On the Way...

Short Stories and Biblical Reflections on Caring for a Loved One in Hospice

COMPANION
For Those Currently Caring for a Loved One

Pam Northrup
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INTRODUCTION

Thank you for being On the Way with me and giving me the opportunity to accompany you as you care for a loved one. We both know that every family’s experience is different, but I suspect that there are some similarities. Maybe through our stories, you will come to know that the anxiety and sadness you feel is not unusual; the chaos and confusion you are experiencing is not unusual. Rest assured that others have journeyed a similar path and survived. I hope that the stories and reflections included in the book provide insight and comfort for your own journey.

When my mother first entered into hospice care I looked for resources that would help us navigate the caregiving experience. Being a lover of books, I sought out stories of other families who’ve lived the reality that we were living. To my surprise, the only books I could find were ones written by professionals from a clinical perspective. These helped me grasp what was happening but fell short in providing insight into the complex and unique human emotional, social, and spiritual dynamics that we were facing.

Caring for a loved one who is dying can be a difficult and lonely experience. Typically, it’s on-the-job training since many of us are not professional caregivers. Navigating through this time means learning as you go, making mistakes along the way, while trying to do the best you can for the one you love. I share our experience in the hope that you will be strengthened for your own caregiving experience.

This Companion is my gift to you. It’s a way for you to make a personal connection to the stories and biblical reflections in the book as you provide care to someone you love. Each chapter in the book has a corresponding chapter in this companion. Reflection questions and action ideas are included to support you while you are on your way.

You may reach me at pam@onthewayliving.org if you have questions or would just like to connect.

May your journey be peaceful.

Pam
WIGIAT?
WHERE IS GOD IN ALL THIS?

I’m thankful to The Rev. Dr. Tony Everett, my professor of Pastoral Care at Lutheran Theological Southern Seminary, for providing this framework of thinking about God’s presence in the everyday moments of our lives.

It’s easy to become preoccupied with what’s happening around us and fail to see God’s presence in every situation. Being preoccupied means that we miss witnessing the in-breaking of the holy into each day and each situation. We miss the gentle ways that God sustains and supports us as we care for the ones we love.

While caring for mom, we found that the more stressed and exhausted we got, the more we started thinking that we were responsible for everything, that we needed to handle things all by ourselves. This way of thinking only made matters worse. It made us even more stressed, more exhausted, more emotional, and more isolated. Absorbed in what we were doing narrowed our focus so that it was hard to see what God was up to.

When we ask the WIGIAT question, we’re prompted to pause and name where God is and what God is doing. WIGIAT reminds us to be intentional about looking for God. It provides the lens through which we can see everything and everyone.

When we started intentionally looking for and naming God’s presence, we experienced a significant relief from stress and felt more equipped to deal with each day. By leaning into God’s presence in the everyday moments of what was happening we were strengthened for the tasks before us. We were able to laugh at the absurdity around us; solve whatever problems showed up that day and interact with each other in love and compassion.

Asking WIGIAT helped us recognize and give thanks for God’s presence in the friends who came to visit, in the care provided by the hospice team, and in each moment that we had with mom.

At the end of each story in the book, I ask and answer the WIGIAT question as an intentional recognition that God was actively present and involved in every aspect of our caregiving journey. Even ten years after our experience, this gives me great comfort.

In this Companion, I provide a place for you to reflect upon the WIGIAT question. I hope that intentionally pondering this question, you will be inspired by the reality that God is indeed present and active in your caregiving journey.

May God’s presence inspire and comfort you!
Part One

Short Stories on Caring for a Loved One in Hospice
Chapter 1

On the Way

In this chapter, I introduce my mother, provide some examples of how she was always on the way somewhere, describe how she was diagnosed, and our reaction to the diagnosis.

Describe what you love about your loved one.

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How did you find out about your loved ones’ disease?

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What is your loved one’s reaction to their diagnosis? What is your reaction?

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Reflect on WIGIAT.

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Chapter 2

The Brain

Having a support system who helps care for the one who is sick makes the caregiving experience easier for everyone. Mom’s support system consisted primarily of me, my sister, and my husband. Each one of us provided our own perspective and contributed our unique set of skills to the task of caregiving.

Identify the members of your support system.

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What gifts and skills do each of them contribute to the task of caregiving.

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Reflect on WIGIAT.

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Chapter 3

The Hospice Decision

My mother decided to enroll in hospice because the treatment for her disease wasn’t working. It had a negative affect of her quality of life. She decided to let the disease run its course and to live out whatever life she had left in the best way that she could.

What factors contributed to your loved one’s decision to enter hospice?

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How did this decision impact you? How did it make you feel?

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We marked the decision by having a family dinner and sharing memories. How did your family mark this decision?

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Reflect on WIGIAT.

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Chapter 4

“I want to die right now!”

Hospice can be very confusing. Often people entering hospice care have a variety of questions and expectations that impact their impression of this philosophy of care. Even though we’d explained what hospice was all about to Mom, she was still confused and expected something from her hospice nurse that couldn’t be provided. The mixed expectations were very upsetting.

What are your questions about hospice care?

What are your expectations of hospice care?

Mom asked the question, “What do I do now?” I responded with three ways that she could show us how to die well. How would you answer that question for your loved one?

Reflect on WIGIAT?
Chapter 5

Taking Care of Business

There are a lot of business affairs that need to be taken care of while your loved one is able to manage those things. For us, it included arrangements with the funeral home and cemetery; planning for the memorial service; and ensuring that the will and advance directives were up-to-date.

What business affairs do you need to handle?

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Chapter 6

Surrounded by Love

We were surrounded by a lot of people during our time of caring for Mom. Greeting cards, phone calls, and visits brought great joy into our hearts.

Who is surrounding you in love during this time?

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In what ways are you being blessed by their presence?

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How can you express your appreciation to them?

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Reflect on WIGIAT.
The commitment to care for Mom at home stretched us in many ways, especially in the area of providing medical care. Thankfully, we had wonderful support from our hospice team, but they couldn’t be with us all the time. This meant that we had to take on some of the responsibility as we tended to Mom’s medical needs.

Describe the medical care that you’re providing to your loved one?

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How is this making you feel?

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What’s challenging you the most and how are you responding to the challenges?

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Reflect on WIGIAT.

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Chapter 8

Managing Medications

Managing Mom’s medications was our attempt at trying to control an uncontrollable situation. We felt so out-of-control during this time so being able to tackle what we perceived as a big problem gave us something to focus on. Unfortunately, we drove ourselves and mom crazy in the process. Thankfully, our hospice nurse helped us put things in perspective.

What part of caring for your loved one is making you feel out-of-control?

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How are you responding to that?

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How are you keeping things in perspective? Who or what is helping you?

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Reflect on WIGIAT.

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Chapter 9

On Hazel’s Team

Mom was weary from being unable to care for herself. This made her very sensitive to what was happening around her. Believing that Jenny and I were arguing, she reacted in a way that surprised us.

Mom wanted to make sure that we were all on the same team, Hazel’s team. Who’s on your loved one’s team? How is your team functioning?

What can you do to minimize the stress your loved one is experiencing?

How can you reduce your own stress?

Reflect on WIGIAT.
Chapter 10

Trip to the Beach

One of the things that Mom most wanted to do before she died was a beach trip. With the support of her hospice team, we were able to make this a reality. While it was stressful, doing this for and with Mom was a blessing for everyone.

What are the things that your loved one most wants to do before they die?
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What can you do to make one or more of those things happen?
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What will the challenges be and how can they be overcome?
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Reflect on WIGIAT.
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Chapter 11

The Talking Stick

Mom was struggling with all of the activity in her house, but it was so much more than that. She was really struggling with the loss of control and all that she had given up, or surrendered, during this time. She was angry. Her reaction was to exert her authority over us, over everything that was happening in her house, and ultimately over cancer.

What has the life-limiting disease taken from your loved one? What has your loved one surrendered?

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How is your loved one exerting their authority over the chaos and loss they are experiencing?

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How are you coping with the chaos and loss you are experiencing?

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Reflect on WIGIAT.

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Chapter 12
The Branch

The time under hospice care takes its toll on a person’s mental, emotional, physical, and spiritual health. Thankfully, the hospice team made sure that Mom was comfortable and in very little pain. This opened up opportunities to tend to her mental, emotional, and spiritual well-being. Sometimes the promises of God seem too good to be true. That’s what prompts us to doubt, to question, to seek reassurance so that we can hear the promises again and again.

How is the journey under hospice care impacting your faith and the faith of your loved one?

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What are your loved one’s favorite Bible passages? What are yours?

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Reflect on WIGIAT.
Chapter 13

The Shower

In this story, Mom insists that Jenny and I do somethings that made us feel very uncomfortable. Yet we did them anyway because we loved her. This whole experience stretched us so far beyond our comfort zone!

What has your loved one asked you to do that stretched you out of your comfort zone?

Describe the experience here so that you can share it with others one day.

How do you cope when you’re being stretched beyond your comfort zone?

Reflect on WIGIAT.
Chapter 14

A Visit from Daddy

Nearing the end of her physical life, God blessed my mother with an experience that gave her much comfort and assurance. In this time, the thin veil that separated our physical lives from our eternal lives opened up and my dad, who died in 1983, came to visit Mom. This was a precious and holy thing to witness and still impacts my experience of God today.

In what ways is God blessing your loved one and you today?

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How are these blessings impacting you and your loved one?

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Reflect on WIGIAT.

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Chapter 15

The Final Hours

It’s sometimes difficult to know when death is approaching. Thankfully, the hospice team shared information with us about how we might recognize the signs. Using this information, we were able to anticipate what was happening. We marked Mom’s final hours by sharing a meal together, remembering stories, and having worship. These were tender moments filled with laughter and tears.

How does your loved one want to mark the final hours of their life? Who do they want around them? Is there anything special they’d like to happen or not happen?

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How do you want to mark the final hours? Who do you want to be there with you? Is there anything special you’d like to do or say?

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What are your feelings as you think about this time?

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Reflect on WIGIAT.

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Chapter 16

The Days After

The days immediately after the death of a loved one are often emotional and complex. There are many people to contact as you implement plans that were made earlier. You begin taking care of business. Thankfully, Jenny and our family maneuvered through this time in compassion and peace. Take care of yourself. Be kind and patient with yourself and others.

What are the things that need to be taken care of right away?

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What challenges are you facing?

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What strategies are you using to overcome the challenges?

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How are you coping during this time?

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Who can you reach out to for support?

We went shopping in the days after Mom died. What can you do to have fun?

Reflect on WIGIAT.
Part Two

Biblical Reflections on Caring for a Loved One in Hospice
LECTIO DIVINA

I invite you to use an ancient practice known as Lectio Divina to meditate on the Bible passages included in the book. Lectio Divina is a different way of praying and being present to God.

Lectio Divina is not a Bible study. Instead, it’s an approach that moves you out of your head and into your heart, into your soul, so that by the presence of the Holy Spirit, God will encounter you in a holy way.

To hear God, you need to turn off the critic or cynic in your mind that questions whether or not you’re really hearing God. If God speaks it’s usually in thoughts that come into your mind. Listening for God, listening to God, is a matter of faith. How God speaks to us is a mystery. Lean in to that mystery as you spend your devotion time with God.

Through Lectio Divina, you’ll read the passage three times, reflecting quietly on a focus prompt after each reading, and then praying quietly. Each reading takes you deeper into the passage.

Silence is important in Lectio Divina, so you’re encouraged to build in several minutes of silence between each reading. If you’re not used to being quiet, then you’ll probably feel some discomfort, perhaps getting distracted, anxious, or antsy. That’s okay. Getting used to silence with God takes practice. You might start with a shorter time at first and then slower increase the time of silence as you get comfortable. If distractions are bothersome, try keeping a pad of paper and pencil nearby where you can note what’s distracting you and then return to silence.

Space is provided in this Companion for you to journal about your experience and insights.

Opening Ritual: Set the stage for your devotion time. Gather your favorite Bible (maybe even a second one in another translation) and this companion. Light a candle and get into a comfortable position. Open with the Lord’s Prayer or another prayer of your choosing.

First Reading: Read slowly through the passage. Consider reading it aloud. Pause to honor the punctuation in the text.

First Focus Prompt: Listen for one word or phrase from the text that resonates with you. Hold on to that word or phrase by repeating it over and over again.

First Response: [After a few minutes of silence.] If you haven’t received a word yet it’s okay, keep listening as it may come later. If God has given you a word or phrase, record it in the Companion — without any explanation or commentary.

Second Reading: Read slowly through the passage again. Consider reading it aloud. Adjust the pacing this time. Be sure to honor the punctuation of the text.

Second Focus Prompt: Enter into the Scripture passage. What do you feel? What are your emotions? What specific situation in your life today resonates with this passage?
Second Response: [After a few minutes of silence.] In the Companion, note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

Third Reading: Read slowly through the passage again. Consider reading it from a different translation. If you haven’t done so, read the passage aloud. Adjust your pacing and be sure to honor the punctuation of the text.

Third Focus Prompt: What is God’s personal invitation to you from the Bible passage? What is God calling you to do, or how is God calling you to be, through this passage? Rest with these questions for a while.

Third Response: Note your responses to these questions in the Companion.

Ending Ritual: End your devotion time with prayer of your choosing. Rather than praying for others or for situations you are facing, pray for yourself, being sure to thank God for the insight you’ve received in this devotion time. Extinguish the candle. Rest in this space for as long as you can.
REFLECTION ON 1 CORINTHIANS 13:4-8, 13

First Response: Note the one word or phrase that God gives you in this passage.

Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

Use this space to note any additional thoughts, reactions, or insights from this passage.

Reflect on WIGIAT.
REFLECTION ON COLOSSIANS 3:12-14

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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REFLECTION ON ECCLESIASTES 3:1-8

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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REFLECTIONS EPHESIANS 3:14-16

First Response: Note the one word or phrase that God gives you in this passage.

Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

Use this space to note any additional thoughts, reactions, or insights from this passage.

Reflect on WIGIAT.
REFLECTION ON HEBREWS 12:1-3

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?”

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.
REFLECTION ON ISAIAH 43:1-5A

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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REFLECTION ON MARK 2:1-5

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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REFLECTION ON PHILIPPIANS 4:4-9

First Response: Note the one word or phrase that God gives you in this passage.

Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?”

Use this space to note any additional thoughts, reactions, or insights from this passage.

Reflect on WIGIAT.
REFLECTION ON PSALM 6

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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REFLECTION ON PSALM 23

First Response: Note the one word or phrase that God gives you in this passage.

Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

Use this space to note any additional thoughts, reactions, or insights from this passage.

Reflect on WIGIAT.
REFLECTION ON PSALM 95:1-7

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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REFLECTION ON PSALM 139:1-14

First Response: Note the one word or phrase that God gives you in this passage.
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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.
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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage”
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Use this space to note any additional thoughts, reactions, or insights from this passage.
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Reflect on WIGIAT.
REFLECTION ON ROMANS 5:6-11

First Response: Note the one word or phrase that God gives you in this passage.

Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

Use this space to note any additional thoughts, reactions, or insights from this passage.

Reflect on WIGIAT.
REFLECTION ON ROMANS 8:31-35, 37-39

First Response: Note the one word or phrase that God gives you in this passage.

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Second Response: Note the feelings and emotions that are stirred by the passage. Describe the situation in your life that resonates with this passage.

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Third Response: What is God’s personal invitation to you? What is God calling you to do, or how is God calling you to be, through this passage?

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Use this space to note any additional thoughts, reactions, or insights from this passage.

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Reflect on WIGIAT.

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About the Author

Pam Northrup is a hospice chaplain and a graduate of Lutheran Theological Southern Seminary. She was ordained in the Evangelical Lutheran Church in America (ELCA) in 2006. She’s served as pastor at Our Saviour Lutheran Church, Southern Pines, NC; St. Mark by the Sea Lutheran Church, Palm Coast, FL; and St. Philip Lutheran Church, Raleigh, NC. As a trained Stephen Leader, she has prepared countless lay people to serve as Stephen Ministers who provide confidential Christian caregiving to people in need.

Her passion in ministry is journeying with people as they face the ups and downs of life. She sees the movement from life, through death, to eternal life as the holiest moment in a person’s life. Her passion in life is spending time with friends and family, especially her grandchildren. She enjoys playing board games, assembling puzzles, making music, coloring, and making art collages.

Pam is recognized as an outstanding preacher, gifted teacher, compassionate listener, and skilled facilitator. Pam is proud to identify herself as an Army Brat. She believes that this experience, her vocation as a parent, and her work as a special education teacher, Girl Scout professional, adult educator, and pastor influence the way she makes sense of the world.

Pam lives in Knightdale, NC with her husband, Bob, and their two dogs. You can read a collection of her sermons and blog posts and learn more about her at www.onthewayliving.org.

Contact her at pam@onthewayliving.org if you’d like to talk about speaking and teaching opportunities.