

Healthy Caregiving

PERSPECTIVES FOR CARING PROFESSIONALS
IN COMPANY WITH

HENRI J. M. NOUWEN

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Foreword by Wayne Muller



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Introduction

Care, compassion and suffering are concepts recognized by virtually all cultures and wisdom traditions as core elements of the human condition. Yet, they each hold nuances which shine differently when viewed from various perspectives, akin to the effects noted when one holds a diamond to the light. Exercising compassion and caring for another is something most people have experience with, whether they have cradled a newborn baby, listened to the story of a friend who was distraught, or cared physically for ailing family members or friends. For those who have chosen professions in the caring realm, these concepts are particularly important, since both their personal and professional lives are impacted by how they perceive and experience care and caregiving.

In my own life, I have come to learn about providing as well as receiving care through my roles as a mother, wife, daughter, sister and friend. I have also been privileged to experience more than 40 wonderful years in the nursing profession, with a portion of those years also dedicated to theological study and pastoral care ministry. Many rich encounters of caring have formed who I am today, teaching me much about suffering as I attempt to continue working through my own understanding of caring with a compassionate heart.

And yet, time and again I have witnessed how beautiful hearts, including my own, become tired and broken when the burden of caring becomes onerous. With millions of people involved in caring professions in North America, and millions

more caring for their own family and friends in an unpaid role, supporting and nourishing caregivers is a monumental but essential task. This inspirational resource has been developed to provide awareness, tools and encouragement, particularly for those engaged in formal caregiving roles. The Henri Nouwen Society is dedicated to the important work of supporting caregivers, and continues to publish and develop materials and programs for those who provide care to others, either personally or professionally.

Years ago, in my personal attempt to learn more about the nuances of care and compassion, specifically care for the dying, I was fortunate to discover the extensive writings of Henri J. M. Nouwen. Henri's words resonated with me on many levels, deeply impacting my life both personally and professionally. Accompanying those who are dying often involves exploring existential and spiritual landscapes, confronting many of life's mysteries and questions. Henri's work helped me become more comfortable exploring not only my patients' questions with them, but ultimately my own questions as well.

Nouwen lived a very full life in many different circles, until his untimely death in 1996 at the age of 64. Born in the Netherlands, he was ordained a Roman Catholic priest in 1957 and found himself involved in a progressive post-war church that was more open to the laity and focused on outreach. It was a church attempting to speak to the needs of modern people in a changing world, trying to become more inclusive and attentive. These qualities would become hallmarks of the spirituality he would teach and promote for the rest of his life.

After obtaining further education and an advanced degree in psychology, Henri moved to the United States and enrolled in a new program of studies in religion and psychiatry at the Menninger Institute in Kansas. This would become the birthplace of Clinical Pastoral Education – what modern-day chaplains and pastoral counsellors know as CPE. Henri believed that there was a deep connection between the mind and the heart, and was convinced that true care should reflect what we refer

to now as “whole-person care” – the need to provide care not just for the body, but for the mind and the spirit as well.

Nouwen went on to teach at the University of Notre Dame, and in the Divinity schools at Harvard and Yale. After many years in academia, he followed the urgings of his restless heart, exploring other life experiences, including periods as a missionary in South America and time in a monastery. Eventually, he became friends with Jean Vanier, a Canadian philosopher and theologian living in France. It was there that Henri was introduced to the L’Arche movement. (This is the French word for “The Ark” – a place of refuge and safety.) Vanier initiated L’Arche in the 1960s, establishing first one home, then several, where persons with intellectual and physical disabilities could live in small communities with their caregivers (called assistants) instead of in institutions. The movement flourished; today there are more than 150 L’Arche communities in over 40 countries and on five continents. In 1986 Henri was invited to Canada and lived the final ten years of his life as a pastor at L’Arche Daybreak in Richmond Hill, Ontario.

During those years at Daybreak, Henri continued to write and teach. He spent time developing deep friendships while also providing physical and spiritual care to the “core members,” as they are called, experiencing for himself the profound mutuality present in the gifts you not only give but receive while caring for another. It was also during this period that he found himself struggling with his own mental health, taking time away at one point for intense therapy to treat a profound psychological and emotional crisis. During this dark period, he kept a journal that was eventually published as *The Inner Voice of Love: A Journey through Anguish to Freedom*. It is one of his most well-loved books, appealing to people from all walks of life who relate to his pain and anguish, his depression and loss of hope.

A prolific writer, Henri went on to publish nearly 40 books during his lifetime; these have been sold internationally and translated into more than 20 languages. His books remain popular, inspiring new readers from bankers to politicians,

teachers, religious leaders, seekers, activists, parents and caregivers. Writers and researchers continue to explore his literary legacy, and works associated with him continue to be published. Although Henri's formation is rooted in the Christian tradition, and his writing often reflects this perspective, his desire was to engage people of all faiths and walks of life. His background in spirituality and psychology, along with his rich lived experience, allowed him to provide insights and language that bridged the sacred and the secular, appealing to wide and varied audiences.

Healthy Caregiving features not only Nouwen's work, but also the work of other experts in various fields. It is filled with caregiving stories, where sometimes the names have been changed to maintain the confidentiality of the person's identity. The self-reflective questions at the end of each section encourage the reader to explore their own care experiences and inner landscape to find support and nourishment for their caregiving journey. As you move through this resource, Henri's perennial wisdom is apparent; it lays a firm foundation that originates from the understanding that "caring is the privilege of every person and is at the heart of being human."¹

The Call to Care

*Caring is the privilege of every person
and is at the heart of being human.*

Henri Nouwen

Perspectives on Care and Compassion

Although all of us would like to believe that we are people who care, our society tends to use the word “care” in many ambiguous and indifferent ways. “Do you want a coffee?” “I don’t care.” Or, “Who will look after the house while I’m gone?” “I’ll take care of it.” We can also care *about* something or someone, which is different than caring *for* someone and actually addressing their needs. Most of us have experienced caring for someone’s needs at some point in our lives. We can appreciate that in many respects, caring for another is a universal experience in human life. People often provide care for others in more informal or unpaid caregiving roles – parents caring for children, children caring for aging parents, loved ones caring for family or friends who are ill, or spouses caring for one another as they age. Caregivers in these instances usually find that this is not something they necessarily chose to do; they can

feel overwhelmed and unprepared for what they are undertaking. It is sometimes referred to as the “unchosen profession.”

For those engaged in an occupation or a more formal role tied to caring for others, the word “care” takes on different understandings or perspectives. A professional caregiver would normally be hired or engaged by an organization to use their skills and insights to address a client’s needs and to take “care” of them. Whether they are involved in health care, social services, teaching or ministry, or have trained and engaged in a care sector as a volunteer, it is easy for this more formal caregiver role to be understood as something functional or practical. Basically, someone has a need and the care provider offers a skill or a service to meet that need, providing medical care, physical care, counselling or support, to name a few.

Understanding care solely from a service perspective can consciously or unconsciously foster an attitude of power between those providing care and those receiving care. The care provider viewpoint, put simply, would be “I have something that you need.” Their sense of power may not be intentional, but each care encounter runs the risk of creating the type of perception associated with “I am strong and you are weak”; “I am healthy and you are sick and vulnerable”; “I am powerful and you are powerless.”

Yet, many of us involved in caring professions believe that the care we offer is more than providing a service. We also desire to offer comfort, encouragement and a personal touch as we engage with those who require our expertise. Henri Nouwen would agree that true care is not ambiguous, or indifferent, and is not tied solely to service. His writings go even further to invite us to consider looking at the word “care” and our response to suffering from a perspective we may not have considered.

The word care finds its roots in the Gothic *Kara*, which means lament. The basic meaning of care is “to grieve, to experience sorrow, to cry out with.” I am very much struck by this background of the word care because we tend to look at caring as an attitude of the strong toward

the weak, of the powerful toward the powerless, of the haves toward the have-nots. And, in fact, we feel quite uncomfortable with an invitation to enter into someone's pain before doing something about it.¹

When I first reflected on this definition, it was a new concept for me. Working for many years as an emergency room nurse, I was very focused on “fixing” things for people or using my skills to assess their needs and triaging them to have their acute physical or psychological problems taken care of efficiently and effectively. I was never invited to consider “entering into someone else's pain before doing something about it.” Although I believe I had empathy for others and tried to treat people with compassion, I had not consciously thought about entering into their pain before attempting to “fix” it.

Later in my career, as the coordinator of a residential hospice, I became convinced that this kind of approach to care was invaluable. Working with palliative care providers at our local hospital and those caring for people at home, part of my role was to determine the appropriate time to offer someone admission to our residence.

Fred was a very independent man who truly wanted to remain at home to die, but his family needed respite not only from his physical care but also his tendency to be stubborn on a number of fronts. One day, the community nurse called me to see if we had a bed. After weeks of coaxing, she had finally caught Fred in a weak moment and he conceded to come to hospice. His family was so relieved! Shortly after his arrival, the staff came to me and asked me to speak with him and his family. Apparently, he was bent on leaving already!

Upon entering his suite, I found him fully clothed, sitting up straight in bed, with an exasperated look on his face. I sat down beside the bed with his wife and daughter and introduced myself to everyone. Instead of beginning by trying to convince him to stay, I wanted to find out more about Fred and why he didn't want to be at hospice. I listened as he explained, “If you think I am just going to sit in this room and stare at these walls until I die, you've got another thing coming.” The tears in the

eyes of his wife and daughter and the looks on their faces cued me into their conflicting feelings: their love for him, their embarrassment at his candour, and their definite need for a break from caregiving.

What he shared with me shaped my response. “Fred, I have a secret to tell you. Hospice care is not really about dying – it is all about living. We don’t want you to sit in this room staring at the walls until you die. This is your home now, and you can live here the same way you would live at home. You have a fridge here to keep whatever you like to eat or drink, your friends and family can come and go anytime they wish, and you are free to transform this room to your own liking and use the whole facility as much as you want to. Nobody knows if you have two weeks or two months or more to live, but however long that time is, we are here to keep you comfortable and well so you can do the best living you can with the time you have left.” He seemed to soften with these words, and over the next while, as we got to know Fred, we were able to help him to not just live but to thrive – so much so that he was able to be temporarily discharged home for a short while when his condition plateaued.

Our spiritual care coordinator, Bridget, spent lots of time getting to know the residents and their families, including their hobbies, likes, dislikes, fears, questions and more. Bridget and the staff found out two things about Fred: one, that he was a serious Toronto Maple Leafs hockey fan, and two, that he loved building and racing remote-control cars. With the encouragement of one of our personal support workers (PSWs), Fred’s family transformed his room into a Maple Leafs shrine, surrounding him with things from home that made him feel comfortable. Hockey games on his flat screen TV were special events! He also was able to convert the sofa in his suite into a workbench of sorts, laden with tools and car parts as he worked away on the hobby he loved. It was great fun to watch his cars racing down the hallway of the hospice!

Henri Nouwen’s invitation to enter into someone else’s pain before addressing it encourages us to be present to that person

– fully present to them – with our intellect and our skills as well as our heart, our time and our listening ears. We are encouraged to respond to the one who is suffering by recognizing their situation and stopping to consciously “be” with them, before we “do” anything about it. This is not so much about the amount of time we spend as it is about our attitude, the way we engage them, and the way we respond to what they *truly* need beyond the obvious. Although our natural impulse might be to begin our care encounter with a more intellectual problem-solving response, Henri asks us to take even a moment and first respond with who we are, not just what we know: one person to another, equals in our shared humanity and vulnerability. As I reflect on entering Fred’s room for the first time, I recall that I was afraid that I would not know how to convince him to stay. Allowing him to speak his truth instead of dismissing it, and attending to his fears and frustrations, helped us to establish our relationship with Fred and his family on a good footing.

This type of response relates to how Henri would describe compassion. “The word *compassion* is derived from the Latin words *pati* and *cum*, which together mean ‘to suffer with.’ Compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion, and anguish... Compassion means full immersion in the condition of being human.”² Compassion invites us to become vulnerable ourselves, and to come close to the one who suffers. We can respond that way only when the other ceases to be “someone else” and becomes like us. We find it is easier to show pity than compassion, because the suffering person calls us to be aware of our own suffering.

Shane Sinclair and his colleagues published an article in *Palliative Medicine* in 2017 that reflected data collected on palliative care patients and their understandings and experiences of three elements offered by their health care providers: sympathy, empathy and compassion. It noted how these related constructs are often used interchangeably within the health care literature, despite some notable differences.

The relationship between sympathy, empathy, and compassion.			
SYMPATHY	EMPATHY	COMPASSION	
Definition	A pity-based response to a distressing situation that is characterized by a lack of relational understanding and the self-preservation of the observer	An affective response that acknowledges and attempts to understand an individual's suffering through emotional resonance	A virtuous response that seeks to address the suffering and needs of a person through relational understanding and action
Defining characteristics	Observing/Reacting/Misguided Lack of understanding Unhelpful Ego based Self-preservation	Acknowledgement of suffering Understanding the person Affective response	Supererogatory Non-conditional/Virtuous Altruistic/Instrumental Action-oriented response
Response to suffering	Acknowledgement	Acknowledgement, understanding and emotional resonance	Acknowledgement, understanding, and emotional resonance linked with action aimed at understanding the person and the amelioration of suffering
Type of response	A visceral reaction to a distressing situation	An objective and affective response to a distressing situation	A proactive and targeted response to a distressing situation

Emotional state of observer	Emotional dissonance	Emotional resonance and emotional contagion (“feeling with”)	Emotional engagement and resilience
Motivators of response	Pity/ego/obligation	Circumstantial/affective state of observer/duty/relatedness to patient/deservedness of patient	Virtues/dispositional
Relationship of observer to suffering	External	Proximal/isomorphic	Instrumental/relational/transmorphic
Intended outcomes	Self-preservation of observer	Objective and affective understanding of sufferer	Amelioration of multifactorial suffering
Patient-reported outcomes	Demoralized/Patronized Overwhelmed Compounded suffering	Heard/Understood Validated	Relief of suffering Enhanced sense of well-being Enhanced quality of caregiving
Examples	“I’m so sorry” “This must be awful” “I can’t imagine what it must be like”	“Help me to understand your situation” “I get the sense that you are feeling ...” “I feel your sadness”	“I know you are suffering, but are there things I can do to help it be better?” “What can I do to improve your situation?”

Shane Sinclair et al., Sympathy, Empathy and Compassion: A Grounded Theory Study of Palliative Care Patients’ Understandings, Experiences, and Preferences, *Palliative Medicine* 31:5 (2017), 442.

In the preceding chart, we see the subtle but important differences not only in the definitions, but also in the response motivators as well as the patient-reported outcomes. Sympathy, perceived as an unwanted pity-based response, had a largely detrimental effect on patient well-being. Instead of having a healing effect, sympathy often left the care receivers feeling demoralized, depressed and sorry for themselves. Providers offering more empathic responses left the patients feeling more understood and validated, but the ones providing a compassionate response seemed to assist more in relieving suffering and enhancing a sense of well-being. One patient in particular described empathy and compassion this way: “I think empathy is more of a feeling thing where you’re aware of somebody’s suffering, and compassion is when you act on that knowledge.”³

In our task-oriented society, with health care and social service systems focused on streamlining services, it might seem difficult, if not impossible, to be able to offer truly compassionate care to the people we support. Trying to attend to the care of the whole person in light of the constraints of time and the boundaries of the therapeutic relationship is not always easy. It is hoped that the material you find in this resource will nourish and support you as you attempt to become more aware of this type of care and how you might offer it to others and to yourself.

Questions for Reflection

1. Are these definitions of care and compassion that Nouwen uses new for you? In what ways?
2. What is it like for you to care about someone or something? To be there in that situation?
3. When does it feel good to care? When does it not feel good to care?
4. What differences do you notice when you look at Sinclair’s comparisons of sympathy, empathy and compassion? Which one do you see yourself working out of for the most part? Does the patient/client experience of these surprise you?

5. When you engage with a client/patient/resident, do you try to discover what their needs are, beyond the obvious? How do you do that? How can you expand what you do to accomplish this more often?
-

Care versus Cure

Another perspective that Henri invites us to reflect on is the difference between care and cure. In a culture and a health care system focused on cure, it can be difficult to know what to say to people who are living with life-limiting or life-threatening diseases, advanced dementia, or chronic diseases with lifelong challenges. This reality is also faced by many people living with disabilities who are not seeking a cure or a change to their bodies, and do not see their lives as particularly filled with pain and suffering. Their abilities are part of their identity. The changes they desire do not revolve around a cure; instead, they focus on removing the barriers inherent in our society that affect attitude, access, communication and more.

Henri understood that the ability to care for one another was a universal gift of being human, and believed that care and compassion were always able to be shared, even when a cure was not possible. We often hear of the person who has been told by their specialist that there is no more treatment available for their disease – that there is “nothing more we can do.” The truth is, at this moment, there is usually much more that can be done. This is exactly the time when we can offer a tremendous amount of care and compassion, despite the fact that a cure is not on the horizon.

Being able to cure, at its foundation, is born out of a desire to relieve suffering and restore the person to a greater state of health. We are all happy when we hear that someone has been cured of their disease or condition. However, the desire to cure can keep us focused on “success,” which can build a sense of power and prestige in some people and a sense of loss or defeat in those who do not experience that outcome. When people finish their sessions of chemo or radiation, we often applaud

as they ring the bell or the gong at the cancer centre to indicate their final treatment. Yet, how does that impact those who are in the cancer suite, undergoing treatment that will not end before they die? How does it make them feel to hear that bell if they know their own disease is not curable?

In cancer care especially, we also tend to focus on using “battle” language, encouraging people to “fight” their disease. Those who will die from their cancer can be left feeling like they were a failure because they didn’t fight hard enough. “If I had enough faith or enough willpower, I would have made it. I am so sorry I let you down.” Some don’t want to be remembered as “losing a brave fight” against cancer, and would rather be remembered for how they made a difference in the world. Others don’t want to be defined by their cancer: that they “conquered it” or that they are a “survivor.” Yet, some find this language helpful and comforting. Each person is different, and it is important to engage them in conversations about their own wishes and comfort regarding language around their disease, instead of assuming we know what they want or need. This is another way we enter into their pain before naming it or addressing it.

The ability to focus on care above the need to cure helps us to see the person first, instead of the disease or disability. It gives us the opportunity to learn from them and their experiences, and can help us to become more comfortable with our own aging, weakness and dying. As we accompany those who teach us these important life lessons, we often discover that both parties experience growth and healing. This is a true gift. When our response to another person’s suffering can be more about being with them before doing something about it, we learn that our very presence is often enough to bring healing to that situation.

Still, when we honestly ask ourselves which persons in our lives mean the most to us, we often find that it is those who, instead of giving much advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or

confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not-knowing, not-curing, not-healing and face with us the reality of our powerlessness, that is the friend who cares.⁴

In our professional circles, we have been taught to maintain a professional distance from the person seeking care. This may make us nervous or unsure about Nouwen's understanding of care, which asks us to be more intentional, wholistic and even vulnerable with how we respond to those we care for every day. Mike Martin, who writes about professional ethics, explains that professionals can be criticized for being too detached, but also for not having enough distance. "Professional responsibilities do call for some forms of distance that limit the expression of personal values in professional life. Distance does not, however, imply the absence of caring and personal involvement. On the contrary, limited detachment often promotes ideals of caring that are simultaneously personal and professional."⁵

Henri struggled early in his professional life with finding this balance in caring for the other. His background in psychology and his training in the new field of Clinical Pastoral Education focused on the clinical and academic aspects of this work. Yet, a large body of his writing addressed what he felt was the overprofessionalization of caring and the need to transcend the temptation of too much distance, focusing on the essence of the person through ministry and compassion. His books *Compassion* and *The Wounded Healer* were just two of many that referred to the need to care deeply for the whole person, at the same time recognizing our own needs and brokenness as we walk in human solidarity with those we are called to care for or serve. For decades, Henri became an important guide in humanizing care. I believe his words remain true today as we seek to address the more mechanical, industrial model of care we have adopted as we institutionalized our systems and developed metrics that reflect impact and production instead of the uniqueness and dignity of each human person we care for.

Questions for Reflection

1. Recall a caregiving experience where you have been faced with care that was not related to cure. What elements do you remember? What did you learn about the difference between care and cure?
2. What are some of the struggles you face in providing this kind of care to others?
3. What are your thoughts on the language or rituals we use sometimes to promote cure? Does this impact how you provide care?
4. Does the language influence how you communicate with other clients and other professionals involved in their care/ services?

Care: Our Response to Suffering

Helen Keller, a woman whose early illness left her deaf and blind, knew suffering intimately. She is credited with saying that “although the world is full of suffering, it is full also of the overcoming of it.” This wisdom gives us hope and a sense that we all have the capacity to respond to another person’s pain with some ability to help them towards healing.

Dr. Eric Cassell, in *The Nature of Suffering and the Goals of Medicine*, defined suffering as “the state of severe distress associated with events that threaten the intactness of the person.”⁶ All the aspects of personhood – the lived past, the family’s lived past, culture and society, roles, the instrumental dimension, associations and relationships, the body, the unconscious mind, the political being, the secret life, the perceived future and the transcendent dimension – are susceptible to damage and loss. Cassell concludes that transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When experienced, transcendence locates the person in a far larger landscape where the sufferer is no longer isolated by pain but is brought closer to a transpersonal source of meaning and to a human community that shares those