Toward a New Understanding of Maternal Self-Care During Family Crisis

Initiating a Shared Legacy of Strength and Hope

This narrative explores the author's experience of suddenly becoming a caregiver for a spouse while also caring for minor children. The author uses reflection and research to describe what she learned about self-care, how she integrated her needs with the needs of her children, and why prevailing concepts of self-care as an individual construct can undermine its effective conceptualization and practice. The importance of self-care for caregivers is well documented, as is the failure of most caregivers to successfully achieve it. This failure carries particular poignancy for mothers of minor children. Studies document the academic, social, and emotional challenges that children experience when families face the upheaval associated with serious health problems. The children's need to navigate new ways of being within their families requires the support of their mother, which can be difficult if she becomes too overburdened by her caregiving role. Avoiding this cycle requires better education for families in caregiving situations and the adoption of a new understanding of self-care for mothers. This article combines the experiences of one family with research about caregivers, the effect of paternal brain injury on children, and typical recovery phases. It shares insights about the importance of modelling effective self-care as a healthy maternal legacy.

Every mother knows the challenge of self-care—our propensity to put the care of others before our own needs and the subsequent toll that has on both our physical and emotional health and on our professional and intellectual identities. In my decade of being a mother, I have had fairly typical struggles with this challenge, but it wasn't until our family faced a serious crisis that I had to confront my weaknesses, reflect on my most essential needs, and readjust how I define self-care to sustain our family for the long-term challenges confronting us.

Through time, muddled efforts, and reflection, I learned a lot about new ways of being that sustain me through the ongoing difficulties associated with this crisis. I learned I needed to adjust my reasonable expectations of self-care to the stage we were experiencing within our crisis. I also learned it was appropriate for a time to let go of the expectation that I should engage in self-care at all because sometimes that expectation becomes more a burden than a reasonable objective. I gained understanding about the effects of ignoring my own needs for too long, finding that my neglect of essential self-care affects my strength and ability to give to my family. In neglecting my own needs, I miss opportunities to care for my children, and I also run the risk of negative modelling that could affect their understanding of their own roles in relation to others in the world.

Over time, I realized my understanding about how to approach self-care was hindered by the way self-care is conceived and defined, both by me and within our broader culture, including those in the medical establishment upon whom we relied during an unfamiliar journey. The primary narrative of self-care in much popular literature focuses on individual needs, but this directly conflicts with my role and responsibilities as a mother. Through an unexpected journey of challenges and loss, I struggled to adapt this narrative into a reality I could reasonably achieve, both for the sake of my own care and to create a healthy legacy for my children to model. In the end, I rejected the more individualistic definitions I previously understood as the very essence of self-care and instead learned to integrate the needs of my children into the emerging rhythm of my care in both understanding and practice.

My journey toward this new understanding included acknowledging that the healthcare system inadequately addresses the needs of caregiving in families, although these medical experts laboured in so many other effective ways to help us. Their orientation reflected appropriate respect for the importance of caregivers, but did so in an often cursory way that perpetuated an individualistic approach to self-care and overlooked the more holistic needs of the families, who are so essential to patient recovery. A descriptive explanation of our anticipated challenges should have been possible—as research I did later confirms that the stages we experienced were predictable—yet the prevailing message we repeatedly received was one of superficial optimism. This rather vague and artificial approach left my children and me unprepared for the difficult journey ahead of us, which, in turn, created repercussions within my own journey toward better self-care. For me, this experience suggests that a more robust understanding of maternal self-care needs among medical providers could lead to more dialogue and, possibly, improved patient recovery outcomes.

Our journey began as a family road trip with my husband, daughters who were aged eight and ten, and our Golden Retriever. Six states into our vacation,

my husband had a massive stroke so serious that he was not initially expected to recover. My role immediately became one of rescuer, as he was driving, and we were on a mountain road with steep cliffs threatening at each curve. When his driving became erratic, I beseeched him to pull over, at which he alarmed me further by responding in a vague tone that he was not sure how to do so. From the point where I began helping him pull over, to getting him back into the car after we realized that he couldn't walk, and to figuring out the nearest medical centre in a remote corner of Colorado, emergency was for too long the operative word. After finally arriving at a medical clinic, my role quickly switched to one of caregiver to support his emergency medical needs and, almost simultaneously, to address the immediate emotional needs of daughters who were traumatized by his strange behaviour, my alarmed response, and the state of emergency with which medical personnel had greeted our arrival. Although I did not know it at the time, we had entered the "opening phase" of the poststroke journey, in which, according to a review of literature in the Journal of Clinical Nursing, "the initial shock is lived through. Medical stabilization and damage minimization are absolute priorities. The family grows closer together and directs all its energy toward the injured person" (Verhaeghe et al. 1007). Other researchers affirm this stage is traumatic, but note that it does not require particular attention to self-care, as "in the early stages of caregiving, negative effects may not occur" (Schulz and Sherwood 4).

Learning that research clearly defined our "opening phase" reassured me; recognizable patterns within what felt like evolving chaos showed me that our journey was one that other families had weathered effectively before us. Although this stage occurred even before the need for new understandings about self-care emerged, learning its definition felt prescient, for I later began to improve my own understandings of self-care both by integrating my children's needs within my own, which started at this stage, and by remembering my own values. A lesson I had learned through years of backpacking reemerged as one that informed both my approach to motherhood and my not-yet-emerging sense of self-care in this new journey. My memories of backpacking operated as an analogy that reminded me that I find strength when engaged in activities for which I have competence, feel joy, and have opportunities to simultaneously support others. As a backpacker, I have pushed myself on extended trips until I have literally wept alongside the trail. However, the worst days were always relative, and if someone else was further back and in more agony, that knowledge gave me the strength to get beyond my own exhausted pain to help. Throughout the agonizing journey of creating a new understanding of maternal self-care after my husband's stroke, I found myself relearning lessons I had learned while backpacking and integrating them in ways that moved away from an individualistic focus to

one that opened up my definition of maternal self-care to incorporate values of community, friendship, solicitude, and conversation.

Relearning those lessons and integrating them within the context of motherhood in crisis was a long process of discovery. The "opening phase" description reflected our reality, although the experience at the time felt magnified because of our remote location and isolation from the resources we would have had at home. Within a few hours, the medical clinic had my husband on a medical transport plane en route to the nearest stroke centre, which was several hours' flight away. In the meantime, I embarked on a seven-hour journey with our children through the night over pitch-black rural and mountain roads. Arrival at the stroke centre very early in the morning meant a continuation of this chaotic stage of emotional, medical, and logistical challenges, now exacerbated by a lack of sleep. Locating a place to stay the next night, finding a way to clean the car of his vomit, reassuring and being attentive to our children, and then searching for more affordable lodging options occupied the first few days of our emergency. Self-care was tied to family survival, and my actions in support of it went no further. I recall trying to do laundry during this time—managing to get quarters for the machines, then returning out of necessity twice to get more coins because I kept mistaking the washer for the dryer and putting the clothes in the wrong place. I do not normally face challenges with appliance use, but I was at that point befuddled to the point of incoherence. Although self-care did not cross my mind during this time, in retrospect, this initiation into our poststroke world carried prescient warnings about the way that my own self-care would remain intricately tied to the needs of my family.

For the six weeks my husband remained in this Colorado hospital before transferring to a rehabilitation centre close to home, we stayed in that survival mode. Even though the situation certainly took a toll, the very concept of self-care was postponed as I felt suspended between the crisis event and some measurable conclusion. During this stressful time, well-meaning friends did begin to ask me what I was doing to take care of myself—a question often posed and interpreted in individualistic terms. At this stage of our crisis, away from home and dealing with daily challenges of finances and lodging and childcare, that question did nothing to relieve my burden. I recognized it intellectually as the right question to ask—indeed, I had posed similar queries to friends in difficult situations in the past—but at the height of my stress, the very concept seemed to be yet another obligation cast upon me, something more to do, something else to solve. The gap between what I needed and what life was throwing at me was just too big to bridge with the little imagination I could conjure, and I found myself frustrated by the good intentions of questioners. I felt berated by a question that I could not even begin to act upon. A more cohesive understanding of maternal self-care and the expected stages of our journey would have relieved my angst with more a more realistic approach to appropriate and needed support.

Getting home was a long and complicated process, and was a continuation of the emergency mode. After the hospital discharged my husband to my care, I spent a physically and emotionally taxing day dragging, pushing, pulling, and manoeuvring him in and out of wheelchairs, cabs, and airplane seats across four states to a rehabilitation centre within an hour's drive of our home. He spent the next seven weeks there, and we experienced what researchers have labeled "phase two," which involves "emotional relief, denial, and unrealistic expectations with regard to the evolution of the injury" (Verhaeghe et al. 1007). Although the degree to which our expectations were unrealistic emerged only later, our return home did reflect a milestone that prompted me to face the question of self-care again. Unfortunately, I continued to experience the question as a burden, not only because my caregiving obligations continued but because my family leave had ended and my professional obligations emerged. But now it was with the added pressure of knowing that I was likely to be the sole financial provider for my family for the extended future and that that future included considerable debt associated with the medical bills. This dynamic of new obligations conflicted with my need to figure out how to meet my physical, emotional, and spiritual needs. And it was exacerbated by the fact that I had neither the support nor the wherewithal to discern what I needed in terms of self-care. The situation was still too new, too raw, and too complex for me to extricate my own needs from those for whom I was caring in a thoughtful way, and I did not have the wherewithal to begin to redefine self-care within the context of motherhood. My failure to do so would catch up to me.

To provide substantial care for an extended period of time, I needed to stay strong myself. Multiple research studies affirm the importance and challenge of self-care for caregivers. A 2008 article in the American Journal of Nursing highlights the health effects of family caregiving by summarizing caregiving as a process that "creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance (Schulz and Sherwood 1). An article in the American Medical Association indicates that family caregivers provide care "at considerable cost to themselves" (Schulz and Beach 2215), and a 2004 article in the Journal of Clinical Nursing notes in a review of literature about stress and recovery among families of people with brain injuries that stress is greater when it involves children living at home" (Verhaeghe et al. 1006). Literature in other recent articles continues to document this issue while lamenting the lack of research on the needs of family members. For example, a 2004 study notes that "the sometimes profound losses

and individual suffering of the children of parents with a head injury have been neglected in the literature" (Butera-Prinzi and Perlesz 83), and a 2015 article in *Community Mental Health* notes that in the recovery of patients of brain-related injuries, the effect on the family "has been neglected" (Spaniol and Nelson 761).

I had begun searching for resources about care for children of a parent with brain injury within weeks of my husband's stroke, but inquiries of therapy teams and social workers revealed no insights, nor were they able to suggest appropriate research. This lack of information, juxtaposed with apparently contradictory yet solicitous questions about my self-care, suggests a need for a broader understanding of self-care within the maternal construct as an essential component of sustaining caregivers. Instead, I found some resistance to the very idea that children should need support during this time, as some adults openly criticized our girls for their imperfect behaviour, especially around their father. Keeping the patient's needs a priority makes sense, but these criticisms were an early warning of the emerging conflict between their needs and his. I later found that research supports rather alarmingly that minor children of a parent who have experienced brain injury are, indeed, vulnerable. A study that looked at the effects of parental brain injury on children concludes that "children living with a parent with a head injury are negatively impacted at a high risk of emotional and behavioral difficulties" (Butera-Prinzi and Perlesz 96). The discussion in the study notes that in one very small sample group, the children were "at risk of high levels of anxiety, sleep and eating disturbances, withdrawal, depression and anti-social problems such as aggression" (96). The Journal of Clinical Nursing reaches similar conclusions: "children find it especially difficult ... [as a result,] they have lower self-concept, behavior problems, [and] symptoms of depression" (Verhaeghe 1006). These studies reinforce the importance of focusing on our shared self-care needs during a recovery process because the wellbeing of children is intricately tied to maternal self-care within such a shared journey.

Other research supports that link. Factors that protect children from some of the negative effects of a parental brain injury include "the presence of supportive and consistent or 'healthy' figures" (Butera-Prinzi and Perlesz 84). Thus, though initially counterintuitive both to me and to many who offered well-meaning suggestions, I learned that I needed to define "self" broadly as encompassing all three of us, both because we were all involved in the logistics of the care and because we alone were at the heart of the dramatic changes associated with my husband's stroke recovery.

Although at that stage of our journey we assumed that the worst was over, we were, in fact, just beginning to confront some of the complicated elements of self-care when there are conflicting needs. When our children visited my

husband in the rehabilitation centre, the toll of the stroke began to reveal itself in his changed cognitive understandings and different personality and preferences. The girls, in turn, began to show emerging signs of grief for the father that they had known, although I did not at first recognize their behaviour as such. Again, caregiver support oriented toward a holistic definition of maternal care would have helped inform our expectations because I later discovered that this grief is a normal and healthy:

grief that results from a loss that is final, such as the death of a loved one, is a healthy and normal process that is often eased by the rituals and active support that come with such events, [whereas] the grief that accompanies ongoing caregiving does not come with that same sort of closure and is often ongoing, which can lead to a cascade of negative emotions and behaviors. (Sullivan and Miller 3)

Our children's grief manifested in a greater need for my presence—both as a reassuring sign of continued parental care and as their shared partner in a very small circle of people experiencing the more hidden effects of this intimate and unwanted journey. Their need again contradicted the popular narrative of self-care as individualistic, yet, ironically, it simultaneously postponed my changed understanding about defining self-care because I became focused on the behaviour resulting from the grief instead of the shared care that would alleviate it.

At this point, when others would ask me what I was doing to care for myself, I began to panic. I sensed I could no longer avoid doing something to support myself, but I had no idea how to add more to plates already overflowing with emotional, practical, and spiritual needs. The suggestion that I ought to be doing more, even if for myself, felt like a staggeringly unfair expectation. The question of self-care was especially irksome to me because in my exhaustion, I was beginning to need it so desperately. I was sleep deprived, and I had not exercised for months. I knew that I was stretched too thin, and I felt that I was failing daily in minor ways in every aspect of my identity—as caregiver, mother, and employee. The well-intentioned queries about self-care felt like loathsome reminders that I was failing yet again.

I did need to find time to be outside, to be alone, to run, to pray. However, even with the benefit of time and experience to inform my reflection, I can see that the pressure I felt to create this time for self-care came in ways that were too esoteric. The suggestions were focused in ways that seemed to hedonistic in comparison with the trauma that my children continued to experience. How could I pull myself away from time they needed with me to get a haircut or a massage? How could I miss a daily visit to my husband just to give in to

a need for sleep? These questions plagued my conscience, but the question I most critically needed to address was one that hadn't quite occurred to me: how I could merge my role as caregiver to others with my own need for self-care? How could I integrate these needs into a maternal understanding of self-care in a way that authentically addressed our shared journey of care of one another and of my husband?

Long before I had acknowledged this dilemma, my husband was released from rehabilitation suddenly and ahead of schedule, which felt like a happy surprise. I was certain that the transition's challenges would be minor in comparison to those we had already weathered. However, I soon realized that we had entered "phase three," in which family members of brain injury patients can experience "bewilderment, anxiety, dejection, depression, feelings of guilt, despair, and the feeling of imprisonment ... [and some] families eventually evolve into a final phase or sorrow and mourning, role reorganization and role distribution" (Verhaeghe et al. 1007).

Indeed, rather than a smooth transition, we found wait lists for therapists that delayed needed care, and encountered new philosophies on care that differed from the ones in the rehabilitation center, which left his recovering brain frustrated and confused. Worse, the self-orientation required for a survivor's recovery was in stark contrast to the needs of young kids who had hoped and expected that their dad would return to his parental role, demonstrating care and showing interest in their activities. Instead, they found "a father with the same body but who appeared to be a different person" (Vergaeghe 1007).

Although they needed and had missed his reassuring and familiar presence, we were confronted instead with attempts at violent forms of discipline and terribly abusive comments that devastated the kids. None of his medical providers had warned me of this, and when I sought help from his primary provider, she dismissed the problem with a comparative description of physical abuse she had received as a child. Yet our situation deteriorated. On at least two occasions, we barricaded ourselves inside a bedroom while he shouted violent threats and tried to break down the door. Her implication that this behaviour was acceptable left me devastated, and I felt alone and exhausted beyond words. Research suggests that our situation should have been anticipated by medical providers had they integrated a holistic approach to caregiver needs in their concerns about my husband's recovery. One study with a small sample group notes the significance of "reported high level of violence" in every single one of the families they followed (Butera-Prinzi and Perlesz 90), even when there was no such violence in the home prestroke.

This nightmare of a transition period lasted for about two impossible months during which my own increasing needs for basic self-care were utterly thwarted and were buried under worry about daily confrontations between dramatically

conflicting needs. I felt determined to protect the husband I knew from the poststroke version of himself. I knew the man I married would have fought tooth and nail to protect, not threaten, the children he loved. Yet I was pummelled between his need to have me act as his advocate and the kids' need for physical safety and emotional security. Our days were filled with inauthenticity. I tried to present a calm and reassuring face to him, as I hoped to calm his responses so that he would return to a prestroke parenting style. I did the same with our children: I separated them from their father as much as needed and carefully monitored their time together to ensure peace. I was not always successful. Moreover, the nature of the situation intensified the isolation that we were already feeling as our community of support began to withdraw. This "social abandonment by family friends and even extended family" in which "expected supports ... were reported as unreliable or absent" is evidenced in the research, which also shows that children experience this as "unexpected and extremely disappointing" (Butera-Prinzi and Perlesz 91).

The self-care I had postponed again took a back seat as I found us again in survival mode and in ways that felt more traumatic even than the original poststroke period. The *American Journal of Nursing* warns that this is part of a dismal and declining pattern: "caregivers first experience distress and depression, which are followed by physiologic changes and impaired health habits that ultimately lead to illness and possibly to death" (Schulz and Sherwood 5).

Later, after we worked through this horrible period, I was able to hear the self-care questions again and process the fact that I did need to take some action to sustain my new roles as caregiver and provider for all family needs. My state of mind was not unlike the confusion I felt in trying to operate the washer and dryer at the inn on the day after the stroke when normal activities created such challenges. I was too overwhelmed by the accumulated stress of the situation to conceive of solutions without relevant advice and support. In frustration, I began to push back on the questioners. I asked what they meant by self-care, and hoped for some insight or solution that my now-muddled mind hadn't happened upon.

In response, most people offered suggestions reinforcing individualistic understandings of self-care: a massage, a dinner out, or a weekend away, which was not realistic in terms of my needs, my time constraints, or our already-stretched finances. My frustration in feeling inadequate to reconcile these suggestions to my ability to meet my self-care needs in the face of other challenges associated with this stage of the caregiving process led to much reflection. I realized that my primary need was for more time with my children alone to express both the concerns and hope that we each felt within a journey we alone travelled. My husband was on a parallel path, to be sure, but his experience as survivor differed from ours as caregivers. The girls and I needed to find a way to honestly

express ourselves and to find relief in expressing our shared burden of sadness, frustration, optimism, recollection, and hope. Caregiving can be "isolating" and a "lonely and frightening feeling"; caregiver emotions "can range from anger (at their partner, the illness, their [G]od), to a depression and regret at their own weakness, to a deep sadness about the loss of the life they had hoped and planned for as an individual and a couple of family. Often grief is the root negative emotion" (Sullivan and Miller 2-3). When I realized the importance of combatting the inherent isolation of our experience by processing these emotions together, I carved out time to do special things with our children. I gave my husband a break from the chaos of living with rambunctious and intense kids, which simultaneously gave them a break from having to adjust to the poststroke and newly emerging personality of their dad.

At the time, this did not fit my definition of "self-care" because it was oriented toward others' needs. However, as time passed, I learned combining my own needs with those for whom I was providing care was the best way to give and receive the nurturing we all needed and that could only come from each other, since no one else carried our challenges or could understand our particular journey. Understanding that self-care is not necessarily an individual process but one that I could engage together with our daughters broke my existing paradigm and allowed our joint care and healing to begin. I was reminded of how intricately our identities are linked to those around us and how the concept of solicitude relates to self-care. In my preunderstanding, I was stuck between caring for them and caring for me—a dance of futility that only broke when I brought us into the same rhythm of care.

The time that we spent together also turned out to be necessary because my girls' behaviour began to manifest itself in additional expressions of sadness and anger. Understanding that they were processing the stages of grief allowed me to better understand their behaviour and to provide space and support so that they could work through their emotions safely. This focus allowed me to see the integration of our need for self-care in poignant ways. Research shows that "children worried about ... their mothers' emotional state, her safety, and losing her altogether" (Butera-Prinzi and Perlesz 90). For us, this was revealed when someone with good intentions asked our daughters if I was doing enough to support them, and they responded with unexpected protectiveness. The intent had not been rude, but their response affirmed the time we had spent together as a supportive team—merging the care that they needed with my own needs and taking shelter in each other through a terrible journey that no one else could share.

Other research affirms similar findings that a mother's emotional strength is extremely important to the recovery of the family: "If ... the mother displays symptoms of depression, behavioral problems among children rise significantly"

(Verhaeghe et. al 1008)—a finding that places even more emphasis on the importance of my own self-care. I did have personal needs, and acknowledging and sharing the grieving process with my children allowed me the clarity to understand them. These needs included time to address my professional obligations without interruption, exercise, quiet time to think and pray, and emotional support to replace the elements of friendship and camaraderie that my husband could no longer provide. I also needed to learn to say no as a caregiver.

The latter revelation was painful, whereas acknowledging the need for new friendships became a silver lining to the whole crisis. I found it difficult to say no to any of my husband's needs because his poststroke personality is so sensitive, and he seems to take every rejection personally. For example, when he asked for a ride to a volunteer event that he wanted to attend and I had to decline because of professional obligations at the same time, his shoulders slumped, and he slowly shuffled out of the room. My heart fell, as I was agonized by the knowledge that I had hurt him, however unavoidably. I had to remind myself that the stroke has left him disabled from a more reasonable reaction, and to commit to act with kindness and compassion despite feeling unfairly blamed for his disappointment. I have learned that kindness and compassion expressed as continuous daily actions have to suffice to express my commitment to him, though they cannot rectify the sadness that I feel for such manifestations of a reality that I can only carry, not fix (Lawrence). I do hope that my children will learn from this example and that one legacy of this experience will be a model of caregiving that accepts and even reframes elements of situations we cannot change.

My need to cultivate new friendships emerged for two reasons, and the appreciation of this need helped support our children's needs to similarly connect through friendship with others. First, because caregiving is so exhausting and time consuming, I had lost valuable time I needed for my intellectual work, which is part of my professional identity and a needed outlet. For me, exercising my brain is as important as exercising my body, and new friends who encouraged this element of my being aided my self-care. Furthermore, just as my girls had lost the father they had known, I had also lost a partner and co-parent, someone with whom I could share my parenting worries. My husband could no longer share this; the stroke had left him without the judgment to share reflective conversations about our children's behaviour, needs, or future. Finding a friend with whom I could share parenting challenges helped enormously and morning email chats became a lifejacket of self-care, which allowed me to vent about childcare issues while exploring new research pursuits. That said, admitting that our situation required I replace some parts of the friendship I had shared with my husband with new friendships felt like a betrayal. It helped again to recognize it as a shared journey—comparable in many ways to what our children experienced when they began the difficult process of grieving for the father they had lost even while interacting with the very different version of him every day. Part of the process of learning to see self-care as a shared journey included giving one another the permission to acknowledge such sadness honestly, which, in turn, helped provide the strength to act with kindness toward one another and to my still-recovering husband.

The grieving process enables family members to "let go of old hopes and expectations and begin to create new ones," and this "new awareness also creates a crisis in meaning [and] [q]uestions about oneself, one's relationship to others, to one's living, learning, and work environments, and to meanings and purpose in life become important" (Spaniol and Nelson 764). Acknowledging the shared elements of self-care through an intentional approach to grief allows families to reassess their relationships, their careers, and their communities, and through this "seek a life connected but differentiated from their ill relative" (Spaniol and Nelson 764). Doing so requires ongoing negotiation, stroke recovery brings continuous changes, complicated by the fact that "the 'loss' for children [who have] a parent with a head-injury is never final" (Butera-Prinzi and Perlesz 84). Moreover, "achieving acceptance is neither realistic nor desired. Living with a person who has [a brain injury] demands a never-ending cycle of adaptation" (Verhaeghe et al. 1007). Spending the time researching this issue and at times reading studies together has helped us realize that others have walked this route before—a realization that came with the relief of much-needed solidarity.

My self-care remains imperfect, within and separate from the shared maternal self-care as I have redefined it for myself and my children. I should sleep more, pray more frequently, exercise more regularly. Still, changing my perspective about self-care has helped me to reimagine solutions that can work, even when they are not necessarily the solutions I most want. The hours I crave to train again for a marathon have not materialized in my life, but I have found ways to exercise a bit, to carve out some moments for prayer, and to attempt better sleep habits. I combine time with our girls with intellectual work by doing much of it while they sleep so that I can be responsive to their more acute needs for my presence while still engaging individually and collaboratively on intellectual interests. Most importantly, we continue to talk openly and without judgment about our feelings through this journey, and we discuss ways to support each other in providing appropriate support to my husband with kindness as a guiding principle as we navigate ongoing ways of being. Slowly, ever slowly, I am even finding time to increase my emphasis on my physical health, spending time outside together, walking to activities, and beginning to envision that next marathon, actual or as a metaphor for a different challenge. The lessons I learned backpacking—that I need to engage in activities that I love in a safe and healthy environment while sharing that experience and

helping others—continue to translate to my evolving understanding of my journey with my children. I know that continued and shared reflection with our children is essential to this journey because it brings forth imagination about future possibilities, which is essential not only to maternal self-care in the present, but for our children's own future possibilities of caring and of being in this world.

Works Cited

- Butera-Prinzi, Franca, and Amaryll Perlesz. "Through Children's Eyes: Children's Experience of Living with a Parent with an Acquired Brain Injury." *Brain Injury*, vol. 18, no. 1, 2004, pp. 83-101.
- Lawrence, Tim. "8 Simple Words to Say When Someone You Love Is Grieving." Upworthy, Oct. 2015, www.upworthy.com/8-simple-words-to-say-when-someone-you-love-is-grieving. Accessed 11 Apr. 2018.
- Schulz, Richard, and Scott Beach. "Caregiving as a Risk Factor for Mortality. The Caregiver Health Effects Study." *Journal of the American Medical Association*, vol. 282, no. 23, 1999, pp. 2215-219.
- Schulz, Richard, and Paula Sherwood. "Physical and Mental Health Effects of Family Caregiving." *American Journal of Nursing*, vol. 108, no. 9, pp. 23-27.
- Spaniol, LeRoy, and Ann Nelson. "Family Recovery." *Community Mental Health Journal*, vol. 51, no. 7, 2015, pp. 761-67.
- Sullivan, Amy, and Deborah Miller. "Who Is Taking Care of the Caregiver? *Journal of Patient Experience*, vol. 2, no. 1, 2015, pp. 7-12.
- Verhaeghe, Sofie, et al. "Stress and Coping among Families of Patients with Traumatic Brain Injury: A Review of the Literature." *Journal of Clinical Nursing*, vol. 14, no. 8, 2004, pp. 1004-12.