, 169.

¹¹ Ibid.

¹² Joan Chittister, *The Rule of Benedict: A Spirituality for the 21st Century* (New York: The Crossroad Publishing Company, 2010), 174.

I spent a weekend with the Benedictine sisters at Mt. St. Scholastica in Atchison, Kansas. Within that community, like in all communities, there were those on whom life had taken its toll. They reached a point where they could no longer care for themselves. The elderly and ill were nurtured and cared for in a nursing home type environment by others of the community. They were cared for up until they took their last breath. The community cared for their own. No, the vast majority of us do not live in this type of

communal setting, however we may learn from their caring. Joan Chittister wrote in her commentary on this particular Benedictine rule, "We have to ask ourselves how willing we are to take a little of our own energy on behalf of those who are no longer the life of the party, the help on the job. How much of our own precious time do we spend on those with little time left?"¹³

Craddock and the Goldsmiths noted as well that within the history of the church the birth of the hospital was found and within religions care for the dying was frequently discovered.¹⁴ Who is better than the community of faith to come alongside one of their own; and perhaps others as well, and participate in their care and their life at this critical

junction? Who better indeed! Not only is it our place, but our mandate. Caring for such is what helps us be Christian; it is what makes us the Church. Jesus illustrated as much in His final discourse that we find in Matthew 25. He gave a critical evaluation on what marked out those who are Kingdom people. Matthew recorded Jesus words:

Matthew 25:31-40 (NASB)

31 But when the Son of Man comes in His glory, and all the angels with Him, then He will sit on His glorious throne. 32 All the nations will be gathered before Him; and He will separate them from one another, as the shepherd separates the sheep from the goats; 33 and He will put the sheep on His right, and the goats on the left.

¹³ Ibid, 176.

¹⁴ Craddock, 169-170.

34 Then the King will say to those on His right, "Come, you who are blessed of My Father, inherit the kingdom prepared for you from the foundation of the world. 35 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; 36 naked, and you clothed Me; I was sick, and you visited Me; I was in prison, and you came to Me." 37 Then the righteous will answer Him, "Lord, when did we see You hungry, and feed You, or thirsty, and give You something to drink? 38 And when did we see You a stranger, and invite You in, or naked, and clothe You? 39 When did we see You sick, or in prison, and come to You?"

40 The King will answer and say to them, "Truly I say to you, to the extent that you did it to one of these brothers of Mine, even the least of them, you did it to Me."

What have we done for Jesus' brothers, the least of these? That again is what marks us as the Church.

Just who are 'the least of them'? It perhaps confuses the issue even more when 'brothers of mine' is connected to 'the least of them/these.' In his commentary Donald Hagner listed the following as options of which there were four: everyone (the most

needy of all humans); all Christians; Christian missionaries; and Jewish Christians.¹⁵

Michael Wilkins added Tribulation martyrs as a fifth group to the four Hagner referenced.¹⁶

Wilkins noted the Tribulation martyrs were those who suffered and were killed because of their faith during the Great Tribulation. The Lord will bring these with Him at His second coming.¹⁷ Little weight if any was given that Jesus was referring to this group. This would be a far too restrictive interpretation in light of the context here in this passage and all that Jesus shared in this final discourse in Matthew 23-25.

What about Jewish Christians? Could the fate of all the nations' be based solely on how they treated such a narrowly defined group? Hagner noted to opt for this choice takes too literally the term 'brothers'. It was far too restrictive to affirm this was only

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¹⁵ Donald A. Hagner, *Word Biblical Commentary, vol. 33B, Matthew 14-28*, (Dallas, TX: Word Publisher, 1995), 744.

¹⁶ Michael J. Wilkins, *The NIV Application Commentary: Matthew* (Grand Rapids, MI: Zondervan, 2004), 811.

¹⁷ *Ibid.*

¹⁸ Hagner, 744.

referencing Christians who are of Jewish birth.

Assigning this group to being Christian missionaries carried more weight.

Thomas Long wrote,

Some argue that 'the least of these who are members of my family' (my brother' in Greek) refers specifically to Christians, especially to Christian missionaries who

went about with no money and no possessions (Matt. 10:9-10). The case for this view is strong because, in Matthew, the term 'brothers' always refers to a member of the Christian community, as does the phrase 'little ones' (see Matt. 10:42, 18:6). If this is the proper interpretation of the parable, then the message is that the church is Christ's presence in the world, and the world will be judged on the basis of how it treats the Christian community and receives those sent to it on behalf of Christ.¹⁹

One must acknowledge that if this were the case then Christian missionaries and the next group, all Christians, were in essence, one and the same in referring to the church.

In his commentary, Hagner made a similar analysis. Unless one used the term missionary in a very narrow sense, it must be acknowledged that all Christians were representatives of Christ and of His Gospel. He alluded to Matthew 10:32 in support of

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this.TM "Every one therefore who shall confess Me before men, I will confess him before My Father in Heaven" (Matthew 10:32 NASB). This passage gave a far broader definition to missionary and those who represent Christ. All who knew the risen Christ were to reach out in His name and carry forth the word of life.

Long noted if this was referring to 'all Christians,' then "the parable becomes a narrative expression of Jesus' statement to the disciples as he was sending them out to

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¹⁹ Thomas G. Long, *Westminster Bible Companion: Matthew* (Louisville, KY: Westminster John Knox Press, 1997), 285.

²⁰ Hagner, 744.

²¹ Long, 285.

minister in his name." He then referenced Matthew 10:42. However, I have affirmed verses 40 and 41 were relevant as well. "He who receives you receives Me, and he who receives Me receives Him who sent Me. He who receives a prophet in the name of a

prophet shall receive a prophet's reward; and he who receives a righteous man shall receive a righteous man's reward. And whoever in the name of a disciple gives to one of these little ones even a cup of cold water to drink, truly I say to you he shall not lose his reward" (Matthew 10:40-42 NASB). Hagner cited another as he indicated agreement. He acknowledged the close connection between Matthew 10:40-42 and Matthew 25:31-46 and noted this confirmed the correctness of aligning 'the least of these' with all Christians.

Wilkins weighed in on this interpretation as well; however he narrowed it a bit. He noted that Matthew's consistent use of 'brothers' as being Jesus' disciples, points to all Christians. However, he went on and stated that by including the word 'least' narrows the meaning to 'needy' disciples. He pointed out how the needy disciples were often excluded from care and how the more prominent within the discipleship community received special attention. Wilkins pointed us to Jesus' words in Matthew 18. The disciples were arguing over who is the greatest in the Kingdom. Jesus said they should become like little children "and receiving children in his name is like receiving Jesus

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himself." Perhaps Wilkins stretched it a bit even though children indeed were representative of the least of these' and Jesus expressed great care and concern for children and the poor and needy, those passed over. However, to assign judgment based on such a narrowly defined group could not have been Jesus' intention and who would have been able to judge just which disciple was needy and which was not?

²² Hagner, 745.

²³ Wilkins, 811.

Everyone, all needy humans, has been the traditional and most familiar interpretation of this parable in referring to 'the least of these.' The focus has been that all nations will be judged based on how they have responded to, or failed to respond to hurting people; i.e., the hungry, the thirsty, the stranger, the naked, the sick, the imprisoned. Ralph Earle's words expressed this point clearly: "There has been considerable discussion as to what is meant by my brethren (40). Some have held that this expression refers to the Jews and that is the Gentile nations that are being judged on the basis of their treatment of God's chosen people. It seems better to hold that, in the Incarnation and in His compassionate love for all men, Christ is referring to suffering humanity as my brethren."²⁴

Again, though the long-held option, it seemed to ignore Jesus' reference to His followers as His brothers throughout Matthew's gospel. One prime example of this was found in chapter 12. Mary and Jesus' brothers came to see him and He was informed that they were 'standing outside' and desiring to speak to Him. Jesus affirmed by "stretching out His hand toward His disciples, He said, 'Behold, My mother and My brothers! For whoever shall do the will of My Father who is in heaven, he is My brother and sister and mother'" (Matthew 12:49-50 NASB). This passage spoke to Jesus' use of brother as well as getting at the heart of the passage at hand. Jesus' use of brother/brothers should also be noted in 5:24 and 7:5. Much of current scholarship holds with Roger Hahn who wrote, "Though this parable does not reject general humanitarian concern for the needy;

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that is not its point." What then is the point here?

²⁴ Ralph Earle, A. Elwood Sanner, and Charles L. Childers, *Beacon Bible Commentary, vol. 6, Matthew, Mark, Luke* (Kansas City, MO: Beacon Hill Press, 1964), 228.

²⁵ Roger L. Hahn, *Wesleyan Bible Commentary Series: Matthew* (Indianapolis, IN: Wesleyan Publishing House, 2007), 303.

With mission and eschatological judgment in mind, one must ask, What is the key focus here? What is Jesus' point through the pen of Matthew? How are we to be ready for Jesus' Second Advent and what are we to do in this interim? Hahn noted in his commentary, "The point is that all the peoples of the earth will be judged on the basis of their response to the message of the Kingdom. That message is always brought to them by brothers or little ones or disciples. Readiness for Christ's coming does not happen simply by being kind to everybody."²⁶ If this were the case, preparedness and mission would simply be 'doing.' If one could do enough good things or do more good things than bad things, the interim would be filled with 'activity' and one's fate would be set when the King returns.

However, in his thought-provoking article, Sigurd Grindheim declared, "Like the judgment scene in 25:31-46, the conclusion to the Sermon on the Mount stressed that eschatological vindication is the result of right action (7:21-27). Even good works done in Jesus' name may be insufficient in the final judgment, as they do not necessarily qualify as doing the will of the Father in heaven (7:21). Not merely action, therefore, but right action is imperative." Grindheim cited this and other passages from the Sermon on the Mount as relevant here. This was indeed very appropriate as one considers Jesus' words in Matthew 5-7. Jesus declared this is how citizens of the Kingdom are to live. One cannot deny that the theme of the Kingdom is perhaps the thread that ties this all together and that is the *Missio Dei*, Christ's proclamation, and His followers' mission/message.

²⁶ Ibid.

²⁷ Sigurd Grindheim, "Ignorance Is Bliss: Attitudinal Aspects of the Judgment according to Works in Matthew 25:31-46," *Novum Testamentum*, vol. 50, issue 4, (October 2008): 320, <http://www.ebscohost.com/page.aspx?url=/ehost/abstract/summary.aspx?tid=15&hid=122&sid=ce991634-7a3b-4c85-ac1f-436703e1b987%40sessionmgr104> (accessed July 12, 2012).

Grindheim made several other relevant connections with the Sermon on the Mount. He noted that right action was a mark of the radical love Jesus called His followers to exhibit. When this was evident in heart and life it was evident they were children of God (of their heavenly Father) as is noted in (5:45, 48). The fulfilling of this command was only made possible by having the right attitude, the kind of attitude that is laid out in the Beatitudes. He wrote, "These *makarisms* anticipate the eschatological judgment which resurfaces in the eschatological discourse in chapters 24-25. Matt. 5:3 proleptically predicates the eschatological blessing, possession of the kingdom of heaven, of those who are poor in spirit."

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Another connection with our passage from the Sermon on the Mount according to Grindheim has to do with "Lord, when did we see You..." (25:37). He noted how this coincided with Matthew 6:3-4 and Christ's command for His followers not to let their right hand know what their left had was doing in regards to works of mercy. Those on the right did not do their good works to be seen by others, they did not even remember they had done the works themselves. "The blessed person of the Beatitudes (and I would note a citizen of the Kingdom) demonstrates the virtues that are perfectly exemplified by Jesus himself. Those who are praised are those who are so conformed to the model of

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their master that they are persecuted for his sake." Was that not what it meant to a great

extent to be on mission, living the Kingdom, partnering with God in the *Missio Dei*?

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ibid.

²⁹ Ibid., 322-3.

D. A. Carson spoke in this same vein. "But Jesus is interested in a righteousness of the whole person, righteousness from the heart (see 5:20; 13:52)." He noted how true followers of Jesus loved one another and they served one another and as this was lived out, they were serving the Lord. This affirmed what others have said about right

attitudes and motives and a life that mirrored that of the Master. Those who lived like this were being and living as Kingdom persons whose eyes were not set on anything other than the King and those around them, 'the least of these.'

In his book, *Transforming Mission*, David Bosch devoted a section of a chapter to 'God's Reign and Justice-Righteousness.' There he noted the Greek word *dikaiosyne*. He elaborated on the English translation of this word. He wrote that it can mean 'justification' in the sense of God declaring one just; it is a change of status. It can mean 'righteousness' as an attribute of God or a spiritual quality of which He endows us. It can also be translated 'justice.' In this sense, it is the right conduct of a person in relation to others.

David Bosch wrote, "*Dikaiosyne* is faith in action, the practice of devotion or, as Matthew 6:1 suggests, an act of right conduct 'before your Father'; it is doing the will of God." ³¹

Once again, we find the Kingdom aspect present and doing the will of God. For that was what it meant to be a Kingdom person, to live out one's calling and purpose and mission. It meant to care for 'the least of these.'

Discipleship was vital as one considered living out the Kingdom and mission.

Bosch saw discipleship as a central theme in Matthew and also central to Matthew's

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³¹ David J. Bosch, *Transforming Mission: Paradigm Shifts in Theology of Mission* (Maryknoll, NY: Orbis Books, 1991), 71-73.

³² *Ibid.*, 74.

understanding of the church and mission. Discipleship was a call. As Jesus walked along the shores of the Sea of Galilee and dusty roads of His native land, He issued the call to the Twelve and others. The call was to follow. The call was not merely for their benefit, but for the benefit of the Kingdom. They could join in what God was doing. Darrell Guder noted, "The biblical focus is upon the relationship of the benefits of salvation to God's call to serve. It is common to all the biblical accounts of calling that to be called means being given a task." Jesus' followers were to be doing out of their being in the period prior to His return. Bosch noted, "Mission involves, from the beginning and as a matter of course, making new believers sensitive to the needs of others, opening their eyes and hearts to recognize injustice, suffering, oppression, and the plight of those who have fallen by the wayside."³⁴ After all, this will determine the validity of one's faith; what has been done for 'the least of these.' Followers of Christ were not to be reservoirs of what God had poured into their lives through others, but were to be a channel of those blessings. It was to continue the promise to Abraham that the entire world would be blessed.

So the Christian church is sent out to the world on a vital mission—to bear witness to the gospel of Jesus Christ. The 'good news of the kingdom will be proclaimed throughout the world, as a testimony to all the nations' (Matt. 24:14). The gospel, however, is more than mere words, and the church proclaims the gospel by living in the world as Jesus lived. The disciple is to be like the teacher

(Matt. 10:24); the church must become humble like a child and show hospitality to those in need (Matt. 18:1-5). In Matthew's Gospel, if you want to find Jesus, look among those who are 'harassed and helpless, like sheep without a shepherd (Matt. 9:36). The church that is faithful will be found in precisely the same
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place.

Darrell L. Guder, *The Continuing Conversion of the Church* (Grand Rapids, MI: William B. Erdmann Publishing Co., 2000), 130.

³⁴ Bosch, 83.

³⁵ Long, 286.

As one considers missions, being missional, the *Missio Dei*, the gospel of Matthew has a great many things to say and Matthew 25:31-40 in particular. At an appointed time, 'all the nations' will be gathered before the 'Son of Man'. One cannot deny that group will include each of us. In regards to 'the least of these, brothers of mine,' we must find ourselves here as well regardless of who these are. If one still favors the more traditional and long-held interpretation, judgment will be in regards to how we

(Christians) have treated others as representatives of God and His Kingdom. If one does not show love and meet the needs of others, he/she has not shown love for the King. If the 'least of these' are those sent out by the King to proclaim the good news of the Kingdom, then judgment will come as a result of how these are treated, how they and the message has been received, in essence, how the King has been received. There was a time when all of us were in this camp, away from God before becoming His follower. Did we receive the messenger, the message, the King Himself and live out the Kingdom values?

Partnering with God and what He is doing in His world bears a great measure of accountability. This was pointed out by Wilkins as he wrote, "Rather, our privilege and

charge are to maximize the precious moments of life with which we have been gifted to make a difference for the sake of the kingdom."³⁶ For a true citizen of the Kingdom this service is not burdensome or heavy. It simply flows from a life that has been changed from the kingdom of this world to the Kingdom of God. Wilkins stated "but caring for the most needy among Jesus' disciples is the clinching evidence of kingdom life. We serve because we have been served, we love because we have been loved, we lift because we have been lifted up—and we never forget it. But a heart that has been truly transformed by the righteousness of the kingdom of God will serve out of humility."³⁷

³⁶ Wilkins, 816.

³⁷ Ibid., 821.

In light of what has been said, to profess that the dying are the least of these or the only 'least of these' would not be faithful to scripture. However, we cannot deny that they are a part of the 'least of these'. They are indeed often overlooked and pushed to the margins as their life is ebbing away. We must bring them back front and center, or at least go to them and journey with them through the dark places in the margins. They need those who are unafraid and undaunted by their circumstances and who will walk with them 'through the valley of the shadow of death.'

Having been in the ministry of caring for the dying and their families through hospice care for the past nine years, I have noted that the needs of the dying and those who love them are heavy. It is a burden that cannot be carried alone. What are the needs and burdens of this group to which the Church may partner with others in addressing?

There is a jolt that comes with a diagnosis that one's days are numbered in weeks or months, rather than years. Those receiving such news often shake their head attempting

to clean out their ears thinking they did not hear correctly when a terminal diagnosis is given. Yet, the reality is there. Louis Heyse-Moore, in his book, *Speaking of Dying*, noted that in these situations often "our emotions are intimately connected with

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survival." Even though we as humans may be old and/or ailing, there is a strong desire to cling to life. Heyse-Moore enumerated several emotions that I feel based on my years in hospice work give us a useful glimpse into what the dying are thinking, feeling, and facing.

³⁸ Louis Heyse-Moore, *Speaking of Dying: A Practical Guide to Using Counseling Skills in Palliative Care* (Philadelphia: Jessica Kingsley Publishers, 2009), 94. Heyse-Moore, 96.

Anger was the first of Moore's enumerated emotions. He wrote, "In a way it is surprising that anger isn't more overt in the dying. More prevalent is partially suppressed anger which makes itself known in many ways: irritation, grumbling, brooding, self-destructiveness, bitterness, coldness, and so on."³⁹ Of course there can be the overt anger, the outbursts of yelling, screaming, and throwing things. A time or two in my hospice work I have been on the receiving end of these. I knew it was not personal. In

Intricately connected with anger was pain noted Heyse-Moore. The reference here was not to physical pain, but the emotional variety. He wrote, "Nevertheless, underneath the anger is pain, pain that may be so unbearable that she doesn't want to let it into awareness, pain at the prospect of losing her life, her loved ones, her career."⁴⁰ Those dying are not only left with the pain of the diagnosis, but all that it represents. They are not only losing what is, but also what was to be. They are not only losing their job/career, but a large part of what gave them meaning and purpose, what made them feel like they

were contributing and making a difference. The dying will not only know the pain of the losing their spouse, but must face they will not be able grow old with the love of their life as they dreamed. They are not only losing their children, but they will never have the joy of being called grandpa/grandma. I still remember the pain on my dad's face and in his eyes when he said, "I would give anything if I could just go out in the yard and play catch with Josh (my son)." My dad had done this countless times with my brother and me and desired to do so with the next generation. However, Multiple System Atrophy had robbed him of the use of his legs. The dying anguish in the pain of what is lost and what they are losing. ⁴⁰ Ibid.

the midst of the receipt of the terminal diagnosis there was the action and reaction of lashing out and blaming God, spouse, children, the dog, the mailman, and anyone else with whom one has crossed paths. Again, it was not personal. However far more often than not, Heyse-Moore was correct; the anger is muted and takes quieter forms. The dying may turn inward and be churning inside. The coldness, bitterness, brooding, etc. that he mentioned often simmer and may come out in external ways, but more frequently they are kept internal and eat away at the individual because of all that has been lost.

Anxiety was another emotion the dying faced stated Heyse-Moore. In hospice care, those with chronic breathing issues have been the most likely sufferers of anxiety, those with lung cancer or chronic obstructive pulmonary disease (COPD), though not exclusively. Heyse-Moore wrote:

In palliative care, anxiety may be related to the following:

- physical suffering - such as severe pain or breathlessness

- loss - of health, body parts, mental faculties, sexuality, mobility, control, status, beauty, family and friends, work
- re-evocation of unhealed past memories
- the prospect of death - extinction of life, and painful death or going to hell.

Anxiety wears on one mentally and emotionally. It causes the mind to race and one worries and frets and imagines all kinds of things. All that is imagined leads to fear and the dying are caught up in a storm they believe will engulf them. Anxiety not only wears on one mentally and emotionally, but physically as well. Anxiety leads to restlessness and often sleeplessness. When one is drained of energy problems are multiplied.

Depression was another emotion the dying wrestled with according to Heyse-Moore. It was not necessarily clinically diagnosed depression. Those who have suffered from clinical depression have often exhibited certain attitudes, actions, and behaviors. He noted that palliative care patients may not have matched up with such criteria, the criteria that would demonstrate clinical depression, but they have suffered from depression nonetheless. He emphasized there are attitudes, actions, and behaviors that ought to be looked for in the hospice/palliative care patient. In this, Heyse-Moore leaned on the work of J. Endicott and stated, "Thus, instead of change of weight, she put in, 'tearfulness and depressed appearance'; for sleep changes, she substituted, 'social withdrawal or decreased talkativeness'; for loss of energy, 'brooding self-pity, or pessimism'; for thinking difficulties, 'cannot be cheered up, doesn't smile, no response to good news or funny situations'." I have noticed frequently when my hospice patients appear depressed it is as if the life has been 'sucked' out of them. To a certain degree, they seemed to have shut down and to a degree were not thinking or feeling. Their hopes have

been dashed leading to meaninglessness and despair. Heyse-Moore referred to this as 'disempowerment'. There was the attitude of 'what's the use, all is lost'.

Heyse-Moore wrote as well how depression was often seen to be the result of 'in-turned anger' and/or 'unresolved grief. He added that there was often no short supply of these with the dying. He could not be more correct. Shortly after a terminal diagnosis is received, one rarely knows how to handle all that comes with it. The person is often unsure what to say, do, think, or anything. What makes matters worse, those they know and love does not know what to say, think, do, or anything. The dying are often shut up in their own world because others are afraid to use the 'd' word or let the dying know that it is ok to use the 'd' word. When this is the case, there is nowhere for hospice patients to turn except inward. That being the case, depression is prominent.

Suicidal thoughts or feelings have been common with hospice/palliative care patients according to Heyse-Moore, although rarely carried out. This was certainly understandable with the blow that has been dealt to them. 'What's the use of going on, I'm dying anyway.' 'I'm dying; why not hurry the process along?' 'I don't want to be a

burden and I'm of no use to anyone.' What motivated or caused suicidal thoughts or feelings in the dying according to Heyse-Moore?

- to escape unbearable pain or other physical symptoms
- to escape psychological pain such as depression
- as part of the syndrome of clinical depression
- a response to loss of physical abilities - paralysis, loss of speech, incontinence
- a considered anticipatory response to a progressive fatal illness such as motor neuron disease

- a wish to make others close to the suicidal person suffer - 'Look at what you made me do, it's your fault'
- the ultimate form of self-destructiveness in people with extreme self-hatred - 'I'm worthless, the world would be better off if I were dead'
- a primitive, instinctive regression - patients who take to their bed, refuse to eat or drink and become mute
- sacrificial - the person who gives up his life for another.

In my experience as a hospice chaplain, I would add another, a tremendous fear of being alone. What if there comes a time when no one will be with me and walk with me on this journey? This can be seen as darkness worse than death itself.

Two additional related feelings in the dying according to Heyse-Moore were guilt and shame. He wrote, "Guilt is the feeling associated with the belief that we have done wrong whether by commission or omission. Shame is the feeling that we are wrong or bad or deficient in ourselves."⁴⁷ If not a strong cause, then at least a contributing cause of shame is that of self-esteem, or more appropriately, a lack thereof. We have all noticed people beating themselves up over a variety of issues. They see themselves as being inept, insignificant, not worthy of love/care/concern, and the like. All these matters can fester over a lifetime, whether long or short, and result in one seeing him/herself as far less than God and others see them. Heyse-Moore stated in this regard, "Such themes

come home to roost in the dying - they may see their impending death as their ultimate

⁴⁸ failure." What a shame.

Guilt can be good in the spiritual realm leading to repentance or in the relational realm leading to reconciliation; however in the context of blame with the dying, there is no value. Even if perhaps warranted, such as a smoker blaming himself/herself for their

lung cancer, there is likely nothing beneficial to be gained. The same could be said for IV drug users and homosexuals dying with AIDS. It is past time for all that. On the other hand, there are those who say, 'If only I had been this or done that, things would be different.' In dwelling on such scenarios, those dying only succeed in pushing themselves further into darkness and hopelessness.

Grief was a feeling that was always before the dying. Heyse-Moore suggested these are at least some of the issues:

- The dying person may have been recently bereaved of a family member.
- There may be unresolved past losses such as of a son or daughter dying in childhood.
- Anticipatory grieving - the dying person grieves for the family he will lose when he dies, his family begins to grieve for him as his health steadily deteriorates. Sometimes, with slowly progressive illnesses such as dementia, family members may slowly distance themselves over months or longer from someone they feel is no longer the person they knew. In a sense, he has become dead to them while his body still lives.
- Social losses - of status, money and work.
- Bodily losses - losing a leg, a breast, an eye or any other body part. Furthermore, individual organs will connote losses related to their *raison d'etre*. Thus, a mastectomy may result in feeling of loss of sexual attractiveness.
- Loss of function - becoming, for example, paraplegic, blind or
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incontinent.

There is rarely a day the dying are not experiencing grief and loss, especially when their disease is progressing at a rapid rate. Every day is the unwanted anticipation of what will disappear today. 'What will I not have today that I had yesterday?' Loss upon loss must be faced. One by one, things are being snatched from their life with no end in sight. This is a fearful way to exist.

⁵⁰ Elisabeth Kubler-Ross, *On Death and Dying* (New York: Scribner, 1969), 51.

⁵¹ Fred Craddock and others, *Speaking of Dying: Recovering the Church's Voice in the Face of Death* (Grand

Here, in addition to Heyse-Moore's inventory I have added some helpful insights from Elisabeth Kubler-Ross. In combination these have enabled us to see more comprehensively into the needs of the dying. Heyse-Moore began his list with anger, but Kubler-Ross preceded anger in her enumerated emotions with thoughts and feelings of denial and isolation. I focused on the denial aspect here as it has been my experience that isolation can and does weave itself in and out of all the feelings and emotions at various times. Anyone who has worked with the dying can identify with Kubler-Ross' statement: "Among the over two hundred dying patients we have interviewed, most reacted to the awareness of a terminal illness at first with the statement, 'No, not me, it cannot be true.'"⁵⁰ Even though the mortality rate is one hundred percent, even though people get sick and die, there is something within us that makes us feel we can beat the odds, it won't happen to me. The younger the person getting the terminal diagnosis, the more prominent this feeling might well be. There were thoughts that perhaps records were mixed up or the doctor was just plain wrong. Is one in denial over a terminal diagnosis? Perhaps one of the most telling signs of denial is that of silence.⁵¹ It has been my experience that a couple of aspects are helpful to keep in mind here. Denial can ebb and flow. One may think the patient had come to grips with the diagnosis then they demanded more tests be run to prove all were wrong. Also, if family was in denial, this added fuel to the patient's fire of denial and the diagnosis was harder to accept.

Kubler-Ross included the emotions of anger and depression in her list as did Heyse-Moore, but rather than anxiety sandwiched between them as with Heyse-Moore's

list, she inserted bargaining between the two. She noted the dying often involve themselves in bargaining. Not always, but the bargaining was usually with God. The dying assessed that if God didn't respond to my anger, perhaps He will to a softer approach. The dying often promised a myriad of things relating to being better or doing better. Most likely these promises were in exchange for a little more time. These 'being betters' and 'doing betters' were likely issues the dying person was struggling with and was concerned about. These matters needed to be dealt with even if more time was not given. There is reward to be found in being at peace with oneself, with others, or with any institution or situation from which one may feel she/he has distanced oneself. Knowing what matters the dying are facing will better enable us to enter their world and journey with them.

In our modern world, death is far from an everyday topic of conversation except likely in hospice and palliative care. Conversations regarding death and dying are avoided like the plague; they make most uncomfortable at the very least. In his article, Hiromasa Mase wrote, "The word death has become almost unmentionable in the West,"⁵² Kubler-Ross, 93-95.

As I pondered how to provide care and counsel for the dying and their families in addressing these issues, it seemed good to consider how society viewed death and dying, and what a biblical and theological view of dying looked like. Perhaps we need to ask ourselves and others: What does it mean to die well?

particularly in the United States."⁵³ He further noted that Americans speak of 'passing on' or 'passing away' instead of 'dying.' I have heard these terms so often in dealing with

hospice patients and families and from those in the church arena as well. If not careful, I find myself as a hospice worker and clergy member caught up in this attitude. In reality, death is as much a part of life as is birth. Birth is natural and death is natural. Yet again, our society does not view it in this manner; we must avoid speaking of such matters.

Craddock and the Goldsmiths in their work, *Speaking of Dying*, wrote very plainly to this point. "Unfortunately, there is a clear cultural model, and it is the only one generally available to the terminally ill: be strong, don't mention it, don't give in, fight it. This is the default position to which the church has outsourced the facing of impending death. It combines the individualism and toughness of American culture in a manner that focuses all interest and resources on the dying. The secular narrative has taken over."⁵⁴ The Christian voice or voice of the church has either fallen silent in this matter or we have allowed it to be drowned out by the world. Perhaps somehow if you do not talk about it, it makes it less real.

One might understand this attitude in regards to those who see this world as the end of all. If you are born, live, and then die and that is it, one would certainly desire to shun even the thought of death because it represents finality. Clinging with all one's might and strength to the temporal is all we have.

⁵³ Hiromasa Mase, "Death and Dying: Towards an Ethic of Death." *Currents in Theology and Mission* 12, no. 2 (April 1985), 69. <http://web.ebscohost.com.proxynts.kclibrary.org/ehost/search> (accessed Jan 22, 2013).

⁵⁴ Craddock, 47.

Medical technology has often created obstacles to care for the dying and care giving as well. There seems to be a pill or surgery to cure everything. That being the

case, often those receiving a terminal diagnosis are averse to accepting care because they believe there is a treatment out there and they are going to get better. Perhaps the church and others are reluctant to offer help and care because those might perceive it as taking away hope. Medical science has done much. It has much to offer. Craddock and his coauthors pointed out in this regard, "Astonishing discoveries occur on an almost daily basis and new medical applications are constantly reported, often with significant promise for reversing or eliminating diseases. So when a patient's symptoms point to a terminal diagnosis, rather than submit to the inevitable, the typical American establishes a new fervent allegiance to whatever good news medicine and modern health care may promise."⁵⁵ One cannot deny the lives of many have been extended, and not just extended in regards to quantity of years, but quality of years as well. Yet this has led to a denial of reality. Not all ill patients get better.

Medical technology is great, but it cannot help everyone, not all overcome illness. Craddock and the Goldsmiths wrote, "Medical advances have changed the world and certainly have changed dying. Because of new and improved medical insights, medicines and health-care procedures, we find ourselves in a good news/bad news situation. The good news is that there are cures and relief not earlier available. The bad news is that while it often takes longer to die, the dying is done without the sweetness that such extension might avail because of the rigor of the treatment."⁵⁶ This is so true. There are numerous instances that I have been witness to where the supposed cure takes a heavier toll on the patient than the disease itself. I am often reminded as well in the midst of death and dying as a hospice chaplain that some do get their healing in this life, but many

others have to wait for the next.

An all-to-real example of such a case was the story of the wife of one of my hospice patients. He was dying with congestive heart failure and she received a cancer diagnosis. She elected aggressive treatment. She would go for treatment on Tuesday. She would then be horribly sick for the next five days. She would feel good on Monday and then start the cycle all over again. In a short time she went from walking independently to being pushed in a wheelchair by others. Her hope for minimal side effects and some indication the treatments were working was not achieved. She had neither quality nor quantity of life. Why do treatments work on some and not on others? Hindsight is always 20/20. Yet she was evidence that not all get better even with valiant efforts to heal and cure. I do not know what options she was given at diagnosis or what percent chance there was of the treatment being effective, but there were other choices. Perhaps she pursued this course of aggressive treatment because she saw no one to stand alongside her on the journey if she took another path. A kind, caring hospice nurse that I worked with for many years often said, "I never want my patients to give up, but I do want them to embrace reality."⁵⁷ The embrace of things as they truly are is not giving up or throwing in the towel. It is living, living with courage, living life to its fullest, making the most of each day.

Allen Verhey echoed the above sentiments in his book, *The Christian Art of Dying*, when he spoke on what he referred to as 'medicalized dying' or the 'medicalization of death'. He noted that this came about following World War II and leading into the

⁵⁷ Quote from Cheryl Vannaman, hospice nurse for Hospice Care of Kansas, Deember, 2006.

third quarter of the twentieth century. Leading the way in this regard were advances in medicine and improved surgical techniques. Dying moved from the home to the hospital. All of this improved medical technology began to be utilized on the dying. Now, those dying were no longer treated as they were dying, but were treated as one recovering from

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a serious disease or surgery. Verhey wrote, "So, suddenly no one was 'dying' any more. They were just 'sick.'" He said as well, "The body of the dying person became the battlefield where heroic doctors and nurses waged their war against death." Again, it must be said that medical technology has done much for us. There are tremendously talented and caring medical professionals, my wife being one, who sacrifice so much to give care. However, they and we must be reminded that even though not the original intent for humans, death has become our final fate in this life. Again, not everyone will get better and recover from illness before death will ultimately take them one day in the distant future.

⁵⁸Allen Verhey, *The Christian Art of Dying: Learning from Jesus* (Grand Rapids: William B. Erdmann Publishing Company, 2011), 13-4.

What does it mean to die well? What is the Christian view of death? Do we embrace it as part of life as it now stands? I, having served as a pastor for eleven years and in hospice care for more than nine years, would affirm not. Robert Ellis seemed to agree, for in his article he stated, "If to live is Christ, to die is gain," as Paul suggests in Phil. 1:21, then why is death experienced or construed negatively, even within the Christian community?" Ellis then continued with this thought referencing the writing of

Paul Fiddes. He noted that death was experienced as a boundary and as an enemy.

He stated Fiddes used the Old Testament and "charts a view of death first as a destructive force that abruptly ends relationships — including that between a person and God." My experience in this arena has told me as well that we have not embraced death and dying in the Christian community. "Precious in the sight of the LORD is the death of his saints" (Psalm 116:15 NIV) may be grasped at death, or after death, but not prior as the terminal diagnosis is heard and one moves toward death. I believe this to be true in many cases with the dying, even the dying of believers.

How then should the believer, the church, those in the community of faith view death in order to allow oneself to be cared for and to offer care? If death is not a foe or a boundary to be crossed, what is it then? In his article Christopher Vogt gave, certainly not the only Christian view, but what I saw as one view of death and dying that was faithful to God, Scripture, and the Christian tradition. The abstract at the beginning of the articles affirmed, "Four centuries ago, Christian moral theologians addressed the issue of dying by turning to scripture and the virtues. This work revives that tradition by showing that careful theological reflection upon the nature of Christian patience, compassion, and hope illuminates the shape of the Good Death." A Good Death, just what is a good death? Is there such a thing as a Good Death? Are we searching for something that does not and cannot exist? My experience has shown me no, as did Vogt's enlightening article.

Vogt spoke of the art of dying, 'ars moriendi.' He wrote,

Beginning in the fifteenth century, a new genre of theological literature known as the "*ars moriendi*" emerged which sought to prepare readers for the task of dying. The authors of these works viewed dying as a task or an art—a learned behavior that one could perform either well or badly. These authors urged their readers to live the whole of their lives in such a way that they would become patient, hopeful, and faithful; only by living well and nurturing these virtues over time could one expect to be patient, to be faithful, to be hopeful, and thereby to die well.

If we are to see death and dying as a part of the circle of life, then we must not fade at the end. If one has lived well, surely he/she must want to continue through to death in the same manner, in patience, in hope, and with compassion. If we have whole-heartedly embraced God in life, then we must continue to embrace Him even in our dying and death.

Thomas Long advocated for this as well. He wrote,

There is life and there is death, but there is also the time of dying—the in-between season when the reality that a person will soon die looms large and becomes a magnetic force around which the thoughts and actions of others are organized. Christian faith views this time in between not with resignation, not merely as a season of passing time before someone passes away, but as a period filled with meaning and opportunity for communion with the one who is dying.

I would add as well this is a period to be filled with purpose and meaning and opportunity for the one dying. It is a time to finish strong, to finish well as one has lived. If Long was correct and this is the 'Christian view,' we do a poor job, in my estimation, of conveying just what Christian dying is to look like. How often do we as clergy speak of death/dying? When was the last time we addressed the topic in a sermon or Bible study? How often have we steered the conversation in another direction when it was brought up by a parishioner in conversation? If to see dying as a time to be filled with meaning is

the Christian view, it certainly needs more favorable press. The body of believers will take the lead from us clergy and pastors as to our view and our comfort with death and dying.

Thomas Long noted that within the *Ars Moriendi* literature there were devotions that were read and recited and these were a 'dress rehearsal' for the Christian in his/her dying. He stated these readings would aid the dying in dispelling their fear when their time was near at hand because through the reading they had been in that territory before. Long commented as well how Martin Luther participated in this practice.⁶⁶ He then wrote, "While Christians today are probably not going to be attracted to the old practice of *Ars Moriendi* devotions, it is urgent that the core of the tradition be retrieved, if for no other reason than to break the code of silence about death."⁶⁷ To that I would add a hearty, 'Amen'. That is a great place to start, however we need to go further in leading and teaching people of faith the 'art of dying', what it means to die well.

⁶⁶ *Ibid*, 111.

⁶⁷ *Ibid*, 112.

⁶⁸ Craddock, 85.

Any theology of Christian dying begins with a theology of Christian living. One cannot picture dying well if one has not lived well. Craddock, Goldsmith, and Goldsmith reminded us, "For any theology of dying, the serious, long-term commitment to Jesus Christ in the midst of others of like faith is a necessary precondition to receiving, experiencing, and expressing the full benefits of the gospel story. If we have practiced the Christian life, when the time of dying approaches, the whole experience of our past is at our disposal as a treasury of coping resources."⁶⁸ If faithful Christian living is to be

cruciform in nature, perhaps that was why Christopher Vogt looked so intently at the passion narrative where he gleaned insight that portrayed the essence of faithful living and dying.

In his article, Vogt sought to portray virtues that would shape one for Christian living and for 'Christian' dying. He believed and wrote how appropriate it is and how pastoral it is for clergy to cause their parishioners to see a connection between their dying and the dying of Christ as their death approaches. He drew upon Luke's passion narrative "to describe the shape of Christian patience, compassion, and hope in the context of dying."⁶⁹ He went on to ask, "Can we find in these stories a biblical model for dying well? If so, what exactly is it about Jesus' way of dying that is to be imitated?"⁷⁰ He added that he chose the passion account from Luke because there was evidence in the narrative that a part of the author's purpose was that the story should be read as a replica for dying as a Christian. He did affirm this interpretation was only a part and perhaps a less significant part than other purposes, nevertheless, it is there.⁷¹ One could certainly argue against this point, however, as one considers it and looks more deeply, much fuel for thought is apparent.

Vogt certainly does not stand alone in believing there is much to be mined from the death of Jesus to benefit us in our dying. Allen Verhey noted that in the cross of Christ believers will find a paradigm for their own dying and this tenant permeated the

Ars Moriendi literature.

⁶⁹ Vogt, 136. Ibid.

⁷¹ Ibid, 136-7.

⁷² Verhey, 297.

Again, Vogt noted three virtues in Jesus' dying that were tremendously relevant and worthy of imitation in regards to Christian dying. The first virtue was patience and he affirmed this to run the length of the passion narrative. Vogt saw this most clearly illustrated however in Jesus' prayer in the Garden of Gethsemane. He affirmed it to be illustrated in four ways. "First, we observe in Jesus the *reluctant* endurance of suffering; patience seeks to avoid suffering if possible, but to endure it if necessary."⁷³ This patience was not a seeking of suffering. It was not even a giving up, but a giving in. One would acknowledge that if he/she cannot go over or around, they would press on and move through and accept this part of the journey of life in the same manner as past sections of the journey whether positive or negative. This would be to acknowledge that to finish well, if that was indeed where this event was to lead, was as important as to begin well or any portion in between. Vogt reminded us a bit further down in his article this patient endurance of suffering was not sought after, but those who follow Christ must come to grips with the fact "that some suffering is a necessary part of faithfulness to God."⁷⁴ As I pondered this aspect of the virtue of patience, I found myself back in Jerusalem at the beginning of the *Via Dolorosa* focused on these words, "If any man would come after me, let him deny himself, and take up his cross daily, and follow me" (Luke 9:23 ASV). If we choose this path and following Him in our living, should we seek another path, a path of avoidance in our dying? Again, a path not sought after, but followed as it comes.

Vogt wrote this patience also was embraced with a sense of divine purpose. "Second, the patience of Jesus rests upon a profound sense of Providence, or of divine purpose in the events that are about to unfold."⁷⁵ I did not see that Vogt was meaning a

predetermination as God micromanaged every minute detail, but as Jesus saw God's hand at work in His dying, God too is at work in ours. If we believe in committing ourselves to God, joining His Kingdom, He uses us in life, is He unable to do so in death or our

dying? If we submit ourselves to be used by God in our prime and vitality, is He unable to utilize us in the weakness of our disease or advance of years? Can there be no divine providence as we are moving towards closing the circle of life? Indeed, there surely must be. A bit further down Vogt drew us to Jesus' words as recorded in Luke 22:42, "If you are willing" and "Not my will but yours be done." He then wrote, "Exactly why one should be willing to wait is not generally obvious. Jesus' concern with God's planning and his desire to be obedient to God's will explains why such a capacity is virtuous from a Christian perspective. This requires the development of patience in the sense of waiting; we must wait for events to unfold for God's will or purposes to be made known to us."⁷⁶ In making choices at the end-of-life, God is often left out of the equation. If we pray for God's will in life (place of service, marriage partner, career choice, etc.), should we abandon this as life begins to wane? Does He cease to have purpose for us?

Whether in life or death, there is far more to consider than just me. Vogt noted this as another aspect of patience in Jesus' dying. "Third, Jesus' patience can be interpreted as demonstrative of a particular understanding of autonomy; one of the things Christians must specifically be prepared to endure is some limitation on their exercise of autonomy."⁷⁷ Then a bit further into his article Vogt stated, "In his decision not to flee the difficult end he foresees for himself, Jesus chooses to endure physical suffering, but more importantly to endure what we today might call the loss of absolute autonomy. The

example of Jesus makes clear that the expression of patience entails relinquishing the

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exercise of absolute or total control over one's own fate."⁰ When we follow Christ in life, the believer would state that it is not all about me, why should this not be one's

attitude as death approaches. Just as we are not an island and there are others to consider prior to the diagnosis of a terminal illness or the advance of years, there are others to consider when death and dying seem more imminent. We are not alone in health care decisions. There are others to consider when we ponder treatment, or to let nature take its course, or contemplating something extreme like suicide to exit our situation at the time of our own choosing. There may be a spouse of fifty, sixty, or seventy years to consider. There may be children that have looked to mom or dad all these years. There may be grandchildren, great-grandchildren, and other family members that are vitally connected to this event in time as well. In addition, connecting to the previous point, there is a God whose we are as a believer, we are not our own.

In this area of patience and autonomy, the community of faith must be taken into consideration. As a believer, we are part of the body of Christ and as such, we cannot act in autonomy. How we live and how we die are a reflection upon the God we serve and the community of faith to which we belong. Vogt pointed out a connected aspect when he stated, "for a dying person to give him- or herself over would be to allow oneself to be cared for. I am not advocating throwing oneself over to a hostile crowd or allowing the will of other to be imposed upon us; I am recommending merely a willingness to become the subject of the care of others—of one's family, or one's family in concert with medical

personnel."⁷⁹ In addition, in my view, to give oneself over to care affords the church a grand opportunity to be the church. It provides the community of faith the privilege coming alongside one of their own in a difficult situation; the privilege of bearing one another's burden; the privilege of suffering with one who suffers.

A final way Vogt saw patience exhibited was in connecting it with love. "Fourth, Jesus shows a connection between patience and love for his disciples and many others.

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In this way, patience is an unmistakably social virtue." Vogt pointed out that Jesus saw in His suffering a good coming out of it for God, friends, and the world. Jesus believed

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"that some good is to come from his crucifixion." If our life in Christ is in large part for the benefit of others, and to be a blessing to others, then surely this purpose will not end until we draw our final breath. If we are to have a holy dying, then we must believe as well that there is meaning and significance in how we close our days; that it will make a difference for others.

The second virtue Vogt noted in Jesus' dying worthy of imitation in one's own dying was that of hope. In his article, Vogt pointed us to Jesus' prayer here, the prayer that the cup be removed from Him if possible. His noteworthy point was God's response to His son. The cup was not removed. However, an angel was sent from Heaven to

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minister to Jesus. Vogt affirmed, "Hope is not a distraction from what is to take place, nor an empty promise that no harm will ever come; rather, it is a reorganization of the

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⁸⁰ Ibid, 138.

⁸¹ Ibid, 143.

⁸² Ibid, 144.

⁸³ Ibid.

significance of the facts at hand: you will suffer, you will die, *but I will be with you.*" A grand and glorious hope is indeed the knowledge that come what may, God will not abandon me. The believer can faithfully face life or death if he/she clings to the knowledge that God is faithful and His abiding presence is assured. Vogt declared it was this blessed hope that gave Jesus the fortitude to move forward and face what was before

Him. Our Lord did not pull back, but pushed toward what He believed the Father had set before Him.⁸⁴

We may have this kind of hope as we face our own mortality, but do we? Is it not possible for us to cling steadfastly to the same promise, the promise that we will not be forsaken? Are Jesus' words not for us? "And I will ask the Father, and he will give you another Counselor to be with you forever—the Spirit of truth. The world cannot accept him, because it neither sees him nor knows him. But you know him, for he lives with you and will be in you. I will not leave you as orphans; I will come to you" (John 14:16-18 NIV). Surely, knowing that God has not, cannot, and will not abandon us will enable us to face come what may in life or in death. This is the believers' hope.

The third virtue in Jesus' dying Vogt listed for us to mirror in our own was that of

compassion. Vogt noted when one considered this virtue in relation to death and dying; compassion for the one dying was where the focus most often lay rather than pondering

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the compassion of the one dying. Compassion and care for the dying and their family was in large part my focus. However, the compassion of the one dying was worthy of time and consideration according to Vogt, "Thus what a turn to this biblical material adds to the contemporary discussion about dying well is the suggestion that not only the reception but also the expression of compassion by the dying is important."⁸⁶ This only stands to reason, for the believer, if our dying is to be a holy dying then we should finish our course as we have faithfully traveled on it, as one who not only receives but also extends mercy and kindness.

Vogt highlighted a couple of examples where Jesus extended compassion to others before His death. The first recipient was Peter. After Peter denied Christ in Caiaphas' courtyard, our Lord still looked on him with compassion. That look Jesus gave Peter could be interpreted in a number of ways, but I believe Vogt to be correct as he affirmed it to be a look of compassion based on what we know of our Lord and the

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context of this situation. Vogt penned, "In this scene we find both the expression of

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compassion as empathy and compassion as mercy or forgiveness." As His death neared, Jesus continued to extend compassion to Peter as He had done to others numerous times when death was not so near.

A second portrait of compassion came as Jesus hung between the malefactors.

Jesus was in excruciating pain and agony. The crowds mocked him as they passed by. If that was not bad enough, even those in the same predicament derided Him. He did not respond in a negative way that could easily be justified, but extended compassion. Vogt wrote, "At the same time, in addition to its richness as a source of reflection on eschatology, soteriology, and more, this passage is demonstrative of Jesus' compassion in dying. The scene depicted a very intimate encounter in which Jesus yet again offered mercy to someone in an unenviable position, providing him with comfort and hope." Jesus at His death continued to do and live in the same manner as He had done on numerous other occasions.

It is so appropriate to extend this type of compassion as one nears death. So often, things have gone unsaid. "I love you" has not been spoken. "I am proud of you" has not been verbalized. "I accept you" has not been voiced. "I forgive you" has not been uttered. There is healing for both the receiver and giver of these words as life draws to a close. Perhaps, and indeed so, the words should have been spoken sooner, but if not, compassion can still be given at the end. It is holy dying to extend mercy and forgiveness; to show compassion as life comes full circle.

Christian dying, holy dying, is there such a thing? Vogt wrote, "Christians seem unwilling to see the experience of dying as something to be mined for insight into what God has called us to in life, or as a part of our lives that might present an opportunity to serve God."⁹⁰ If we were to begin to see our dying in this manner and the dying of other believers, it would change our perspective on how we face death. It would also change our perspective on how we view the dying of others, especially believers.

In continued thought regarding death and dying, Alexander Schmemmann has shed important theological light into the arena. He has echoed what has been said about buying into the secular narrative and the fact that there is indeed a Christian view of death that the Church needs to recover. He also spoke to the Church being present with the dying.

⁹⁰ Ibid, 148.

⁹¹ Alexander Schmemmann, *For the Life of the World: Sacraments and Orthodoxy* (Crestwood: St Vladimir's Seminary Press, 1963), 100-1.

Schmemmann wrote, "Before death, however, there is dying: the growth of death in us by physical decay and illness. Here again the Christian approach cannot be simply identified either with that of the modern world, or with the one that characterizes 'religion.'"⁹¹ He noted that in our modern secular world, the normal condition for man is that of health. Disease and decay must be fought vigorously and we do this very well. However, science, medicine, and the hospital have their limits and death comes, but it is not seen as a part of life. In contrast to the secular view, Schmemmann commented the religious narrative of the normal state of man is one of disease rather than health. Sickness, sorrow, and suffering are the natural conditions of life. Modern medicine is supplied in the religious arena but only as a duty, not because of a real interest in health. Any health and healing are in the realm of the miraculous and as such come from God in

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His mercy.

Schmemmann affirmed these two views to be incompatible and the greatest illustration of this truth is that Christians have bought into the fact that both are equally valid. We have attempted to Christianize the secular with chaplaincy and secularize the

Christian hospital with all the latest science and medicine possible. Must we in the church merely accept these as appropriate and right in regards to death and dying and care for these? No!

⁹² Ibid, 101.

Schmemmann recorded, "We must discover the unchanging, yet always contemporary, *sacramental* vision of man's life, and therefore of his suffering and disease-the vision that has been the Church's, even if we Christians have forgotten or misunderstood it. " He alluded to the fact that healing is considered a sacrament by the Church. Over the centuries the Church has come to be identified with religion and this sacrament as well as others have suffered as a result. The ¹ *sacrament of oil* became a last rite, the sacrament of death used to assist mankind on his/her journey to the next life. Schmemmann stated as well that in our contemporary times with the fascination on healing there is the very real danger of this sacrament becoming a sacrament of health that has

been used as complimentary with secular medicine. He noted both of these views are incorrect and miss the sacramental nature of the act.⁹⁵

Schmemmann declared a sacrament to be a transformation or a passage. "Yet it is not a 'passage' into 'supernature,' but into the Kingdom of God, the world to come, into

the very reality of this world and its life as redeemed and restored by Christ. It is the transformation not of 'nature' into 'supernature,' but of the *old* into the *new*.⁹⁶ He affirmed the sacrament not to be a miracle of God breaking into nature but is a manifestation of the ultimate Truth of the world and life and that Truth is Jesus Christ. This sacrament of healing is not per se for the restoration of physical health, but again entrance into the Kingdom of God, life in Christ. In Christ pain and suffering are not eliminated, but is transformed into victory in the Kingdom which is the only true healing.⁹⁷

It is this truth of which the church and the dying are reminded when they journey together at the end-of-life. We teach and we learn what life and death are about. We are reminded that we are one in Christ and dying need not separate us from one another or Him. We embrace life and we embrace death/dying together not because it is normal or God's original intent, but because it is.

Schmemmann wrote,

Here is a man suffering on his bed of pain and the Church comes to him to perform the sacrament of healing. For this man, as for every man in the whole world, suffering can be defeat, the way of complete surrender to darkness, despair and solitude. It can be *dying* in the very real sense of the word. And yet it can be also the ultimate victory of Man and of Life in him. The Church does not come to restore *health* in this man, simply to replace medicine when medicine has exhausted its own possibilities. The Church comes to take this man into the Love,

the Light and the Life of Christ. It comes not merely to 'comfort' him in his sufferings, not to 'help' him, but to make him a *martyr*, *switness* to Christ in his very sufferings. A martyr is one who beholds 'the heavens opened, and the Son of Man standing on the right hand of God' (Acts 7:56)⁹⁸

In this the dying are prompted once again that they are not alone in their dying. They have the presence of Christ and that of His Body. They are reminded that even though death and dying is their fate, it does not have the final word. This reality should cause

clergy and the community of faith to rally around the dying one and their family to be a part of life coming to a close.

⁹⁸ Ibid, 103.

⁹⁹ Brooks, 67.

Before I address the community of faith's part in caring for the dying, we must recognize this is a ministry that takes many hands. Such hands should include those of professional caregivers. Hospice and palliative care providers are the 'experts' in providing end-of-life care. A number of years ago Congress enacted law that added a hospice benefit to Medicare. Medicare is not the only payer source for hospice services, but is the primary one. Hospice services or care is for those who because of illness or simply the complications of advanced years have a life expectancy of six months or less. These patients choose comfort care (the management of their pain and symptoms) instead of aggressive treatment to possibly cure and simply desire to let nature take its course and live out the rest of their days as comfortable as possible. In his book James Brooks wrote, "Ironically, patients who choose hospice may be choosing to live longer. A recent study by the National Hospice and Palliative Care Organization found that of 4,493 terminally ill patients, those in hospice live an average of one month longer than similar patients who did not have such care."⁹⁹ This is a clear illustration that hospice is not less

care, but I would advocate it is more care. It is simply care focused in a different direction.

Hospice care is given in a variety of locations. The primary places are nursing homes, assisted living facilities, and private homes, but hospice services may also be

administered in hospitals and hospice inpatient units.

Hospice care is a team approach. Physicians (the patient's primary care physician or specialist and hospice medical director), nurses, chaplains, home health aides, social workers, counselors, and trained volunteers all partner together to take care of the needs of the hospice patient and family; the whole person and the entire family unit are cared for with hospice. Physical, emotional, spiritual, and social needs are all addressed with the hospice plan of care.

The hospice team:

- manages pain and symptoms, including providing medications related to the life-limiting illness, medical supplies and equipment such as hospital beds, wheelchairs and oxygen
- helps with personal care needs such as bathing and grooming
- offers emotional, spiritual and social support
- helps with insurance and other benefit issues
- coaches caregiver on how to provide care
- offers short-term inpatient care if pain or symptoms become too difficult to manage at home or the caregiver needs a break
- helps the dying people and family members understand what to expect as the disease progresses and through the dying process, and
- provides grief support to surviving loved ones and friends.

Hospice care plans are developed with the specific needs of each patient and family in mind. Each patient and family is unique and the plan of care is developed with this knowledge. Again, the physical, spiritual, emotional, and social needs are all taken into consideration, both patient and family needs.

Hospice services begin with a ninety-day certification period with constant monitoring of the patient's condition. A second ninety-day certification period and then an

unlimited number of sixty-day certification periods follow this first period. Since no one has a crystal ball, hospice patients may continue to receive services as long as their prognosis is six months or less. If the patient's condition improves at any point during their hospice care to where the prognosis for their disease is greater than six months, they may be discharged from hospice. We in hospice refer to this as 'graduating' from services. There are a certain number of folks who get better on hospice services with the increased attention and care. Patients, families, and the hospice team celebrate this. Patients may however be readmitted to hospice services in the future when their health begins to decline again and their anticipated prognosis is less than six months. Patients may also revoke hospice services at any point while under care if they decide to seek aggressive (curative) treatment or simply wish to stop the service.

Hospice services are available from nonprofit and for-profit providers. Both types of providers are reimbursed for the care they provide at the same rate. Medicare or Medicaid most often pays for hospice. In addition, many private insurance policies have a hospice rider. Some patients may have some out-of-pocket costs, however, many hospices, including the one that I work for, do not fail to provide services for anyone despite their inability to pay.¹⁰¹

¹⁰¹ Brooks, 67-8. (This section on hospice care and services are from Brooks' work and the knowledge and experience of the author of this project having served in the field for 9 years.)

Again, caring for the dying and their families takes many hands. In addition to the experts, the church is uniquely positioned to add to the equation what no one else can. It is our duty, our obligation, our privilege. John Wesley noted as much in his sermon 98.

In his sermon entitled, 'On Visiting the Sick,' he wrote, "But these things you must do in

your own person; you see they cannot be done by proxy." Wesley affirmed this type of service, the ministry to the sick, as a means of grace.¹⁰³ Surely we cannot but take from Wesley that caring for the sick (or dying) must be done in a very tangible way. It ought to be done in the very same manner as Jesus when He reached out and touched the untouchable with love and compassion.

Wesley addressed caring for the sick within his Methodist Societies. The Stewards were the primary ones in charge of visiting and ministering to the sick. However, these individuals had become overburdened with the task. Evidently, many of those carrying out duties to the sick also had full-time employment. This matter was brought before the whole society. It was made known how the Stewards were unable to attend to all the sick in all parts of town.¹⁰⁴ The question was posed among the classes of the society, "Who among you is willing as well as able to supply their lack of need?"¹⁰⁵ That question must continue to reverberate within our communities of faith today. Who indeed is willing and able to supply what is lacking?

Wesley stated that the very next day many willingly stepped forward. He chose forty-six of whom he judged to have a tender and loving spirit. The city was divided into twenty-three sections and two individuals were assigned to each part.¹⁰⁶ The following instructions were then given,

¹⁰² John Wesley, 77ie *Complete Works of John Wesley*, Vol. 7, Sermon 98,135 (*The Master Christian Library*, Version 8, CD-ROM). Ibid.

¹⁰⁴ Rupert E. Davies, ed., *The Works of John Wesley: The Methodist Societies History, Nature, and Design*, Volume 9 (Nashville: Abingdon Press, 1989), 274.

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Ibid.

¹⁰⁶ Ibid.

It is the business of a *Visitor* of the sick:

To see every sick person within his district thrice a week;
To inquire into the state of their souls, and advise them, as occasion may require;
To inquire into their disorders, and procure advice for them;
To relieve them, if they are in want;
To do anything for them which he (or she) can do;
To bring his accounts weekly to the Stewards.^{1 7}

No, we are not in Eighteenth Century England; however there is much we may glean.

We ought to visit, show genuine concern, counsel, relieve burdens, and meet every possible need that is within our power. Wesley then stated, "Upon reflection I saw how exactly in this, also we had copied after the primitive church. What were the ancient

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deacons? What was Phebe the deaconess, but such a visitor of the sick?" What a noble task and calling within the community of faith, to be a visitor of the sick and dying.

ibid.
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ibid.

It must be reiterated that dying is much a spiritual matter and as such, the church family is needed as death approaches. The church must not fail to realize what we possess to care for our own and others. As we believers ponder caring for those within the body of Christ, Allen Verhey made some very pointed comments. He wrote, "It is not so much that Christians gather as that they are gathered. They come together in response to the call of God." I do not believe it is unfaithful to Verhey's comment to state that when there are those who cannot come inside the four walls of the church and gather with us, we must be gathered to them, go to where they are. We are God's people wherever we meet and wherever we meet, we care for one another. We minister to 'the least of these.' Verhey cut

to the heart of the matter again when he stated, "It means learning to rejoice with those who rejoice and to weep with those who weep. It means learning that sickness, withering, and dying cannot separate us from the love of God and need not

alienate us - or another - from the community. It means learning to care and to be cared for. Here we learn to love." Amen, let it be so. In this we portray what it means to be the body of Christ and to fulfill His call and purpose.

Craddock and the Goldsmiths illustrated a manner in how the community of faith may provide care in a most unique, but appropriate way as we are the body of Christ.

They utilized the acronym TABLE:

In this case, the term 'table' serves both as an acronym for elements or aspects of a strategy as well as a metaphor—indeed more than a metaphor—for the central powerful narrative of our faith: the Eucharist. It is Jesus Christ who invites us to the table: his Table. It is that Lord who we celebrate at the Eucharistic table and our conviction is that as long as we are gathered at that table and focused on that Christ, our ministry to the dying will go forth to all as a comprehensive alternative to anything available elsewhere.

They reminded us it is Christ who has invited us, as His church, to meet the needs of the dying in a manner that provides greater fulfillment than what the secular arena alone can provide.

¹¹²Ibid.

In Craddock's and the Goldsmith's acronym, 'T' stood for talk. I can imagine that when my physical decline becomes more rapid and death is more imminent, I will want a variety of folks around me. I have friends who are unbelievers whom I have enjoyed their

company in life, I cannot imagine not welcoming them at the end. They have affected me and I them and this would offer another opportunity for me to influence them for eternity. However, I would want and need those around me with whom I share the greatest thing, life in Christ. These authors wrote, "The talk to which we are invited and to which we contribute is rooted in a Christology of the Word." They also note, "So

the church invites the dying person and gathers itself at the table for talk and deep listening." They stated this is informal, like a gathering around the kitchen table and Christ is present with us "and ready to feed us from his own suffering and strength."

This talk to which we are invited to share together may include the sharing of stories, expressing hopes, and even weeping. This talk to which we are invited to share with the dying includes prayer. Verhey added that with prayer "we not only commune with God but find new strength - new virtue - for daily life and for dying and caring for the dying." Verhey reminded us of many aspects of prayer of which we are all familiar; invocation, adoration, confession, thanksgiving, and petition. One aspect I omitted from the above list because it deserves special notation is that of lament. Verhey



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described lament as the "crying out to God and against God in anger and in anguish." I must add that God is not afraid of our questions and questioning. Some of His choicest

saints cried out for answers and explanations. Verhey wrote, "We marginalize, then, not only suffering but also sufferers. When we make so little room in liturgy for lament, then in their hurt and their anger and their sense of absurdity, sufferers think they sit alone in the congregation." Can it be wrong to seek to understand and to be understood? There may be no answers for the dying, but they still need space to cry out to God and perhaps to us and we must be available to share in this aspect.

¹¹⁸ibid, 313.

Talk could include song and Scripture. God's word has illuminated the path of the believer all his/her life, it will continue to do so as life draws to a close as it is read and

shared. Perhaps when no human words come, God's words are what are called for.

Verhey reminded us "in this practice of reading Scripture, the church remembers the

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story of God's grace." We do indeed need grace to live well, but perhaps greater grace to die well. In talk, perhaps there may be times where our presence and touch say it all.

Gathering around and sharing the living Word makes not only our living better, but our

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dying as well.

The 'A' in the acronym stood for awareness. We are often reluctant to speak of death and dying, but within the church and its fellowship, the truth can and should be spoken and reality embraced. Craddock, Goldsmith, and Goldsmith wrote, "It is not the medical arena; instead there is unending space for social, spiritual, and emotional anxieties to be aired and cared for."¹²² They noted that another layer of awareness dealt

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with time and the faith community "being aware of the messages surrounding them." In dealing with the dying, there may not be a quantity of time, but time should be made; time to listen to stories, memories, questions, complaints, and perhaps even what is left unsaid. They also noted in our world of limits that there need be no limits on the patience, gentleness, and kindness coming from the community of faith. After all, we are ones called by God to be aware and make the most of every opportunity. This awareness has no agenda other than that of the one who is dying and the deserved focus of the church's attention at this special time.¹²⁴

¹²⁰ Ibid, 302.

¹²¹ Craddock, 182-4.

¹²² Ibid, 184.

¹²³

ibid.

¹²⁴ Ibid, 184-6.

The Body of Christ was the 'B' in the acronym. Scripture reminds us that when one suffers, we all suffer; this is what it means to be a part of the Body. Craddock and

the Goldsmiths noted so eloquently, of what it means be part of the Body. "The body is characterized by the intimate connection of each part with every other part and by the fact

that each part is utterly distinct from, but absolutely necessary for the well-being of, every other part." This speaks volumes to the dying and to the community of faith. If each is absolutely necessary for the other, then there will never be a time when the one who is dying ceases to be important and vital to the Body. They should be reminded that God has meaning and purpose for them until they draw their last breath. The community of faith is reminded that no one no matter how weak should be left out or left behind. We must reach out and embrace all the members. These authors affirmed, "The church is the community, the family, the social environment in which individuals who are dying can receive the comforting safety net of caring others"¹²⁶ In the church every member is somebody and worthy of love and compassion to the very end.

'L' signified listening deeply within this acronym. Craddock and his co-authors wrote that time to listen is a tremendous gift to bestow on the dying and it may perhaps be the only gift they can give to others. They stated we may provide an 'ongoing presence' to the dying that allows stories to be told over and over if need be and presence just to be there. They also stated that in the medical world there is the hurry, hurry; patients in and patients out; often no time for questions or answers. "The church can provide a truly different environment. It can offer a leisurely, calm, personally interested place and all the time in the world in which attention can be paid and the sufferer can be

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¹²⁵ Ibid, 187.

¹²⁶ Ibid, 189.

¹²⁷ Ibid, 190-1.

heard." Within this deep listening, the story of the dying is comingled with the story of the hearer and all is comingled with the grand narrative of the gospel. In deep listening

things are not rushed and the dying are given time to ponder all that is happening to them and those around them. There is time to express and face what lies before them. In this listening, these authors noted that we bring to fruition Galatians 6:2, we bear one another's burdens.

The final letter in this TABLE acronym of course was 'E' signifying Eucharist. "The celebration of the dying of Christ is an ongoing reminder to the whole church, and can be especially so to one in the valley of the shadow of dying, that the Christ is with

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them in their suffering." Verhey echoed this same sentiment. He wrote that despite Christ's absence, He is somehow present with us. Verhey added, "He is the host to our gathering for this meal, and once again we take, eat, remember, and believe."¹³⁰ As the dying consider the death of Christ and their own death, they are reminded that there is no Good Friday without an Easter Sunday. Those in Christ cannot ponder death without resurrection. It is this hope that the community of faith bring to the dying in their situation and circumstances. Craddock and the Goldsmiths wrote, "This is where dying and death meet hope and faith, and we can emerge with renewed life in the here and now, in the church, sustained by God."¹³¹ They stated that in the Eucharist and remembering, unfinished business may be attended to, God's acceptance can be acknowledged, and one

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places his/her trust in Jesus Christ to sustain him/her. What an honor and privilege it is to share at the Lord's Table with the dying, to break bread together.

¹²⁸ Ibid, 190-2.

¹²⁹ Ibid, 192.

¹³⁰ Verhey, 329.

¹³¹ Craddock, 192.

¹³² Ibid, 192-3.

Helen Wilson Harris stated the following regarding the role of the church in ministering to the dying and their families:

It is the congregational family that can offer presence when extended family is absent. Sitting with the patient to give family a break and sitting with the family to share the load offer the ministry of presence. Jesus, at the end of his earthly life, asked the disciples to be with him in the garden and pray. It is the congregational family that can offer hope and faith when the days are darkest. It is the congregational family that can allow family members to live the questions and keep their faith even when belief is difficult. And it is the congregational family than can provide the tangible, concrete supports that make a difference day after day; the help with meals, with transportation, with laundry, and most of all with waiting together. Together.

What a blessed position that pastors and churches finds themselves in, to minister to their members that are rounding the final turn and heading home. Caring for the dying is only right. We can do no more and must do no less.

Chapter 3: Research Design: Equipping the Church

The purpose of this Project was to encourage/challenge the community of faith to become involved in a greater way in ministering to their fellow-parishioners and families at the end-of-life. It was the goal as well to equip them for this important ministry. Within this issue, I believed it to be important and spoke to what it meant to die well. I communicated barriers to a good death which were essential in this arena. I highlighted the needs of the dying which was critical to grasp. I noted as well what professional caregivers (hospice) contribute to end-of-life care. I illustrated what the church brings to the table in caring for the dying, and practical matters of care. A primary point of my Project was to deepen and broaden what the church may know regarding death and dying and to challenge and equip them to walk with their fellow-believers in more effective

ways at the end-of-life.

I believe many congregations and pastors would desire to walk with those in the community of faith at the end-of-life, however the subject of death/dying is often taboo. Many do not know how to navigate the subject and understand how to walk with their brothers and sisters at this critical part of their journey. We find in the Old Testament many instances where God commanded His people to care for those in need. Jesus powerfully illustrated in Matthew 25 that to care for 'the least of these' was evidence of kingdom life. I have noticed in the church how we dedicate, baptize, and disciple. I have noticed how we marry and bury. What about our ministry to the dying and their families? Can we not do more? I remind us that Wesley addressed the topic of ministering to the sick in his Sermon 98. That sermon is titled, 'On Visiting the Sick.'

He referred to this type of ministry as a means of grace. Allen Verhey stated that Wesley's last words were, "Best of all, God is with us." This he said was in regard to Wesley's confidence in God's presence even in death. This is indeed so through the presence of His Spirit, but I affirm as well that God is with the dying through the presence of His people.

We as Nazarenes, from Dr. Phineas F. Bresee onward, have a long tradition of caring for 'the least of these'. Dr. Bresee set the example for caring for those in need; those who often found themselves pushed to the margins. In his case, it was not the dying, but the poor. He believed so strongly in his call to minister to this oft neglected group that he petitioned his Methodist conference for his ministry assignment to be to work with the poor in a mission setting. His request was not granted and he was forced to make a choice

between his mission plans or remaining with the conference. Dr. Bresee's passion for the poor resulted in his separation from the church he had served for more than thirty years.

Those in need, those in the margins, must be cared for.

This example was carried forward. Caring and believing the gospel had social

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¹³⁴ Wesley, 135.

¹³⁸ Church of the Nazarene, "Rescue the Perishing, Care for the Dying," Sources and Documents of Compassionate Ministries in the Nazarene Archives, 2nd Edition, 1, <http://www.nazarene.org/files/docs/rpcdl.pdf> (accessed February 14, 2016).

implications was woven into the warp and woof of what it meant to be Nazarene.

"Compassionate ministries were so widespread in early Nazarene life and so fundamental to the founders' ideas of what it meant to be Christian that the Church's first generation

bore a stamp unique in the history of the denomination." This mark of the denomination was found at the very first General Assembly in 1907. When Eastern and Western Nazarenes were united, there were two standing committees with clear social overtones.

The one with relevance here was the Committee on Deaconess Work. What was the work of a Deaconess? In the Nazarene Manual for 1923 we find: "The duties of a Deaconess are manifold, such as: Ministering to the sick and poor; praying with the dying and pointing them to the Savior; comforting the sorrowing; seeking the lost and wandering; and endeavoring by all means to lead them to Christ and salvation." The poor, lost, and wandering were mentioned, but specifically noted as well were the sick, sorrowing, and dying. Our Nazarene forbearers believed these must receive the care of the church. Even though the role of Deaconess may no longer be found within our church structure, many of the noted roles and responsibilities are found within the duties of the steward role in our more recent Manuals and church structure.

I noted in Chapter 1, the research group with which I worked was Pastor Jay Bessmer (Bethany Church of the Nazarene; Hutchinson, Kansas) and those from his congregation who desired to become more informed on end-of-life matters and understand in a greater way how to care for those at the end-of-life. He focused on recruiting those from his homebound/hospital visitation team. Being their pastor, Pastor Jay and I believed it best for him to approach these folks. He had face-to-face conversations with these individuals to determine their interest in participating in the seminar. Three indicated interest from this group, but due to conflicts and other events only one was able to actually take part.

However, I had several who committed to participate from my home church (Hutchinson First Church of the Nazarene). Well in advance of the seminar, one of the staff pastors, Pastor Bones Nay, arranged for me to speak to two large adult Sunday

school classes on a Sunday morning. I shared with them regarding my project and the seminar. Through speaking to these groups and word of mouth, there were six who signed up and participated in the seminar from Hutch First Nazarene.

I also recruited participants from a third Nazarene church in town, New Life Church of the Nazarene. I worked through Pastor Gary Worthington in this effort. He publicized through printed and electronic means regarding my project and the seminar. There was one individual who signed up for the seminar and took part from New Life.

In an effort to broaden my participant search, I also reached out to an associate pastor from an independent Christian church located across the street from Hutch First Nazarene. I had met Pastor Kevin Guffy a couple of years prior and had worked with him on occasion as he was interested in hospice and end-of-life care. He publicized through written media, a flier that I provided to him advertising the seminar. He was unable to stir interest from anyone to participate in the seminar.

There were nine individuals who actually participated in the two-day seminar. Eight of these individuals were from the three Nazarene churches in Hutchinson, Kansas, and one was a staff pastor from an independent Christian Church in Hutchinson. Just below, I have given more detailed information on the participants, but again, all the participants had a heart for ministry within the church and desired to gain a greater knowledge and understanding of end-of-life issues and care for the dying and their families. These could also be catalysts in spreading this type of ministry within their congregations.

Two of the participants in the seminar were serving on the hospital/shut-in

visitation team in their church. One of these was a layperson and the other was a former missionary and retired chaplain. The youngest participant in the group was in his mid-twenties and has served his church in ministering to the youth. He had seen firsthand youth being touched by the death of grandparents and has expressed a desire as well in ministering to the elderly. Two of the participants were staff pastors in their church, one full-time and the other part-time. Both have been involved in counseling ministries. One of these has done much work in the area of grief and has served as a PRN hospice chaplain. One participant was a registered nurse with experience in the long-term care environment and also as an oncology nurse. She was also a hospice volunteer. Two other of the participants were long time hospice volunteers. One of these had a good deal of experience with death and dying that was close to home as she had cared for family members at the end-of-life. The final participant was a layperson in her church. She has cared for nearly half-dozen friends and family members with terminal illnesses, the last one being her husband who battled cancer for seven years. It is perhaps important to note as well that six of the nine participants had actually been present when a friend/family member had died and were a part of that experience.

As a group, there was certainly diversity, but they all had in common the desire to learn more about end-of-life issues and care. Perhaps more importantly, they saw the need for this vital ministry within the church. They knew families needed to be involved in caring for their loved ones at the end-of-life because many of them had done so. They saw the need for professional caregivers (hospice) to be involved with the terminally ill, because several had hospice connections and knew the value of such focused care. They

also believed it was critical for the church to be involved in a greater way in caring for and supporting the terminally ill and their families as life comes to a close.

The primary part of this project was the two-day seminar on two consecutive Saturdays conducted at Bethany Church of the Nazarene in Hutchinson, Kansas. A two-day seminar seemed the preferable method to present the material to the participants. A one-day seminar would have been an extremely long session without sufficient time for the group to have processed what was being presented. There were simply too many important issues to be presented and discussed in one sitting. Also, spreading the seminar out over several weeks would have heightened the probability that conflicts would have developed and participants would have to have missed sessions. It seemed that it would not be unreasonable to get participants to commit to the two days and then be able to follow through. As well, two sessions (approximately 5 hours each) allowed sufficient time for the material to be covered as well as time for questions, discussion, and breakout groups.

The training material for the seminar was divided into thirteen chapters (topics). The chapter highlights are:

Chapter 1- Caring for the Least of These - Our Call from Scripture Matthew 25: 31-40 was a great place to begin. I emphasized how we care for infants through maturity, but often as a community we are unsure how to care for the dying. Caring for the dying (the least of these) was in the history of the church. I pulled from

the early part of the literature review (Chapter 2 of this project) as to 'the least of these' and how it is only right and our privilege to care for our brothers/sisters during this part of

their journey.

Chapter 2 - Our Death Denying Culture - Barriers to Care/Care Giving

I spoke to how beginning in the aftermath of World War II great strides were taken in medicine and medical technology. Cures and treatments were now available to bring healing to the ill and injured, however, these cures and treatments began to be used on the dying and care for the dying moved from the home to the hospital. We must come to grips with the fact that not all can/will recover from illness; death comes.

Chapter 3 - Dying Well - Grace for the Journey

What does it mean to die well? How may we close out our days with purpose? I illustrated lessons that can be learned from Christ's dying that will assist us in helping others die well. I expounded upon the virtues of patience, hope, and compassion and how these feed into equipping us/others to die well. Meaning and purpose can be mined even from the experience of death/dying. Chapter 4 - An Introduction to Hospice

I gave a brief history of hospice, addressed the hospice philosophy of care, noted the three key principles of hospice (offer choice, maintain dignity, promote individuality), and related the essential characteristics of a hospice program. Chapter 5 - HIPAA - Patient Privacy

I addressed what HIPAA is and what it governs. More importantly however, I noted how it relates to the church in caring for the ill/dying. Pastors and visitation teams should not assume just because someone is sick/dying that they desire all about them be broadcast to

the church in order to open the door for prayer and care. We must always ask, "What would you like me to share with the church?" Chapter 6 - Universal Precautions

I spoke to universal precautions to prevent the spread of disease. I addressed infection control to protect the visitor and the patient. I also touched on tuberculosis.

Chapter 7 - The Needs of the Dying - Concepts of Death/Dying/Grief

I addressed in some detail issues the dying face and with which they deal. The list included denial, anger, pain (emotional), bargaining, anxiety, depression, suicidal thoughts/feelings, guilt, shame, and grief. To care for the dying we must understand the struggles they face.

Chapter 8 - Visiting the Hospice Patient and Family

I dealt with visiting patients in the home and also in nursing facilities, and most importantly, visiting the dying patient. I also noted some visiting do's and do not's; may's and may not's. I shared some practical tips to help those facing serious illness from the patient's point of view. I related information regarding boundaries as well. Chapter 9 -

Communication Skills

I focused on listening, active listening, techniques and skills. I noted helpful hints and things to avoid. I also focused on building a rapport with and talking with the hospice patient and family.

Chapter 10 - Care/Comfort/Symptom Management

I noted the signs and symptoms of impending death - this included psychosocial changes and physiological changes. I addressed creating a good death for the patient - physical comfort, emotional well-being, and spiritual serenity. I also addressed the tasks of dying

- getting affairs in order, making medical decisions, planning for the immediate future, coping with emotional and physical changes, letting go, opposing tasks of family

members, and unfinished business. Chapter 11 - The Church's Care

Dying is much a spiritual matter and there is much the church has to contribute to the care of the dying. When those from the body of Christ cannot gather any longer with us, we must be gathered to them. I utilized the acronym TABLE (Talk - Awareness - Body of Christ - Listening Deeply - Eucharist) and illustrated how the church may come alongside the dying and their family and minister in a meaningful way. We as the church are representatives of Christ and are a constant reminder to the dying and the family that they are not alone.

Chapter 12 - The Bereavement Process

I began with a brief overview of the bereavement services that hospice provides. I then spoke to grief and loss issues before death, during the dying process and at death, and then following the death. I also noted some ways to help grieving people. Chapter 13 -

Managing Personal Stress

I related how important it is to care for ourselves if we are going to care for others. I pointed out that for care givers it is important to know when stress affects us and how it affects us. I then offered some helpful hints for relieving stress and caring for oneself.

The complete training material is found in Appendix B.

I utilized assessment tools (questionnaires) as a part of the training. The pre-seminar assessment tool was given to the participants and returned prior to the seminar for processing. Those connected to the Bethany church, Pastor Jay hand delivered these

two weeks prior to the training with a self-addressed stamped envelope and instructions to return them to me within a week. Those participating connected to First Nazarene and

New Life Nazarene, I hand delivered or emailed two weeks out with instructions to return them to me within a week. The participants were encouraged to take careful thought and consideration in answering. These timeframes gave ample time to process the answers to the questionnaire prior to the seminar.

The pre-seminar questionnaire measured such things as the participants' comfortableness and awareness with death/dying and related issues, their experience with such matters, views on end-of-life care and church involvement with such care, and what they hoped to gain from this experience. I utilized the information obtained as a means to break into the seminar and create dialogue as we began. Certain of the questions were utilized as well for a couple of breakout group times. The pre-seminar questionnaire is found in Appendix A along with the post-seminar questionnaire.

The pre-seminar questionnaire consisted of nine questions. Once the questionnaires were returned, the participants' responses were combined and summarized. Questions one through four and nine were shared along with a summary of participants' responses to begin session one of the seminar. The participants were offered time for additional commentary or to ask related questions as we touched on each of the questions. Question five was utilized during the training in breakout groups that discussed it as we prepared to move into chapter two. It was read and reiterated in this way: "In the case of a terminal prognosis, is there ever a time (are there times) when aggressive treatment should be forgone and let nature take its course? Or should we always do everything in the way of treatment that can possibly be done?" The groups

took fifteen to twenty minutes to discuss and then came back together and shared

responses and we moved forward into the chapter two material of the training. Question six was used as an introduction into chapter four of the seminar training material dealing with an overview of hospice care. Questions seven and eight were used in session two of the seminar. These served as fuel for the breakout group discussions as we prepared to move into chapter eleven of the training dealing with 'The Church's Care'. The groups were given fifteen to twenty minutes to discuss and then we came back together, shared, and moved into the chapter material.

In addition to the breakout groups to provide an interruption from lecture and discussion, I utilized role-play as we moved into the chapter five training material dealing with HIPAA. One of the participants served as a doctor and the other as an incoming patient who had noticed his/her friend leaving the doctor's office as they arrived. The incoming patient attempted numerous arguments to solicit information from the doctor because he/she was concerned about their friend. (A variety of role-play scenarios could be utilized here.) Following the interaction, the group critiqued the role-play and we transitioned in the chapter five material.

In regard to the training material, each of the participants received a notebook containing the material upon the completion of the pre-seminar questionnaire. It was in their hands a week prior to the first session affording them the opportunity to familiarize themselves with the topics and content. Again, I did not want them to have the material prior to the completion of the pre-seminar questionnaire so as to not influence their answers and responses to those questions. Should the training material impact the

participants' responses to the questions, I wanted that to be reflected on the post-seminar

questionnaire.

The purpose of the post-training questionnaire was to gauge the effectiveness of the training, perhaps more precisely what the participants had gleaned from the seminar and whether or not perceptions on death/dying/care had been shaped by the training. This questionnaire was given to the participants at the end of the seminar with a self-addressed stamped envelope with instructions to return it to me within two weeks. This questionnaire contained only six questions. It was a mirror of the pre-seminar questionnaire with questions two, four, and six being omitted. The participants were given explicit instructions to answer the questions in light of the training over the past two weeks and how it may have shaped their thinking in these areas. This questionnaire is found in Appendix A along with the pre-seminar questionnaire.

Interviews were conducted with one-third of the seminar participants four to five weeks after the seminar. The selection of the three participants to interview was not completely random. Three of the nine participants were clergy; I desired one of the interviewees to come from this group. For the others I interviewed, I selected two who had more experience with death and dying than the others had and perhaps would have more to share. Also, these were extroverts and would perhaps be more disposed to share. The interview time was not highly structured. I desired these participants to reflect further on issues and expound in a greater way regarding death/dying and care, and any experiences they may have had since the training. The interviews allowed me to probe a bit deeper with a limited number of the participants. My anticipated outcomes from the training were that the participants would understand in a greater way issues surrounding

death and dying and be more confident in meeting the needs of the dying within the life and ministry of their church.

Chapter 4: Research Data and Results: The Church Outfitted for End-of-Life Care

What did the seminar participants know and understand about death and dying, care for the dying, end-of-life issues, hospice, how they and the church should be involved in end-of-life care, and what did they hope to gain from the seminar? Their particular responses are outlined below.

As noted also in chapter three, there were nine seminar participants. One of the participants was the first reader of this project. He did not complete the pre or post-seminar questionnaires, as he was familiar with the literature review of this project and the training material. His responses would have been shaded by that familiarity. However, he was an active participant in the seminar.

Therefore, you will note there are only eight responses to the pre and post-seminar questionnaires below. By following the participant numbers down through each question, one may track that individual participant's response to each question.

Pre-Training Assessment Tool 1. What are your thoughts and feelings about death and dying in general?

(1) "It is hard to see those I love suffering but what a difference when they know and love our Lord and are ready to go to Heaven. I look forward to Heaven but often the process of getting there is hard. To go to sleep and wake up with Jesus would be much easier but I want to be ready at all times."

(2) "The end of earthly life and the continuation of eternal life, with two destinations, dependent on whether or not one has accepted Christ."

(3) "Necessary, exciting, scary."

(4) "It is all part of the life cycle. It is most tragic if the person was not a believer in Christ. I am not fearful of death. My only concern, really, is the mode."

(5)

(5) "It is as natural a part of life as birth. It is not something to be feared, although I acknowledge it is not something I desire to have happen any time soon. Death is merely a transition from this life to eternal life."

(6) "I am for the most part very comfortable with death and dying for others. Some of my best life sharing with others has been as they love someone home to the Lord. It is a very special time and I feel very honored to share that time with others. The two most moving experiences in life must be the birth (sorry I did not experience that personally) and the death of a person. Most of our society fears death and dying for self and others. For me I still have some fear about my own death."

(7) "We all know that death and dying are going to come we just don't know the time. When the person has suffered for a long time it is a good feeling they won't have any more pain and will be joining loved ones again in heaven."

(8) "Much different than 10 years ago. I used to be afraid. Now there are so many of my family in heaven and since I accepted Christ even better I understand we will all die, no get out of 'death' free card. So it makes sense to prepare for it."

2. Have you ever provided care to anyone who was dying? If so, please share your experience.

(1) "Yes, with good friends. It was difficult to see them in pain but the peace I could see when they closed their eyes and went home with Jesus because those I have been with when they were dying were all Christians."

(2) "Yes! All who were Christians left me inspired and encouraged, the few who were not left me emotionally drained."

(3) "No."

(4) "Yes, several times. Each time is different. Once an older man who wanted to talk about his regrets and rededicate himself to Christ. It was good to help him find peace. Another time it was a man only a few years older than me with young children. It was heartbreaking, but amazing to see his faith. Another man was very similar to this one and we became good friends. His faith was amazing and very encouraging."

(5) "Yes. It was my privilege while working in a nursing home to provide comfort and care for several residents who were dying. I now work in an infusion center and daily

help cancer patients come to grips with issues of death and dying. Also, I have helped care for my mother who died 3 years ago and now am helping care for my father."

(6) "Yes, the first time was in 2000 when my mother died after a ten-year time of living with cancer it was my first exposure to hospice care and was very positive but quick we moved like many from the hospital way of avoid death at all costs to hospice care for less than twelve hours. Second time was eight months of all stages of hospice care for my

(7) mother-in-law ending in the front room of our home providing total care for the end care. We shared that experience with some of (my husband's) family. A long but very thorough exposure to all that hospice care can offer. Third time was a friend in a nursing home that was not hospice founded. However the nurses at the facility provided a hospice like care for her. I was blessed to talk her home to the Lord as I stopped just to check on her and found her very close. As the nurse asked me how did I know to come then I told her that the Lord just nudge me the right way at the right time to be there. The final and perhaps the best was the perfect forty days of loving and caring for my Daddy when he was diagnosed with choleoangiocarcinoma. Hospice care and staff provided all we needed to accomplish more than we could ask for or imagine."

(7) "There have been several times that I have gone to the Hospice House on Tuesday evenings when we go to sing and the family has asked us to sing a special song and they have moved their feet under the cover in time to the music. Later we were told that they passed away an hour after we were singing their favorite song."

(8) "Yes, my mom - stroke and cancer for 4 years. My step father-in-law - cancer and emphysema for 9 months. My mother-in-law - cancer for 3 years. My husband - cancer for 7 years. My friend - breast cancer for 6 years, died at 40, very difficult. My daughter - at age 16, cancer (tumor) removed; she is 40 now and doing great, only one still alive of these."

3. When thinking about your own death, what words best describe death to you? Please elaborate somewhat. These could be words such as release, terrifying, freedom, scary, new life, dark, inevitable, etc.

(1) "It would depend if Jesus took me home with Him so I'd go to sleep and wake up in Heaven. If I have to be in pain and suffer for some time that would be so scary but what a relief when Jesus would take the pain and take me home with Him."

(2) "Inevitable - we all have an appointment with death. Release - from time, space, and temptation. Peace - the end of struggles and conflicts."

(3) "Necessary - everyone has to die. Exciting - experience God's promise. Scary - not knowing when or how."

(4) "As I have grown in my faith, my view of death has changed. Now, the words would

be freedom, joy, expectation, relief. I will not do anything to fast forward the process, but I look forward to eternity with the Lord."

(5) "Peace - will be in the presence of God. Release - from pain and suffering. Sadness - leaving others behind, experiences that will be missed."

(6) "Frightening yet exciting. Dreaded yet inevitable. Avoided but will happen. Unexpected yet may be known. Hope to plan and be prepared. Do not want to leave my partner, (husband).

(7)

(7) "I am ready to go when my time comes and know that I will be going to a better place. It will be a new experience because we really don't know how wonderful it will really be."

(8) "Peace, sweet peace, love the thought. No suffering - no pain (both physical and emotional) - no tears - sadness over the world issues weigh heavy. No struggle to be perfect. Letting go of earthly things, money, possessions."

4. Have you ever been with someone at the time of their death? If so, please describe briefly.

(1) "It was very peaceful, a relief to know they have gone to their Heavenly home."

(2) "Yes, my mother-in-law who seemed to be conflicted about leaving her husband with no one to care for him. When assured by us that it would be well and we would look out for him you could see and sense her tranquility as she slipped into the next world."

(3) "No."

(4) "Yes, four times. For two of them, it was difficult seeing them struggle for breath. For a teenager, he went peacefully, but those around him (the room was full) were in various emotional states - wailing, sobbing, stunned, etc. For an older man, it was peaceful, though sad."

(5) "No, only within minutes before or after."

(6) "My mother. First death, very quick, no time to learn, just react. Husband's mother. Lots of family, a blessing and perfect ending to Thanksgiving weekend. Friend. First time not in hospice care, God urged me to her bedside just in time. Friend's husband, blessed to share a wife loving her husband home and me to help. Friend's wife at the Hospice House, sat many days as she transitioned back between this life and heaven. A privilege to help and share. Friend's father. Two sons not knowing what to do when 92 year old Dad is at Hospice House with no wives to help. My father. Forty perfect days of Hospice Care as Daddy taught me how to die with the words and actions of 'God's will be done!'"

(7) "No, I have not been with them at the time of their death."

(8) "Yes, many. Most recent my husband. He died at home with family and friends around him. I held him till he breathed his last and laid him down in God's waiting arms. It was a gentle and peaceful home-going. My mother-in-law's was horrible, in ICU. She was struggling to breath and the doctors gave her 5 shots, sent us all out and 5 minutes she was gone - very bad."

(9)

5. Do we always need to do utilize every possible medical treatment for one whose life is waning, or is there a time to provide comfort and let nature take its course?

(1) "For myself I would rather not be kept alive but to let nature take its course. God is in charge of my life and I want Him to have His way in my life to the very end."

(2) "Artificial life may comfort the living, but for the dying it seems a prolongation of their pain, therefore, the most loving thing to do is to allow nature to take its course."

(3) "I think it should be up to the individual when it is time to let go and when it is time to keep fighting."

(4) "I believe we do not need to utilize every possible treatment. I believe there are times where we provide comfort and let nature take its course. Age often is a factor with this."

(5) "I believe we need to provide for the dying person's wishes. Even when educated about hospice/comfort care some wish to fight death to the bitter end; others desire the peace and 'letting go' hospice care provides."

(6) "Absolutely not as we do not need to fight death rather embrace it as much as we treasure the birth of a new child or marriage. Sad to say that many doctors and medical providers only know how to extend life when sometimes it is not doing anything but prolonging pain and agony. The time to provide comfort and allow natural death is first determined by the dying person who then needs the complete support of their family and friends to accept and assist in the provision of care, physical, spiritual, emotional. Allowing natural death ends the fight and begins the living."

(7) "I feel that the person should be able to say when they don't want any more medical treatment, especially experimental chemo."

(8) "NO...there is a time when prolonging it is torture on everyone. When there is nothing more to gain back a reasonable life, let nature take its course as nature or God intended. Give comfort, encouragement, reminding them they will soon be with those they love that are waiting for them."

6. What do you know about hospice/hospice care?

(1) "In the 90's I volunteered in the hospice library and a few times went to visit those in

hospice care. I re-did the library when hospice was in the hospital and the library in a patient's room. Then it, hospice, moved to a building on Compound Drive and there was a nice room for the library. I was able to order books, then process them to be used by the staff, patients, their families and friends."

(2) "They provide loving and gentle care to terminal patients and their families."

(3)

(3) "I know that it is an organization/means for a person and their family to be guided and comforted during their last days."

(4) "It is a wonderful organization that helps make people comfortable who are very ill or dying. They care for the whole family, making sure everything goes as well as possible. It can be either non-profit or for profit. They provide medical, physical, emotional, and spiritual support."

(5) "I have worked with hospice nurses in the nursing home and provided comfort care. I know it involves patients for whom their diagnosis is believed terminal within 6 months. No treatment is given for the diagnosis and the patient is kept comfortable as nature takes its course."

(6) "I have been a volunteer for five years with the ability to be trained in many aspects of hospice - friendly visits, respite visits for caregivers, No-one-dies-alone training and how to interact with those suffering from dementia. I feel comfortable with all aspect of hospice care."

(7) "Hospice provides care and support for people in the last stages when they have a disease and are in the dying process of life. Hospice care is given to help not only the patient but also their family in the last phase of life. They will always be there to help the family after their loved one's death. Hospice is 24/7 to give help whenever needed by providing a team of qualified professionals and volunteers."

(8) "My mother had hospice care for 6 weeks in her home. It was difficult in the beginning. They came in and just took over. We were in shock from the diagnosis. But we worked through it, nurses were great."

A chaplain friend of mine once said, "They say that death is a physical matter with a spiritual component, but I say that death is a spiritual matter with a physical component." If this is true, or we are to give any validity to this statement, then:

7. How should the church be involved in caring for their people at the end of life?

(1) "That is when I would want our pastors and church family the most. I do realize some people have a hard time visiting the sick and dying."

(2) "It is the body of Christ's, the Church's, responsibility to ensure that all its members

both living and dying receive all the care and support that our physical bodies provide for its members...total involvement."

(3) "To the same extent that they are during life. If the church is only going to be there for you during just one part of your life then during your death would be the most important."

(4)

(4) "The church should be very involved, checking on the people regularly, along with their families, taking meals, helping with things like lawn mowing, pet care, etc. We should minister to them and comfort them with prayer and the Word, we should help them find peace, help them reconcile relationships if possible. We should walk alongside them to the end and with the family beyond."

(5) "Congregations should be supportive of the dying and the family members to help them in practical ways during this time and help them come to a peaceful understanding of how God is working in their lives. Support for the family should continue long past the funeral as the adjustment is made to life here without the deceased family member."

(6) "Our churches should be in a position of leadership to embrace and support all aspects of hospice. Whether it is providing chaplains, recruiting volunteers, or creating awareness of our spirituality and hospice care. Even those who are not regular church attendees will very often accept spiritual care in hospice. To repeat, the church and their leadership should be on the front lines to education and support of hospice."

(7) "Most people want to have their ministers with them but when that's not possible there should be members trained to step up and able to give them the spiritual help they are needing. I also feel that there should be a team that can follow up and help their families."

(8) "Definitely if they want it. Although the family left behind will need the church to be there for them for support, a shoulder, and questions, reassurance, guidance to salvation if needed so they can meet them in heaven. Church needs to understand about how to minister to the family even up to years after."

8. As a member of the body of Christ, what do you see as your role?

(1) "To be there for my family and friends especially when they are going through a hard time."

(2) "Serve, support and encourage as directed by Christ."

(3) "To be there for other believers as they need during their death."

(4) "As a minister, I provide spiritual care, but also do whatever else is needed, as mentioned above. Often, I try to mobilize the congregation to meet needs."

(5) "To be open to opportunities to aid the dying and to encourage others to open their eyes to the needs of those dying around them."

(6) "My role is at any opportunity to be a Hospice evangelist who not only educates and advocates Hospice by providing emotional, physical, and spiritual support to those in our church community. I feel that often 'Church Christians' feel they have to temper all their feelings and statements with their 'I know where they are going' attitude instead of their

(7) true feelings that they are not happy with God that they are suffering the anticipated loss of a loved one."

(7) "I have gained and been blessed by patients that are dying just by visiting with them and talking with them. I feel like it is part of my ministry by spending time with people that are in the last stages of their life."

(8) "Wow, never seen it as a role, maybe a fellow 'family member'. We had done so much with dying, we were just always called to sit with family, extended family even before the pastor was called, we were. Mainly I just listen and cry with them. Sometimes I have to be honest with them and it's always been needed. I pray a lot before I go to the family. It's very draining emotionally, but also very rewarding."

9. What do you anticipate obtaining from this training on end of life issues and care?

(1) "I would like to learn how to better help and care for my family and friends."

(2) "A better understanding on how I can best serve and encourage."

(3) "A wider knowledge and understanding of how I can help those suffering and their families during a loss."

(4) "More insight and wisdom to care for those at the end of life - practical ways to help, etc."

(5) "Information on how the church can be encouraged to more actively assist those in the congregation who are dying or have a loved one who is dying."

(6) "More knowledge and ability to assist others in their living until they die."

(7) "I feel like I will be better equipped to go and care for special people."

(8) "How better to understand ministry to the family/caregiver. How to help the church recognize the needs, spiritually, physically, socially, personally. What not to say. To be better prepared for my own death."

* A notation is needed here. As I processed the participants' responses to the pre-seminar questionnaires, it seemed a more logical flow to reverse questions two and three. You will note below as I summarized responses, this was the order I utilized. In the future, those two questions should be reversed on the questionnaire.

The participants' responses regarding death and dying were fairly consistent. This was not surprising as all those who participated were believers and connected to a church. Death was seen as a part of the cycle of life; we are born, we live, and then we die. Death was something to be prepared for. Death and dying were not something that for the most part were to be feared, however some noted apprehension. The apprehension came through at least in a couple of instances regarding the process and the mode of death. There is certainly the possibility of pain and suffering involved when one dies and perhaps this was the source of some of the uneasiness. A number noted they were not in a rush to die, but the thought of heaven and joining those who have already passed brings a certain degree of peace and completion.

Connected to the question regarding death in general were the participants' thoughts about their own death. There was the acknowledgment of the inevitableness of death, but as with death in general, their own death was not to be feared. Some of the words used in pondering their death were peace, release, exciting, freedom, joy, expectation, and relief. Other feelings were that of no suffering, pain, struggle, tears, and sadness. There was again the sorrow of leaving others behind and the apprehension of not knowing the time or mode by which one would die.

When asked about their involvement in caring for anyone who was dying, seven of the eight respondents stated they had cared for someone who was dying. That was a bit surprising; however, it revealed their heart in desiring to be involved in this type of ministry and to see it be adopted by the church on a much broader level. The care they had provided included both physical and spiritual. For some, it was in their 'professional' role so to speak as a nurse or minister. Others had cared for the dying as a hospice volunteer. Yet others, the care involved being there and caring for friends and/or family members as they were dying.

Related to being involved in caring for one who was dying was the question concerning being present with one as they died. Five of the eight respondents noted they had been present when one had drawn their last breath. Of the deaths attended, a number noted the death was peaceful. For others, there seemed to be some conflict with the one dying about remaining or going. Something I have noticed in my years of hospice work in this regard was that when family members have assured the dying that they will be ok and have assured them they will care for those they are leaving behind, this brought a great deal of peace to the dying and allowed them to let go knowing all will be well.

Respondent number eight's comments must be noted here. Her commentary perhaps illustrated polar opposites in death and dying. This is certainly true when speaking about patients/individuals who are terminal in their disease process. One death was at home surrounded by friends and family. "It was a gentle and peaceful home-going." The other death was in a hospital intensive care unit hooked up to machines with family being pushed from the presence of the one dying.

This leads us into the next topic of the questionnaire; the question regarding the utilization of any and all medical treatment to keep a person alive that is dying. The primary response to this question was a resounding, 'No'. For those who are terminal, prolonging life just because it can be done accomplishes nothing. The respondents noted we should let nature take its course. There was a comment regarding the dying person's wishes being honored and another that the patient should be allowed to say when enough is enough. The first I saw as allowing the person to undergo treatments as long as they desired; to fight to the bitter end if that was what they chose. To my knowledge, at least at this juncture, no one can force a person to cease treatment if the person so chooses. The second I interpreted as the family and friends honoring the person's choice to stop treatment and testing that in their opinion had not accomplished its desired/hoped for purpose. This second scenario is far more common. In my nine years in hospice I have seen patient after patient undergo sometimes painful testing/treatment just to pacify a family member who cannot bear to let them go.

Respondent number one's answer in regards to allowing nature to take its course must be mentioned. She concluded with, "God is in charge of my life and I want Him to have His way in my life to the very end." In paralleling my comments in chapter two, this is indeed what it means to die well. We recognize that God has purpose for us and our life has meaning whether we are in our youth, our prime and vitality, our waning years, or in our death and dying.

The participants' responses as to what was known about hospice were likely atypical. Four of the eight have in the past or are now volunteering for hospice. Their

answers reflected the fact they knew more about hospice and what is involved in hospice care than the general public. However it is noteworthy that during the training session in the Hospice 101 section, there was the acknowledgment many gaps in what they knew and understood about hospice were filled.

All respondents stated the church ought to be, I would even say must be, involved with their members and families at the end-of-life. They stated in death and dying was often when church members want/need their pastors and church family the most. The same care that is offered all throughout life's journey must not fade at the end. They stated it is our, the church's, responsibility to be there. There was the acknowledgment pastors cannot be everywhere and do everything, but this was where the body was needed. We are to be equipped to minister to one another with the pastoral staff leading in these matters. The comment regarding bereavement care must be shared as well. The pastor and church must continue to provide care to the 'widows and orphans' long after the funeral flowers have faded. Life will never be the same for them. However, that was not the focus of this project, but is a needed ministry in the church as well.

The participants were vitally interested in this topic and project and naturally they saw themselves as being ones who would be involved in this type of ministry within their own church. Providing spiritual and emotional support was mentioned first and foremost, however meeting physical needs came across as well and was certainly a part of discussions that took place surrounding the seminar. Respondent number six stated she saw herself as an ambassador for hospice and end-of-life care and that came through in our discussions as well and was noted in some of the post-seminar responses. For any

ministry to take hold there must be a push from those who are passionate about it and see the need.

What did the participants hope to gain from our time together? This group already had a passion for this subject. Many wanted to know how to better provide care, serve, encourage, and help the dying and their families. They wanted greater knowledge and understanding in the area of death and dying. They wanted to know how to open the eyes of the church to recognize what we have to offer the dying and their families.

As shared in a prior chapter, the seminar was held in two five-hour sessions on consecutive Saturdays. The training manual can be found in Appendix B of this project.

I utilized a power point presentation in leading the seminar. It can be found in Appendix C.

The seminar included lecture and discussion. The group was small enough to where the participants felt free to, and at ease to ask questions and add commentary. The first break-out group during the seminar related to our death denying culture and the topic of when is enough, enough in regards to treatment. This related to question five on pre-seminar assessment tool and question three on the post-seminar assessment tool. There was certainly lively discussion on the topic, but nothing of substance outside of what the participants included on their pre and post-seminar questionnaires. However, a couple of things were noteworthy from the discussion; the patient's wishes should be honored and there was the belief the terminal patient's age would play a part in the equation of when to cease aggressive treatment measures and to let nature take its course.

There were a couple of the training topics that elicited more discussion than I

anticipated and raised issues that are important and relevant. The first was on the topic of HIPAA. There was an example brought forward where a pastor had shared what he knew about an illness when he should not have, and this was not only a HIPAA issue, but also an issue of trust with the family. Perhaps many of us in ministry may have done similar in an effort to share prayer requests or we felt caught in a situation where we answered a question when we should have said, "I cannot say anything further at this time."

Related to this issue, the participants spoke of weighing sharing versus not sharing prayer requests with the pastor or church leaders, which may then be shared as an 'unspoken' prayer request. I can attest to the fact when as a pastor at a parishioner's request, I would simply state their request as 'unspoken' and would then at times be bombarded by church members wanting to know details. Many times this was out of legitimate concern, but often it may have been for purposes not so noble; people just want to know to satisfy their curiosity. There are always going to be situations and circumstances where the pastor, staff, church leaders, and members of hospital/homebound visitation teams will know details regarding parishioners that not everyone in the church knows or needs to know. Also, it is not necessary to know all the details regarding someone's illness in order to pray for them and show genuine concern.

In these scenarios raised by the participants, they believed that if there was not a written policy on 'church HIPAA,' there should at least be a stated policy. The policy would allow church members the freedom to have privacy, and also give the pastor the freedom to decline to comment in situations and the congregation can expect this and respect it. There is not always a 'need to know' in many situations. As well, in the midst of

diagnoses, especially terminal diagnoses, the person and family may need time to process and have privacy, while at the same having the support of a church family that does not need to have all the details. They will simply pray and love.

The second issue in the training that elicited further attention above what I anticipated was infection control. As the topic was brought to the fore, I remembered a quote from an unknown source my mother-in-law had hanging on her wall: "My home is dirty enough to be happy and clean enough to be healthy." As a hospice chaplain I have been in homes that were far too dirty to be happy and not nearly clean enough to be healthy. I have been in homes with stained and moldy sheetrock from water leaks, furniture stained with smoke and urine, and cockroaches crawling across the floors and along the walls. Evidently, there were those within the group who had experienced similar in ministering to others, or else they would not have raised the issue.

It was stated we must be reminded, not all live as perhaps the majority of folks do. There are those for whom because of economics or a variety of other reasons the home environment is less than ideal. One of the participants stated in essence, and I believe he echoed the thoughts, feelings, and what all of us had attempted to do in serving others and ministry, "I go into these situations and try my best not to be shocked, serve the best I can, and pray that God will protect me." The point that came from this issue was not to say we are noble for going into such places and situations, for our Lord Himself did. There was the need to inform, or remind, those within the body of Christ that imperfect situations such as this will arise when they go and minister outside the walls of the church to the dying and their families. There is the need for acceptance and also preparedness.

The participants' responses to the post-seminar questionnaire are as follows. **Post-**

Training Assessment Tool 1. What are your thoughts and feelings about death and dying in general?

(1) "It depends if a person is ready to go or not. It is those who aren't ready that scares me. I would like to be able to help someone but they have to want the help first of all. That is when some come to accept our Lord as Savior. My exit into the arms of Jesus for me."

(2) "Graduation."

(3) Survey Not Returned

(4) "They haven't really changed. I look forward to being with Jesus, but don't want to speed up the process. The seminar has made me think more about others who are dying and how we can take care of them. It has made me think about who I want around me when I'm dying (if I have that choice)."

(5) "It is the process by which we transfer from this life to eternal life."

(6)

(6) "I am for the most part very comfortable with death and dying for others. Some of my best life sharing with others has been as they love someone home to the Lord. It is a very special time and I feel very honored to share that time with others. The two most moving experiences in life must be the birth (sorry I did not experience that personally) and the death of a person. Most of our society fears death and dying for self and others. For me I still have some fear about my own death."

(7) "We were instructed from verses in the Bible to care for the dying. We are all going to die when our time comes. We definitely as a church need to be more aware of the people that are dying and be there for them. I feel like I will be better prepared to be with someone that is critical after taking this training."

(8) "I'm against it! Really, I think it's a part of life, to be embraced not feared. It's both physical and spiritual. My thinking is the mental is so tied to the spiritual I can't make it separate."

2. When thinking about your own death, what words best describe death to you? Please elaborate somewhat. These could be words such as release, terrifying, freedom, scary, new bfe, dark, inevitable, etc.

(1) "Since the class (Seminar) I am happy to know there are pain medications available to ease the suffering."

(2) "The transitioning from limited to unlimited freedom."

(3) Survey Not Returned

(4) "For my own death, I think of words like freedom, joy, peace, presence of God, beauty, majesty, paradise."

(5) "Not to be feared."

(6) "Frightening yet exciting. Dreaded yet inevitable. Avoided but will happen. Unexpected yet may be known. Hope to plan and be prepared. Do not want to leave my partner, (husband).

(7) "The most effective word that describes my dying is a new life with no more pain or suffering. Being reunited with all friends and relatives that have passed before me."

(8) "Due to my last few years in dealing with death of many, my thoughts have changed. More and more I'm looking forward to it, even want it, sometimes look forward to the internal pain being gone and having peace."

3. Do we always need to do utilize every possible medical treatment for one whose life is waning, or is there a time to provide comfort and let nature take its course?

(1) For me I don't care to linger on when it is time for me to go. I want to go. Just provide comfort is all I ask. It depends on the person involved and they should have their desires at that time."

(2) There is always a point at which we must let go..., release."

(3) Survey Not Returned

(4) "No. There are times to help people find comfort and relief from pain and help them enjoy their last days as much as possible. Age and having young children probably have a big effect on a person's decisions at this point."

(5) "There is a time and place for both."

(6) "First of all there is hardly ever a situation that requires always! However in end-of-life situations, when end-of-life is approaching almost always there should be a frank and open discussion about life expectancy and life quality with 'heroic' or any medical treatment. Second, almost always there should be a discussion and consideration to explore the choice of quality of life, not life extension without quality. I feel often the ill person will know themselves and their health situation better than any family member or medical member. So often those approaching the end of their physical life are blessed with 'knowing and feeling' their approaching death. Any decision should be covered in

prayer and loving support by family members and church supporter and medical providers and once the decision is made those same people should provide loving support."

(7) No, we don't have to use every possible medical treatment. Hospice care describes the best way is to keep the person comfortable."

(8) "No, if we have tried everything and there is no options of healing. Sometimes if the diagnosis is advanced, patients ought to be given the option of not doing anything. It's hard when it's a child to say that, easier on an old person. Some would want to pull out all the stops, go to any lengths, try all crazy products just to get a little more time. But at what expense and for what cost on the body not to mention the family. Many times it's better to let them go."

A chaplain friend of mine once said, "They say that death is a physical matter with a spiritual component, but I say that death is a spiritual matter with a physical component. If this is true or we are to give any vabdity to this statement, then:

4. How should the church be involved in caring for their people at the end of life?

(1) "Mainly to be sure those that are dying are ready to meet Jesus. To be thoughtful, caring, respectful, encouraging, give them privacy, call before going, and go at their time, then don't stay too long. Check before taking anything to them, there could be things they can't have or would rather not have. It is about them and their caregivers not us.

They may want some there in silence. We should not go if they don't want us to come. We can pray for them without being there."

(2) "Unobtrusively, compassionately provide help/aid everyway feasible."

(3) Survey Not Returned

(4) "The church should help in all ways possible to meet physical, emotional, and especially support spiritually. We should minister in prayer, in the Word, and by giving communion. We should provide counsel and someone to talk to. We should bring food, clean the house, mow, or whatever else needs to be done."

(5) "The church should be as present in a person's life at end-of-life as they are from birth to that point."

(6) "Our churches should be in a position of leadership to embrace and support all aspects of hospice. Whether it is providing chaplains, recruiting volunteers, or creating awareness of our spirituality and hospice care. Even those who are not regular church attendees will very often accept spiritual care in hospice. To repeat, the church and their leadership should be on the front lines to education and support of hospice."

(7) "They should reach out and show love and compassion to them. Be available to talk and be there for the patient and family. Praying for the family before and after death."

(8) The spiritual life of the ill person should be prime concern. We as a church need to 'be prepared' to bring the patient/client/friend/church member/unbeliever to the point of decision, or at least where they are in their journey. It shouldn't begin at the end-of-life but as soon as they are a part of your life. That is when you meet them not when they are diagnosed. We need to be watching, looking for those 'opportunities', not wait till someone asks, a plan of action."

5. As a member of the body of Christ, what do you see as your role and what do feel you have to contribute?

(1) I am sensitive to other's feelings and needs, to be a friend, hold their hand, pray for them, read Scripture to them. Make and send cards with encouraging notes. If the person wants to talk, just listen and not tell my stories unless they ask for them. Ask the family for advice on the patient and how best to help, also to help the caregiver, they get exhausted quickly."

(2) "Present in prayer."

(3) Survey Not Returned

(4) "I can listen, pray, read the Word, provide communion, and also enlist the body to help also."

(5)

(5) "We must help people understand, and help fulfill, the spiritual needs of others at end-of-life as well as their physical needs."

(6) "My role is at any opportunity to be a Hospice evangelist who not only educates and advocates Hospice by providing emotional, physical, and spiritual support to those in our church community. I feel that often 'Church Christians' feel they have to temper all their feelings and statements with their 'I know where they are going' attitude instead of their true feelings that they are not happy with God that they are suffering the anticipated loss of a loved one."

(7) "I am willing to go visit and spend time with the dying in the way they feel most comfortable. I would be able to talk to them, read to them, run errands, do small things like fixing a meal, cleaning up the dishes and just sit quietly with them. I would also be willing to pray with them."

(8) "Keep my ears open, prayer requests are a good way to connect. Take it on to call, send a note, pray, stay in contact, offer services-cleaning, cooking, babysitting, run errands. Develop friendships not just with the ill person, but family as well. Support both physically and spiritually by answering questions, etc. Support by helping the family cope. Being a listening ear. Be honest."

6. What do you feel that you obtained from this training on end of life issues and care?

(1) "I would recommend the class to anyone that is interested in helping others in their last days. The information you had for us was excellent, to have the notebook to go back and go over is great to have on hand. The class reaffirmed what I had learned in the past from being there with others. Wish I had the class before I had the opportunity. I hadn't realized how important it is for family but also for friends to be there in anticipating one's death."

(2) "A clearer picture of what is needed to support and encourage persons and/or families going through this valley."

(3) Survey Not Returned

(4) "It has made me aware of some practical ways to help families. It has encouraged me not to forget these folks but help them finish feeling loved by the church. I am working on setting a date to play pitch with one of our 'senior saints'. She mentioned she likes to play, so I asked her if she would teach my children and me how to play. Her eyes lit up and she said, 'That would be fun!' We tried yesterday, but she wasn't feeling well. I am much more aware now. Thank you!"

(5) "More aware of the obstacles to be overcome in getting churches to 'come alongside' the terminally ill."

(6)

(6) "A wealth of information that I pray that I will utilize until my death. I would love to help implement this at our church or another church. If our churches cannot manage to accomplish this support we can't expect those outside of the church to do it. It must start with the pastoral staff. I have never heard a sermon from the pulpit about end-of-life care issues. We all hear about how important it is to prepare for our death spiritually however never from a legal, pre-planning, end-of-life discussion with family and hospice in view."

(7) "I feel more prepared to help the patient as well as the family when end of life is critical to them. I appreciated you asking me to be involved and know that I am better prepared for any situation."

(8) "Greater awareness of the issues surrounding end-of-life. Different ways the church can help. I'm not alone. How important HIPAA is in ministry. Learning how stress affects the whole ministry aspect. Helping others serve as well."

The purpose of this post-training questionnaire, as stated in chapter three, was to gauge the effectiveness of the training, perhaps more precisely what the participants had gleaned from seminar and whether or not perceptions on death/dying/care have been

shaped by the training. First, I have considered the issue of any change in perceptions and then moved to what the participants obtained from being a part of the seminar.

In regards to death and dying in general, there were no significant differences in the responses on the pre and post-questionnaires. However, for some there seemed to be a heightened awareness for preparation for death and needed attentiveness to those who are dying.

When the participants considered thoughts about their own death following the seminar as opposed to prior, there was perhaps one thing noteworthy. Some stated pre and post-seminar there was not necessarily a fear of death, but at least apprehension about the process and perhaps pain and suffering. One participant shared she had been made aware of the fact pain medications are available to ease suffering. When the subject is broached, the subject of death and dying, and information obtained, a measure of worry and anxiousness will fade.

Thoughts of choice, age, family situation, goals, and quality of life were seen in the responses when considering aggressive treatment versus comfort care following the seminar. One respondent wrote, "There is a time and place for both." Another respondent, number eight, raised a critical issue. So many times when someone receives a diagnosis for an illness that will potentially, if not likely shorten their life, all the treatment options are laid out with the possible exception of "not doing anything." It is not taking her out of context, to state she was meaning "not doing anything" in the way of possible life prolonging aggressive treatment. Aggressive treatment is ok. However, those with terminal diagnosis need to know as well; not choosing aggressive treatment is ok. This

option needs to be made known because there are indeed times when the treatment takes a heavier toll on the patient and family than the disease itself.

Several matters were pushed to the fore by respondent number six. The first was that of frank and open discussion. When talking about death/dying and treatment options, this was not a time to tiptoe around the issues. All the cards ought to be on the table with the pros and cons, life expectancy, quality of life, all options, side effects, etc.; nothing should be left out of the discussion because it was too tough to mention. Another matter was that of the patient herself/himself. If the patient was mentally able to make their own decisions, others should weigh in, but ultimately it needs to be up to the patient. They should not be made to feel guilty because of their wishes and desires whatever they may be regarding treatment. A third matter she touched on was the people involved in the treatment/care discussion. Naturally, family and medical providers were a part of the process, but she added 'church supporter.' If life and death are spiritual matters and we are a part of the body of Christ, why should the pastor and/or Christian friends be left out of the discussion? This is however, often the case. Also, where is God in the process? A fourth issue that I see she raised was prayer. I have often heard "my doctor wants me to do this" or "my family wants me to do this," but rarely do I hear even with believers in addition to doctors and family, "I prayed about this decision and I have a peace about treatment or peace regarding comfort care."

Regarding church involvement with those at the end-of-life, several issues were pushed forward in the post-questionnaire. A first or prevalent concern was of the dying individual's spiritual condition; were they prepared to die? There were at least a couple of

threads running from the pre through the post-questionnaire. A number of the participants believed the care of the church should be seamless, from cradle to grave. In theory it is, but the respondents have evidently noted it is not. The care offered by the church at the end of a person's life should be holistic in nature. That was, spiritual, physical, emotional, etc. No type of care was menial or insignificant when ministering to this group of the least of these.' There was notation as well in the post-questionnaire of the need for the family to be cared for and supported as well.

The respondents were very hands-on when answering regarding their personal involvement in caring for the dying and their families as a representative of the body of Christ. They listed a number of ways to minister in these situations; again, no task was insignificant and the family must be cared for as well. Some of the responses were very similar to the pre-questionnaire, but I drew attention to a number of their responses that I believed should stand out in regards to the post-questionnaire.

What can I contribute? Hold their hand, pray for them, read Scripture to them, send cards and encouraging notes, listen, provide communion, run errands, fix a meal, clean, babysit, call, and support the family just to mention the highlights. It must be noted within these tasks to assist the dying and their family; many can be performed without always 'knowing what to say.' These simply take a willing, loving heart and a desire to 'be there.'

What was gleaned from the seminar? Here, I did not wish to rehash the participant responses from the post-questionnaire, but perhaps the highlights, as I saw them, in their own words might serve best. "I would recommend the class to anyone that is interested in

helping others in their last days. Wish I had the class before I had the opportunity." "A clearer picture of what is needed to support and encourage persons and/or families going through this valley." "It has made me aware of some practical ways to help families. It has encouraged me not to forget these folks but help them finish feeling loved by the church. I am much more aware now." "More aware of the obstacles to be overcome in getting churches to 'come alongside' the terminally ill." "A wealth of information that I pray that I will utilize until my death. I would love to help implement this at our church or another church." "I feel more prepared to help the patient as well as the family when end-of-life is critical to them." "Greater awareness of the issues surrounding end-of-life. Different ways the church can help. Helping others serve as well."

Four to five weeks following the seminar, I met with and interviewed three of the nine participants who had been involved. The interviews were not tightly structured.

I merely wanted to engage them in their thoughts/feelings on the seminar and its issues in the aftermath of the seminar.

There were primarily three issues that emerged from meeting with the first participant. She made a statement that likely all who have been involved in end-of-life care would agree. She noted for those who have received a terminal diagnosis, and their families, this is a most vulnerable time for them in their life and we (caregivers) must guard that trust. We must be careful to only share what they desire for us to share. There must be privacy for the individual and the family. It was reiterated that those within the church do not always need to know all the details in order to pray for them. Allow their prayer requests to be unspoken until the patient and the family are ready to share openly.

A second matter she raised was dealing with question three on the post-seminar questionnaire. That question dealt with medical treatment chosen at the end-of-life. Do we always treat aggressively or is there a time to let nature take its course? She stated that we must ask when sitting in an intensive care unit and when major procedures are being done on frail elderly, "What are we doing?" No, we should not do everything possible just to save or extend life. She even offered an example of how it was seen by a friend that one at the end-of-life was committing suicide when they refused a feeding tube. How sad. The patient's and family's choices must be honored and then we love and support them in their decision.

A third issue we discussed was of breaking the silence on speaking of death and dying, hospice, and related issues. She noted if the church is silent on these matters, if the church does not embrace hospice and end-of-life care, then how will society be comfortable with them. She stated that in the church there is no education on the 'spiritual way to die.' During the seminar, we had addressed what it meant to die well at some length. She said if we in the church were more comfortable with our own death, then we would be able to be more supportive of others in their death. She added there is a tremendous need for this type of ministry in the church (end-of-life care ministry) and the leaders in the church need to be brought on board and then they must take the lead in advocating for the church to become involved. She said it is perhaps at the end and in grief when those in the church need their community of faith the most. In all likelihood, those in the church would have a desire and want to care for these, but there is not the awareness created or knowledge given. This must be rectified.

The second participant I interviewed commented first regarding the seminar. He stated he felt the training in the seminar was very good. He added however that the two-day seminar format we utilized might not work in many situations. He suggested video training and also stated the curriculum could be used in Sunday school or small group settings over a number of weeks. He affirmed such training and information is vitally needed, however the church doesn't like to think about or face such issues, referring to end-of-life matters. He stated this is an issue all congregations deal with, but we must ask, "Do we do it well?"

He declared the training gave him the opportunity as an associate pastor to think more about how we minister, the fulfilling of the wishes and dreams of the dying. He noted it opened his eyes to the needs of others, to really pay attention, seeing things differently, discerning the real needs.

A part of our discussion as well centered around question three on the post-seminar questionnaire. Again, that question dealt with medical treatment chosen at the end-of-life. Do we always treat aggressively or is there a time to let nature take its course? He said we need to be more aware and sensitive to the needs of the elderly/dying and the part hospice can play. He stated that at times we are an overly medicated and treated society. We must ask, "Are all medicines and all treatments always needed?" The desires of the patient must be honored. If a parishioner chooses to let nature take its course and not just pursue aggressive treatment because it is available, we must be willing to journey with our fellow believers down this path.

The third participant noted she felt the discussion and breakout groups were a

couple of the strong points of the seminar. She too stated as the other two participants I interviewed, that addressing end-of-life issues and training such as this is needed in the church, "it is a must." She added that in order for this type of ministry to be adopted in the church, there must be a buy-in of the leadership. She went on to say parishioners may be reluctant to be involved in ministering to the dying because they are unsure what to say. It must be noted here that the seminar training dealt with that topic at length. In connection to this, she stated it is not only parishioners who receive a terminal diagnosis, but pastors as well. They must have the support they need and be ministered to also.

She also made comments regarding a couple of topics in the training. The first was that of HIPAA. She emphasized how important it is at times for those receiving a terminal diagnosis to have space and time to process before they share with others, notably the church family. The second matter was regarding things the dying face, specifically depression. She stated based on her experience in caring for dying family members, they do not want anyone feeling sorry for them. With that being the case, they often hide how much they may be suffering from their illness. This is certainly helpful information to consider when ministering.

Towards the end of our discussion, she commented as to how there may be certain dying whom giving care to could be 'difficult.' She mentioned those with habits and those who have chosen to forgo treatment. In regards to those with habits, it must be said for those who have lived in a certain manner for many years you likely cannot change them at the end. They need to be loved and cared for as they are. With those who have chosen to forgo treatment, it is as another participant has stated, we must honor their choice even

though we may not agree with it. They simply need to be cared for where they are. We could gather from this that we are simply to love and care for all of 'the least of these.'

This participant and I discussed other matters, but those are more appropriate to include in chapter five in the area of 'where do I go from this point' rather than noting them here.

Chapter 5: Summary and Conclusions: Caring for These Least of These

Perhaps it is second nature to second guess one's work. In the not too distant past I was asking myself if in reality, would there be a significant population outside of my seminar participants who would see the need and be interested in such a project and ministry, ministering to the dying and their families. Had I operated with blinders on, imagining a problem that was in reality very small or insignificant? On one particular afternoon, I was reminded of the veracity for which I have advocated.

In my hospice ministry, I have the awesome privilege of meeting some of the best folks under the worst circumstances. It is naturally a shock when patients and families are forced to come to grips with the fact the patient's remaining time is measured in months or weeks, or sometimes days, rather than years. One afternoon I met a new patient and by chance her daughter was visiting from the East Coast. The patient was very hard of hearing and struggled with memory loss. Most of my interaction on that day was with her daughter. When I meet a patient for the first time, I always ask about church affiliation/connection. This dear lady was connected with a church in town that was just a few blocks from the long-term care facility in which she resided. Things became a bit

awkward when I asked the daughter if anyone from the church visited her mother. I always hope the answer is yes. The daughter shared how she had visited with the pastor about a year and a half prior about either him or someone from the church visiting her mom to provide spiritual support and to let her know that she was not forgotten. The pastor stated the church was working towards a ministry for shut-ins and nursing home folks. The daughter had to sadly say, to her knowledge, eighteen months have passed and no ministry and no visits.

On that same afternoon, I was visiting with the husband of one of my patients who suffers with Alzheimer's. She is in a nursing home memory care unit and her husband lives in an apartment complex connected to the facility. For a number of years he has been caring for his wife attentively. He often goes and feeds her at meal times and takes her for wheel chair rides when she is awake. As I was visiting with him in his apartment, he mentioned his church. I asked him if he was able to attend his church's services. He sadly stated he had not been attending. He shared of how his lack of church attendance was partly due to caring for his wife. He noted too, he very rarely drives because of health issues. He then stated his lack of attendance was due as well to disappointment. He spoke of his disappointment in his church and pastor and of how over the years that he had been caring for his wife, he feels they have been forgotten. He said, "You would think that the pastor could leave the ninety-nine and come and visit the one." Perhaps his interpretation of the particular scripture referenced is off base in relating it to his situation. Perhaps his application of that scripture is amiss also. However, his heart cannot be ignored.

I related these events not to point a finger nor to lay blame, but simply to illustrate

the need. As well, this is not to shame the church, but to cause her to open her eyes to the tremendous potential she possesses to meet that need. Again, we ought to be reminded of the words of Craddock, Goldsmith, and Goldsmith: "If there is criticism in our words it is of the church's forgetfulness of its own treasures that can be brought to the ministry of the dying." These treasures simply need to be awakened and instructed on how best to meet the need.

The conclusion one may draw from these two examples is certainly in line with the seminar participants' perspective on the matter. They pointed out the need to care for the dying and their families is indeed present. Following are snippets from the pre-seminar questionnaire regarding the need for church involvement. "That is when I would want our pastors and church family the most." "It is the body of Christ's, the Church's, responsibility to ensure that all its members both living and dying receive all the care and support that our physical bodies provide for its members, total involvement." "If the church is only going to be there for you during just one part of your life then during your death would be the most important." "The church should be very involved, checking on the people regularly, along with their families. We should walk alongside them to the end and with the family beyond." "Congregations should be supportive of the dying and the family members to help them in practical ways during this time and help them come to a peaceful understanding of how God is working in their lives." "Our churches should be in a position of leadership to embrace and support all aspects of hospice. To repeat, the church and their leadership should be on the front lines to education and support of hospice." "Most people want to have their ministers with them but when that's not

possible there should be members trained to step up and able to give them the spiritual help they are needing."

If we as the church are to care for and nurture one another, we must be there through all the stages of life and that includes at the end. Seminar participant number four stated in regards to the seminar: "It has encouraged me not to forget these folks but help them finish feeling loved by the church." As noted just above, the seminar participants have seen the need for the dying and their families to be cared for. It is one

thing to see a need, but another to be willing to step forward and be willing to be a part of the solution, be one who will bridge the gap between the need and it being met. The participants have shown they are such individuals. Surely, they are not alone. The participants surely represent others who will see and respond to care for these 'least of these.' The church indeed has a great many treasures that we may pour into the lives of the dying and their families. We simply need to be reminded and outfitted.

Were the participants enriched and equipped to better meet the needs of the dying and their families? Here is what some had to say. "I would recommend the class to anyone that is interested in helping others in their last days. Wish I had the class before I had the opportunity." "It has made me aware of some practical ways to help families. It has encouraged me not to forget these folks but help them finish feeling loved by the church. I am much more aware now." "A wealth of information that I pray that I will utilize until my death. I would love to help implement this at our church or another church." "Greater awareness of the issues surrounding end-of-life. Different ways the church can help. Helping others serve as well." As noted earlier, many of the seminar

participants had a good deal of experience with death and dying, hospice, and ministering to the ill and dying. These comments came from those who have served on hospital and shut-in visitation teams, those involved in full-time ministry, those who have been longtime hospice volunteers, and those who have been at the bedside caring for many dying individuals. Though as a result of participation in the seminar and process, they stated they received vital information on end-of-life issues and care that has equipped them to serve in a greater capacity. They shared as well they have been challenged to spread this type of ministry to others and into the local church.

It is my belief these folks are representative of many. I firmly believe many churches will rally around the dying and their families when they become more aware of the need and are more confident in how to undertake this ministry; when they know what to say, what to do, and simply be present and be the church.

In considering the ministry implications for a project such as this, I am reminded of a statement made to me by a fellow pastor a number of years ago. He said that in the church it is better to be able to work a few ministries well than many haphazardly. This is a vital point and it is certainly true that a church can stretch its resources and staff/volunteers too thin. However, it must also be stated that as our population ages, this is a vital ministry that cannot be easily dismissed. Folks today are living longer and dying more slowly. With the elderly and dying making up a larger population of many churches, these and their families are in need of the body of Christ standing with them.

It is good to be reminded here, as was stated earlier; I have not advocated for something new and novel to be undertaken, but simply a reorientation of something that

has gotten lost. As the body of Christ, we need to simply refocus our efforts in the care for the dying and their families. We need to reconnect with our New Testament roots. We ought to regain the precedent of the Benedictine orders. We must recapture this essence from the Wesleyan society and classes. These might serve us well in modeling what it means to care for this group of the least of these,' the dying and their families.

To undertake a ministry such as this, the wheel would not have to be reinvented within the life and ministry of a church. A ministry to the dying and their families, whether in a home or facility setting, can simply be an extension of existing ministries to shut-ins and those in hospitals and nursing homes. Yes, additional training would be needed. Yes, this type of ministry has a different focus. Yes, perhaps not all involved in these other ministries would desire to, or be comfortable caring for the dying and their families. However, these other ministries can and would be a springboard to caring for those at the end-of-life and their families.

What would be that next step and where would a congregation go who desired to move forward into ministering to the dying and their families? The training material utilized as part of this project is available through Nazarene Theological Seminary. I may be contacted regarding the training material and seminar as well. I would welcome the opportunity to consult or assist in any way possible any community of faith who desires to launch out and minister to those at end-of-life along with their families. I can be contacted through Nazarene Theological Seminary or First Church of the Nazarene in Hutchinson, Kansas. Also, there are many local hospice programs that conduct regular volunteer trainings. (It must be noted these would not have the spiritual bent of this

project.) Many of these hospices would relish the opportunity to educate and train individuals or faith communities on end-of-life issues and care even if the individuals or congregation did not desire to become official hospice volunteers. One could simply call their local hospice office and ask to speak to the director or volunteer manager.

If someone simply wanted to increase their knowledge on end-of-life issues or care, there is an abbreviated bibliography at the end of the training material located in Appendix B. If one desired broader information on the subject, a much longer bibliography is located following the appendices.

As we believers consider caring for those within the community of faith that are at end-of-life, Allen Verhey's words again remind us, "It means learning to rejoice with those who rejoice and to weep with those who weep. It means learning that sickness, withering, and dying cannot separate us from the love of God and need not alienate us -or another - from the community. It means learning to care and to be cared for. Here we learn to love."¹⁴⁴ In caring for the dying, we learn what it means to be the body of Christ and to fulfill His call and purpose. In this, we are a blessing and are greatly blessed.

There is one alteration that might prove helpful for others who would desire to conduct a training seminar such as this. I feel it has given both depth and breadth to this project that I have had the privilege of serving as a pastor for some eleven years and then serving in hospice ministry, end-of-life care, for the past nine years. I have had one foot in each world so to speak. The training material is complete in content, I believe, however, in teaching and in discussions, I found myself leaning on my hospice experience from which I drew many examples. Should a pastor be conducting the seminar it would likely

prove helpful to him/her to enlist an experienced hospice worker (chaplain, social worker, nurse, or administrator) to co-lead the seminar. This would provide expertise in both church ministry and end-of-life care.

A solid working relationship between a local hospice and the churches in the community could certainly have greater benefits than simply a partnership in a training ¹⁴⁴

Ibid, 301.

It should not be difficult to recruit an experienced hospice worker as hospice is becoming more widespread and there is in all likelihood a hospice office in most areas. It has been my experience that those in hospice ministry are more than willing to assist in getting the word out concerning end-of-life care. Though not an absolute necessity, it would certainly be best for the hospice worker to be a believer and connected to a faith community as that is our context.

seminar. All hospice programs are mandated by the Centers for Medicare and Medicaid Services to have a vibrant volunteer program. The church ought to be a prime place to recruit such volunteers. Are we not one of the places where kind, caring, compassionate people can be found? This would not be a relationship where the benefits flow only one way. The church would certainly benefit from interactions and connections with those who are considered the experts in end-of-life care. Education and training could be provided to the church to enlighten and equip them to better serve.

A strong connection and working relationship between the local hospice and churches would likely benefit the dying and their families most of all. I recall a few short years ago when I first spoke to Pastor Jay Bessmer about the seeds of this project, he

shared his desire as a pastor and for the church to be involved in a greater way when parishioners are placed on hospice. As meetings were held and information shared and care decisions made, he noted that he would like to be a part of the conversation. As hospice would share what they would do for the patient and the family would share what they would be able to do for the patient and themselves that he would like to be present to share what the church could bring to the table to fill the gaps and see that all the needs are met. How tremendously beneficial it would be for all involved for there to be this kind of working relationship between hospice, family, and faith community.

In one sense this final chapter is the end, but in a far greater sense it is only the beginning. As I recruited participants for the training seminar, I was asked by one individual, "When the seminar is completed and all the writing finished and submitted are you done?" My response was, "I hope not." It is my desire to see this project move from the drawing board so to speak to the church. A number of the participants of the seminar were not only open to being a part of such a ministry, but desired to be a part of implementing such a ministry within their church. It is my hope this ministry, caring for the dying and their families, will take root in the Nazarene churches in Hutchinson, Kansas and then spread from there.

I must also say, as I recruited individuals to participate in the seminar, there were a number of folks who had conflicts but asked me to please contact them the next time I offered the training. Also, I alluded at the end of chapter four, as I conversed with one of the participants in my post-seminar interviews she made comments that fit better in this context. She is not only involved in her local church, but also at the district level and

denominational level through work and witness trips. As she has travelled and conversed with others since she became involved with this project, she has been sharing and being an advocate for end-of-life care/ministry. As she shared concerning the seminar and the ministry that I have advocated, she noted there were pastors from our Kansas District and other districts who had shown interest. She is willing to continue being an advocate and to connect me with these interested parties.

Where do I go from here?

35 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;
36 naked, and you clothed Me; I was sick, and you visited Me; I was in prison, and you came to Me."...40 The King will answer and say to them, "Truly I say to you, to the extent that you did it to one of these brothers of Mine, even the least of them, you did it to Me" (Matthew 25 NASB).

The answer is forward. I continue to advocate for ministry to the dying and their families in a greater way within the life of the church. I also offer my help and assistance. The dying and their families are not the only 'least of these;' however, they are one group of the 'least of these.' Again, I must state that for any church willing to undertake

intentional ministry to the dying and their families, they will be a tremendous blessing and they will be abundantly blessed.

Appendix A Seminar Questionnaires

Pre-Training Assessment Tool 1. What are your thoughts and feelings about death and dying in general?

2. Have you ever provided care to anyone who was dying? If so, please share your experience.

3. When thinking about your own death, what words best describe death to you? Please elaborate somewhat. These could be words such as release, terrifying, freedom, scary, new life, dark, inevitable, etc.

4. Have you ever been with someone at the time of their death? If so, please describe briefly.

5. Do we always need to do utilize every possible medical treatment for one whose life is waning, or is there a time to provide comfort and let nature take its course?

6. What do you know about hospice/hospice care?

A chaplain friend of mine once said, "They say that death is a physical matter with a spiritual component, but I say that death is a spiritual matter with a physical component." If this is true or we are to give any validity to this statement, then:

7. How should the church be involved in caring for their people at the end-of-life?

8. As a member of the body of Christ, what do you see as your role in caring for the dying and/or their families?

9. What do you anticipate obtaining from this training on end-of-life issues and care?

Post-Training Assessment Tool 1. What are your thoughts and feelings about death and dying in general?

2. When thinking about your own death, what words best describe death to you? Please elaborate somewhat. These could be words such as release, terrifying, freedom, scary, new life, dark, inevitable, etc.

3. Do we always need to do utilize every possible medical treatment for one whose life is waning, or is there a time to provide comfort and let nature take its course?

A chaplain friend of mine once said, "They say that death is a physical matter with a spiritual component, but I say that death is a spiritual matter with a physical component. If this is true or we are to give any validity to this statement, then:

4. How should the church be involved in caring for their people at the end-of-life?

5. As a member of the body of Christ, what do you see as your role and what do feel you have to contribute in caring for the dying and their families?

6. What do you feel that you obtained from this training on end-of-life issues and care?

Appendix B Seminar Training

Care for the Dying **Involving Congregations in End-of-Life Care**

Rev. Randall Turner, M.Div.

Church Training Manual

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CHAPTER 1 - CARING FOR THE LEAST OF THESE - OUR CALL FROM SCRIPTURE

We often hear, and speak ourselves of life-changing moments. These times impact us in such a way that we are profoundly affected and transformed. For me, this came in October, 2006. I had left congregational ministry and began serving as a hospice chaplain less than a month prior. Our director, one of our nurses, and I had been spending more focused time with a patient and her family as time was drawing close. Then on that particular day, it occurred. I was present as this dear lady drew her last breath. I had attended, been present at my first death.

Death was not new to me, I had grown up on a farm where livestock had become ill or struck by lightning and had died. Yet this was very distinctive. It was very different when one created in the image of God died and you were there in the midst of this event. I understood in a much deeper way words spoken to me several weeks earlier. During my interview for the position of which I now occupied, the chaplaincy director for the company had made a statement in regards to death and dying. He said, "They say death is a physical matter with a spiritual component, but I would say death is a spiritual matter with a physical component." If the death of a person is a spiritual matter, and I firmly believe that no one who has been present when one has died would deny this, then one must ask, 'where the nurturers of the soul are in the midst of this experience.' If we as the church are to care for and nurture one another, it has been my experience over these past nine years that this care is often strangely absent at the end-of-life.

We have within our rituals in The Church of the Nazarene 'The Dedication of Infants or Small Children.' After the family and infant/child are summoned to the front of the church before the congregation, the pastor reads a portion of Scripture. He/she offers a challenge to the parents of which they are to respond in the affirmative. The pastor then turns to the congregation and states: "I now ask you, the congregation; will you commit yourself as the Body of Christ to support and encourage these parents as they endeavor to fulfill their responsibilities to this child and to assist _____ by nurturing his (her) growth toward spiritual maturity?" The congregation is to respond with, "We will."³ It is often a very resounding, "We will!" However when life comes full circle, there is too often a strange silence from the congregation, the church.

¹ Quote from Frank McKinley, Director of Chaplains for Hospice Care of Kansas, during my interview in August 2006.

² *Manuai/2001-2005 Church of the Nazarene* (Kansas City: Nazarene Publishing House, 2001), 253.

³ Ibid.

James Brooks notes this as well. He comments how some are born into the community of faith. There are others who come through conversion, baptism, or perhaps a transfer

of membership, or some other means. He adds that we nurture, educate, connect with, share together, etc. all throughout life as the community of faith. Yet he notes there comes a time whether through serious illness or care giving there are those who are unable to participate in the congregation as they did before. This may develop slowly or be sudden, but the individual's or the family's relationship to the church undergoes a significant shift. Brooks writes, "For many people, this is the moment when the circle of care is most likely to be broken." Folks slip from the circle of care unnoticed. Rev. Brooks illustrates this in a powerful way:

When Andrea was diagnosed with cancer three years ago, she moved in with her sister Lenora for support. Andrea was devastated a few months ago when it became clear that the cancer was no longer responding to the treatment. The burden of illness and care giving had been so great for so long, Andrea and Lenora had not stayed connected with their faith community. At the same time, the congregation lost touch with them. Now that Andrea was dying, she and Lenora missed their faith community even more and longed to be a part of it.

Brooks alludes to a vital point in this whole scenario. He notes the sisters do not stay connected and the church loses touch with them. Nothing intentional happens on anyone's part, it just happens in the midst of circumstances and the busyness of life.

As the body of Christ, we must seek to refocus efforts once again in the care for the dying and their families. Fred Craddock notes that caring for the ill was a part of the Church from very early. "Illustrative in this respect is the history of the ways in which Christians have practiced the ministry of what Paul Ramsey calls 'only caring,' which is seen in Scripture in the practice of visiting and anointing the sick (James 5:14)".⁶ Craddock and his co-writers go on to record that the *Rule of St. Benedict*, developed in the monastic tradition, formalized and maintained a community approach in caring for those who were dying. They note as well that within the history of the church one finds the birth of the hospital and within religions care for the dying is frequently found. Who is better than the community of faith to come alongside one of their own; and perhaps others as well, and participate in their care and their life at this critical juncture?

⁴ James L. Brooks, *The Unbroken Circle: A Toolkit for Congregations Around illness, End of Life and Grief* (Durham, NC: Duke Institute on Care at the End of Life, 2009), 4-5.

⁵ Ibid, 4.

⁶ Fred Craddock and others, *Speaking of Dying: Recovering the Church's Voice in the Face of Death* (Grand Rapids: Brazos Press, 2012), 169.

⁷ Ibid, 169-70.

Who better indeed! Not only is it our place, but our mandate. Caring for such is what helps us be Christian; it is what makes us the Church. Jesus illustrated as much in His

final discourse that we find in Matthew 25. He gives a critical evaluation on what marks out those who are Kingdom people. Matthew records Jesus words:

MATTHEW 25:31-40 (NASB)

31 But when the Son of Man comes in His glory, and all the angels with Him, then He will sit on His glorious throne. 32 All the nations will be gathered before Him; and He will separate them from one another, as the shepherd separates the sheep from the goats; 33 and He will put the sheep on His right, and the goats on the left.

34 Then the King will say to those on His right, "Come, you who are blessed of My Father, inherit the kingdom prepared for you from the foundation of the world. 35 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; 36 naked, and you clothed Me; I was sick, and you visited Me; I was in prison, and you came to Me." 37 Then the righteous will answer Him, "Lord, when did we see You hungry, and feed You, or thirsty, and give You something to drink? 38 And when did we see You a stranger, and invite You in, or naked, and clothe You? 39 When did we see You sick, or in prison, and come to You?" 40 The King will answer and say to them, "Truly I say to you, to the extent that you did it to one of these brothers of Mine, even the least of them, you did it to Me."

What have we done for Jesus' brothers, the least of these? That again is what marks us as the Church. Just who are 'the least of them'? It perhaps confuses the issue even more when 'brothers of mine' is connected to 'the least of them/these.' In his commentary Donald Hagner lists the following as options of which there are four: everyone (the most needy of all humans); all Christians; Christian missionaries; and Jewish Christians. Michael Wilkins adds Tribulation martyrs as a fifth group to the four Hagner references.

Donald A. Hagner, *Word Biblical Commentary, vol. 33B, Matthew 14-28*, (Dallas, TX: Word Publisher, 1995), 744.

⁹ Michael J. Wilkins, *The NIV Application Commentary: Matthew* (Grand Rapids, MI: Zondervan, 2004), 811.

Everyone, all needy humans has been the traditional and most familiar interpretation of this parable in referring to 'the least of these.' The focus has been that all nations will be judged based on how they have responded to, or failed to respond to hurting people; i.e., the hungry, the thirsty, the stranger, the naked, the sick, the imprisoned. Ralph Earle's words express this point clearly: "There has been considerable discussion as to what is meant by **my brethren** (40). Some have held that this expression refers to the Jews and that is the Gentile nations that are being judged on the basis of their

treatment of God's chosen people. It seems better to hold that, in the Incarnation and in His compassionate love for all men, Christ is referring to suffering humanity as **my brethren.**"¹⁰

Again, though the long-held option, it seems to ignore Jesus' reference to His followers as His brothers throughout Matthew's gospel. On prime example of this is found in chapter 12. Mary and Jesus' brothers came to see him and He was informed that they were 'standing outside' and desiring to speak to Him. Jesus affirms by "stretching out His hand toward His disciples, He said, 'Behold, My mother and My brothers! For whoever shall do the will of My Father who is in heaven, he is My brother and sister and mother'" (Matthew 12:49-50). This passage speaks to Jesus' use of brother as well as getting at the heart of the passage at hand. One might also note Jesus' use of brother/brothers 5:24 and 7:5. Much of current scholarship seems to hold with Roger Hahn who writes, "Though this parable does not reject general humanitarian concern
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for the needy; that is not its point." What then is the point here?

With mission and eschatological judgment in mind, one must ask, 'What is the key focus here?' 'What is Jesus' point through the pen of Matthew?' 'How are we to be ready for Jesus' Second Advent and what are we to do in this interim?' Hahn notes in his commentary, "The point is that all the peoples of the earth will be judged on the basis of their response to the message of the Kingdom. That message is always brought to them by brothers or little ones or disciples. Readiness for Christ's coming does not happen simply by being kind to everybody." If this were the case, preparedness and mission would simply be 'doing.' If one could do enough good things or do more good things than bad things, the interim would be filled with 'activity' and one's fate would be set when the King returns.

Discipleship is vital as one considers this passage and living out the Kingdom and mission. David Bosch sees discipleship as a central theme in Matthew and also central

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Ralph Earle, A. Elwood Sanner, and Charles L. Childers, *Beacon Bible Commentary, vol. 6, Matthew, Mark, Luke* (Kansas City, MO: Beacon Hill Press, 1964), 228.

¹¹ Roger L. Hahn, *Wesleyan Bible Commentary Series: Matthew* (Indianapolis, IN: Wesleyan Publishing House, 2007), 303.

¹² Ibid.

¹³ David J. Bosch, *Transforming Mission: Paradigm Shifts in Theology of Mission* (Maryknoll, NY: Orbis Books, 1991), 74.

to Matthew's understanding of the church and mission. Discipleship is a call. As Jesus walked along the shores of the Sea of Galilee and dusty roads of His native land He issued the call to the Twelve and others. The call was to follow. The call was not merely for their benefit, but for the benefit of the Kingdom. They could join in what God was doing. Darrell Guder notes, "The biblical focus is upon the relationship of the benefits of salvation to God's call to serve. It is common to all the biblical accounts of calling that to

be called means being given a task." Jesus' followers are to be doing out of their being in the period prior to His return. Bosch notes, "Mission involves, from the beginning and as a matter of course, making new believers sensitive to the needs of others, opening their eyes and hearts to recognize injustice, suffering, oppression, and the plight of

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those who have fallen by the wayside." After all, this will determine the validity of one's faith; what has been done for 'the least of these.' Followers of Christ are not to be reservoirs of what God has poured into their lives through others, but are to be a channel of those blessings. It is to continue the promise to Abraham that the entire world would be blessed.

So the Christian church is sent out to the world on a vital mission—to bear witness to the gospel of Jesus Christ. The 'good news of the kingdom will be proclaimed throughout the world, as a testimony to all the nations' (Matt. 24:14). The gospel, however, is more than mere words, and the church proclaims the gospel by living in the world as Jesus lived. The disciple is to be like the teacher (Matt. 10:24); the church must become humble like a child and show hospitality to those in need (Matt. 18:1-5). In Matthew's Gospel, if you want to find Jesus, look among those who are 'harassed and helpless, like sheep without a shepherd (Matt. 9:36). The church that is faithful will be

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found in precisely the same place.

Being missional, partnering with God and what He is doing in His world bears a great measure of accountability. This is pointed out by Wilkins as he writes, "Rather, our privilege and charge are to maximize the precious moments of life with which we have

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been gifted to make a difference for the sake of the kingdom." For a true citizen of the Kingdom this service is not burdensome or heavy. It simply flows from a life that has been changed from the kingdom of this world to the Kingdom of God. Wilkins goes on to state "but caring for the most needy among Jesus' disciples is the clinching evidence of kingdom life...We serve because we have been served, we love because we have been loved, we lift because we have been lifted up—and we never forget it...But a heart that has been truly transformed by the righteousness of the kingdom of God will serve

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out of humility."

Darrell L. Guder, *The Continuing Conversion of the Church* (Grand Rapids, MI: William B. Erdmann Publishing Co., 2000), 130.

¹⁵ Bosch, 83.

¹⁶ Thomas G. Long, *Westminster Bible Companion: Matthew* (Louisville, KY: Westminster John Knox Press, 1997), 286.

¹⁷ Wilkins, 816.

¹⁸ *Ibid.*, 821.

In light of what has been said, to profess that the dying are the least of these or the only 'least of these' would not be faithful to scripture. However, we cannot deny that they are a part of the 'least of these'. They are indeed often overlooked and pushed to the margins as their life is ebbing away. We must bring them back front and center, or at least go to them and journey with them through the dark places in the margins. They

need those who are unafraid and undaunted by their circumstances and who will walk with them 'through the valley of the shadow of death.'

CHAPTER 2 - OUR DEATH DENYING CULTURE - BARRIERS TO CARE/CARE GIVING

In our modern world, death is far from an everyday topic of conversation except likely in hospice and palliative care. Conversations regarding death and dying are avoided like the plague; they make most uncomfortable at the very least. In his article, Hiromasa Mase writes, "The word death has become almost unmentionable in the West,

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particularly in the United States." He goes on to note that Americans speak of 'passing on' or 'passing away' instead of 'dying.' I hear these terms so often in dealing with hospice patients and families and from those in the church arena as well. If not careful, I find myself as a hospice worker and clergy member caught up in this attitude. In reality, death is as much a part of life as is birth. Granted, not God's original intent, but death has become our lot. Birth is natural process and death is natural process. Yet again, our society does not view it in this manner; we must avoid speaking of such matters.

Craddock and the Goldsmiths in their work, *Speaking of Dying*, write very plainly to this point. "Unfortunately, there is a clear cultural model, and it is the only one generally available to the terminally ill: be strong, don't mention it, don't give in, fight it. This is the default position to which the church has outsourced the facing of impending death. It combines the individualism and toughness of American culture in a manner that focuses all interest and resources on the dying. The secular narrative has taken over."²⁰ The Christian voice or voice of the church has either fallen silent in this matter or we have allowed it to be drowned out by the world. Perhaps somehow if you do not talk about it, it makes it less real.

One might understand this attitude in regards to those who see this world as the end of all. If you are born, live, and then die and that is it, one would certainly desire to shun even the thought of death because it represents finality. Clinging with all one's might and strength to the temporal is all we have.

Hiromasa Mase, "Death and Dying: Towards an Ethic of Death." *Currents in Theology and Mission* 12, no. 2 (April 1985), 69. <http://web.ebscohost.com.proxynts.kclibrary.org/ehost/search> (accessed Jan 22, 2013).

²⁰ Craddock, 47.

As well, medical technology often creates obstacles to care for the dying and care giving. There is a pill or surgery for everything. Those receiving a terminal diagnosis are averse to accepting care because they are going to get better. Perhaps the church and others are reluctant to offer help and care because those might perceive it as taking away hope. Medical science has done much. It has much to offer. Craddock and his coauthors point out in this regard, "Astonishing discoveries occur on an almost daily basis and new medical applications are constantly reported, often with significant promise for reversing or eliminating diseases. So when a patient's symptoms point to a terminal

diagnosis, rather than submit to the inevitable, the typical American establishes a new fervent allegiance to whatever good news medicine and modern health care may

²¹ promise." One cannot deny the lives of many have been extended, and not just extended in regards to quantity of years, but quality of years as well. Yet this can lead to a denial of reality. All do not get better.

Medical technology is great, but it cannot help everyone, all do not overcome illness. Craddock and the Goldsmiths write, "Medical advances have changed the world and certainly have changed dying. Because of new and improved medical insights, medicines and health-care procedures, we find ourselves in a good news/bad news situation. The good news is that there are cures and relief not earlier available. The bad news is that while it often takes longer to die, the dying is done without the sweetness that such extension might avail because of the rigor of the treatment."²² This is so true. There are numerous instances that I have been witness to where the supposed cure takes a heavier toll on the patient than the disease itself. I am often reminded as well in the midst of death and dying as a hospice chaplain that some do get their healing in this life, but many others have to wait for the next.

An all-to-real example of this is the story of the wife of one of my hospice patients. He was dying with congestive heart failure and she received a cancer diagnosis. She elected aggressive treatment. She would go for treatment on Tuesday. She would then be horribly sick for the next five days. She would feel good on Monday and then start the cycle all over again. In a short time she went from walking independently to being pushed in a wheelchair by others. Her hope for minimal side-effects and some indication the treatments were working was not achieved. She had neither quality nor quantity of life. Why do treatments work on some and not on others? Hindsight is always 20/20. Yet she is evidence that not all get better even with valiant efforts to heal and cure. I do not know what options she was given at diagnosis or what percent chance there was of the treatment being effective, but there were other choices. Perhaps she pursued this course of aggressive treatment because she saw no one to stand alongside her on the journey if she took another path. A kind, caring hospice nurse I worked with for many years

often said, "I never want my patients to give up, but I do want them to embrace reality." The embrace of things as they truly are is not giving up or throwing in the towel. It is living, living with courage, living life to its fullest, making the most of each day.

Allen Verhey echoes the above sentiments in his book, *The Christian Art of Dying*, when he speaks on what he refers to as 'medicalized dying' or the 'medicalization of death'. He notes that this came about following World War II and leading into the third quarter of the twentieth century. Leading the way in this regard was advances in medicine and improved surgical techniques. Dying moved from the home to the hospital. All of this

improved medical technology began to be utilized on the dying. Now, those dying were no longer treated as they were dying, but were treated as one recovering from a serious disease or surgery. Verhey writes, "So, suddenly no one was 'dying' any more. They were just 'sick.'" He says as well, "The body of the dying person became the battlefield where heroic doctors and nurses waged their war against death." Again, we must say that medical technology has done much for us. There are tremendously talented and caring medical professionals, my wife being one, who sacrifice so much to give care. But they and we must be reminded that even though not the original intent for man, death has become humankind's final fate. Again, not everyone will get better and recover before death will ultimately take them one day in the distant future.

²⁴ Ibid, 14.

²⁶ Robert A. Ellis, "And the Life Everlasting¹: A Theological Reflection on Death and Dying." *Transformation* 24, no. 2 (April 2007), 88. <http://web.ebscohost.com/proxynts.kclibrary.org/ehost/search> (accessed Jan 22, 2013).

What does it mean to die well? What is the Christian view of death? Do we embrace it as part of life as it now stands? I, having served as a pastor for eleven years and a hospice worker for nine years, would affirm not. Robert Ellis seems to agree, for in his article he writes, "If 'to live is Christ, to die is gain,' as Paul suggests in Phil. 1:21, then why is death experienced or construed negatively, even within the Christian community?" Ellis then continues with this thought referencing the writing of Paul Fiddes. He notes that death is experienced as a boundary and as an enemy. He states Fiddes uses the Old Testament and "charts a view of death first as a destructive force that abruptly ends relationships - including that between a person and God." My experience in this arena tells me as well that we do not embrace death and dying in the Christian community. "Precious in the sight of the LORD is the death of his saints" (Psalm 116:15 NIV) may be grasped at death, or after death, but not prior as the terminal diagnosis is heard and one moves toward death. I believe this to be true in the vast majority of cases with the

dying, even the dying of believers.

CHAPTER 3 - DYING WELL - GRACE FOR THE JOURNEY

How then should the believer, the church, those in the community of faith view death in order to allow oneself to be cared for and to offer care? If death is not a foe or a boundary to be crossed, what is it then? In his article Christopher Vogt puts forth, certainly not the only Christian view, but what I see as one view of death and dying that is faithful to God, Scripture, and the Christian tradition. The abstract at the beginning of the articles affirms, "Four centuries ago, Christian moral theologians addressed the issue of dying by turning to scripture and the virtues. This work revives that tradition by showing that careful theological reflection upon the

nature of Christian patience,

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compassion, and hope illuminates the shape of the Good Death." A 'Good Death,' just what is a good death? Is there such a thing as a Good Death'? Are we searching for something that does not and cannot exist? My experience tells me no as does Vogt's enlightening article.

Vogt speaks of the art of dying, 'ars moriendi.' He writes

Beginning in the fifteenth century, a new genre of theological literature known as the "*ars moriendi*" emerged which sought to prepare readers for the task of dying. The authors of these works viewed dying as a task or an art—a learned behavior that one could perform either well or badly...These authors urged their readers to live the whole of their lives in such a way that they would become patient, hopeful, and faithful; only by living well and nurturing these virtues over time could one expect to be patient, to be

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faithful, to be hopeful, and thereby to die well.

If we are to see death and dying as a part of the circle of life, then we must not fade at the end. If one has lived well, surely he/she must want to continue through to death in the same manner, in patience, in hope, and with compassion. If we have wholeheartedly embraced God in life, then we must continue to embrace Him even in our dying and death.

Thomas Long advocates for this as well. He writes,

Christopher P. Vogt, "Practicing patience, compassion, and hope at the end of life: mining the passion of Jesus in Luke for a Christian model of dying well." *Journal of the Society of Christian Ethics* 24, no. 1 (Spring/Summer 2004), 135. <http://web.ebscohost.com.proxynts.kclibrary.org/ehost/search> (accessed Jan 22, 2013). ²⁹ Ibid, 135-6.

There is life and there is death, but there is also the time of dying—the in-between season when the reality that a person will soon die looms large and becomes a magnetic pose around which the thoughts and actions of others are organized...Christian faith views this time in between not with resignation, not merely as a season of passing time before someone

passes away, but as a period filled with meaning and opportunity for communion with the one who is dying.³⁰

I would add as well this is a period to be filled with purpose and meaning and opportunity for the one dying. It is a time to finish strong, to finish well as one has lived. If Long is correct and this is the 'Christian view,' we do a poor job, in my estimation, of conveying just what Christian dying is to look like. How often do clergy or believers speak of death/dying? When was the last time the topic was addressed in a sermon or Bible study? How often have we steered the conversation in another direction when it was brought up by a parishioner? If it is the Christian

view, it certainly needs more favorable press.

Thomas Long notes that within the *Ars Moriendi* literature there were devotions that were read and recited and these were a 'dress rehearsal' for the Christian in his/her dying. He states these readings would aid the dying in dispelling their fear when their time was near at hand because through the reading they had been in that territory before. Long then writes, "While Christians today are probably not going to be attracted to the old practice of *Ars Moriendi* devotions, it is urgent that the core of the tradition

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be retrieved, if for no other reason than to break the code of silence about death." To that I would add a hearty, 'Amen'. That is a great place to start, however we need to go further in leading and teaching people of faith the 'art of dying', what it means to die well.

Any theology of Christian dying begins with a theology of Christian living. One cannot picture dying well if one has not lived well. Craddock, Goldsmith, and Goldsmith remind us, "For any theology of dying, the serious, long-term commitment to Jesus Christ in the midst of others of like faith is a necessary precondition to receiving, experiencing, and expressing the full benefits of the gospel story. If we have practiced the Christian life, when the time of dying approaches, the whole experience of our past is at our disposal as a treasury of coping resources."³² If faithful Christian living is to be cruciform in nature, perhaps this is what lies behind Christopher Vogt looking so intently at the passion narrative to glean insight that portrays the essence of faithful living and dying.

Thomas G. Long, *Accompany Them With Singing: The Christian Funeral* (Louisville: Westminster John Knox Press, 2009), 107-8.

³¹ Ibid, 112.

³² Craddock, 85.

In his article Vogt seeks to portray virtues that would shape one for Christian living and for 'Christian' dying. He believes and writes how appropriate it is and how pastoral it is for clergy to cause their parishioners to see a connection between their dying and the dying of Christ as their death approaches. He draws upon Luke's passion narrative "to describe the shape of Christian patience, compassion, and hope in the context of

dying." He goes on to ask, "Can we find in these stories a biblical model for dying well? If so, what exactly is it about Jesus' way of dying that is to be imitated?" Vogt certainly does not stand alone in believing there is much to be mined from the death of Jesus to benefit us in our dying. Allen Verhey notes that in the cross of Christ believers will find a paradigm for their own dying and this tenant permeates the *Ars Moriendi* literature.

PATIENCE IN DYING

Again, Vogt notes three virtues in Jesus' dying that are tremendously relevant and worthy of imitation in regards to Christian dying. The first virtue is patience and he affirms this to run the length of the passion narrative. Vogt sees this most clearly illustrated however in the Jesus' prayer in the Garden of Gethsemane. "First, we observe in Jesus the *reluctant* endurance of suffering; patience seeks to avoid suffering if possible, but to endure it if necessary." This patience is not a seeking of suffering. It is not even a giving up, but a giving in. One acknowledges that if he/she cannot go over or around, they will press on and move through accepting this part of the journey of life in the same manner as past sections of the journey whether positive or negative. This would be to acknowledge that finishing well, if that is indeed where this event is leading, is as important as beginning well or any portion in between. Vogt reminds us a bit further down in his article this patient endurance of suffering is not sought after, but those who follow Christ must come to grips with the fact "that some suffering is a necessary part of faithfulness to God." In pondering this aspect of the virtue of patience I find myself back in Jerusalem at the beginning of the *Via Dolorosa* and reading these words from Luke's gospel, "If anyone would come after me, he must deny himself and take up his cross daily and follow me" (Luke 9:23). If we choose this path and following Him in our living, should we seek another path, a path of avoidance in our dying? Again, a path not sought after, but followed as it comes.

Vogt writes this patience also is embraced with a sense of divine purpose. "Second, the patience of Jesus rests upon a profound sense of Providence, or of divine purpose in the

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³³Vogt, 136.

³⁸Ibid, 138.

events that are about to unfold." I do not see that Vogt is meaning a predetermination as God is micromanaging every minute detail, but as Jesus saw God's hand at work in His dying, God too is at work in ours. If we believe in committing ourselves to God, joining His Kingdom, He uses us in life, is He unable to do so in death or our dying? If we submit ourselves to be used by God in our prime and vitality, is He unable to utilize us in the weakness of our disease or advance of years? Can there be no divine providence as we are moving towards closing the circle of life? Indeed there surely must be. A bit further

down Vogt draws us to Jesus' words as recorded in Luke 22:42, "If you are willing" and "Not my will but yours be done." He then writes, "Exactly why one should be willing to wait is not generally obvious. Jesus' concern with God's planning and his desire to be obedient to God's will explains why such a capacity is virtuous from a Christian perspective...This requires the development of patience in the sense of waiting; we must wait for events to unfold for God's will or purposes to be made known to us."³⁹ In making choices at the end-of-life, God is often left out of the equation. If we pray for God's will in life (place of service, marriage partner, career choice, etc.), should we abandon this as life begins to wane? Does He cease to have purpose for us?

Whether in life or death, there is far more to consider than just me. Vogt notes this as another aspect of patience in Jesus' dying. "Third, Jesus' patience can be interpreted as demonstrative of a particular understanding of autonomy; one of the things Christians must specifically be prepared to endure is some limitation on their exercise of autonomy."⁴⁰ Then a bit further into his article Vogt states, "In his decision not to flee the difficult end he foresees for himself, Jesus chooses to endure physical suffering, but more importantly to endure what we today might call the loss of absolute autonomy...The example of Jesus makes clear that the expression of patience entails

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relinquishing the exercise of absolute or total control over one's own fate."⁴¹ In following Christ in life, the believer would state that it is not all about me, why should this not be one's attitude as death approaches. Just as we are not an island and there are others to consider prior to the diagnosis of a terminal illness or the advance of years, there are others to consider when death and dying seem more immanent. We are not alone in health care decisions. There are others to consider when we ponder treatment, or to let nature take its course, or contemplating something extreme like suicide to exit our situation at the time of our own choosing. There may be a spouse of fifty, sixty, or seventy years to consider. There may be children that have looked to mom or dad all these years. There may be grandchildren, great-grandchildren, and other family members that are vitally connected to this event in time as well. In addition, connecting to the previous point, there is a God whose we are as a believer, we are not our own.

In this area of patience and autonomy, the community of faith must be taken into consideration. As a believer, we are part of the body of Christ and as such, we cannot act in autonomy. How we live and how we die are a reflection upon the God we serve and the community of faith to which we belong. Vogt points out a connected aspect when he states, "for a dying person to give him- or herself over would be to allow oneself to be cared for...I am not advocating throwing oneself over to a hostile crowd or allowing the will of other to be

imposed upon us; I am recommending merely a willingness to become the subject of the care of others—of one's family, or one's family

in concert with medical personnel." In addition, in my view, giving oneself over to care affords the church a grand opportunity to be the church. It provides the community of faith the privilege coming alongside one of their own in a difficult situation; the privilege of bearing one another's burden; the privilege of suffering with one who suffers.

A final way Vogt sees patience exhibited is in connecting it with love. "Fourth, Jesus shows a connection between patience and love for his disciples and many others. In this way, patience is an unmistakably social virtue." Vogt points out that Jesus saw in His suffering a good coming out of it for God, friends, and the world. Jesus believed "that some good is to come from his crucifixion." If our life in Christ is in large part for the benefit of others, and to be a blessing to others, then surely this purpose will not end until we draw our final breath. If we are to have a holy dying, then we must believe as well that there is meaning and significance in how we close our days; that it will make a difference for others.

HOPE IN DYING

The second virtue Vogt notes in Jesus' dying worthy of imitation in one's own dying is that of hope. In his article, Vogt points us to Jesus' prayer here, the prayer that the cup be removed from Him if possible. His noteworthy point is God's response to His son. The cup is not removed. However, an angel is sent from Heaven to minister to Jesus. Vogt affirms, "Hope is not a distraction from what is to take place, nor an empty promise that no harm will ever come; rather, it is a reorganization of the significance of the facts at hand: you will suffer, you will die, *but I will be with you.*" A grand a glorious hope is indeed the knowledge that come what may, God will not abandon me. The believer can faithfully face life or death if he/she clings to the knowledge that God is faithful and His abiding presence is assured. Vogt declares it is this blessed hope that gives Jesus the fortitude to move forward and face what lies before Him. Our Lord does not pull back, but strives toward what He believes the Father has set before Him.

⁴² Ibid, 141-2,

⁴⁶ Ibid.

We may have this kind of hope as we face our own mortality, but do we? Is it not possible for us to cling steadfastly to the same promise, the promise that we will not be forsaken? Are Jesus' words not for us? "And I will ask the Father, and he will give you another Counselor to be with you forever—the Spirit of truth. The world cannot accept him, because it neither sees him nor knows him. But you know him, for he lives with you and will be in you. I will not leave you as

orphans; I will come to you" (John 14:16-

18 NIV). Surely, knowing that God has not, cannot, and will not abandon us will enable us to face come what may in life or in death. This is the believers' hope.

COMPASSION IN DYING

The third virtue in Jesus' dying for us to mirror in our own is that of compassion. Vogt notes when one considers this virtue in relation to death and dying, compassion for the one dying is where the focus most often lies rather than pondering the compassion of the one dying. Compassion and care for the dying and their family is in large part our focus. However the compassion of the one dying is worthy of time and consideration here according to Vogt, "Thus what a turn to this biblical material adds to the contemporary discussion about dying well is the suggestion that not only the reception but also the expression of compassion by the dying is important."⁴⁷ This only stands to reason, for the believer, if our dying is to be a holy dying then we should finish our course as we have faithfully traveled on it, as one who not only receives but also, extends mercy and kindness.

Vogt highlights a couple of examples of Jesus extending compassion to others before His death. The first recipient is Peter. After Peter denied Christ in Caiaphas' courtyard, our Lord still looked on him with compassion. That look Jesus gave Peter could be interpreted in a number of ways, but I believe Vogt to be correct in affirming it to be a look of compassion based on what we know of our Lord and the context of this situation. Vogt pens, "In this scene we find both the expression of compassion as

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empathy and compassion as mercy or forgiveness." As His death neared, Jesus continued to extend compassion to Peter as He had done to others numerous times when death was not so immanent.

A second portrait of compassion came as Jesus hung between the malefactors. Jesus is in excruciating pain and agony. The crowds mock him as they pass by. If that is not bad enough,

even those in the same predicament begin to deride Him. He does not respond in a negative way that could easily be justified, but extends compassion. Vogt writes, "At the same time, in addition to its richness as a source of reflection on eschatology, soteriology, and more, this passage is demonstrative of Jesus' compassion in dying. The scene depicts a very intimate encounter in which Jesus yet again offers mercy to

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someone in an unenviable position, providing him with comfort and hope." Again, Jesus at His death was continuing to do and live in the same manner He had done on numerous other occasions.

It is so appropriate to extend this type of compassion as one nears death. So often, things have gone unsaid. I love you has not been spoken. I am proud of you has not been verbalized. I accept you has not been voiced. I forgive you has not been uttered. There is healing for both the receiver and giver of these words as life draws to a close. Perhaps, and indeed so, the words should have been spoken sooner, but if not, compassion can still be given at the end. It is holy dying to extend mercy and forgiveness; to show compassion as life comes full circle.

Christian dying, holy dying, is there such a thing? Vogt writes, "Christians seem unwilling to see the experience of dying as something to be mined for insight into what God has called us to in life, or as a part of our lives that might present an opportunity to serve God."⁵⁰ If we were to begin to see our dying in this manner and the dying of other believers, it would change our perspective on how we face death. I believe it would also change our perspective on how we view the dying of others, especially believers. This should cause clergy and the community of faith to rally around the dying one and their family to be a part of life coming to a close.

CHAPTER 4 - INTRODUCTION TO HOSPICE

A BRIEF HISTORY

The term **hospice** comes from two Latin words. Let's look at those two words.

The Latin word **hospitium** means hospitality, inn or lodging. The Latin word **hospes** means host or guest.

The concept of Hospice dates back to the Middle Ages. In that time a hospice was a place where weary travelers could stop and rest. Many of these resting places were located at churches or monasteries. For travelers on foot these "hospices" served as a respite and a place to soothe aching feet, catch up on sleep, and mend wounds or other physical ailments.

Over time, hospices turned their attention to treating only medical needs. Eventually, they became focused solely on caring for people with terminal illnesses.

FAMILY LIFE ALSO INFLUENCES THE BIRTH OF HOSPICE

Before modern health care, it was common for multiple generations to reside in one home. It was considered "normal" to birth at home, to be ill at home and to die at home. Families knew how to care for the sick or dying. However, as health care became more modern, the sick and dying moved into hospitals. At the same time it became more common for families to live separately. Multiple generations no longer shared a single household. As a result, families lost the knowledge and skills for providing care at home. Healthcare professionals took over responsibility for major health events in life.

THE MODERN-DAY AMERICAN HOSPICE MOVEMENT

The modern-day American hospice movement began in 1974. The first American hospice was the Connecticut Hospice in Branford, which was modeled after the now-famous Saint Christopher's Hospice. Dame Cicely Saunders, MD, in Sydenham, England, founded St. Christopher's in 1967. It is considered the model for comprehensive whole person and family end-of-life care.

In the Tax Equity and Fiscal Responsibility Act of 1982, Congress included a provision to create a Medicare hospice benefit; which was then made permanent in 1986. States were also given the option of including hospice in their Medicaid programs. That same year, hospice care became available to terminally ill nursing home residents.

Dr. Elisabeth Kubler-Ross' book, *On Death and Dying*, brought the needs of dying people to the public's attention. Kubler-Ross greatly influenced the growth and promotion of hospice care.

THE HOSPICE PHILOSOPHY OF CARE

Death is inevitable. It is a part of the life cycle. People are born, grow, develop, and age. People die. Like birth, death is experienced only once. And like birth, death should be made as positive as it can possibly be.

Hospice is a **philosophy of care**, not a place and can be based anywhere. Hospice focuses on care which enhances quality of remaining life, provides relief or comfort, and supports the patient and family when there is no cure for the terminal condition

Hospice does **not** focus on **curing** the patient and the disease. Rather on what is important to the patient and family. The hospice goal is to improve the dying patient's treatment and care through control of common symptoms of terminal illness.

A patient should be allowed to die in the place of his or her choice if it enhances quality of life. That may be *wherever* he or she calls home.

HOSPICE FOCUSES ON QUALITY OF REMAINING LIFE

Hospice views dying as a part of the life cycle. It focuses on maintaining the quality of remaining life and affirms life. It does not rush death, nor postpone it. Through appropriate care, hospice **prepares** the patient and family both mentally and spiritually for death. Most hospices offer care to terminally ill patients and their families without regard to: age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, ability to pay, or the availability of a primary caregiver.

HOSPICE CARE IS INDIVIDUALIZED

A hospice patient's care is individualized and does not necessarily exclude any specific therapies. Instead, any therapy or treatment the patient, her family, physician and the Interdisciplinary Group (IDG) feel necessary is provided.

Treatments are chosen based on how they will affect the patient's quality of life and symptoms. They are not chosen to have an effect on the terminal illness. Again, hospice care is palliative, not curative. Palliative treatments can be as aggressive as curative treatments. However, they focus on comfort, quality, and affirming the patient's choice.

Other times, palliative treatments can do more harm than good. For example, a patient might receive chemotherapy to shrink a tumor. The tumor shrinks, but the chemotherapy is causing such severe nausea and vomiting that the patient decides to stop the chemotherapy. At this time, team members play a critical role in educating the patient and family and helping them to make informed decisions about continuing treatments. The final decision is up to the patient and family.

THE FAMILY REQUIRES CARE ALSO

In hospice, the patient and family are cared for. Family members experience emotions and stress about their loved one's illness requiring emotional support. They need education to prepare them for involvement in the patient's care. Furthermore, concern and responsibility to the family unit does not end with the patient's death. A structured bereavement program providing continued support is offered to the family.

THREE KEY PRINCIPLES OF HOSPICE

1. OFFER CHOICE

Offering choices enables a patient a degree of control over his or her life. Offering choices encourages independence and involves the patient in decisions regarding care.

A patient's degree of choice is based on the individual ability to choose. For example, a confused patient might become overwhelmed and frustrated when faced with many choices. Another patient might prefer to have options.

How a choice is offered is just as important as the number of choices. A patient may respond in very different ways based on the words used.

Hospice helps patients focus on what they still have. They still have choices.

2. MAINTAIN DIGNITY

Dignity is a person's value or esteem — being worthy of respect. Maintaining a patient's dignity involves:

Showing respect: Hospice patients need help in some very personal and private ways. Hospice staff must always honor a patient's dignity.

Protecting privacy: An important principle of hospice is to "*protect each patient's right to privacy.*" Another way to affect a patient's dignity is to help him or her maintain privacy.

Encouraging independence: The tendency to generalize, stereotype or assume a patient cannot do something diminishes his or her dignity. Always look for ways to encourage a patient's independence.

3. PROMOTE INDIVIDUALITY

Promoting individuality means finding ways to celebrate how each person is special. Patients may have similar needs; however, each patient has his or her own likes, dislikes, routines and lifestyle.

Visitors and those giving support should caution against becoming routine when they visit. Instead, be alert to and remember the individualized needs of the patient. It is important to consider ways patients can be treated as an individual. Then they will feel supported in their final stage of life.

ESSENTIAL CHARACTERISTICS OF A HOSPICE PROGRAM

The following table outlines the essential characteristics of a hospice program. Without these characteristics, the patient may not have all she deserves at the end-of-life.

The Service Is:	Description
Physician Services	The hospice physician leads the medical component of the patient's care. The patient's personal physician may also continue to be involved.

Nursing Services	Each patient has a primary nurse case manager assigned to provide care. Nursing care focuses on relieving distressing physical symptoms often occurring with life-limiting illnesses.
Medical Social Worker Services	The social worker assists hospice patients and families in finding community resources and in dealing with psychosocial needs. This may include: Assessment of financial needs, family therapy sessions, and individual counseling
Spiritual Care Services	Hospice recognizes the spiritual needs of patients and their families. We strive to assist in meeting those needs either directly or by coordinating with the patient's place of worship. The spiritual care coordinator plays a key role in providing spiritual support.
Certified Nursing Assistant Services	Hospice patients often need help with activities of daily living (ADLs). Certified Nursing Assistants/Home Health Aides (CNAs/HHAs) play an important role helping patients with: Eating Bathing Grooming Dressing Toileting Light housekeeping
Volunteer Services	Volunteer services are an important part of any hospice program, providing support in many areas: Companionship/Socialization Caregiver relief/Respite care Administrative work in the hospice office Special projects

CHAPTER 5 - HIPAA: THE HEALTH INSURANCE PORTABILITY & ACCOUNTABILITY ACT OF 1996

WHAT IS HIPAA AND WHAT DOES IT GOVERN?

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) is a multifaceted piece of legislation covering three areas:

- **INSURANCE PORTABILITY** ~ ensures that individuals moving from one health plan to another will have continuity of coverage and will not be denied coverage under pre-existing condition clauses.
- **ACCOUNTABILITY (Fraud Enforcement)** — significantly increases the federal government's fraud enforcement authority in many different areas.
- **ADMINISTRATIVE SIMPLIFICATION (Reduction in Healthcare Costs)** - arguably the most significant part of the legislation, and is the focus of the following material.

ADMINISTRATIVE SIMPLIFICATION received little attention when the law was first enacted because its implementation date was later than the other two components; however, two of its rules, privacy and security, generate much discussion and debate in the health care community today. The debate stems from the administrative, technical, and policy changes that the rules require health care organizations to make to protect their patients' privacy and the confidentiality of protected health information (PHI).

HIPAA privacy and security regulations punish individuals or organizations that fail to keep patient information confidential. Until these regulations were enacted, there was no federal framework to protect patient information from being exploited for personal gain. Currently, the Office for Civil Rights and the Department of Health and Human Services have been charged

with enforcing the HIPAA privacy rule.

HIPAA states that "covered entities" must comply with its regulations. Covered entities for HIPAA privacy and security regulations include most providers, clearinghouses, and health plans.

ENFORCEMENT

Breaking HIPAA privacy or security rules can mean either a civil or a criminal sanction. Civil penalties are fines of up to \$100 for each violation of a requirement per individual.

EXAMPLE: If a hospital released 100 patient records, it could be fined \$100 for each record—a total of \$10,000. The annual limit for violating each identical requirement is \$25,000.

Criminal penalties for *wrongful disclosure* can include large fines as well as jail time. Criminal penalties increase as the seriousness of the offense increases. *EXAMPLE: Selling patient information is more serious than accidentally letting it be released, thus warranting a stiffer penalty.*

Egregious violations—e.g., selling a celebrity's medical record information to the tabloids or selling health information to marketing or pharmaceutical companies for personal profit—could result in criminal penalties. Penalties can be as high as fines of \$250,000 or prison sentences of up to ten years.

- Knowingly releasing patient information can result in a one-year jail sentence and a \$50,000 fine.
- Gaining access to health information under false pretenses can result in a five-year jail sentence and a \$100,000 fine.
- Releasing patient information with harmful intent or selling the information can lead to a ten-year jail sentence and a \$250,000 fine.

WHAT IS CONFIDENTIAL?

All information about patients is considered private or confidential, whether written on paper, saved on a computer or spoken aloud. This includes their names, ages, Social Security numbers, and any other personal information. Confidential information also includes the reason a patient is sick or in the hospital, the treatments and medications he or she receives, caregiver notes, and information about past health conditions. If you reveal any of this information to someone who does not need to know it, you have violated patient confidentiality, and you have broken the law!

DO YOU NEED TO KNOW?

Most of HIPAA is common sense. Just follow the simple *need-to-know rule*. If you need to see

patient information to perform your job or give care you may do so. One does not have the right to look at information on all patients.

Before looking at a patient's health information, ask yourself this question: *Do I need to know this to do my job?* If the answer is *No*, stop. If the answer is *Yes*, you have nothing to worry about.

I COULDN'T HELP OVERHEARING

Not all patient information is under lock and key or protected by a computer password. At some time you may overhear private health information while going about your work tasks. If you keep the information to yourself, you have nothing to fear.

NOTE: Patient information also includes the fact that he or she is in a company facility. If you encounter a friend in the waiting room, you might want to tell another friend or

family member later. **KEEP IT TO YOURSELF.** The person you saw may not want anyone to know about the visit.

EVEN THE TRASH IS PRIVATE

Patient information on paper or computer disk should never be thrown into a trashcan. Reason: Who knows who may rummage through the "trash" before or after it is taken from the work place. If you see patient information in an open trash container, inform a supervisor so she can dispose of it properly, either into a paper shredder or a locked bin until it can be destroyed.

REPORTING AN INFRACTION OF THE PRIVACY RULE

Each organization has a privacy official to make sure that no one breaks the privacy rule. This person is responsible for establishing the organization's privacy policies and enforcing them. If you witness anyone breaking the rules, report him or her either to your supervisor or the privacy official.

BEST PRACTICE

The HIPAA privacy rule went into effect in April 2003; however, patient privacy protections have always been a wise policy for all healthcare providers to follow.

WHAT DOES ALL THIS MEAN FOR ME?

You note there are serious consequences for violating HIPAA as a healthcare worker, fines and possible jail time. As a fellow church member who is visiting and offering support to another in the body of Christ, how might this apply? I must note that perhaps offending and failing to guard a brother's/sister's privacy is weightier than fines or jail time. So often we assume that

when one is ill that it is their desire that all those within the community of faith know all about their condition so that they may pray for them. However, we must not make this assumption as one on the visitation team or one offering support to the patient and family. For clergy and laity alike it is always good to ask the patient if they are capable of responding appropriately and the family if the patient is unable to do so, "What would you like for me to share with the church family about your/your loved one's condition?" It may be fine to share anything and everything that has been shared with you in the course of your visit. Yet on the other hand, the patient/family may want certain things kept private for a time or never shared. PLEASE ASK.

CHAPTER 6 - UNIVERSAL PRECAUTIONS, INFECTION CONTROL AND TUBERCULOSIS

WHAT ARE UNIVERSAL PRECAUTIONS?

Universal precautions are taken to prevent exposure to blood and body fluids which may carry disease-causing organisms. Healthcare workers and others are to consider all patients to be infectious and are to use universal precautions when visiting with patients and their families.

WHY TREAT ALL PATIENTS AS POTENTIALLY INFECTIOUS?

Neither medical history nor examinations can reliably identify all patients with disease-causing organisms; therefore, precautions should be used consistently for all patients when a visitor or caregiver may come in contact with blood and other potentially contaminated materials.

ARE THERE TIMES WHEN I SHOULD NOT VISIT PATIENTS?

To protect patients and yourself, do not visit if you have any of the following:

- Symptoms of respiratory infection (cold, flu)
- Symptoms of a GI infection (diarrhea)
- Dermatitis
- Draining of open skin lesions

HOW DO I PROTECT THE PATIENT AND MYSELF?

Hand washing is the single most effective method of controlling the spread of disease. Personal Protective Equipment (PPE) should be worn any time there is a chance you may handle or be splattered by blood and/or body fluids.

HOW DOES PPE PROTECT?

Gloves are worn for touching blood and body fluids. Masks and/or goggles are worn when

splashes, sprays, or splatters of blood or body fluids are likely to occur. Gowns are worn when clothing is likely to be contaminated with blood or other body fluids.

INFECTION CONTROL

Infection control is defined as precautions taken to prevent exposure to disease-causing organisms. It involves controlling diseases and preventing infections from spreading.

HAND WASHING

- Is the single most important factor in preventing the spread of disease.
- Hands should be washed:
 - Before and after working with a patient.
 - Before and after using the restroom, serving food and eating.
 - After sneezing or nose blowing, removing gloves and handling soiled linens.

HAND WASHING PROCEDURES

- Roll up long sleeves and remove watch and jewelry.
- Wet and soap hands thoroughly using warm water.
- Wash entire surface of hands.
- Scrub under nails.
- Lower hands in sink to allow soapy water to drain off hands; then rinse from wrist down to fingers.
- Dry carefully with a clean towel.
- Be careful not to rub nose, eyes, or mouth after hand

washing. **ALCOHOL-BASED HAND RUBS**

Washing one's hands with soap and water is always preferred, but if not available or hands are not visibly soiled, using hand sanitizer is acceptable. I would recommend having a bottle of hand sanitizer close at hand when you are coming in close contact with others on a frequent and regular basis. It is good protection for you and those whom you are visiting. It should be noted that if hand sanitizer is utilized in the absence of soap and water, one should wash hands at the first opportunity.

TUBERCULOSIS (TB)

WHAT IS TB?

Tuberculosis (TB) is a disease caused by germs that are spread from person to person through the air. TB usually affects the lungs, but it can also affect other parts of the body, such as the brain, the kidneys or the spine. Without treatment, a person with TB can die.

WHAT ARE THE SYMPTOMS OF TB?

The general symptoms of TB disease include feelings of illness or weakness, weight loss, fever, and night sweats. The symptoms of TB disease of the lungs also include coughing, chest pain, and bloody phlegm (the coughing up of blood). Symptoms of TB disease in other parts of the body depend on the area affected.

HOW IS TB SPREAD?

TB germs are put into the air when a person with TB disease of the lungs or throat coughs, sneezes, speaks, or sings. These germs can stay in the air for several hours, depending on the environment. Persons who breathe in the air containing these TB germs can become infected. This is called latent TB infection.

HOW IS TB DISEASE TREATED?

TB can be treated by taking several drugs for 6 to 12 months. It is very important that people who have TB disease finish the medicine, and take the drugs exactly as prescribed. If they stop taking the drugs too soon, they can become sick again; if they do not take the drugs correctly, the germs that are still alive may become resistant to those drugs. TB that is resistant to drugs is harder and more expensive to treat. In some situations, staff of the local health department meets regularly with patients who have TB to watch them take their medications. This is called directly observed therapy (DOT). DOT helps the patient complete treatment in the least amount of time.

WHY IS TB A PROBLEM TODAY?

Starting in the 1940s, scientists discovered the first of several medicines now used to treat TB. As a result, TB slowly began to decrease in the United States. But in the 1970s and early 1980s, the country let its guard down and TB control efforts were neglected. As a result, between 1985 and 1992, the number of TB cases increased. However, with increased funding and attention to the TB problem, we have had a steady decline in the number of persons with TB since 1992. But TB is still a problem; more than 14,000 cases were reported in 2005 in the United States.

CHAPTER 7 - THE NEEDS OF THE DYING - CONCEPTS OF DEATH, DYING AND GRIEF

Dying is not just a physical experience. It is also a spiritual, emotional, and social experience. It

has far-reaching implications for patients and families.

There is a jolt that comes with the fact that our days or the days of a loved one are numbered in weeks or months, rather than years. We may shake our head attempting to clean out our ears thinking we did not hear correctly when a terminal diagnosis is given. Yet, the reality is there.

Louis Heyse-Moore, in his book, *Speaking of Dying*, notes

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that in these situations often "our emotions are intimately connected with survival." Even though we as humans may be old and/or ailing, there is a strong desire to cling to life.

Heyse-Moore goes on to innumerate several emotions that I feel based on my years in hospice work will give us a useful glimpse into what the dying are thinking and feeling. No list is likely all-inclusive, so in the midst of Moore's inventory I will insert some helpful insights from Elisabeth Kubler-Ross. In combination these will be very helpful in aiding us in understanding the dying and their needs.

DENIAL

Heyse-Moore begins with anger, but Kubler-Ross precedes anger with thoughts and feelings of denial and isolation. I will focus on the denial aspect here as it has been my experience that isolation can and does weave itself in and out of all the following feelings and emotions at various times. Anyone who has worked with the dying can identify with Kubler-Ross¹ statement: "Among the over two hundred dying patients we have interviewed, most reacted to the awareness of a terminal illness at first with the statement, 'No, not me, it cannot be true.'"

Even though the mortality rate is one hundred percent, even though people get sick and die, there is something within us that makes us feel we can beat the odds, it won't happen to me. Perhaps the younger the person getting the terminal diagnosis, the more true this is. There are thoughts that perhaps records were mixed up or the doctor is just plain wrong. Is one in denial over a terminal diagnosis?

Louis Heyse-Moore, *Speaking of Dying: A Practical Guide to Using Counseling Skills in Palliative Care* (London: Jessica Kingsley Publishers, 2009), 94.

⁵² Elisabeth Kubler-Ross, *On Death and Dying* (New York: Scribner, 1969), 51.

⁵³ Craddock, 44.

Perhaps one of the most telling signs of denial is that of silence.⁵³ It has been my experience that a couple of aspects are helpful to keep in mind here. First, the denial can ebb and flow. One may think the patient is coming to grips with the diagnosis today

and then tomorrow they demand more tests be run to prove all are wrong. Secondly, if family is in denial, this adds fuel to the patient's fire of denial and the diagnosis will be harder to accept.

ANGER

Moving on to anger, the first of Moore's enumerated emotions. He writes, "In a way it is surprising that anger isn't more overt in the dying....More prevalent is partially suppressed anger which makes itself known in many ways: irritation, grumbling, brooding, self-destructiveness, bitterness, coldness, and so on."

Of course there is the overt anger, the outbursts of yelling and screaming and throwing things. A time or two in my hospice work I have been on the receiving end of these. I know it is not personal. In the midst of the receipt of the terminal diagnosis there is the action and reaction of lashing out and blaming God, spouse, children, the dog, the mailman, and anyone else with whom one has crossed paths.

Again, it is not personal. However far more often than not, Heyse-Moore is correct; the anger is muted and takes quieter forms. The dying may turn inward and be churning inside. The coldness, bitterness, brooding, etc. that he mentions often simmer and may come out in external ways, but often they are kept internal and eat away at the individual because of all that has been lost.

PAIN

Intricately connected with anger is pain notes Heyse-Moore. The reference here is not to physical pain, but the emotional variety. He writes, "Nevertheless, underneath the anger is pain, pain that may be so unbearable that she doesn't want to let it into awareness, pain at the prospect of losing her life, her loved ones, her career."

Those dying are not only left with the pain of the diagnosis, but all that it represents. They are not only losing what is, but also what was to be. Not only will they be losing their job/career, but will lose a large part of what gave them meaning and purpose, what made them feel like they were contributing and making a difference. Not only will there be the pain of the loss of their spouse, but they will not be able to enjoy retirement together and growing old together. Not only will they be losing their children, but they will never have the joy of being called grandpa/grandma.

⁵⁴ Heyse-Moore, 96.

I still remember the pain on my dad's face and in his eyes when he said, "I would give anything if I could just go out in the yard and play catch with Josh (my son)." My dad

had done this countless times with my brother and me and desired to do so with the next

generation. However, Multiple System Atrophy had robbed him of the use of his legs. The dying anguish in pain of what is lost and what they are losing.

BARGAINING

Following pain, Kubler-Ross notes the dying often involve themselves in bargaining. Bargaining isn't always, but is usually with God. The dying will assess that if God didn't respond to my anger, perhaps He will to a softer approach. The dying will promise a myriad of things relating to being better or doing better. Most likely these promises would be in exchange for a little more time.

These 'being better' and 'doing better' are likely issues the dying person is struggling with and is concerned. These need to be dealt with even if more time is not given. There is reward to be found in being at peace with oneself, with others, or with any institution or situation from which one may feel she/he has distanced oneself.

ANXIETY

Anxiety is another emotion the dying deal with notes Heyse-Moore. In hospice care, those with chronic breathing issues are most likely to suffer with anxiety, those with lung cancer or chronic obstructive pulmonary disease (COPD), though not exclusively. Heyse-Moore writes:

In palliative care, anxiety may be related to the following:

- physical suffering - such as severe pain or breathlessness
- loss - of health, body parts, mental faculties, sexuality, mobility, control, status, beauty, family and friends, work
- re-evocation of unhealed past memories
- the prospect of death - extinction of life, and painful death or going to hell.

Anxiety wears on one mentally and emotionally. It causes the mind to race and one worries and frets and imagines all kinds of things. All that is imagined leads to fear and the dying are caught up in a storm they believe will engulf them. Anxiety not only wears on one mentally and emotionally, but physically as well. Anxiety leads to restlessness and often sleeplessness. When one is drained of energy problems are multiplied.

DEPRESSION

⁵⁶ Kubler-Ross, 93-95.

Depression is another emotion the dying wrestle with according to Heyse-Moore. It may not be clinically diagnosed depression. He notes that palliative care patients may not

match up with such criteria, but they suffer from depression none the less. Leaning of the work of J. Endicott, he writes, "Thus, instead of change of weight, she put in, 'tearfulness and depressed appearance'; for sleep changes, she substituted, 'social withdrawal or decreased talkativeness'; for loss of energy, 'brooding self-pity, or pessimism'; for thinking difficulties, 'cannot be cheered up, doesn't smile, no response

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to good news or funny situations'."

I have always noticed when my hospice patients appear depressed it is as if the life has been 'sucked' out of them. To a certain degree, they seem to have shut down and to a degree are not thinking or feeling. Their hopes have been dashed leading to meaninglessness and despair. There is the attitude of 'what's the use, all is lost'.

Heyse-Moore notes as well how depression is often seen to be the result of 'interned anger' and or 'unresolved grief. He adds that there is often no short supply of these with the dying. He could not be more correct. Shortly after a terminal diagnosis is received, one rarely knows how to handle all that comes with it. He/She is often unsure what to say or do or think or anything. And what makes matters worse, those they know and love do not know what to say or think or do or anything. The dying are often shut up in their own world because others are afraid to use the 'd' word or let the dying know that it is ok to use the 'd' word. When this is the case, there is nowhere for hospice patients to turn except inward. That being the case, depression is prominent.

SUICIDAL FEELINGS

Suicidal feelings are common with hospice patients according to Heyse-Moore, although rarely carried out. This is certainly understandable with the blow that has been dealt to them. 'What's the use of going on, I'm dying anyway.¹ 'I'm dying; why not hurry the process along?' 'I don't want to be a burden and I'm of no use to anyone.'" Thoughts such as these among patients are not uncommon in hospice.

What motivates or causes suicidal feeling in the dying? Heyse-Moore notes the following:

⁵⁸ Ibid, 104.

- to escape unbearable pain or other physical symptoms
- to escape psychological pain such as depression
- as part of the syndrome of clinical depression
- a response to loss of physical abilities - paralysis, loss of speech, incontinence
- a considered anticipatory response to a progressive fatal illness such as motor neuron disease
- a wish to make others close to the suicidal person suffer - 'Look at what you made me do, it's your fault'

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- the ultimate form of self-destructiveness in people with extreme self-hatred -"I'm worthless, the world would be better off if I were dead"
- a primitive, instinctive regression - patients who take to their bed, refuse to eat or drink and become mute
- sacrificial - the person who gives up his life for another.

In my experience as a hospice chaplain, I would add another, a tremendous fear of being alone. What if there comes a time when no one will be with me and walk with me on this journey? This can be seen as darkness worse than death itself.

Suicidal feelings are prominent with the dying, but thankfully as Heyse-Moore pointed out that they are seldom carried out. That fact however should not be a cause for us caregivers to relax. The dying struggling with such feelings should cause concern in us and move us to definitive action to aid them.

GUILT AND SHAME

Two additional related feelings in the dying according to Heyse-Moore are guilt and shame. He notes, "Guilt is the feeling associated with the belief that we have done wrong whether by commission or omission. Shame is the feeling that we are wrong or bad or deficient in ourselves."

I might speak to the latter first. If not a strong cause, then at least a contributing cause of shame is that of self-esteem, or more appropriately, lack thereof. We have all noticed people beating themselves up over a variety of issues. They see themselves as being inept, insignificant, not worthy of love/care/concern, and the like. All these can fester over a life time, whether long or short, and result in one seeing him/herself as far less than God and others see them. Heyse-Moore writes in this regard, "Such themes come home to roost in the dying - they may see their impending death as their ultimate failure."⁶³ What a shame.

Guilt can be good in the spiritual realm leading to repentance or in the relational realm leading to reconciliation; however in the context of blame with the dying, there is no value. Even if perhaps warranted, such as a smoker blaming themselves for their lung cancer, there is likely nothing beneficial to be gained. The same could be said for IV drug users and homosexuals dying with aids. It is past time for all that. On the other hand, there are those who say, "If only I had been this or done that, things would be different.' In dwelling on such scenarios, those dying only succeed in pushing themselves further into darkness and hopelessness.

GRIEF

Grief is a feeling that is always before the dying. Heyse-Moore suggests these are at least some of the issues:

- The dying person may have been recently bereaved of a family member.
- There may be unresolved past losses such as of a son or daughter dying in childhood.
- Anticipatory grieving - the dying person grieves for the family he will lose when he dies, his family begins to grieve for him as his health steadily deteriorates. Sometimes, with slowly progressive illnesses such as dementia, family members may slowly distance themselves over months or longer from someone they feel is no longer the person they knew. In a sense, he has become dead to them while his body still lives.
- Social losses - of status, money and work.
- Bodily losses - losing a leg, a breast, an eye or any other body part. Furthermore, individual organs will connote losses related to their *raison d'être*. Thus, a mastectomy may result in feeling of loss of sexual attractiveness.
- Loss of function - becoming, for example, paraplegic, blind or incontinent.⁶⁴

There is never a day, likely, that the dying are not experiencing grief and loss, especially when their disease is progressing at a rapid rate. Every day is the unwanted anticipation of what will disappear today. 'What will I not have today that I had yesterday?' Loss upon loss must be faced. One by one, things are being snatched from their life with no end in sight. This is a fearful way to exist.

CHAPTER 8 - VISITING THE HOSPICE PATIENT AND FAMILY

VISITING THE PATIENT AT HOME

Call the family before your visit to confirm

Calling before you visit will build trust and spares inconvenience. For instance, a patient may be unexpectedly hospitalized; if the family knows that you phone before visits, there is one less responsibility on their shoulders. Confirming phone calls also provide additional opportunities to talk with the patients and caregivers.

What to do during the visit

While you are visiting the patient or family, you could write letters for the patient, give a hand massage, tidy-up, walk or feed the dogs, run errands, play cards/games, fix lunch, look at photographs, share hobbies, rent a movie, or read to the patient. One of the most important things to know is when your visit is over. Remember, the patient will not have the same energy level as you do.

If you are providing respite care/caregiver relief for the family, bring something along to occupy your time in case the patient is tired or sleeping.

Let the patient or family control your visit

When you arrive, ask: "What may I do for you today?" If the patient does not have any ideas,

you may suggest something. "Would you like me to read to you?" or "May I put the dishes in the dishwasher for you?" You may just begin talking and let the conversation lead to your suggestions. Remember if the family is involved in some project, keeping out of the way is often the best thing to do.

VISITING THE NURSING HOME HOSPICE PATIENT

- Observe facility rules (such as sign in at the front desk, observe visiting hours, parking only in designated areas)
- Remember you are working with 2 families, the patient's family and the nursing home staff. Be open to talk to staff if they have concerns about the patient.
- If you bring food, such as candy, cookies, or cake to the patient, check with nursing home staff to ensure the patient is not on a special diet.
- If the patient needs physical assistance, alert the nursing home staff to help.
- Try to schedule your visits at optimum times for the patient. Find out if the patient takes meals in the cafeteria. Does the patient have a tendency to nap in the morning or afternoon? Some patients may have regularly scheduled therapy. You may want to visit at times when the patient is alone and would appreciate company. Work out a schedule.
- Remember, for your patient, the nursing home is home.
-

VISITING THE DYING PATIENT The following suggestions are actual comments made by terminally ill patients during their last hours of life.

- Show that you still consider the person among the living. It's all right to be frank about what you are feeling, but don't make the dying person feel isolated or deserted.
- Don't expect to make things better. The patient doesn't expect solutions but does appreciate your presence.
- You don't need an agenda for the visit. Just be willing to follow the ill person into whatever context is desired. Learn to "be there." Silence is fine. You may sit with your friend, read aloud, read to yourself or meditate.
- Be yourself. Say what you are feeling. It is perfectly acceptable to say, "I feel scared and I don't know how to act around you right now." Let the dying person be real with you. Show that you will listen even when things aren't going well.
- Don't be hesitant or afraid to cry.
- If the patient wants to talk, don't change the subject, even because it makes you feel uncomfortable.
- Support the dying person's sense of control.
- Try to consider what death means to this person. Death may mean release or separation. Whatever it means, it is always individual and should be respected.
- Be prepared to confront your own fears before or after the visit. Confrontation with your own mortality is inevitable.

- Remember to touch. A hug, hand massage, or other caring gesture may express what you can't put into words. Be careful... get permission!
- Encourage reminiscing to remind the patient of the value of his/her life. Using photos is a great idea.

Know your own limits and honor them in giving. Ministering to the dying and their families is rewarding, but can be difficult. If you feel overwhelmed or in need of support yourself, speak to your pastor.

PRACTICAL TIPS TO HELP THOSE FACING A SERIOUS ILLNESS

When someone is facing a serious illness, we often feel helpless. Here are some practical tips to help written from the patient's point of view.

- Don't avoid me. Be the friend, the loved one, you've always been.
- Touch me. A simple squeeze of my hand can tell me you still care.
- Call me to tell me you're bringing my favorite dish and what time you are coming. Bring food in disposable containers so I won't worry about returns.
-
- Weep with me when I weep. Laugh with me when I laugh. Don't be afraid to share this with me.
- Call me before you visit, but don't be afraid to visit. I need you. I am lonely.
- Help me celebrate holidays (and life!) by decorating my room or home, or bringing me tiny gifts of flowers or other natural treasures.
- Help my family. I am sick, but they may be suffering.
- Be creative! Bring me a book of thoughts, taped music, a poster for my wall, or cookies to share with my family and friends.
- Let's talk about it. Maybe I need to talk about my illness. Find out by asking me: "Do you feel like talking about it?"
- Don't always feel we have to talk. We can sit silently together.
- Help me feel good about my looks. Tell me I look good, considering my illness.
- Please include me in decision-making. I've been robbed of so many things. Please don't deny me a chance to make decisions in my family or in my life.
- Talk to me of the future. Tomorrow, next week, next year. Hope is so important to me.
- Bring me a positive attitude. It's catching!
- What's in the news? Magazines, photos, newspapers, verbal reports, keep me from feeling the world is passing me by.
- Just send a card to say: "I care."
- Pray for me and share your faith with me.
- Tell me what you'd like to do for me and, when I agree, please do it! *From St.*

Anthony's Hospital "Make Today Count"

BOUNDARIES

CREATING PERSONAL BOUNDARIES

Working with patients who are terminally ill can be physically and emotionally tiring. We care for patients who need to express their sadness or anger. Patients and families will expect a lot of you and you will expect a lot of yourself.

Sometimes, though, patients and families do not know where to draw the line on how much you can give them. They forget that you may see other patients and families. They forget you have a life outside of their home.

If you lose perspective on your role, you may:

- Experience burnout
- Lose your sense of emotional and mental balance
- Become stressed and tired or angry
-

This is especially true if the patient and family are stepping over boundaries that you thought you had clearly identified and defined. To maintain a sense of emotional and mental balance, you must create boundaries.

WHAT HAPPENS WHEN YOU DO NOT SET BOUNDARIES?

When a patient and family are dealing with a terminal illness and choose hospice, the family's social system changes. In fact, it will never be the same. The family member who is ill will die. That will change the family's structure. The hospice team will come and be a great help. Eventually, though, they will go, which also changes the structure. When you do not set boundaries, you can be put into a position to assume the role of a family member. You might choose that role. You might inadvertently assume the role. Or, the family might try to force the role on you.

Either way, the relationship becomes unhealthy. You get tired and stressed. The family becomes too dependent on you. They lose their ability to adjust to the many changes affecting their lives.

When you or a patient and his or her family do not have clear boundaries, you will have trouble. The family may:

- Challenge the care/services you provide
- Seek services beyond the scope of your supportive role
- Initiate a relationship that goes beyond what you are expected to provide
- Become disappointed and upset when others do not do the extra things you

do

Some people are better at setting boundaries than others. You may have a problem with boundaries if you:

- Think you can or like to solve other people's problems
- Let patients and families become too dependent on you
- Have a hard time saying "no" to others

BENEFITS OF SETTING BOUNDARIES

Your ability to set boundaries has many benefits. When you set boundaries, you experience:

- Less tension and mental stress
- A greater ability to cope with your own loss issues
- A lower likelihood of being accused of an inappropriate relationship
- The ability to provide more objective care
- A more positive working experience
- Less likelihood of legal liability
- An ability to adhere to professional practice guidelines
- More personal time
-
- An ability to role-model boundary definitions to other volunteers, patients, and families

The following checklist offers several signs of crossing boundaries. If you find yourself in a situation and you are not sure if you are crossing boundaries, use this checklist as a "test."

YOU KNOW YOU ARE CROSSING BOUNDARIES WHEN:

- You feel like you have to stay near the phone in case a patient/family calls.
- You find yourself gossiping with the patient/family.
- You spend more time than usual on visits with a patient and family.
- You visit the patient even when you are not scheduled.
- You bring your own family to meet the patient.
- You accept personal gifts from patients and families.
- You buy gifts for individual patients and/or families.
- You share personal problems with patients and/or families.
- You share information about one patient/family with another patient/family.
- You loan money or personal belongings to patients and/or families.

- You transport the patient and/or family in your own car
- You take someone into a patient's home without the approval of the patient.

SOME UNIVERSAL BOUNDARIES

What follows are some universal boundaries:

- Do not work with patient/family to be their only volunteer
- Do not give your home phone number, personal cell phone number to the patient/family until you trust it will be used only when appropriate
- Do not make promises for others
- Do not make promises that violated federal, state, regulatory, law/policy or that cannot be fulfilled
- Do not promise to "be there" when the patient dies or promise to be at the funeral
- Do not try to do it all. Partner with others to solve issues, meet needs
- Do not assume responsibility for areas of care outside your area of expertise
- Do not voice your personal opinions about patients and family members

TIPS for SETTING BOUNDARIES

Setting boundaries sometimes requires you to be tough. Often, when you set a boundary, you feel you are letting someone down. So, you may feel ashamed or afraid. You have to be firm. You have to believe that what you are doing is for everyone's benefit. When you know you need to set a limit with someone:

- Be clear with your words
- Use as few words as possible
- Rehearse the situation with your pastor or another care-giver
- Above all, be calm, not angry
-

CHAPTER 9 - COMMUNICATION SKILLS

COMMUNICATION INCLUDES

- Listening
- Speaking
- Eye contact
- Body language
-

LISTENING

There is more to listening than waiting to speak. Listening is the most important and most difficult of all skills needed to help patients and families and is the foundation of good care. True listening is a form of hospitality, making space in your schedule for the concerns of others. It demands energy and commitment, but does not need to be unduly time consuming.

Silence allows a person to analyze his or her feelings. Silence must be friendly and relaxed and the listener should signal that the silence is comfortable to him or her. Sometimes after a period of silence the question, "What are you thinking about?" bring up a relevant topic for discussion.

HELPFUL HINTS WHEN LISTENING

- Maintain eye contact
- Practice patience. Let the person tell his/her story in his/her own way
- Keep your word!
- Share yourself, but concentrate on listening
- Let the person know you feel honored to listen to his/her thoughts
- Let the person set his/her own pace
- Listen for both verbal and non-verbal messages
- Be aware of your own body language and verbal messages
- Try to give the person your full attention
- Ask questions

AVOID

- Looking around the room to see what else is going on
- Interrupting or finishing a sentence for the other person
- Talking about what someone else told you in confidence
- Talking excessively about yourself
- Saying - "You shouldn't feel that way!"
- Pretending you have all the answers
- Assuming you have all the facts
- Looking horrified when you are told about a problem
- Make hasty judgments

Taken from Lynda D. Elliott, The Counsel of a Friend (Nashville: Nelson, 1993)

LISTENING IS A SKILL AND CAN BE LEARNED

Dr. Edward Wakin of Fordham University offers these guidelines for better listening.

Be interested and show it	Genuine concern and a lively curiosity encourage others to speak freely. Interest also sharpens your attention and builds on itself.
Tune into the other person	Try to understand his/her viewpoint, assumptions, needs and systems of beliefs.

Hold your fire	Avoid jumping to conclusions. Hear the speaker out. Plan your response only after you are certain that you've gotten the whole message.
Look for the main idea	Avoid being distracted by details. Focus on the key issue. You may have to dig hard to find it.
Watch for feelings	Often people talk to "get something off their chests". Feelings, not
Monitor your own feelings and point of view	Each of us listens differently. Our convictions and emotions filter, even distort what we hear. Be aware of your own attitudes,
Notice nonverbal language	A shrug, a smile, a nervous laugh, gestures, facial expressions and body positions speak volumes. Start to "read" them.
Give the other person the benefit of the doubt	We often enter conversations with our minds already made up, at least partially, on the basis of our experience. Prejudgments can shut out new messages.
Work at listening	Hearing is passive. Our nervous system does not work. Listening is active. It takes mental effort and attention.
Get feed back	Make certain you are really listening. Ask a question. Confirm with the speaker what he/she actually said.

ACTIVE LISTENING TECHNIQUES

- Show external signs of listening by eye contact, nodding appropriately, smiling, gestures, and posture.
- Ask open-ended questions: "I don't think I understand." Or "what do you mean?"
- Be careful that your specific questions are to clarify what the other person wants to communicate, not what you hope he or she is leading to.
- Allow time for silence and thought; calm silence is trust building. Learn to feel comfortable with silence, silence is okay.
-
- Observe signals that a person wants to talk: leaning forward, seeking eye contact with you, stealing glances at you, etc. Invite the person to talk.
- Do listen within the framework of the other person's purpose; seemingly light social conversation may be leading to a concern; it may also be a need for light social conversation.
- Listen just as intently to the person's nationality, color, religion, experience,
- conditioning and feelings as you do to words.
- Use words that the speaker uses as much as possible, but be natural.
- Particularly when the person is able to speak only in incomplete ideas, repeat back to him or her the gist of what he/she says briefly so he/she can realize how far he or she has progressed with the idea and can continue further if he or she wants to.
- If words expressing feelings are used, form a question such as "you said that makes you feel alone, what do you mean?" It is the patient's right to expand or not.

HOW TO BUILD A RAPPORT

(a relationship of mutual trust or emotional affinity)

Place yourself at the same level as the person you are visiting. Sit down, if only for a few minutes. Say the person's name. Establish with the person how he or she wishes to be addressed. A first name may be preferred, or it may be experienced as patronizing to use the first name. A 'pet' name, for instance is usually the prerogative of a special relationship. Hearing your own name spoken is very grounding, especially when spoken by one in the same position as the person with whom you are building rapport. It feels particularly good to be known and called by name when you find yourself dependent and in a depersonalizing environment.

- Offer the opportunity for privacy and uninterrupted time for unhurried discussion. Several brief discussions may be better than a single, lengthy one.
- Be yourself. Be ordinary. Take time to settle in. Let the person take your measure. This is a relationship, it cannot be one-sided.
- Observe and match mood and behavior. Do not pit your peace against anger, your exuberance against depression, your openness against protectiveness.
- Be guided by the patient about how much contact is comfortable. Some people want eye contact or physical contact. Others feel that it is an intrusion.
- Match behaviors by breathing or talking at the same pace or by sitting in the same position as the person with whom you are building rapport. It creates the feeling that you are the 'right kind' of person.
- Find common ground (explore interest, patient's preferences in music, patient's background).
- Always acknowledge heaviness, sadness, anger or frustration before any further issues are raised.
-
- Be specific about how you can help and what is going to happen.
- Set boundaries. Boundaries help people to feel safe: the patient needs to know what he or she can and cannot expect from you.
- Establish a time frame and follow through. "I'll see you again next week."
- Look for opportunities to discuss death and funeral arrangements. Not speaking of death suggests that it is too terrible to be spoken of.
- Be respectful. Helpers are ideally consultants who enter the lives of others with great respect.
- Recognize signs that the person is at ease. For example, he or she may match some expression, word, laughter, movement, or posture of yours. Or the person may express agreement verbally. You may lead': make a suggestion, guide, or ask a question.

Source: "Medical Care of the Dying," 2nd Edition, Victoria Hospice Society, Victoria, British Columbia

TALKING WITH THE PATIENT AND THEIR FAMILY

Use these topics to begin and encourage conversation

- Holidays and celebrations
- Memorabilia (i.e., photos, albums, scrapbooks, souvenirs)
- Plants/growing plants/gardening
- Recipes and favorite foods
- Family traditions
- Pets
- Literature: books, poems and stories
- Songs, dance, opera
- Sports heroes
- Dreams
- Travel and trips taken
- Changes in life: war, depression, jobs, moves, natural disasters
- Current events
- Movies

Use questions to evoke memories, feelings, thoughts and attitudes.

- What are the happiest days of your life?
- What is your most enjoyable holiday?
- How does your family celebrate the holidays?
- What was your home life like as you grew up? How has it changed?
- Do you remember your first day of school?
- What were your high school years like?
- Do you remember your first girl/boyfriend?
-
- What kinds of books do you like to read?
- Tell me about your most embarrassing moment.
- Tell me about your father...mother...sister...brother...best friend.
- What is your favorite spot for peace and reflection? Describe it.
-

CHAPTER 10 - CARE, COMFORT AND SYMPTOM MANAGEMENT

SIGNS AND SYMPTOMS OF IMPENDING DEATH

Many decades ago, death was taken out of the home and moved into the hospital setting as was noted above. As a result, most families are not familiar with the signs and symptoms of impending death. They will look to hospice professionals to provide this information.

The dying process is different with each patient. For some, it may take minutes. For others, it may take hours or even days. There is no natural order of things that every person goes through. In fact, some patients fluctuate back and forth from symptom to symptom. There are even times when a patient's symptoms reverse and the condition improves. However, this is typically followed by a quick progression back to the symptoms. Death will often follow soon after. The following outlines common signs and symptoms of impending death.

PSYCHOSOCIAL CHANGES

- Diminished desire for communication due to weakness
- Loss of interest in surroundings
- Difficulty with speech
- Confusion
- Hallucinations
- Disorientation
- May report seeing others who are already dead
- May be talking with unseen persons

PHYSIOLOGICAL CHANGES

- Decreased need for food and fluids
- Difficulty swallowing
- Decreased and wavering level of consciousness
- May pick at the air or bedclothes
- Sleeping more
- More lethargic
- Inability to arouse as easily
- Semi-responsive or unresponsive
- Increased weakness
- Increased agitation (terminal agitation)
- Decreased sensation, reflexive action
- Change in breathing patterns:
 - Periods of apnea - long periods between breaths
 - Labored breathing, Shallow, gasping breathing
 - - o Increase or decrease in respiratory rate
 - o Cheyne-Stokes respirations (a breathing pattern during which the patient stops breathing for 10-60 seconds followed by gradually

increasing depth and frequency of respirations)

- Skin changes:
 - o Cold to touch; extremities cool, clammy
 - o Increased temperature above waist
 - o Progressive mottling
 - o Gray pallor; pallor around mouth
 - o Cyanotic nail beds
- Increased secretions - may collect in throat ("death rattle")
- Decreased urinary output
- Rapid pulse, decreased blood pressure, absence of peripheral pulses
- Incontinence
- Relaxation of eyelids and/or lower jaw
 - o Eyes do not focus, fixed gaze

THE "GOOD" DEATH

The way a person lived his or her life is often reflected in the way that he or she dies. For example, a person may have fought to overcome adversity and challenge during his/her life. Therefore, he or she may fight to live right up to the last breath. Another person may have been angry and resentful throughout life. He or she may have alienated him or herself from family and friends. The patient may continue these patterns throughout the course of his or her illness and death.

CREATING A "GOOD" DEATH FOR THE PATIENT

When we talk about a "good" death, we are talking about a death in which the patient is relatively at ease. The following table outlines some issues the hospice team and other caregivers can address with the patient in order to make her death the best possible.

Physical Comfort	<ul style="list-style-type: none"> • The team offers adequate pain control • The team offers effective symptom management
Emotional Well-being	<ul style="list-style-type: none"> • The patient feels that his/her life had meaning • The patient's sense of identity and dignity is preserved • The patient is able to complete unfinished business and achieve last wishes • The patient remains emotionally connected and able to express feelings (anger, fear, hope, guilt, joy, love, etc.) • Internal and external conflicts are reduced • Important relationships are preserved or restored
Spiritual Serenity	<ul style="list-style-type: none"> • The patient accepts him/ herself, others, and the impending death • The patient lets go of this world (people, possessions, and life)

TASKS OF THE DYING

When a person learns that he/she is dying, he/she typically involves him/herself in preparation. We call this preparation "final tasks." While every person is unique, there are five tasks that dying people typically attend to:

1. GETTING AFFAIRS IN ORDER

The patient takes care of practical tasks such as:

- Preparing or updating a will
- Making funeral and burial arrangements
- Getting finances in order
- Making sure family know how to find investment and insurance information
- Ensuring the welfare of family and friends left behind

Not all patients will choose or be able to address these issues. Some may wait until it is too late. They may leave these matters to family. The hospice team as well as other caregivers can help by educating the patient on the importance of completing these tasks and empowering him or her to do so.

2. MAKING MEDICAL CARE DECISIONS

The patient should consider various treatment options in concert with family, medical professionals, and pastor. For example, he or she will decide whether to consider curative care or to concentrate on palliative care. The patient will decide whether to maximize the quality of time remaining or the quantity. Unless the patient is incapable of decision making, the team should include him/her in all medical care decisions. This will help create a sense of feeling valued as a human being.

3. PLANNING FOR THE IMMEDIATE FUTURE

When a person is facing death, he/ she will often wonder, "What do I want to do with the time I have left?" There may be a special trip or experience that he/she wants to accomplish. There may be a special person he/ she wants to see. He/ she may desire quality time with family. The team should:

- Encourage the patient to identify and prioritize wishes and desires
- Support efforts to accomplish goals

4. COPING WITH EMOTIONS AND PHYSICAL CHANGES ASSOCIATED WITH END OF LIFE

A dying patient experiences a wide variety of feelings and emotions. He/ she experiences many changes in his/ her physical condition. Feelings of vulnerability, grief, anger, fear, and worry can surface as the patient experiences:

- Loss of control
- Increasing helplessness
- Dependency
- Spiritual uncertainty
- Concern for the welfare of loved ones and friends
-

5. LETTING GO

Each person's experience and response to death is unique. A person's death reflects:

- Personality

- Beliefs (cultural, religious, and personal)
- Life experiences
- Expectations

The end-of-life is a time of difficult challenges. It can, however, also be a time of personal growth with opportunities for profoundly meaningful experiences. Letting go becomes easier for a patient as he/she is able to:

- Accomplish necessary tasks
- Complete unfinished business
- Release him/herself of guilt and personal judgments
- Feel assured that his/her family and loved ones will be all right after he or she leaves

OPPOSING TASKS OF FAMILY MEMBERS

While the patient is trying to complete the tasks of dying, the family is often involved in opposing tasks. For example, the family is:

- Holding on while the patient is trying to let go
- Providing care for the patient's increased dependency needs while supporting the patient's continued need for autonomy
- Taking care of the patient's needs instead of taking care of their own needs
- Redistributing family roles and responsibilities while not wanting to call attention to the fact that the patient has lost the ability to do things he or she used to do

The team has to support the family. But, at the same time, they have to help the family see that not all of their actions may be in the best interest of helping the patient through the tasks of dying.

UNFINISHED BUSINESS

Many patients have unfinished business. Unfinished business is something that is incomplete in the patient's life. This incomplete business deprives the patient of a sense of peace. Unfinished business might involve:

- A personal unmet desire or goal
- A regret or guilt over something unresolved between the patient and another person

HOW THE CARE TEAM CAN HELP

When the patient has an unmet desire, the team might explore the possibilities of planning for and accomplishing a particular goal. At the very least, if the goal cannot be

met, the patient will benefit from supportive listening and acknowledgment of the pain of unfulfilled dreams. Life review with the patient can identify goals and dreams that were realized. This will help the patient re-focus on positive accomplishments. A patient might also

have guilt or regret over unresolved relationships. He or she may want to heal old wounds or bridge the distance that has grown between him/her and a loved one. This is a natural part of preparing for death. When possible, the patient and family may benefit by talking directly with each other about unresolved issues. If personal face-to-face contact is not possible, you might encourage them to use the phone, e-mail, or letters.

If the patient is unable or unwilling to express feelings to others, then encourage him/her to be compassionate with him/herself. Encourage the patient to forgive others and forgive him/herself for the things he/she did not do and for the things he/she felt that should have been done.

CHAPTER 11 - THE CHURCH'S CARE

Again, caring for the dying and their families takes many hands. In addition to the experts, the church is uniquely positioned to add to the equation what no one else can. It is our duty, our obligation, our privilege. John Wesley noted in his sermon 98, 'On Visiting the Sick,' "But these things you must do in your own person; you see they cannot be done by proxy."⁶⁵ Surely we cannot but take from Wesley that caring for the sick (or dying) must be done in a very tangible way. It ought to be done in the very same manner as Jesus when He reached out and touched the untouchable with love and compassion.

Again, I must mention that dying is much a spiritual matter and as such, the family of faith is needed as death approaches. In their book, Craddock, Goldsmith, and Goldsmith could be seen as being critical of the church in her neglect of the dying and their families, however they write, "If there is criticism in our words it is of the church's forgetfulness of its own treasures that can be brought to the ministry of the dying." The church must not fail to realize what we possess to care for our own and others. Craddock and his co-authors note that caring for the ill was a part of the Church from very early as noted above.

As we believers ponder caring for those within the body of Christ, Allen Verhey makes some very pointed comments. He writes, "It is not so much that Christians gather as that they are gathered. They come together in response to the call of God." I do not believe it is unfaithful to Verhey's comment to state that when there are those who cannot come inside the four walls of the church and gather with us, we must be gathered to them, go to where they are. We are God's people wherever we meet. And wherever we meet, we care for one another. We minister to 'the least of these.'

Verhey cuts to the heart of the matter again when he states, "It means learning to rejoice with those who rejoice and to weep with those who weep. It means learning that sickness, withering, and dying cannot separate us from the love of God and need not alienate us - or another - from the community. It means learning to care and to be

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cared for. Here we learn to love." Amen, let it be so. In this we portray what it means to be the

body of Christ and to fulfill His call and purpose.

John Wesley, *The Complete Works of John Wesley*, Vol. 7, Sermon 98,135 (*The Master Christian Library*, Version 8, CD-ROM).

⁶⁶ Craddock, 40.

⁶⁷ Verhey, 300.

⁶⁸ Ibid, 301.

Craddock and the Goldsmiths illustrate a manner in how the community of faith may provide care in a most unique, but appropriate way since we are the body of Christ. They utilize the acronym TABLE:

In this case, the term 'table' serves both as an acronym for elements or aspects of a strategy as well as a metaphor—indeed more than a metaphor—for the central powerful narrative of our faith: the Eucharist. It is Jesus Christ who invites us to the table: his Table. It is that Lord who we celebrate at the Eucharistic table and our conviction is that as long as we are gathered at that table and focused on that Christ, our ministry to the dying will go forth to all as a comprehensive alternative to anything available elsewhere.⁶⁹

They remind us it is Christ who invites us, as His church, to meet the needs of the dying in a manner that provides greater fulfillment than what the secular arena alone can provide.⁷⁰

TALK

In Craddock's and the Goldsmith's acronym, T stands for talk. I can imagine that when my physical decline becomes more rapid and death is more immanent, I will want a variety of folks around me. I have friends who are unbelievers whom I have enjoyed their company in life, I cannot imagine not welcoming them at the end. They have impacted me and I them and this would offer another opportunity for me to influence them for eternity.

However, I would want and need those around me with whom I share the greatest thing, life in Christ. These authors write, "The talk to which we are invited and to which

⁷¹

we contribute is rooted in a Christology of the Word." They also note, "So the church invites the dying person and gathers itself at the table for talk and deep listening."⁷² They state this is informal, like a gathering around the kitchen table and Christ is present with us "and ready to feed us from his own suffering and strength."

This talk to which we are invited to share together may include the sharing of stories, expressing hopes, and even weeping.

⁶⁹ Craddock, 182.

⁷⁰ Ibid.

⁷¹ Ibid.

⁷² Ibid, 183.

"Ibid.

⁷⁴ Verhey, 325.

⁷⁵ Ibid, 307-15.

This talk to which we are invited to share with the dying includes prayer. Verhey adds that with prayer "we not only commune with God but find new strength - new virtue -for daily life and for dying and caring for the dying."⁷⁴ Verhey reminds us of many aspects of prayer of which we are all familiar; invocation, adoration, confession, thanksgiving, and petition.⁷⁵

One aspect I omitted from the above list because it deserves special notation is that of lament. Verhey describes lament as the "crying out to God and against God in anger and in anguish." I must add that God is not afraid of our questions and questioning. Some of His choicest saints cried out for answers and explanations. Verhey writes, "We marginalize, then, not only suffering but also sufferers. When we make so little room in liturgy for lament, then in their hurt and their anger and their sense of absurdity, sufferers think they sit alone in the congregation."⁷⁷ Or sit alone in their home. Can it be wrong to seek to understand and to be understood? There may be no answers for the dying, but they still need space to cry out to God and perhaps to us and we must be available to listen.

I might add that talk could include song and Scripture. God's word has illuminated the path of the believer all his/her life, it will continue to do so as life draws to a close as it is read and shared. Perhaps when no human words come, God's words are what are called for. Verhey reminds us "in this practice of reading Scripture, the church

⁷⁸
remembers the story of God's grace." We do indeed need grace to live, but perhaps greater grace to die well.

In talk, perhaps there may be times where our presence and touch say it all. Gathering around and sharing the living Word makes not only our living better, but our dying as

AWARENESS

The 'A' in the acronym stands for awareness. There must be an awareness of reality. We are often reluctant to speak of death and dying, but within the church and its fellowship, the truth can and should be spoken and reality embraced. Craddock, Goldsmith, and Goldsmith write, "It is not the medical arena; instead there is unending space for social,
⁸⁰
spiritual, and emotional anxieties to be aired and cared for."

They note that another layer of awareness deals with time and the faith community

⁷⁶ Ibid, 313. "Ibid.

⁷⁸ Ibid, 302.

⁷⁹ Craddock, 182-4.

⁸⁰ Ibid, 184.

⁸¹ Ibid.

"being aware of the messages surrounding them." In dealing with the dying, there may not be a quantity of time, but time should be made; time to listen to stories, memories, questions, complaints, and perhaps even what is left unsaid. They also note in our world of limits that there need be no limits on the patience, gentleness, and kindness coming from the community of faith. After all, we are ones called by God to be aware and make the most of every opportunity. This awareness has no agenda other

than that of the one who is dying and the deserved focus of the church's attention at

⁸²

this special time.

BODY

The Body of Christ is the 'B' in the acronym. Scripture reminds us that when one suffers, we all suffer; this is what it means to be a part of the Body. Craddock and the Goldsmiths note so eloquently, of what it means to be part of the Body. "The body is characterized by the intimate connection of each part with every other part and by the fact that each part is utterly distinct from, but absolutely necessary for the well-being of,

⁸³

every other part."

This speaks volumes to the dying and to the community of faith. If each is absolutely necessary" for the other, then there will never be a time when the one who is dying ceases to be important and vital to the Body. He/She should be reminded that God has meaning and purpose for them until they draw their last breath. The community of faith is reminded that no one no matter how weak should be left out or left behind. We must reach out and embrace all the members. These authors affirm, "The church is the community, the family, the social environment in which individuals who are dying can

⁸⁴

receive the comforting safety net of caring others" In the church every member is somebody and worthy of love and compassion to the very end.

LISTENING

signifies listening deeply within this acronym. Craddock and his co-authors note that time to listen is a tremendous gift to bestow on the dying and it may perhaps be the only gift they can give to others. They state we may provide an 'ongoing presence' to the dying that allows stories

to be told over and over if need be and presence just to be there. They also write that in the medical world there is the hurry, hurry; patients in and patients out; often no time for questions or answers. "The church can provide a truly different environment. It can offer a leisurely, calm, personally interested place and all

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the time in the world in which attention can be paid and the sufferer can be heard."

Within this deep listening, the story of the dying is comingled with the story of the hearer and all is comingled with the grand narrative of the gospel. In deep listening things are not rushed and the dying are given time to ponder all that is happening to them and those around them. There is time to express and face what lies before them. In this listening, these authors note that we bring to fruition Galatians 6:2, we bear one

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another's burdens.

^a Ibid, 184-6. ^b

Ibid, 187. ⁴ Ibid,

189. ⁵ Ibid,

190-1. ⁶ Ibid,

190-2.

EUCCHARIST

The final letter in this TABLE acronym of course is 'E' signifying Eucharist. "The celebration of the dying of Christ is an ongoing reminder to the whole church, and can be especially so to one in the valley of the shadow of dying, that the Christ is with them in their suffering." Verhey echoes this same sentiment. He writes that despite His absence, He is somehow present with us. It is so very critical that we take the juice and bread outside the four walls of the church and gather with the dying and their family and invite the presence of Christ. Verhey adds, "He is the host to our gathering for this

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meal, and once again we take, eat, remember, and believe."

As the dying consider the death of Christ and their own death, they are reminded that there is no Good Friday without an Easter Sunday. Those in Christ cannot ponder death without resurrection. It is this hope the community of faith brings to the dying in their situation and circumstances. Craddock and the Goldsmiths write, "This is where dying and death meet hope and faith, and we can emerge with renewed life in the here and

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now, in the church, sustained by God." They state that in the Eucharist and remembering, unfinished business may be attended to, God's acceptance can be acknowledged, and one places his/her trust in Jesus Christ to sustain him/her.⁹⁰ What an honor and privilege it is to share at the Lord's Table with the dying, to

break bread together.

THE CHURCH

Helen Wilson Harris has the following to say regarding the role of the church in ministering to the dying and their families:

^{B/} Ibid, 192.

⁸⁸ Verhey, 329.

⁸⁹ Craddock, 192.

⁹⁰ Ibid, 192-3.

⁹¹ Helen Wilson Harris, "What is a congregation to do? Dying in family and congregational life."

Journal of

Family Ministry 17, no. 1 (Spring 2003), 53.

<http://web.ebscohost.com.proxynts.kclibrary.org/ehost/search> (accessed Jan 22, 2013).

It is the congregational family that can offer presence when extended family is absent. Sitting with the patient to give family a break and sitting with the family to share the load offer the ministry of presence. Jesus, at the end of his earthly life, asked the disciples to be with him in the garden and pray. It is the congregational family that can offer hope and faith when the days are darkest. It is the congregational family that can allow family members to live the questions and keep their faith even when belief is difficult. And it is the congregational family than can provide the tangible, concrete supports that make a difference day after day; the help with meals, with transportation, with laundry, and most of all with waiting together. Together.

What a blessed position that pastors and churches finds themselves in, to minister to their members that are rounding the final turn and heading home. Caring for the dying is only right. We can do no more and must do no less.

CHAPTER 12 - THE BEREAVEMENT PROCESS

AN OVERVIEW OF BEREAVEMENT SERVICES

Grief and bereavement issues begin for patients and their families at the time of the initial terminal diagnosis. They continue well after death. An integral part of hospice care, bereavement services are available at the time of admission and continue for at least one year after the patient's death. Bereavement care makes hospice care unique.

Medicare requires every hospice program to provide an organized bereavement program for 12-13 months after the patient's death. Bereavement care enhances the patient's/family's dignity and quality of life. The one-year anniversary of a death can be a vulnerable time of heightened emotion. Many hospices offer the bereavement program for up to 13 months after the patient's death.

A qualified Bereavement Coordinator supervises the bereavement program which is offered to patients and families at the time of admission. Services continue throughout the patient's hospice stay and up to 13 months following her death. The philosophy of bereavement services recognizes that:

- Grief affects both the patient and his/her family
- There are many losses attached to the patient's death
- The patient and family have many emotional, behavioral, physical, spiritual, and cognitive experiences
- Healthy grieving is a process that lasts over time and gradually leads to adjustment
- Everyone grieves differently

BEREAVEMENT SERVICES

- Help the patient and family through a normal grieving process
- Identify patients/families who may show pathological grief reactions and refer them to other professionals
- Assist the patient's family in identifying and utilizing a support system
- Prepare the patient's family to cope when their hospice services end

Members of the hospice team, including volunteers, provide formal and informal bereavement services. These services might include:

- Support groups
- Phone calls, Newsletters
- Individual and family grief counseling
- Bereavement resource materials (books, pamphlets, videos, etc.)
- Memorial services
-

When necessary, community resources are recommended to help the patient and family. Ex: private counselors, therapists, or community support groups.

INITIAL LOSS ISSUES

Most patients and their families begin to experience loss as soon as the patient receives a life-limiting diagnosis. These issues of loss may include:

- Loss of career
- Loss of physical capabilities
- Loss of financial security
- Loss of future hopes and plans

In addition to feeling a sense of loss, the patient and family are facing situations that are:

- Unfamiliar
- Confusing
- Fearful

AN INDIVIDUALIZED APPROACH

Every patient and every family member is different. Each family member deals with their loved one's illness and death differently. Our job is to be sensitive to these differences and help patients and family members work within their own emotional, spiritual and social framework.

THREE IMPORTANT TIMEFRAMES

Bereavement programs have three important timeframes as outlined by the following.

LIVING WITH ILLNESS

The IDG (Inter-Disciplinary Group) works with the patient/family in meeting their goals by:

- Helping the patient/family to recognize and accept how they cope as individuals as well as a family "unit"
- Sharing information whenever possible
- Helping to maintain realistic hope
- Actively listening to their concerns in a non-judgmental manner
- Providing education on developmental issues, children, and loss, with attention to how they might want to remember this situation in the future

ACTIVE DYING AND DEATH

The patient's physical and mental decline shows that death is near. This timeframe extends through the funeral or memorial period. The way that the patient's family copes during this time affects how they recount their stories to others, often years later.

During this time, families may be in shock or feel numb. Their memories are recorded, stored, and frozen in vivid form. During this time, the IDG may be involved by:

- Helping the patient and family recognize that death is near
- Providing care, comfort, and presence to the dying patient and family
- Helping family members cope with their emotions
- Helping the patient and family experience the pain of separation
- Helping the patient and family resolve issues that require reconciliation and forgiveness
- Offering assurance to the dying person that he/she will be remembered

FOLLOW-UP BEREAVEMENT

The bereavement staff continues to support the patient's family up to 13 months after the death. The staff assists the family with experiencing the emotional, physical, and spiritual pain of loss and grief.

- Accepting the loved one's death
- Experiencing separation pain
- Developing or maintaining some internal or external element of hope that the pain of loss can be endured
- Maintaining a sense of personal worth
- Finding and using a support system
- Adjusting to changed roles, responsibilities, and an environment without the deceased
- Developing new skills needed for altered lifestyles
- Keeping family relationships intact
- Identifying and coping with secondary losses and unfinished business
- Developing perspectives that will provide insights into both positive and negative aspects of the loss
- Releasing energy from the past
- Transforming the pain of loss into a fuller sense of

being HOW TO HELP GRIEVING PEOPLE

Relatives, friends, and neighbors are supportive at the time of a death, during the wake, and the funeral. Food, flowers and caring presence are among the many thoughtful expressions offered by family and friends.

However, following the funeral many grieving people wonder what happened to their friends. Bereaved people need support and caring even more as the reality of the loss sinks in and the long grieving process ensues. The help of friends is essential as immediate family members frequently are dealing with their own grief and may find it difficult to support one another. Additionally, families may live in

different areas, making such assistance difficult to provide.

The help and understanding of friends and the church family can make a significant difference in the healing process. Unresolved grief may lead to physical or mental illness, suicide, or premature death. A grieving person needs those who are willing to:

- Listen, cry with them, and help them feel loved and needed
- Reminisce, care, and share creative ideas for coping
- Be honest, sit with them, and believe they will survive the grief

The ways of helping people through grief are as limitless as your imagination. The following ideas may be used to help a grieving person.

BE SENSITIVE

- Sometimes, all that is necessary is a squeeze of the hand, a hug or your presence. If you want to say something, say, "I'm sorry" or "I care."
- Let the bereaved tell you, as much or as little as they want to share. A helpful approach might be, "Would you like to talk? I'll listen."
- Be available to listen frequently. Most bereaved people want to talk about the person who has died. Encourage this; do not change the subject or avoid mentioning the person's name.
- Offer to help with practical matters, such as errands, food preparation or caring for children. Be direct in your approach (ex: "I am going to the store, do you need any bread or milk?" rather than "Call me if there is anything I can do.")
- Don't say, "It has been four months, six months, a year, etc. You must be over it by now." Life for the bereaved will never be the same.
- When someone feels guilty and is filled with "If only's," it is not helpful to say, "Don't feel guilty." This will only add to the bereaved person's negative feelings. A better response is, "I don't think that you are guilty. You did the best you could at the time, but don't push down your feelings of guilt. Talk about those feelings until you can let them go."
- Be patient. Don't say, "You will get over this in time." Mourning may take a long time. The bereaved need friends to stand by them -for as long as necessary.
- Encourage the bereaved to express their feelings - cry, hit a pillow, scream, etc. Give special attention to children in the family. Do not tell them not to cry or not to upset the adults. Do not tell children their loved one "Went to sleep."

- Practice unconditional love. Feelings of rage, anger and frustration are not pleasant to observe, but it is necessary for the bereaved to recognize and work through these feelings.

EXPECTED EMOTIONS

- Recognize that the bereaved may be angry. Anger may be directed at God, the person who died, the clergy, doctors, rescue team, or other family members.
- Encourage the bereaved to acknowledge his or her anger and to find healthy ways of managing it.
- The bereaved may wonder why the death occurred. It is often a cry of pain rather than a question. It is not necessary to answer, but if you do, simply reply, "I don't know why."
- Don't be afraid to cry openly if you were close to the deceased. The bereaved will understand and appreciate your tears and won't feel so alone in her grief.
- Understand that a bereaved person's self esteem may be very low.
- Depression often accompanies grief. To be able to talk things over with an understanding friend or loved one may help prevent severe depression.
- Help the bereaved avoid unrealistic expectations as to how they "should" feel and when they will feel better. It is helpful when appropriate to say, "I don't know how you do as well as you do."
- The bereaved may appear to be getting worse as time goes on. Understand this is often due to his or her awareness of the reality of the death.

AWARENESS

- Read about the various stages of grief so you can understand and help the bereaved to understand.
- Suggest that the bereaved person keep a journal.
- Be aware of the physical reactions to death, such as lack of appetite, sleeplessness, headaches, and inability to concentrate. These reactions affect the person's coping ability as well as his or her energy and recovery.
- Watch for drug and alcohol use. Medication only should be taken under the supervision of a physician. Often, such medications delay the grief response.
- Sometimes the pain of bereavement is so intense that thoughts of suicide occur. Don't be shocked by this and know that it is important that the

- bereaved is confiding these feelings to a friend.
- Encourage counseling if grief is getting out of hand.

HELPFUL SUGGESTIONS AND CONSIDERATE ACTS

- Suggest that grieving people take part in support groups. Such groups offer understanding and friendship as well as suggestions for coping with death. Offer to attend a support group meeting with the bereaved person.
- Recommend that the bereaved person postpone major decisions he or she may regret, such as moving or giving away items. It is best to keep decision-making to a minimum at this time.
- Encourage exercise to work off tension and anger, as well as to relax and promote sound sleep.
-
- Practice continuing acts of thoughtfulness - write a note, plan a visit, deliver a plant, bake a special treat or invite the person to coffee. Take the initiative in contacting the bereaved.
- Consider sending a note at the time of their loved one's birthday, anniversary, anniversary of death, or other significant days.
- Understand that weekends, holidays, and evenings may be more difficult for the bereaved.
- Don't avoid the bereaved. This only adds to their loss. As the widowed often say, "I not only lost my spouse, but I lost my friends as well."
-

CHAPTER 13 - MANAGING PERSONAL STRESS

Ministering to others is what we are called to do and is very rewarding. But, it can also be very stressful. Regardless of its source, stress has an effect on our minds, bodies, and spirits. In ministering to others, you must be able to manage your stress. When you do, you are caring for yourself. If you do not care for yourself, how can you care for others?

STEP 1: KNOW WHEN STRESS AFFECTS YOU

The first step for managing your stress is to know **when** it affects you. For example, you may experience stress when:

- You have too much to do and not enough time to do it
- You feel that you have to rush through a patient visit to something else
- You have an unresolved conflict with someone
- You lose several patients within a short period of time
- You feel you are losing the balance between your work, serving, and home life

If you know **when** stress affects you, you will be able to recognize it coming. For example, if you

suddenly find that your schedule is really full, you might say to yourself, "I need to be careful. I could get really stressed with this."

STEP 2: KNOW HOW STRESS AFFECTS YOU

Body awareness is the first step in recognizing and reducing stress. When we are stressed, our body puts out warning signals. People under stress usually show a variety of symptoms. These symptoms are clues to the sources of stress. The following table outlines four types of stress and the symptoms of each.

TYPE OF STRESS			
Physical	Mental	Emotional	Behavioral
Muscular tension High blood pressure Heartburn Headaches Fatigue Upset stomach Nervous tics	Inability to concentrate Poor judgment Forgetfulness	Irritability Depression Apathy Anger	Changes in sleeping habits Overeating Increase in smoking or drinking Reckless driving

When you know **how** stress affects you, you can do things that will prevent these symptoms. For example, you know that you gain weight when you are stressed. Knowing this, you can make sure to eat a healthy and balanced diet while under stress. Or perhaps you can work an exercise routine into your day - even just 15 minutes of walking will make a difference.

STEP 3: KNOW WHAT METHODS HELP RELIEVE STRESS

The next step for managing stress is to know what methods help relieve stress. For example, do you use:

- A physical method such as exercise or playing a sport?
- A spiritual method such as prayer or Bible/devotional reading or meditation?
- An intellectual method such as learning a new skill or reading a good book?
- A social method such as going out with your spouse or friend or talking to a friend on the phone?

POPULAR STRATEGIES FOR REDUCING STRESS

- **EXERCISE** — One of the best ways to reduce the effects of stress is to exercise. Keep it simple. Try brisk walks or follow along with a TV aerobics show. Start playing a sport. Be creative.
- **EAT HEALTHY** — Poor nutrition causes more stress. Eat more healthful foods, such as fruits and vegetables. Cut back on coffee, sugary sodas, and high-fat food. Foods full of vitamins and minerals give your body what it naturally needs to defend and protect itself.
- **GET ENOUGH SLEEP** — Studies have shown that many Americans are short of sleep.

- Make a real effort to get as much sleep as you need on a regular basis.
- LEARN TO RELAX — Take time to sit quietly. Relax your muscles and your mind. Try not to think about anything. This type of focused relaxation energizes you for difficult or stressful tasks.
 - EXPRESS YOUR FEELINGS - If you are feeling stressed, talk to someone who cares about you. Seek out a pastor or friends and ask them to listen. Sometimes a problem gets better just by saying it out loud.
 - REFRAKE THE SITUATION - Look at a stressful situation differently. Try to think about how it could be much worse. Look at the positive sides of it - what is it about the situation that you are thankful for? Try to imagine how someone you admire might handle the situation. Then, try to imitate those actions.
 - REFRESH THE SOUL — Though rewarding, ministering in this manner can drain one even spiritually. It is crucial to keep one's spiritual batteries charged so to speak with worship, Christian music, Bible reading, spiritual readings, and prayer. Be creative; one can mix exercise and Christian music or Scripture on an electronic device. Listen to Scripture or music while commuting. To continue to give one must take into his/her spirit.

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Worth While Reads in the Arena of Death/Dying/Care Giving

Byock, Ira. *Dying Well: Peace and Possibilities at the End of Life*. New York: Riverhead Books, 1997.

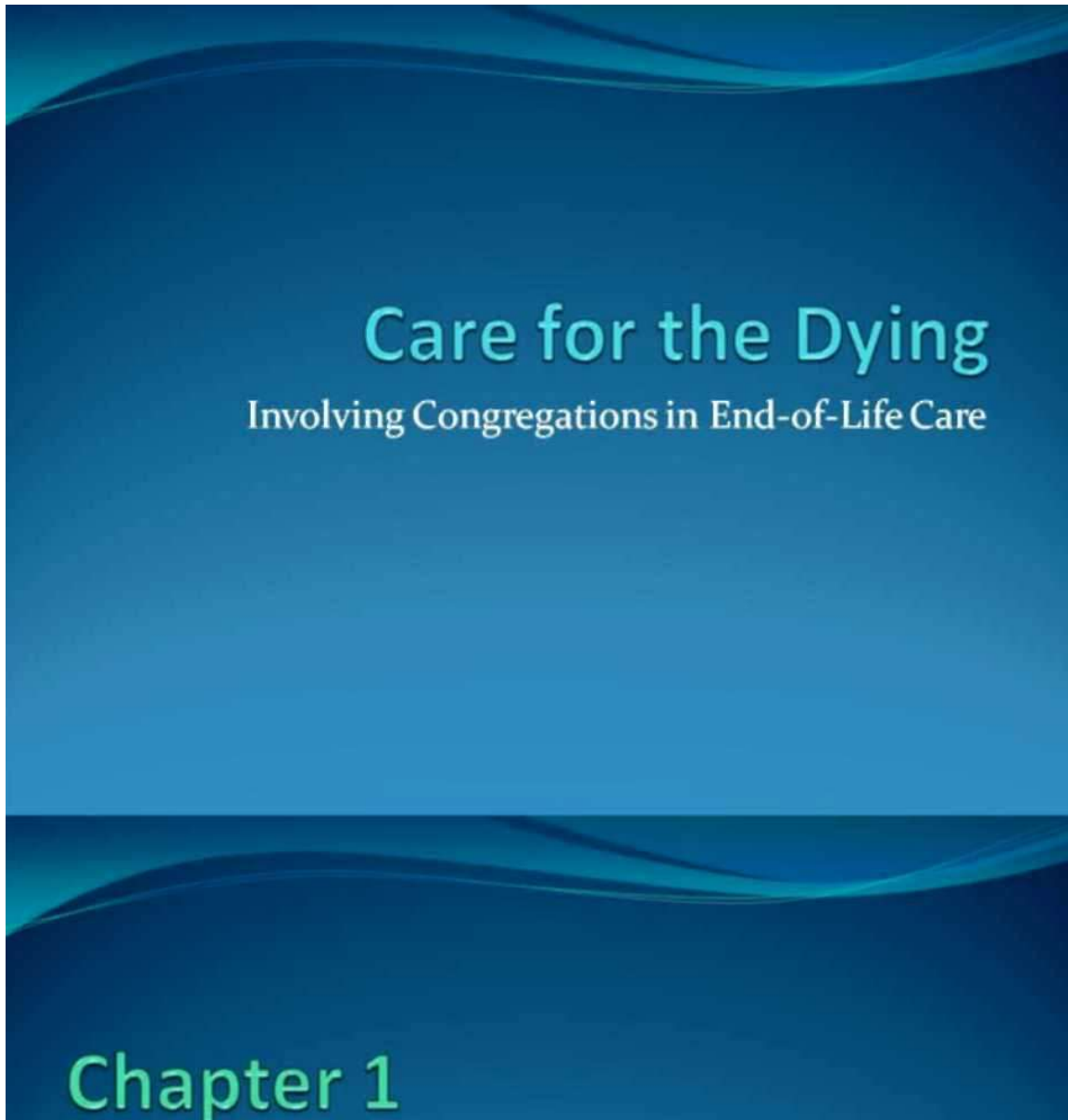
Craddock, Fred, Dale Goldsmith, and Joy V Goldsmith. *Speaking of Dying*. Grand Rapids, MI: Brazos Press, 2012.

Heyse-Moore, Louis. *Speaking of Dying: A Practical Guide to Using Counseling Skills in Palliative Care*. Philadelphia: Jessica Kingsley Publishers, 2009.

Kubler-Ross, Elisabeth. *On Death and Dying*. New York: Scribner, 1969.

Verhey, Allen. *The Christian Art of Dying: Learning from Jesus*. Grand Rapids: William B. Eerdmans Publishing Company, 2011.

Appendix C Seminar Training PowerPoint



When Andrea was diagnosed with cancer three years ago, she moved in with her sister Lenora for support. Andrea was devastated a few months ago when it became clear that the cancer was no longer responding to the treatment.

The burden of illness and care giving had been so great for so long,

Andrea and Lenora had not stayed connected with their faith community. At the same time, the congregation lost touch with them. Now that Andrea was dying, she and Lenora missed their faith community even more and longed to be a part of it.

Care for the Dying

- Rule of Saint Benedict

Within Church history one finds the birth of the hospital

- Within many religions care for the dying is frequently found

-

Matthew 25:31-40

The King will answer and say to them, "Truly I say to you, to the extent that you did it to one of these brothers of Mine, even the least of them, you did it to Me."

The Least of These

- Everyone (the most needy of all humans)
- All Christians
- Christian missionaries
- Jewish Christians
- Tribulation martyrs
-

Discipleship is Key

"The biblical focus is upon the relationship of the benefits of salvation to God's call to serve. It is common to all the biblical accounts of calling that to be called means being given a task."

Darrell L. Guder

Mission

"Mission involves, from the beginning and as a matter of course,

making new believers sensitive to the needs of others, opening their eyes and hearts to recognize injustice, suffering, oppression, and the plight of those who have fallen by the wayside."

- David Bosch

The Church

So the Christian church is sent out to the world on a vital mission—to bear witness to the gospel of Jesus Christ. The 'good news of the kingdom will be proclaimed throughout the world, as a testimony to all the nations' (Matt. 24:14). The gospel, however, is more than mere words, and the church proclaims the gospel by living in the world as Jesus lived. The disciple is to be like the teacher (Matt. 10:24);

The Church cont.

The church must become humble like a child and show hospitality to those in need (Matt. 18:1-5). In Matthew's Gospel, if you want to find Jesus, look among those who are 'harassed and helpless, like sheep without a shepherd (Matt. 9:36). The church that is faithful will be found in precisely the same place.

- Thomas Long

The Least of These

The dying are indeed often overlooked and pushed to the margins as their life is ebbing away. We must bring them back front and center, or at least go to them and journey with them through the dark places in the margins.



Death and Dying Avoidance

In our modern world, death is far from an everyday topic of conversation except likely in hospice and palliative care. Conversations regarding death and dying are avoided like the plague; they make most uncomfortable at the very least.

Speaking of Dying

"Unfortunately, there is a clear cultural model, and it is the only one generally available to the terminally ill: be strong, don't mention it, don't give in, fight it. This is the default position to which the church has outsourced the facing of impending death."

- Fred Craddock

Medical Advances & Obstacles

As well, medical technology often creates obstacles to care for the dying and care giving. There is a pill or surgery for everything.

Medical advances have done much and this can lead to a denial of reality. All do not get better.

Medical Advances & Obstacles

"Medical advances have changed the world and certainly have changed dying. Because of new and improved medical insights, medicines and health-care procedures, we find ourselves in a good news/bad

news situation. The good news is that there are cures and relief not earlier available. The bad news is that while it often takes longer to die, the dying is done without the sweetness that such extension might avail because of the rigor of the treatment."

- Fred Craddock

Medicalized Dying

Following World War II

- Advances in medicine
- Improved surgical techniques
- Dying moved from the home to the hospital
- Improved medical technology began to be used on the dying

Medicalized Dying

"So, suddenly no one was 'dying' any more. They were just 'sick.'" He says as well, "The body of the dying person became the battlefield where heroic doctors and nurses waged their war against death."

- Allen Verhey

What does it mean to die well?

"To live is Christ, to die is gain."

Phil. 1:21

"Precious in the sight of the LORD is the death of his saints"

Psalm 116:15



Ars Moriendi - The Art of Dying

Beginning in the fifteenth century, a new genre of theological literature known as the "*ars moriendi*" emerged which sought to prepare readers for the task of dying. The authors of these works viewed dying as a task or an art—a learned behavior that one could perform either well or badly...

These authors urged their readers to live the whole of their lives in such a way that they would become patient, hopeful, and faithful; only by living well and nurturing these virtues over time could one expect to be patient, to be faithful, to be hopeful, and thereby to die well.

- Christopher Vogt

Finishing Well

There is life and there is death, but there is also the time of dying—the in-between season when the reality that a person will soon die looms large and becomes a magnetic pose around which the thoughts and actions of others are organized...Christian faith views this time in between not with resignation, not merely as a season of passing time before someone passes away, but as a period filled with meaning and opportunity for communion with the one who is dying.

- Thomas G. Long

Dying Well

"While Christians today are probably not going to be attracted to the old practice of *Ars Moriendi* devotions, it is urgent that the core of the tradition be retrieved, if for no other reason than to break the code of silence about death."

- Thomas Long

Dying Well

"For any theology of dying, the serious, long-term commitment to Jesus Christ in the midst of others of like faith is a necessary precondition to receiving, experiencing, and expressing the full benefits of the gospel story. If we have practiced the Christian life, when the time of dying approaches, the whole experience of our past is at our disposal as a treasury of coping resources."

- Fred Craddock

Christian Dying

Believers should see a connection between their dying and the dying of Christ as their death approaches.

"Can we find in these stories a biblical model for dying well? If so, what exactly is it about Jesus' way of dying that is to be imitated?"

- Christopher Vogt

Virtues for Dying Well

i. Patience

A. Patient Endurance

"First, we observe in Jesus the *reluctant* endurance of suffering; patience seeks to avoid suffering if possible, but to endure it if

necessary." - Christopher Vogt

That some suffering is a necessary part of faithfulness to God

"If anyone would come after me, he must deny himself and take up his cross daily and follow me" (Luke 9:23).

Virtues for Dying Well - Patience cont.

B. Patience with Divine Purpose

"Second, the patience of Jesus rests upon a profound sense of Providence, or of divine purpose in the events that are about to unfold."

"Exactly why one should be willing to wait is not generally obvious. Jesus' concern with God's planning and his desire to be obedient to God's will explains why such a capacity is virtuous from a Christian perspective...This requires the development of patience in the sense of waiting; we must wait for events to unfold for God's will or purposes to be made known to us."

- Christopher Vogt

Virtues for Dying Well - Patience cont.

C Patience and Autonomy

"Third, Jesus' patience can be interpreted as demonstrative of a particular understanding of autonomy; one of the things Christians must specifically be prepared to endure is some limitation on their exercise of autonomy."

"In his decision not to flee the difficult end he foresees for himself, Jesus chooses to endure physical suffering, but more importantly to endure what we today might call the loss of absolute autonomy..The example of jesus makes clear that the expression of patience entails

relinquishing the exercise of absolute or total control over one's own fate."

- Christopher Vogt

Virtues for Dying Well - Patience cont.

D. Patience connected with love

"Fourth, Jesus shows a connection between patience and love for his disciples and many others. In this way, patience is an unmistakably social virtue."

- Christopher Vogt

Vogt points out that Jesus saw in His suffering a good coming out of it for God, friends, and the world. Jesus believed "that some good is to come from his crucifixion."

Virtues for Dying Well

2. Hope

"Hope is not a distraction from what is to take place, nor an empty promise that no harm will ever come; rather, it is a reorganization of the significance of the facts at hand: you will suffer, you will die, *but I will be with you.*"

- Christopher Vogt

"And I will ask the Father, and he will give you another Counselor to be with you forever—the Spirit of truth. The world cannot accept him, because it neither sees him nor knows him. But you know him, for he lives with you and will be in you. **1** will not leave you as orphans; I will come to you"

John 14:16-18

Virtues for Dying Well

3. Compassion

"Thus what a turn to this biblical material adds to the contemporary discussion about dying well is the suggestion that not only the reception but also the expression of compassion by the dying is important."

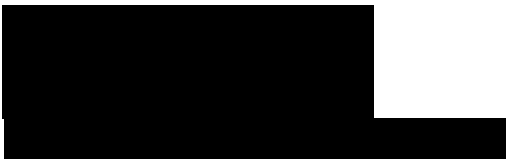
"In this scene we find both the expression of compassion as empathy and compassion as mercy or forgiveness."

- Christopher Vogt

Christian Dying/Holy Dying

"Christians seem unwilling to see the experience of dying as something to be mined for insight into what God has called us to in life, or as a part of our lives that might present an opportunity to serve God."

- Christopher Vogt



Hospice

The Latin word **hospitium** means hospitality, inn or lodging.

The Latin word **hospes** means host or guest.

The Modern-Day American Hospice Movement

Dame Cicely Saunders, MD, in Sydenham, England, founded St. Christopher's in 1967

⁶ The first American hospice was the Connecticut Hospice in Branford in 1974

¹ Congress included a provision to create a Medicare hospice benefit in 1982

Dr. Elisabeth Kubler-Ross' book, *On Death and Dying*, brought the needs of dying people to the public's attention. Kubler-Ross greatly influenced the growth and promotion of hospice care.

The Hospice Philosophy of Care

- Hospice focuses on quality of remaining life
- Hospice care is individualized
- The family requires care also

-

Three Key Principles of Hospice

- Offer Choice • Maintain

Dignity

- Promote Individuality

Essential Characteristics of a Hospice

Program

- Physician Services
- Nursing Services

Medical Social Worker Services

- Spiritual Care Services
- Certified Nursing Assistant Services
- Volunteer Services

-



What is HIPAA & What Does it Govern?

Insurance

Portability

Accountability

Administrative Simplification

Administrative Simplification

- Enforcement • What is

Confidential

- Do You Need to Know?

What Does All This Mean for Me?

What could this mean for me in caring for those within the body of Christ and privy to information all may not know?



What are Universal Precautions?

Universal precautions are taken to prevent exposure to blood and body fluids which may carry disease-causing organisms. Healthcare workers and others are to consider all patients to be infectious and are to use universal precautions when visiting with patients and their families.

Are There Times When I Should Not Visit Patients?

To protect patients and yourself, do not visit if you have any of the following:

- Symptoms of respiratory infection (cold, flu)
- Symptoms of a GI infection (diarrhea)
- Dermatitis
- Draining of open skin lesions

How Do I Protect Patients & Myself?

Hand washing is the single most effective method of controlling the spread of disease. Personal Protective Equipment (PPE) should be worn any time there is a chance you may handle or be splattered by blood and/or body fluids.

Tuberculosis (TB)

- What is TB?
- What are the symptoms of TB?
- How is TB spread?
- How is TB disease treated?



The Needs of the Dying

1. Denial

- "No, Not Me"
- The most telling signs of denial is that of silence

2. Anger

- Partially suppressed anger
- Anger is muted and takes quieter forms

The Needs of the Dying Cont.

3. Pain

- The Emotional Variety
- The dying are not only left with the pain of the diagnosis, but all that it represents

4. Bargaining

- Usually with God
- Being better or doing better
-

The Needs of the Dying Cont.

5. Anxiety

In palliative care, anxiety may be related to the following:

- physical suffering - such as severe pain or breathlessness
- loss - of health, body parts, mental faculties, sexuality, mobility, control, status, beauty, family and friends, work
- re-evocation of unhealed past memories
- the prospect of death - extinction of life, and painful death or going to hell.

The Needs of the Dying Cont.

6. Depression

- May not be clinically diagnosed depression
- Can be the result of 'interned anger' or 'unresolved grief'
- The dying are often shut up in their own world

7. Suicidal Feelings

- Common with hospice patients

What motivates or causes suicidal feeling in the dying?

- Prominent with the dying, but seldom carried out

-

The Needs of the Dying Cont

8. Guilt and Shame

- "Guilt is the feeling associated with the belief that we have done wrong whether by commission or omission. Shame is the feeling that we are wrong or bad or deficient in ourselves." - Louis Heyse-Moore

9. Grief

- Grief Issues
- What will **1** not have today that **1** had yesterday?



Visiting the Patient at Home

- Call the family before your visit to confirm What to do during the visit
- Let the patient or family control your visit

Visiting the Nursing Home Hospice Patient

- Observe facility rules

- Remember you are working with 2 families
- If the patient needs physical assistance, alert the nursing home staff to help.
 - If you bring food, such as candy, cookies, or cake to the patient, check with nursing home staff to ensure the patient is not on a special diet.
- ▶ Try to schedule your visits at optimum times for the patient.
- Remember, for your patient, the nursing home is home.
-

Visiting the Dying Patient

- Show that you still consider the person among the living.
- Don't expect to make things better.
- You don't need an agenda for the visit.
- Be yourself.
- Don't be hesitant or afraid to cry.
- If the patient wants to talk, don't change the subject, even because it makes you feel uncomfortable.
- Support the dying person's sense of control.
- Try to consider what death means to this person.
- Be prepared to confront your own fears before or after the visit.
- Remember to touch.
- Encourage reminiscing to remind the patient of the value of his/her life.

Practical Tips to Help Those Facing a Serious Illness

- Don't avoid me.
 - Touch me.
- Call me to tell me you're bringing my favorite dish and what time you are

coming.

- Weep with me when I weep. Laugh with me when I laugh.

¹ Call me before you visit, but don't be afraid to visit.

- Help me celebrate holidays Help my family.
- Be creative!
- Let's talk about it.
- Don't always feel we have to talk.
- Help me feel good about my looks.

Please include me in decisionmaking.

¹ Talk to me of the future.

- Bring me a positive attitude.
- What's in the news?

Just send a card to say: "I care."

:- Pray for me and share your faith with me.

- Tell me what you'd like to do for me and, when I agree, please do it!

•

Boundaries

- Creating personal boundaries
- What happens when you do not set boundaries? Benefits of setting boundaries

¹ You know you are crossing boundaries when

- Some universal boundaries
- Tips for setting boundaries



Communication Includes

- Listening
- Speaking
- Eye contact
- Body language

Listening

Helpful Hints

- Maintain eye contact
- Practice patience. Let the person tell his/her story in his/her own way
- Keep your word!
- Share yourself, but concentrate on listening
Let the person know you feel honored to listen to his/her thoughts
- Let the person set his/her own pace
Listen for both verbal and nonverbal messages
- Be aware of your own body language and verbal messages
- Try to give the person your full attention
- Ask questions

Avoid

- Looking around the room to see what else is going on
- Interrupting or finishing a sentence for the other person
- Talking about what someone else told you in confidence
- Talking excessively about yourself
Saying - "You shouldn't feel that way!"
- Pretending you have all the answers
- Assuming you have all the facts
Looking horrified when you are told about a problem
- Make hasty judgments
-

Listening is a skill that can be learned

- **Be interested and show it**
- **Tune into the other person**

Hold your fire

Look for the main idea

Watch for feelings

Work at listening

Monitor your own feelings and point of view

- **Notice nonverbal language**
Give the other person the benefit of the doubt
Get feedback

Active Listening Techniques

- Show external signs of listening
- Ask open-ended questions
- Questions are to clarify
- Silence is okay
 - Observe signals that a person wants to talk
 - Do listen within the framework of the other person's purpose
- Listen just as intently to the person's nationality, color, religion, experience, conditioning and feelings as you do to words.
- Use words that the speaker uses
- Rephrase the person's thoughts and ideas
- Ask for clarification
-

How to Build a Rapport

- Place yourself at the person's level

Sit down

* Call the person by name

Talking with the Patient & their Family

- Holidays and celebrations
- Memorabilia (i.e., photos, albums, scrapbooks, souvenirs)
- Plants/growing plants/gardening
- Recipes and favorite foods
- Family traditions
- Pets
- Literature: books, poems and stories
- Songs, dance, opera
- Sports heroes
- Dreams
- Travel and trips taken
- Changes in life: war, depression, jobs, moves, natural disasters
- Current events
- Movies
-

Talking with the Patient & their Family Cont.

- What are the happiest days of your life?

What is your most enjoyable holiday?

How does your family celebrate the holidays?

- What was your home life like as you grew up? How has it changed?

Do you remember your first day of school?

What were your high school years like?

- Do you remember your first girl/boyfriend?
- What kinds of books do you like to read?
- Tell me about your most embarrassing moment.
- Tell me about your
fa ther... mo ther... sis ter...bro ther...best friend.
- What is your favorite spot for peace and reflection? Describe it.
-



Signs & Symptoms of Impending Death

- Psychosocial changes - Mental and Emotional
- Physiological changes - Physical

The "Good" Death

Creating a "Good" Death for the Patient

1. Physical Comfort
2. Emotional Well-Being
3. Spiritual Serenity
- 4.

Tasks of the Dying

1. Getting affairs in order
2. Making medical care decisions
3. Planning for the immediate future
4. Coping with emotions and physical changes associated with end of life
5. Letting go

Opposing Tasks of Family Members

- Holding on while the patient is trying to let go
- Providing care for the patient's increased dependency needs while supporting the
- patient's continued need for autonomy
- Taking care of the patient's needs instead of taking care of their own needs
- Redistributing family roles and responsibilities while not wanting to call attention to the fact that the patient has lost the ability to do things he or she used to do
-

Unfinished Business

A personal unmet desire or goal

- A regret or guilt over something unresolved between the patient and another person



T.A.B.LE.

In this case, the term 'table' serves both as an acronym for elements or aspects of a strategy as well as a metaphor—indeed more than a metaphor—for the central powerful narrative of our faith: the Eucharist. It is Jesus Christ who invites us to the table: his Table. It is that Lord who we celebrate at the Eucharistic table and our conviction is that as long as we are gathered at that table and focused on that Christ, our ministry to the dying will go forth to all as a comprehensive alternative to anything available elsewhere.

- Craddock

Talk

- Friends

Rooted in Christology of the Word

- Sharing stories

® Expressing hopes

- Weeping

- Prayer

- Song

° Scripture

- Presence

-

Awareness

- There must be an awareness of reality

- No reluctance to speak of death and dying

> Truth can and should be spoken and reality embraced

- Time

- The dying set the agenda

Body

"The body is characterized by the intimate connection of each part with every other part and by the fact that each part is utterly distinct from, but absolutely necessary for the well-being of, every other part."

- Craddock

He/She should be reminded that God has meaning and purpose for them until they draw their last breath.

Listening

- A tremendous gift to bestow on the dying
- Perhaps the only gift they can give to others
- Time for stories to be told over and over; if need be
- All the time in the world
- The dying's story is comingled with the story of the hearer and the Gospel narrative

We bear one another's burdens

Eucharist

"The celebration of the dying of Christ is an ongoing reminder to the whole church, and can be especially so to one in the valley of the shadow of dying, that the Christ is with them in their suffering."

"This is where dying and death meet hope and faith, and we can emerge with renewed life in the here and now, in the church, sustained by God."

- Craddock

The Church

It is the congregational family that can offer presence when extended family is absent. Sitting with the patient to give family a break and sitting with the family to share the load offer the ministry of presence. Jesus, at the end of his earthly life, asked the disciples to be with him in the garden and pray. It is the congregational family that can offer hope and faith when the days are darkest. It is the congregational family that can allow family members to live the questions and keep their faith even when belief is difficult. And it is the congregational family than can provide the tangible, concrete supports that make a difference day after day; the help with meals, with transportation, with laundry, and most of all with waiting together. Together.

- Helen Wilson Harris



An Overview

° Bereavement services

- Helpline patient and family

- identify patients/families who may show pathological grief reactions and refer them to other professionals
- Assist the patient's family in identifying and utilizing a support system
- Prepare the patient's family to cope when their hospice services end
- Support groups
- Phone calls, Newsletters
- Individual and family grief counseling

- Bereavement resource materials (books, pamphlets, videos, etc.)
- Memorial services
- **Initial loss issues**
 - Loss of career
 - Loss of physical capabilities
 - Loss of financial security
 - Loss of future hopes and plans
 - In addition to feeling a sense of loss, the patient and family are facing situations that are: Unfamiliar, Confusing and/or Fearful
- **An individualized approach**
-

Three Important Time Frames

i. Living with illness

2. Active dying and death

3. Follow-up bereavement

How to Help Grieving People

- Listen, cry with them, and help them feel loved and needed
- Reminisce, care, and share creative ideas for coping
 - Be honest, sit with them, and believe they will survive the grief

How to Help Grieving People, cont

Be Sensitive

A squeeze of the hand, a hug or your presence; "I'm sorry" or "I care."

- "Would you like to talk? I'll listen."
- Be available to listen frequently
- Offer to help with practical matters
- Don't say "You must be over it by now."
- With "If onlys," say "I don't think that you are guilty."
- Be patient.
- Encourage the bereaved to express their feelings
- Practice unconditional love.
-

How to Help Grieving People, cont

Expected Emotions

- Recognize that the bereaved may be angry.
- ↳ The bereaved may wonder why the death occurred
- Don't be afraid to cry openly if you were close to the deceased.
- Understand that a bereaved person's self esteem may be very low.
- Depression often accompanies grief.
- ↳ Help the bereaved avoid unrealistic expectations as to how they "should" feel and when they will feel better.
- The bereaved may appear to be getting worse as time goes on.

How to Help Grieving People, cont

Awareness

- Read about the various stages of grief so you can understand and help the bereaved to understand.
- > Suggest that the bereaved person keep a journal.
- Be aware of the physical reactions to death
- Watch for drug and alcohol use.
- » Sometimes the pain of bereavement is so intense that thoughts of suicide occur.
- Encourage counseling if grief is getting out of hand.
-

How to Help Grieving People, cont

Helpful Suggestions and Considerate Acts

- Suggest that grieving people take part in support groups.
Recommend that the bereaved person postpone major decisions
 - Encourage exercise
 - Practice continuing acts of thoughtfulness
 - Consider sending a note at the time of their loved one's birthday, anniversary,
 - anniversary of death, or other significant days.
- ' Understand that weekends, holidays, and evenings may be more difficult for the bereaved.

Don't avoid the bereaved



Step 1: Know When Stress Affects You

- You have too much to do and not enough time to do it
You feel that you have to rush through a patient visit to something else
 - You have an unresolved conflict with someone
- You lose several patients within a short period of time
- You feel you are losing the balance between your work, serving, and home life

Step 2: Know How Stress Affects You

- Physical

- Mental

Emotional

Behavioral

Step 3: Know What Methods Help Relieve Stress

A physical method such as exercise or playing a sport?

- A spiritual method such as prayer or Bible/devotional reading or meditation?

An intellectual method such as learning a new skill or reading a good book?

A social method such as going out with your spouse or friend or talking to a friend on the phone?

Popular Strategies for Reducing Stress

- Exercise

- Eat healthy
- Get enough sleep
- Learn to relax
- Express your feelings
- Re frame the situation
- Refresh the soul
-

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