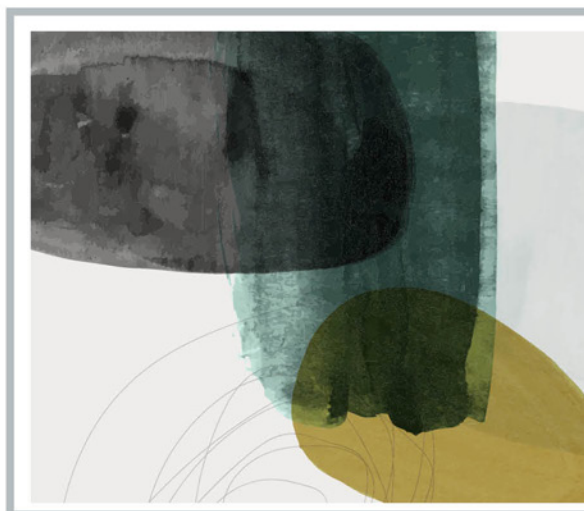


# FORMED TOGETHER

MYSTERY,  
NARRATIVE,  
AND VIRTUE  
IN CHRISTIAN  
CAREGIVING



KEITH DOW

Formed Together

# SRTD

STUDIES IN RELIGION, THEOLOGY, AND DISABILITY

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# Formed Together

*Mystery, Narrative, and Virtue in Christian Caregiving*

Keith Dow

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## *Series Introduction*

*Studies in Religion, Theology, and Disability* brings newly established and emerging scholars together to explore issues at the intersection of religion, theology, and disability. The series editors encourage theoretical engagement with secular disability studies while supporting the reexamination of established religious doctrine and practice. The series fosters research that takes account of the voices of people with disabilities and the voices of their family and friends.

The volumes in the series address issues and concerns of the global religious studies/theological studies academy. Authors come from a variety of religious traditions with diverse perspectives to reflect on the intersection of the study of religion/theology and the human experience of disability. This series is intentional about seeking out and publishing books that engage with disability in dialogue with Jewish, Christian, Buddhist, or other religious and philosophical perspectives.

Themes explored include religious life, ethics, doctrine, proclamation, liturgical practices, physical space, spirituality, and the interpretation of sacred texts through the lens of disability. Authors in the series are aware of conversation in the field of disability studies and bring that discussion to bear methodologically and theoretically in their analyses at the intersection of religion and disability.

*Studies in Religion, Theology, and Disability* reflects the following developments in the field: First, the emergence of disability studies as an interdisciplinary endeavor that has impacted theological studies, broadly defined.

More and more scholars are deploying disability perspectives in their work, and this applies also to those working in the theological academy. Second, there is a growing need for critical reflection on disability in world religions. While books from a Christian standpoint have dominated the discussion at the interface of religion and disability so far, Jewish, Muslim, Buddhist, and Hindu scholars, among those from other religious traditions, have begun to resource their own religious traditions to rethink disability in the twenty-first century. Third, passage of the Americans with Disabilities Act in the United States has raised the consciousness of the general public about the importance of critical reflection on disability in religious communities. General and intelligent lay readers are looking for scholarly discussions of religion and disability as these bring together and address two of the most important existential aspects of human lives. Fourth, the work of activists in the disability rights movement has mandated fresh critical reflection by religious practitioners and theologians. Persons with disabilities remain the group most disaffected from religious organizations. Fifth, government representatives in several countries have prioritized the greater social inclusion of persons with disabilities. Disability policy often proceeds based on core cultural and worldview assumptions that are religiously informed. Work at the interface of religion and disability thus could have much broader purchase—that is, in social, economic, political, and legal domains.

Under the general topic of thoughtful reflection on the religious understanding of disability, *Studies in Religion, Theology, and Disability* includes shorter, crisply argued volumes that articulate a bold vision within a field; longer scholarly monographs, more fully developed and meticulously documented, with the same goal of engaging wider conversations; textbooks that provide a state of the discussion at this intersection and chart constructive ways forward; and select edited volumes that achieve one or more of the preceding goals.

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# *Introduction*

## Giving a Careful Account

The whole trouble lies in that people think that there are conditions excluding the necessity of love in their intercourse with man, but such conditions do not exist. Things may be treated without love; one may chop wood, make bricks, forge iron without love, but one can no more deal with people without love than one can handle bees without care.

Leo Tolstoy<sup>1</sup>

Writing an introduction offers the briefest taste of omniscience; that moment where the author has read through to the end and returns to give a full account. Even so, parts of what follows are already a dim memory. The account is never complete. Along the way, our greatest discoveries are found at the relational intersections of the stories we tell: the accounts that we give of our lives and experiences.

Many people struggle to “give an account” in the way expected of them. This may be because of a speech impediment or difficulty with traditional forms of communication. Perhaps someone has a mobility challenge that prevents her from *getting to* a place where her story might be heard. Someone may have an IQ considered lower than “normal” among the population and so not deliver his account in the way that one might expect.<sup>2</sup> Many people are not able to express their intentions, their actions, or their plans as coherently or intelligibly as is demanded of them.

Through this book, you will encounter “accounts.” Many of these accounts are of my own experiences, often of supporting people with intellectual

disabilities. Any of these accounts or stories are problematic if taken in an authoritative or definitive sense. Yet all reflect the ways that the people I have known have helped to write this book.

## GIVING AN ACCOUNT: NASSIM

I saw Nassim almost daily for four years when I worked as a direct support professional. He was a large man and hairy everywhere except on the very top of his head. He would saunter around his home swaying and singing or laughing with short, gulping chuckles—as though in response to a joke that only he understood. When Nassim became anxious or upset, he would pace quickly. His vocalization became louder and more agitated. He would hit himself on the side of the head. I worried that his colostomy bag might get caught and come undone, leading to a messy and possibly dangerous interaction.

When Nassim was happy, though, he would take you by the arm. At times, he would play with his fingers on your hand, tapping on your palm as though he were sending telegraphs to the remote regions of space. Perhaps to those who heard and laughed along with his inside jokes.

Nassim loved food. One of his favorite activities was to go each week down to the local Lebanese restaurant and gulp down shawarma. They knew him well there. His preference for shawarma tied him to his cultural and social roots. The restaurant workers did not know his grandmother, though. Nassim's grandmother was a short and feisty woman who had raised one grandson with a significant developmental disability and Nassim's father, who had recently passed away.

Nassim's grandmother didn't just call him Nassim. It was "my Nassim." She doted on him in a way I have only seen mothers do with newborn children. She would make sure that his care was top-notch down to the smallest details. One might surmise the blessing and curse of this for those who supported him. There would be moments of intense preparation as we headed out the door to take Nassim to his grandmother's house for the weekend. We needed to match every sock perfectly without signs of grime or dust. We had to be ready to answer for every aspect of the care he had received in the past week. Yes, he had been taking his medication. Yes, he had enjoyed his shawarma. Yes, Nassim had been a "good boy."

As time passed, Nassim's grandmother was no longer able to take him for the whole weekend as she had previously. She was growing older, and Nassim was just as strong as he had always been. She was not able to handle

his times of anxiety and distress anymore. It was remarkable that she was able to support him for as long as she had. Love is miraculous that way.

To those who knew Nassim well, his life may have revolved around food, but his food pointed to his deeper roots in his culture and, more specifically, in his close and sustaining relationship with his grandmother and his father. To observe his relationship with his grandmother was to see his life, his personality, and his interconnectedness with the world.

## THE AIM OF THIS BOOK

What does life look like for Nassim now that his grandmother is no longer able to care for him? These natural relationships lie at the very core of *who he is*. Once these roots are severed, who will be grafted into Nassim's identity? Nassim's grandmother and father are irreplaceable. Nevertheless, those who are with Nassim and care for him most hours of the day also play an integral role. How might these care providers contribute to Nassim's sense of identity and fulfillment? More specifically, what does it mean to *care well*, to fulfill one's moral responsibility to Nassim?

The purpose of this book is to explore accounts of caregiving and related philosophical, theological, and biblical resources to locate the appropriate motivation for, and formation of, ethical Christian care provision.

Many of the experiences here are from my time as a direct support professional with people with intellectual disabilities in a Christian service agency. However, the implications of this work extend beyond the field of intellectual disability. Paying attention to the caregiving encounter with people with intellectual disabilities is a uniquely revealing exercise. These encounters expose the reliance of Western morality on intellectual ability and myths of transparency. We think we are good, because we think that we know—all too well—who others are, who we are, and who God is.

*What if our intellectual hubris was called into question?*

*Can we be good in the absence of knowledge?*

*What, then, might it look like to love and care for each other?*

## A BRIEF OVERVIEW

### Part I: The Call to Care

The first part surveys the ethical resources of vocational language professed by caregivers. People providing care often express a sense of “higher calling” to people with intellectual disabilities, whether they describe this using

religious language or not. This *call to* others is a potential source of ethical motivation.

### *Chapter 1 ~ Vocation and Transcendence: Called to One Another*

*Chapter 1* examines the ways in which Martin Luther shaped the direction of vocational language in his *consecration of the ordinary*. In comparing and contrasting his perspective with that of Søren Kierkegaard, this chapter establishes that *belonging* and *distance* are integral factors in resilient vocational caregiving.

### *Chapter 2 ~ Vocation and Immanence: Called by Each Other*

*Chapter 2* goes on to unpack the nuances of belonging and distance in direct caregiving relationships. Building on a personal account of supporting Michael, it is shown that a kind of “eternal equality” is necessary to maintain ethical distance. However, we are also *called by* those whom we support into relationships of belonging. “True care is mutual care,” but care providers must navigate the complexity of being called *to* support (a transcendent call or a sense of distance) and being called *by* the people they support (a sense of belonging).<sup>3</sup>

### *Chapter 3 ~ A Theological Story: The Limits of Professional Ethics*

*Chapter 3* inquires into current approaches to caregiving ethics as established in the name of professionalism. Do these practices equip caregivers to practice resilient, ethical care? Following Alasdair MacIntyre’s critique of “managerial effectiveness,” I will demonstrate these approaches to be insufficient to explain or support ethical motivation and formation. To adequately address the sense of being “called to” and “called by” others, Christian care provision requires a fuller understanding of theological anthropology and account of human flourishing.

## **Part II: Encountering My Neighbor**

The second part argues that an adequate understanding of *calling* in the Christian tradition entails recognizing that *all people*—including those with intellectual disabilities—have intrinsic value, being created in God’s image. However, preceding intellectual recognition, we first *encounter* one another as image-bearers of God.

### *Chapter 4 ~ Traces of the Divine: The imago Dei and Human Ability*

*Chapter 4* provides an overview of existing approaches to the *imago Dei* and disability. We *receive* our ethical obligation to one another before we develop

any theoretical moral system. We are responsible to one another precisely *as* created in God's image. However, we *live into* the fullness of this image through the *imitatio Dei*. Within the Christian tradition, ethical formation involves conforming to the nature of Christ. This is where we come to appreciate the mystery and revelation bound up in our encounter of others, ourselves, and God.

Encountering one another as created in God's image is not a simple task because of the barriers we face and the presuppositions we carry with us.

Chapters 5 through 7 examine three myths of recognition that underlie these barriers:

*Chapter 5 ~ Seeing You through Me: The Myth of the Transparent Other*

*Chapter 6 ~ The Stories I Tell: The Myth of the Transparent Self*

*Chapter 7 ~ A Mysterious Revelation: The Myth of a Transparent God*

To presume that recognition of the *imago Dei* is easily accessible to our intellect is to presume that our knowledge of one another and ourselves is easily accessible as well. Narrative ethics in the vein of Alasdair MacIntyre look for intelligible accounts that comply with the *tyranny of transparency*—a transparency that is unattainable. We need a moral responsibility tied not to myths of transparency but to the shared opacity of our stories and lives.

### **Part III: Responding to the Call**

The final part sketches the posture that is *called for* by Christ once we encounter one another as created in God's image—both revelatory and opaque. It unearths several *virtues of care* and concludes where the project began, with an exploration of the Source of this mysterious calling.

*Chapter 8 ~ Formed Together in Love: Toward an Ethic of Christian Care*

Within the Christian tradition, caregivers respond to their calling out of an overflow of God's love, already received. It is only out of this love that care arises out of gift rather than solely in response to an ethical demand. "We love because he first loved us."<sup>4</sup>

*Chapter 9 ~ The Virtues of Care: Discovering Who We Are*

The virtues of courageous humility, loving mercy, of confession and forgiveness, of lament and morning, and of quiet attentiveness arise not out of an overreaching estimation of intellectual prowess but out of deep humility. In this way, we encounter everyone, including people with intellectual disabilities, as full moral agents capable of rich human flourishing.



## A NOTE ON METHODOLOGY

What is reasoning? It is the result of doing away with the vital distinction which separates subjectivity and objectivity.

Søren Kierkegaard<sup>5</sup>

This book does not claim detached impartiality or even objectivity in its approach. Its reasoning arises out of a broadly phenomenological or existential tradition. I frequently relay the way experiences of care provision *present themselves* and then attempt to make sense of these experiences in light of diverse theological and philosophical frameworks. In short, I aim to take seriously the vital distinction and interplay between subjectivity and objectivity. My arguments and critical analysis arise not apart from my experience in direct support but precisely out of these encounters and experiences. The people I have met and known have shaped the ways I think. I will share “accounts,” stories of my interactions with others, and proceed to analyze the ways that relevant theories and the Christian tradition might critically interpret these interactions.<sup>6</sup>

One might note that Søren Kierkegaard, Emil Brunner, Henri Nouwen, Emmanuel Levinas, Alasdair MacIntyre, and Judith Butler are diverse thinkers in their interests, areas of expertise, and conceptual frameworks. Each contributes important insights to the overall project. Occasionally I will highlight where they complement or critique one another. Note that my use of their writing is primarily constructive, drawing from their work precisely in those areas that intersect with the questions of this book.<sup>7</sup>

My commitment is to investigate a distinctly theological ethical motivation for caregiving and its posture toward people who receive care.

- *Motivation* can be understood as the “inner or social stimulus for an action.”<sup>8</sup> Motivation is closely linked in the pages that follow to a fundamental *obligation* or *responsibility* to one another.
- Where *posture* is an embodied stance toward others, the positioning of one’s body or one’s attitude or approach, it relates closely to *formation*. Posture is the resulting shape of one’s approach in response to the way that one has been *formed* to do so. In this way, posture will be used in conjunction with a sense of formation throughout this book. *Formation* speaks to those interactions that shape us into an *image* or *form*.<sup>9</sup> Personal formation occurs particularly through those voices and encounters that inspire us, breathing life into our experiences.

Within the Christian tradition, we are *always already* responsible to one another as people created in the image of God. Ethical motivation refers back to this call to love my neighbor as myself. Our posture toward one another is then formed in response to the love of God already received, in the example of Christ through the *imitatio Dei*. We are formed together in the virtues of care as much out of the partial opacity of our shared stories as out of the revelation of who we are *through* our stories.

### Pastoral Deconstruction

In response to God's love, no ethical system or theory is adequate. Systems privilege intellectual ability in a way not reflective of our encounter with God or one another. The intellect is a sharp scalpel, proficient at dissecting the world. Our calling in care is to work to stitch the world back together. This book does not set out to establish an ethical system. It is, instead, an act of *pastoral deconstruction*: in response to a pastoral calling, and out of respect for the people I have known and cared for, I seek to *question* and to *unsettle* assumptions regarding the privilege of intellectual ability in the accounts we give of our shared humanity.

Insofar as we have been given intellectual ability, it is true that our rationality is to be directed to seek the Good and to love God. "Love the Lord your God with all your heart and with all your soul and with all your mind and with all your strength."<sup>10</sup> However, as we are formed to "love our neighbors as ourselves," loving God with our minds is no more virtuous than loving God with any other aspect of who we are. Our neighbors with intellectual disabilities frequently demonstrate the virtues of care relayed in this book without requiring the ability to articulate them.

### THE END OF THE BEGINNING

This book is born partially out of a desire to tell my story, to give an account that inspires care for one another. Madeleine L'Engle observed that "story makes us more alive, more human, more courageous, more loving."<sup>11</sup> I agree that stories *can* do this. I only pray that this particular story is one that does so. I hope that it is a testimony to the far-reaching impact of people with intellectual disabilities on my life and faith and a witness to the ways that God has changed me *through* these friends who are often relegated to the margins of society and the church.

I hope that, upon arriving at the epilogue, you will have a new appreciation for how our shared stories are significant—not because of their intelligibility but because of their relationality. Our partial, shared opacity to ourselves and others binds us together, forms us together. The accounts that

we give gesture toward our goals, projects, hopes, and dreams. These acts of revelation structure us and define us in ways new and old. They help make sense of (reveal) our experience and hide (conceal) aspects of it simultaneously. Our stories offer a mysterious revelation of our origin as people created in God's image, formed in our encounters with one another.

The story that I gave of Nassim's life is only a short account of who he is from the time that I was fortunate to share with him. It is not exhaustive. It is a way of pointing, gesturing, and alluding to Another whose life and love have roots deeper than I can understand. I pray that this book points beyond itself to the fabric of this passing gift we call "life" and the richness of those encounters that we call "care."

# I

## THE CALL TO CARE



## *Vocation and Transcendence*

### Called *to* One Another

Everything calls. We live in a world infused with stimuli that demand our attention, our investment, our *care*. Scrolling through my social media news-feed, I was struck by the phrase “*This is your calling.*” Investigating further, the post turned out to be an ad for creating an online storefront. I kept scrolling. Perhaps I have now missed my vocation in life.

At one point in the not-so-distant past, the language of “calling” was restricted to a life of devoted service to God and the church. The *One who called* was understood to be a transcendent deity, and not everyone could expect to hear this summons to set-apart service. Now, everybody is expected to pursue their calling—whatever this may be. We are no longer sure of who or what *calls*, only that advertising companies compete to generate the most compelling demands on our time and our lives.

Every sense stimulus, every notification, every person or thought cries out for our concern and interest. Is it possible that anything and everything is a calling? If so, we risk succumbing to care fatigue, overwhelmed by the constant mental noise and the demands of modern life.

Related questions emerge:

- Might any occupation or job be a vocation?
- What are the moral implications of the language of vocation?
- What might be the resources here for considering ethical caregiving in the Christian theological tradition?
- Is there any right or wrong way to pursue one’s calling?

The pages that follow ask whether, amid all the cries for our attention, there is still space to hear a call to care for one another—a call that transcends the demands placed on us by everyday life. Perhaps the language of vocation still carries ethical connotations that motivate and sustain care provision.

## WHY VOCATION?

Interpreting one's work as a calling is not unique to Christian caregiving. In light of contemporary nonreligious conversations that also touch on vocation, "calling" may seem to bear little relation to a theological-ethical inquiry. Why does it make sense to begin by considering vocation?

As mentioned in the introduction, this book cannot be detached from my own journey and experiences of caregiving. Friedrich Nietzsche once observed that every great philosophy so far has been "a confession of faith on the part of its author, and a type of involuntary and unself-conscious memoir."<sup>1</sup> As I reflect on my experience of caregiving with people with intellectual disabilities, some aspects of this book are not so involuntary or unselfconscious after all. While many aspects of my caregiving journey remain mysterious to me, a clear sense of being called to others remains.

## Giving an Account: Called to Encounter

Coming to the end of my undergraduate studies in philosophy at a Canadian Catholic university, the shelves in my small room were lined with works by Aristotle, Plato, Thomas Aquinas, David Hume, and Immanuel Kant. They were the cheap paperback versions, of course—the ones I could afford. Each thinker had his own views on how to live a moral life, how one might live into full human flourishing. Even as I sought to understand these diverse frameworks and perspectives, I struggled with the detached theory of it all.

As a Christian, the existentialism of Søren Kierkegaard gave words to some of these tensions for me. It was not enough to *know*. One must *act*. Kierkegaard's critique of Christian scholarship is that it often serves to complicate ethical matters so that one might avoid potentially life-changing ethical demands. "Take any words in the New Testament," he suggests, "and forget everything except pledging yourself to act accordingly. My God, you will say, if I do that my whole life will be ruined. How would I ever get on in the world?" This is where theory and theology come to the rescue: "Christian scholarship is the Church's prodigious invention to defend itself against the Bible."<sup>2</sup> The irony that Kierkegaard highlights goes beyond Christian thought and writing. Ethical discourse without corresponding action accomplishes little.