



## **The Greatest Gift of Caregivers**

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My title includes the word 'greatest;' a word I use with some hesitation. To assert that something is 'greatest' would seem to require some proof that the object or phenomenon exceeds in some quality all of its competition.

Think about ways the term is applied. Muhammad Ali converted the adjective into a noun when he anointed himself 'the greatest.' Ringling Brothers lays claim that its production is 'the greatest show on earth.' Tom Brokaw pronounced the people who endured the Great Depression and the Second World War the 'greatest generation.' A movie dramatizing the life of Jesus bore the title "The Greatest Story Ever Told.' A spectacular IMAX movie several years ago took viewers to seven destinations deemed by the producers the "greatest places' on earth. According to the Gospel of Luke, Jesus formulated the greatest commandment by linking the Shema of the Jewish tradition ('you shall love the Lord God with all your heart, and with all your soul, and with all your might' [Dt. 6:4]) with his added prescription to 'love your neighbor as yourself' (Mark 12:28-31). In his letter to the Corinthians, Paul reasoned that love is the greatest of the three theological virtues of faith, hope, and love (I Cor. 13:13). On a more mundane level, a restaurant on Taft Street claims to be home to the 'greatest po' boy' in Houston!

It seems that commercial use of the word 'greatest' entails some measure of self-promotion and little or no evidence for the claim. Its use in Christian Scripture relies basically

on the authority of the source for justification. It seems unarguable to me that nearly any use of the word greatest entails a measure of subjectivity with respect to what qualities of an object or claim secures the designation of greatest.

Accordingly, I concede that my use of 'greatest' reflects certain of my values, experiences, priorities, and insights regarding the journey of caregiving. I hope by the conclusion of my remarks that I shall have provided a reasoned argument that justifies my counsel to caregivers or, at worse, prompts you to think about what is most important to you and the one for whom you care during this journey together. So let me begin to make the case that presence is the greatest gift you can make as caregiver.

When I talk with caregivers about their role, they typically speak of the tasks they do. Not all undertake the same tasks and not all perform a particular task in the same way because needs and circumstances may differ. Nevertheless, caregivers tend to describe caregiving in terms of tasks such as transportation, escorting to medical visits, shopping, housework, personal care such as bathing, dressing, feeding, and continence, managing medications, cooking, finding activities to occupy time, managing finances, insurance claims, locating resources, and a host of other forms of service that entail 'doing' something.

These and countless other tasks seem to be commonplace and preoccupy caregivers as their journeys progress. Each task may be necessary. Each hopefully adds to the comfort, welfare, and quality of life of the person being served. Some may be more pleasant while others may be more distasteful to execute. Some may require less while others require more effort. Some may require major disruptions in a caregiver's life while others may be barely a

bother. Some may feel like a heavy burden while others are a joy. Each task, however, compensates for some loss of the person for whom you care. Your assistance makes up for that loss and restores some measure of autonomy and control to your loved one. In a sense, something is broken or missing for your loved one and your assistance provides a 'fix' for that loss.

You feel good when you are able to perform these services that add independence and quality to your days with your loved one. Indeed, these forms of care may be tiring, frustrating, and unpleasant, at times. But, you do them because of your unbreakable commitment and gratitude for the gift your loved one is to you. Through these compensatory tasks, you are fulfilling partially your role as spouse, parent, child, sibling, or friend. Your preoccupation with tasks may be fueled, in part, by your loved one's preference to accept assistance from you, rather than a stranger or friend, during a period of vulnerability. Your history together has built a level of trust in you and belief that your care, the tasks that you perform, is intended to make life better for her or him.

I suspect that caregivers focus on tasks and plunge into performing them because you can: these daily tasks are within your power to control. In contrast, you are powerless to cure your loved one's disease, repair an injury, or mitigate pain. These tasks are entrusted to medical and nursing personnel to pursue.

Because assisting with activities of daily living are forms of care that you can perform, you may be seduced into thinking that more is better. You can rush to do everything for your loved one, even though she or he may be able to accomplish a task alone, but with some

difficulty or take more time. You can be constantly busy if your primary focus is on tasks. Your time with your loved one can be all about getting something done. You may refuse genuine offers by others to help because you want to do it yourself as an expression of your love or commitment.

When you concentrate on here and now, on an immediate need or task that you can perform, you can avoid thinking about those aspects of your situation that you cannot control and prefer not to contemplate because it is too painful. By staying active, fully occupied doing something, you feel like you are making a contribution and accomplishing something. Your love and care are demonstrated by the sacrifices you make to perform or assist with tasks. You are engaged in the struggle, not standing idly by feeling helpless in the face of adversity.

Permit me to applaud you for these expressions of care. Without your assistance, the days of your loved one could be more challenging and less enjoyable. Your reward is making days easier and brighter for your loved one. Each task is a gift generously and lovingly made. But, whether taken alone or taken together, tasks are not, in my opinion, the greatest gift a caregiver can make.

I acknowledge the value of tasks in caregiving. What I don't concede is that tasks are the greatest and most meaningful gift you can make. I proposed earlier that presence, not completing a task, is the greatest gift caregivers can make. The gift of presence may be both the easiest and the hardest to make because being present implies more than being physically near. Presence involves emotional openness, sensitivity to the experience of your loved one, readiness to share the journey whether the path is smooth or rough, accepting one's

limitations, appreciating our interdependence and need for one another, affirming and being at peace with the finite and vulnerable nature of the human condition, realizing that a difficult season of life presents opportunities for growth and blessing, and much more that constitutes the rich meaning of relationship and caring. In short, being present, as I am using the term, requires us to be vulnerable and nurturing. Presence may include, but goes beyond, the mechanics of completing tasks. Loyalty and mutuality are elements of presence that is grounded in the nature of your relationship with your loved one and the unique, non-substitutable meaning you have with each other. Many people can be physically present and perform most of the tasks that you routinely do. But no one, underscore no one, can fill the relational role with your loved one that you do. No one can take the place of 'you' in the 'we' of your loved one and you. Let me repeat, no one can take the place of 'you' in the 'we' of your loved one and you. No one cares for her or him exactly as you. No one knows her or him exactly like you. No one has the history that you do. No one feels the need, trust, or love for her or him like you and her or his need, trust, and love for you. Being present does not require you to fix something. Being present means being with each other, awaiting and negotiating all of the emerging joys and sorrows of this season of life. Nel Noddings provides insight to presence and the nature of caring in these words, "We do not begin [caring] by formulating or solving a problem, but by sharing a feeling." A feeling rooted in bonds of relationship that illness, injury, dependency, or threat of death cannot remove.

Our tendency to be busy with tasks is one way to avoid a potentially stressful intimate, emotional encounter with the fragility of life. But, this encounter is inescapable. It is required

of us if we are to be true to our relationship with our loved one. Our presence, robustly understood, demonstrates to our loved one that she or he is not abandoned along a rocky path of weakness or degeneration. Your unique presence at a challenging time demonstrates the strength and quality of your faithfulness, especially at times of hurt, loss, fear, and agony.

References to presence in Scripture may help us appreciate its meaning and significance. God promises humanity to be present with us, not to protect us from travail or fix our problems. God's promise and the assurance it gives is captured in the seminal phrase "I am with you" in Genesis (26:24) and subsequently in the Bible. Confidence in that promise is expressed in Psalm 23, "even though I walk through the valley of the shadow of death, I fear no evil; for thou art with me" (v. 4). For Christians the word of presence reaches its fulfillment in the coming of Messiah, whose name is "Emmanuel," "God is with us" (Matt. 1:23).

Presence in Scripture is a powerful and comforting image. Whether expressed as "I am your shield" (Gen. 15:1), "Do not be afraid, for God has heard the voice," (Gen. 21:17), or "Rest assured, do not be afraid" (Gen. 43:23), it is presence that gives these reassuring words substance. The phrase "I am with you" is not a promise from God to fix our problems, Rather, "I am with you" is a word of grace that has power to overcome estrangement, weakness, failure, pain, or loss. It is an invitation to a relationship that can endure through the dark valleys of life. It is a word of assurance that one does not bear burdens apart from the presence and care of God. And neither should a person bear burdens apart from the presence of people who matter to her or him.

As a spouse, child, sibling, other kin, or friend whose role now includes caregiving, you should realize the unique, meaningful, comforting, and powerful place you have for your loved one that no one, absolutely no one, can fill. You are needed to share this journey in all of its dimensions. You are needed to be physically with them, to provide an embrace that has no substitute, to communicate verbally and non-verbally with a depth of intimacy and understanding impossible for others, to appreciate even more the gift you are to each other, and to draw strength from each other as you face challenges.

At times in life, being present is all we can be or do. At those times, we discover the priority of presence over all else. At those times, being present may be the most intimate and loving gift we can make. While my mother was in a rehab hospital in Louisville 18 years ago, her superior mesentery artery which nourishes the bowel was blocked by a clot. Over the course of most of the day, her pain intensified to the point of being unbearable. She was rushed to an emergency room late in the afternoon where we allowed a surgeon to assess the extent of bowel loss. The surgeon's report dictated her subsequent medical care which was to provide maximum pain relief as her two sons journeyed to join my father at her side. After a few hours of being with her as the morphine drip erased her pain, we sat by her and held her hands as the ventilator was withdrawn and we surrendered her fully to God's care.

There were no tasks for us during those hours. There were no words spoken by her. We had done all we could to assess her condition. The family could not fix her. No one could fix her. All we could do was to be present as the grace of death drew near, to be faithful to the love and life experiences that bound us together as family, to be present to each other during a

heartbreaking time. During those hours, it became existentially clear to me that being present in good times and bad, being present during a course of caregiving of whatever duration, is the greatest gift in caregiving one can make.

Gifts in the forms of completing tasks, as necessary as they can be, pale in comparison. My counsel to you as caregivers is to give priority to being, rather than doing. Who you are and what you mean to your loved one are exponentially more important than attending to a multitude of tasks that may be competently done by others. Look for opportunities to ask and allow others to perform tasks. Don't squander this precious time with your loved one. Seize it. Savor it. Learn from it. Discover blessings on this journey. Draw closer to your loved one. Hold and cherish her or him in every way possible. You will never have these moments again. Do not let the distortions of illness separate you. Let the phrase "I am with you" be the promise you keep. These are words she or he needs and longs to hear more than anything that you can do. These words speak volumes about the quality and strength of your relationship. In keeping this promise, you will discover that presence is the greatest gift you can make. Being present will save you from those thoughts of self-recrimination that begin with the phrases, "if only I had.....," "I wish that I ...," or "if I could do it again, I would ...."

My final word is this. Make the gift of presence without reservation and in abundance. In so doing, you will be blessed now and comforted in the future.

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